Medical guidance for DLA and AA decision makers (adult cases): staff guide

Medical guidance for DWP staff who make decisions on adult cases for Disability Living Allowance and for Attendance Allowance.

This guide is sometimes referred to by staff as the “A to Z of medical conditions”.

...
A-Z of medical conditions

This medical guidance covers medical conditions for adults. It’s for Disability Living Allowance and Attendance Allowance Decision Makers has been developed by the Department's Health and Wellbeing Directorate with help from experts involved in patient care. It contains background information on the more common medical conditions in DLA/AA claims, their treatment, the likely disabling effects together with the likely impact on ability to self care and get around. This guide is for staff who deal with claims for DLA and AA. It covers only the most common conditions they encounter – not all medical conditions. Decision Makers are advised to discuss with the Departments Medical Services provider if necessary.

A-Z

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Bacterial Diseases:

<p>| Tuberculosis | NHS Choices and Decision Makers are advised to discuss with the |</p>
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**Bladder/Penis/Prostate/Testes/Urethra diseases:**

- Benign prostatic hypertrophy
- Bladder calculus (Bladder stone)
- Blockage / stricture of the Urethra
- Enlarged prostate
- Gonorrhoea & Non-gonoccocal urethritis (NGU)
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<td>Bowel cancer including -:</td>
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<td>• Caecal cancer</td>
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<td>• Colon cancer</td>
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- Sigmoid cancer
- Rectal cancer
- Anal cancer

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<td>Bradycardia</td>
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<td>(Cardiovascular syncope)</td>
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<td>Tachycardia</td>
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<td>Conductive hearing loss due to trauma</td>
<td>Hearing Impairment in Adults</td>
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<td>Otitis externa - chronic</td>
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<td>tardive dystonia</td>
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<tr>
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<tr>
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- Absence seizure (Petit mal)
- Atonic seizure
- Clonic seizure
- Myoclonic seizure
- Tonic seizure
- Tonic-clonic seizure (Grand mal) primary or secondary

  Partial seizure (with status epilepticus in last 12 months)
- Complex partial seizure
- Complex partial seizure evolving to generalised tonic-clonic seizure
- Simple partial seizure

  Partial seizure (without status epilepticus in last 12 months)
- Complex partial seizure
- Complex partial seizure evolving to generalised tonic-clonic seizure
- Simple partial seizure

- Unclassified seizure

- Epiphysial dysplasia - multiple
- Essential tremor - benign
- Extrinsic allergic alveolitis

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<tr>
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<td><a href="https://www.nhs.uk">NHS Choices</a> and Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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<td>Sensorineural hearing loss - Other causes of / type not known</td>
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<td><strong>Hearing &amp; balance - Disease affecting , hearing &amp; balance - Other diseases affecting / type not known</strong></td>
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<td>Hepatitis C infection</td>
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<td>Hirschprung disease</td>
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<td>Hirsutism (excess hair growth in women)</td>
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<td>Hughes Syndrome (Antiphospholipid syndrome)</td>
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<td>Joint Hypermobility/Joint Hypermobility syndrome guidance note</td>
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<td>Hyperparathyroidism</td>
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<td>Allergy - risk of anaphylaxis unknown or not fully assessed</td>
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<td>Oral allergy syndrome</td>
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<td>Osgood schlatters disease</td>
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<td>Osteochondritis dissecans</td>
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<td>Recurrent patellar dislocation</td>
<td>Dislocation</td>
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<td>Knee disorder – Other / type not known</td>
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<tr>
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<tr>
<td>Labyrinthitis</td>
<td>Hearing Impairment in Adults</td>
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<tr>
<td>Lacrimal apparatus – Other disease of / type not known</td>
<td>Adult – Visual Impairment</td>
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<tr>
<td>Lateral epicondylitis (Tennis elbow)</td>
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<td>Learning disabilities (General):</td>
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<tr>
<td>ADD / ADHD</td>
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<td>Fragile X syndrome</td>
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<td>Learning disability – Other / type not known</td>
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<tr>
<td>Dysphonia</td>
<td>Medical Services provider if necessary</td>
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<tr>
<td>Dyspraxia - also known as Developmental</td>
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<td>Ascites</td>
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<td>Features of liver failure – Other/ features</td>
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<tr>
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<tr>
<td>Lower limb(s) – Fractures / Sprain / Dislocation / Rupture of tendon</td>
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<td>Lower respiratory tract disease – Other / type not known</td>
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<tr>
<td>Lumbar disc lesion</td>
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<td>Lung transplantation</td>
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<td>Lymphatics – Other disease of / type not known</td>
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<td>Malformation of the heart (Congenital) other / type not known</td>
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<td>Noonan syndrome</td>
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<td>Meningitis (Bacterial, Viral, Fungal)</td>
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<td>Torn Knee Cartilage</td>
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<td>Mental and Behavioural disorders:</td>
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<tr>
<td>Schizoaffective disorder</td>
<td>Schizophrenia</td>
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<td>Schizophrenia</td>
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<tr>
<td>Psychotic – Other / type not known</td>
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<td>Metabolic disease - Other / type not known</td>
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<td>Albinism</td>
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<td>Calcium deficiency</td>
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<td>Vitamin D deficiency</td>
<td>Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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<td>Metabolic &amp; endocrine disorders affecting the musculoskeletal system:</td>
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<tr>
<td>Osteomalacia</td>
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<td>Osteoporosis</td>
<td>Osteoporosis / Fractures</td>
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<td>Paget’s disease</td>
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<td>Rickets</td>
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<td>Other metabolic and endocrine disorders of musculoskeletal system</td>
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<td>Metabolic red cell disorders:</td>
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<td>Glucose 6 phosphate dehydrogenase (G6PD) deficiency</td>
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<td>Metatarsalgia (Forefoot pain)</td>
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<td>Migraine</td>
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<td>Mitral valve disease</td>
<td>Valvular Heart disease</td>
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<tr>
<td>Mixed anxiety and depressive disorder</td>
<td>Anxiety Disorders / Depressive Illness</td>
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<tr>
<td>Mixed hearing loss</td>
<td>Hearing Impairment in Adults</td>
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<td>Mood disorders:</td>
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<tr>
<td>Bipolar affective disorder – Hypomania / Mania</td>
<td>Bipolar Disorder</td>
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<tr>
<td>Depressive disorder</td>
<td>Depressive Illness</td>
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<td>Mood disorder - Other / type not known</td>
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<td>Motor neurone disease</td>
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<td>Movement disorders (Neurological):</td>
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<tr>
<td>Blepharospasm</td>
<td>Dystonia</td>
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<td>Essential tremor - benign</td>
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<tr>
<td>Huntington’s disease</td>
<td>Organic Brain Disorders</td>
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<td>Condition</td>
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<td>Parkinson's disease</td>
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<td>Parkinson's syndrome / Parkinsonism</td>
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<td>Torticollis</td>
<td>Dystonia</td>
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<td>Tourette syndrome</td>
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<tr>
<td>Writer's cramp</td>
<td>Dystonia</td>
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<td>Movement disorder – Other / type not known</td>
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<tr>
<td>Multisystem and extremes of age:</td>
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<tr>
<td>Chromosomal syndrome - other type / not known (i.e. where more than one system is affected)</td>
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<tr>
<td>Old age (Ageing)</td>
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<tr>
<td>Dermatomyositis</td>
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<td>Dystrophia myotonica</td>
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<td>Polymyositis</td>
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<tr>
<td>Spinal muscular atrophy</td>
<td>Medical Services provider if necessary</td>
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<td>Muscle disease – Other / type not known</td>
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<td>Muscular Dystrophy:</td>
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<tr>
<td>Becker type muscular dystrophy</td>
<td>Muscular Dystrophy guidance note</td>
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<td>Duchenne muscular dystrophy</td>
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<td>Facioscapulohumeral dystrophy</td>
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<tr>
<td>Limb girdle muscular dystrophy</td>
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<tr>
<td>Muscular dystrophy – Other / type not known</td>
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<td>Musculoskeletal disease regional / localised - Other / type not known</td>
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<td>Myalgic Encephalomyelitis (ME)</td>
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<td>Myasthenia gravis</td>
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<td>Myocardial infarction/heart attack</td>
<td>Ischaemic Heart Disease</td>
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<td>Myotonic Dystrophy (Dystrophia myotonica)</td>
<td>Muscular Dystrophy guidance note</td>
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<tr>
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<td>Narcolepsy</td>
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<td>NASH</td>
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<td>Neck disorders:</td>
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<td>Cervical disc lesion</td>
<td>Painful Neck guidance note / NHS Choices and Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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<td>Cervical spondylosis (disc disease)</td>
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<td>Whiplash injury</td>
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<td>Neck disorders - Other / type not known</td>
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<tr>
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<td>Neurofibromatosis</td>
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<td>Neurological infections:</td>
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<td>Encephalitis</td>
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<td>Poliomyelitis / Post polio syndrome</td>
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<td>Neurological disorders:</td>
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<tr>
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<td>Idiopathic Intracranial Hypertension (IIH)</td>
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<td>Thoracic outlet syndrome</td>
<td>Work Related Upper Limb Disorder (WRULD) / NHS Choices and Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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<td>Neurological disorder – other / type not known</td>
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<td>Neuropathies:</td>
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<td>Charcot Marie Tooth disease</td>
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<td>Diabetic neuropathy</td>
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<td>Guillain-Barre syndrome</td>
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<td>Neuropathy - Other / type not known including peripheral</td>
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<td>Nocturnal Enuresis</td>
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<td>Non alcoholic steatohepatitis (NASH)</td>
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<td>Drop attack</td>
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<td>Non epileptic attack disorder (Pseudoseizure)</td>
<td>Epilepsy</td>
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<td>Stokes Adams attack (Cardiovascular syncope)</td>
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<td>Syncope (Faint) Other / type not known</td>
<td>Fainting</td>
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<td>Non epileptic disturbances of consciousness - Other / type not known</td>
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<td>Non-specific (Mechanical back pain)</td>
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<tr>
<td>Nystagmus</td>
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<tbody>
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<td>OA spine (Spondylosis/Spondylitis) (if pathological/neurological changes present)</td>
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<td>Obesity</td>
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<td>Oesophagus/Stomach &amp; Duodenum diseases:</td>
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<tr>
<td>Duodenal, Gastric &amp; Peptic ulcer / Gastritis</td>
<td>Dyspeptic disorders</td>
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<td>Hiatus hernia / Gastroesophageal Reflux disease (GORD) / Reflux oesophagitis</td>
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<td>Oesophageal varices</td>
<td>Alcohol related disorders</td>
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<td>Oesophagus/Stomach &amp; Duodenum disease of - Other / type not known</td>
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<td>Osgood schlatters disease</td>
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<td>Osteoarthritis - knee(s)</td>
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<td>Osteoarthritis of other single joint</td>
<td>Osteoarthritis</td>
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<td>Osteochondritis dissecans</td>
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<td>Osteoporosis/Brittle bone disease</td>
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<td>Ovarian cyst - benign</td>
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<td>Disease of Ovary / Uterus / Cervix / Vagina &amp; Vulva</td>
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<td>Diabetes mellitus (category unknown)</td>
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<td>Partial epileptic seizure (with status epilepticus in last 12 months)</td>
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<td>Creutzfeldt-Jacob disease (vCJD)</td>
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<td>Rotator cuff disorder</td>
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<td>Temporal arteritis (Headache)</td>
<td>Temporal Arteritis</td>
</tr>
<tr>
<td>Condition</td>
<td>Additional Information</td>
</tr>
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<td>--------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Vasculitis - Other / type not known</td>
<td>Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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<tr>
<td>Peripheral Venous Disease:</td>
<td>Venous Disorders</td>
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<tr>
<td>Deep vein thrombosis (DVT)</td>
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<td>Phlebitis</td>
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<tr>
<td>Peripheral venous disease - Other / type not known</td>
<td>Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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<tr>
<td>Ventriculoseptal defect (VSD)</td>
<td>NHS Choices and Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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<td>Vertigo</td>
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<td>Vibration induced white finger</td>
<td>Work Related Upper Limb Disorder (WRULD) / NHS Choices and Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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<td>Viral diseases:</td>
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<tr>
<td>Acquired Immune Deficiency Syndrome (AIDS / Symptomatic HIV) / Human Immunodeficiency Virus (HIV)</td>
<td>HIV / AIDS</td>
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<tr>
<td>Viral disease (excluding Hepatitis &amp; Poliomyelitis) - Other / type not known</td>
<td>Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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Viral Hepatitis:
Hepatitis B & D infection
Hepatitis C infection
Hepatitis (Chronic) - other / type not known

Visual disorders:
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Diseases of conjunctiva, cornea, eyelids and lacrimal apparatus:
Corneal ulceration
Entropion
Herpes zoster - ophthalmic
Keratitis
Keratoconus
Orbital cellulitis
Ptosis
Scleritis
Conjunctiva, cornea, eyelids and lacrimal apparatus - Other
diseases of / type not known

Diseases of the retina and optic nerve:
Diabetic retinopathy
Hypertensive retinopathy
Macular degeneration
Optic atrophy
Optic neuritis
Retinal artery occlusion
Retinal detachment
Retinal vein occlusion
Retinitis Pigmentosa
Retinopathy - Other / type not known
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<td>Disorders of eye movement:</td>
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<td>Refractive errors - Other / type known</td>
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<td>Cortical blindness</td>
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<td>Condition</td>
<td>Description</td>
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<td>Vitreous disease:</td>
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<td>Posterior vitreous detachment</td>
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<td>Vitreous disease - Other / type not known</td>
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<td>Vision - Other diseases affecting / type not known</td>
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<tr>
<td>Vitamin ‘D’ deficiency</td>
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<td>Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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<tr>
<td>Volkmann’s ischaemia (Compartment syndrome)</td>
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<td>Compartment Syndrome</td>
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<td>Von Willebrand’s disease</td>
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<td>VSD</td>
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<td>NHS Choices and Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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<tr>
<td>Vulva – other disease of / type not known</td>
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<td>Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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### W

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<tr>
<td>Trigger finger or thumb</td>
<td>Work Related Upper Limb Disorders (WRULD) / NHS Choices and Decision Makers are advised to discuss with the Departments Medical Services provider if necessary</td>
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<tr>
<td>Vibration induced white finger</td>
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<tr>
<td>Wrist / Hand disorder – Other / type not known</td>
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<td>Dystonia</td>
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What you need to know about Alcohol misuse

What is Alcohol misuse?
Many people are able to keep their drinking within the recommended limits of alcohol consumption, so their risk of alcohol-related health problems is low.… [Read more about alcohol misuse.]

What evidence is available?
Self-assessment is the prime source of evidence, but the claim pack should be checked to see who has completed it.… [Read more about evidence sources.]

Activities of Daily Living and Mobility needs
Many people misuse alcohol and experience only minor mental, physical or social disability. Alcohol dependence, in … [Read more about ADL & mobility needs.]

How long will the needs last?
Alcohol dependence is often characterised by periods of remission and relapse. Where a person has received 2 or more.… [Read more about award duration.]

Over 65s
There is evidence that alcohol misuse in people over the age of 65 is increasing, especially in women.… [Read more about effects in the over 65 age group.]

What evidence is available?

General

Self-assessment is the prime source of evidence, but the claim pack should be checked to see who has completed it. If the form has been filled in by the customer, due to the nature of their condition, it might not necessarily be an accurate or reliable description of their problems.

If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.
The Departmental Decision Maker should bear in mind that the completion of the corroborative statement by a Health Care Professional (HCP) does not necessarily mean that they endorse what has been said in the claim pack.

In all cases of severe illness it is highly probable that a consultant psychiatrist and/or physician will have been involved in the management and treatment of the individual. Indeed the absence of any documented history of a psychiatric or hospital medical consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required.

An HCP examination report may be helpful if the person has physical problems

Other sources of information include the following:

**Secondary Alcohol Team**
When the claimant is being supported by a Secondary Alcohol Team the care co-ordinator on that team will be the preferred source of further evidence.

They have lead responsibility for the delivery of the care plan and so they can give details of the support that the claimant has been assessed as needing. They will also know whether the claimant is being helped by an Assertive Outreach or Crisis Resolution team.

**NHS Care Programme Approach (CPA) care plan**
When the claimant is in contact with mental health services there will be a care plan under the NHS Care Programme Approach. The care plan will include information on health and social care as well as domestic support and is reviewed regularly.

The claimant is given their own copy, which could be requested, as it will contain useful evidence of needs.

**Social Services care plan**
Social Services departments may be involved. A community care assessment by a social worker/care manager will be arranged and a care plan produced.

The care plan will include details of the customer’s day-to-day living and the support provided. A copy can be obtained from the customer.

**Social Worker**
Where a social worker has been appointed to support a claimant they will have information about the customer’s ability to cope with everyday living.

Subject to consent to approach them being given, the social worker will be able to provide some useful evidence about the customer’s needs.
Accommodation manager
When the claimant is living in supported accommodation then the type and level of support provided could be helpful in determining their need for help.

A phone call to the accommodation manager could provide useful evidence.

Crisis Resolution Team
The claimant may have been supported during a crisis by the Crisis Resolution Team. The teams are mainly comprised of CPNs, who would make urgent visits, day or night to anyone who is thought to be in need of hospitalisation.

The idea is to provide intensive treatment at home instead. The Crisis Resolution Team would be well placed to provide details of the customer’s condition.

General practitioner factual report
If there is no specialist health professional involvement or evidence cannot be obtained from them, then it may be necessary to request a factual report from the customer’s own doctor.

The GP may have only limited knowledge of customer’s health problems, even when there is no one else involved.

However, if the person has chronic physical or psychiatric complications, the GP may be well placed to provide a report regarding these.

Activities of Daily Living and Mobility Needs
General Information

Many people misuse alcohol and experience only minor mental, physical or social disability.

Alcohol dependence, in the absence of chronic complications should not be expected to give rise to significant ADL and mobility needs.

Episodes of repeated drunkenness on their own cannot be prevented by reasonable supervision, although intermittent intervention by another person at specific times may reduce the risk at those times.

Withdrawal symptoms usually last for a few days and should not require long term help from another person.
Self-neglect in people with alcohol dependency in the absence of chronic complications may require short-term attention from another person. However, such help should not be long term once drinking has stopped.

During periods of rehabilitation the person may require support from others, but this should not amount to a need for attention or supervision.

The onset of chronic complications is likely to imply moderate or severe disability. The onset of serious, potentially life-threatening complications is likely to imply severe disability.

The following tables present pen pictures of customers' likely mobility and ADL needs at varying levels of functional severity – mild, moderate and severe:
# Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pen picture</strong></td>
<td>A person with a mild functional restriction drinks to excess and may suffer some of the milder consequences of alcohol toxicity. Many of these individuals do not contact a Health Care Professional or obtain treatment. If help is enlisted or treatment instituted, it is often in the form of “brief interventions” from the Primary Care Health Team.</td>
</tr>
</tbody>
</table>
| **Effects** | Mild psychiatric symptoms such as anxiety and depression  
Minor physical problems such as gastritis or gout  
Minor social difficulties including relationship, work related, or minor legal problems, such as convictions for drink drive offences. |
| **Mobility** | These people would normally have no difficulty walking and would be able to find their way around outdoors. |
| **ADL** | People with a mild functional restriction would not normally have a level of functional loss that will result in a reduction of their ability to carry out normal day-to-day activities. |

## Moderate Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pen picture</td>
<td>A person with a moderate functional restriction is likely to have been drinking heavily for several years and have developed dependence or chronic complications such as peripheral neuropathy or epileptic fits. They are likely to be under the care of the Secondary Alcohol Team for ongoing treatment and are likely to have attempted detoxification. They are likely to experience gradual deterioration over several years with periods of remission and relapse in spite of treatment.</td>
</tr>
</tbody>
</table>
| Effects    | Effects may include:  
  - Symptoms of dependence  
  - Moderate psychiatric symptoms such as anxiety and depression  
  - Moderate physical problems such as:-  
    - Peripheral neuropathy  
    - Cardiomyopathy  
    - Alcohol induced fits  
    - Blackouts - repeated  
    - Early Cirrhosis  
    - Mild Ascites  
    - Varices  
    - Pancreatitis  
    - Atrial fibrillation  
    - Alcohol amblyopia  
    - Alcohol related social difficulties including divorce, debt, unemployment, legal problems such as theft and crimes of violence  
  However, people with a moderate condition would not normally exhibit significant self-neglect |
| Mobility   | Many of these people would normally have no difficulty walking outdoors, would be safely and independently mobile outdoors and be able to find their way around outdoors. However, some people’s mobility outdoors could be restricted due to one or more of the complications described above. Refer to the relevant links on the ‘How long will the needs last?’ page. |
| ADL        | Similarly, many people will not have any care requirements but again, some activities may be restricted or limited as a result of one or more of the complications described above. Refer to the relevant links on the ‘How long will the needs last?’ page. |
Severe Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pen picture</td>
<td>A person with a severe functional restriction will have been drinking heavily for several years and will have developed chronic, potentially life threatening complications such as cirrhosis, cardiomyopathy and cognitive impairment. They are likely to be under the care of the Secondary Alcohol Team. They will almost inevitably continue to drink despite treatment and their alcohol related disability will deteriorate. The mortality rate for this group is high. 52% of people with cirrhosis die within 5 years if they continue to drink. Even if they stop, 33% die within 5 years.</td>
</tr>
</tbody>
</table>
| Effects    | Effects may include:  
- Symptoms of dependence  
- Serious physical and psychiatric conditions such as: Wernicke- Korsakoff Syndrome  
  Cerebellar degeneration  
  Advanced cirrhosis with chronic liver failure  
  Hepatic encephalopathy  
  Gross ascites  
  Cardiomyopathy  
  Cognitive impairment and dementia  
  Pathological jealousy  
  Self-neglect and homelessness |
| Mobility   | Physical complications may make it difficult for the person to walk, but each case will have to be judged on individual merits. For example:  
Cardiomyopathy may cause severe breathlessness  
Cerebellar disease may cause gross ataxia [unsteadiness] 

Physical inertia and apathy may require someone to encourage the person with a severe alcohol related condition to get out and about. |
The customer may need:
- encouragement to get out of bed in the morning
- encouragement to wash, dress and maintain hygiene
- assistance in preparing meals
- encouragement to go out and engage in social activities
- help with domestic crises
- assistance with toileting
- assistance with taking medication and obtaining prescriptions
- help with attendance at doctors appointments, hospital appointments and day hospital
- Help with correspondence, financial matters and paying bills

How long will the needs last?
Alcohol dependence is often characterised by periods of remission and relapse. Where a person has received 2 or more courses of treatment or alcohol dependency has existed for more than 5 years there is unlikely to be any improvement. Where complications e.g. neurological, liver etc exist, there is unlikely to be any improvement.

If evidence shows that the customer has an arrhythmia or cardiomyopathy as a result of Alcohol misuse, then also consult the Cardiac Arrhythmia or Cardiomyopathy guidance for additional information.

If evidence shows that the customer has Cirrhosis as a result of Alcohol misuse, then also consult the Cirrhosis guidance for additional information.

If evidence shows that the customer has cognitive impairment as a result of Alcohol misuse, then also consult the Organic Brain disorders guidance for additional information.

If evidence shows that the customer has Epilepsy as a result of Alcohol misuse, then also consult the Epilepsy guidance for additional information.

If evidence shows that the customer has Pancreatitis as a result of Alcohol misuse, then also consult the Pancreatic disease guidance for additional information.

If evidence shows that the customer has alcohol related amblyopia as a result of Alcohol misuse, then also consult the Vision guidance for additional information.
<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol misuse</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 5 years</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

**Alcohol misuse – with complications:**

Click on the above links for details of alcohol related complications including date of onset, award periods and disability codes.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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**Alcohol related disorders in people over 65**

There is evidence that alcohol misuse in people over the age of 65 is increasing, especially in women. Although estimates vary, in one study, the prevalence of alcohol dependence in patients over the age of 60 admitted to hospital was 15 percent.

For a variety of reasons, alcohol misuse may go unnoticed in this age group.

Alcohol misuse may be suspected if, for example, there are unexplained falls and fractures, hypertension, confusional episodes, late onset epilepsy, or failure to maintain previous standards of dress or behaviour.

People over the age of 65 years have a lower tolerance to the effects of alcohol and this may result in the confusion associated with intoxication or withdrawal lasting longer than in younger people.

Alcohol misuse is associated with:

- Increased risk of stroke, subdural haematoma (blood clots in the brain) and infection.
- Memory loss.
- Hypertension.
- Peripheral neuropathy.
- Dementia.
- Depression, associated with a high risk of suicide.
- Symptoms of elation, leading to a diagnosis of mania.
- Hallucinations, leading to a diagnosis of psychosis.
- Withdrawal fits, leading to a diagnosis of epilepsy.
- Confusion, sometimes exacerbated by prescription of multiple medications.

The signs and symptoms necessary for a diagnosis of alcohol dependence are the same as for a younger age group, but they may present in unusual...
ways. For example, cognitive impairment may persist for up to a month following the acute withdrawal syndrome.

Treatment is similar to that for a younger age group, with some minor differences. For example, the death rate in untreated withdrawal syndrome is high at 10 to 15 percent, and must be considered a medical emergency.
What you need to know about Amputation

What is an Amputation?
There are two main types of amputation: lower limb amputation, where the foot and part of the leg are removed; and .... Read more about amputation.

What evidence is available?
The most appropriate sources would be the GP, physiotherapist or Disablement Services Centre.

Activities of Daily Living and Mobility needs
ADLs will depend very much on the remaining natural function of the limb and the type of prosthesis fitted. Loss of .... Read more about ADL & mobility needs.

How long will the needs last?
Needs will vary with many factors, including age, general health, reason for amputation, level of amputation and .... Read more about award duration.

Over 65s
Adapting to a new amputation is more difficult over age 65......Read more about effects in the over 65 age group

Activities of Daily Living & mobility needs

Upper Limb Amputations
Levels vary from loss of the tip of a finger to the removal (or absence) of a whole limb or limbs, including the whole shoulder (forequarter amputation).

Activities of Daily Living (ADLs)
ADLs will depend very much on the remaining natural function of the limb and the type of prosthesis fitted. Loss of significant parts of both upper limbs is likely to be very disabling and to result in care needs.

Care needs may also depend on the dominance of the affected limb. Loss involving the dominant limb (i.e. the right arm in a right-handed person) is likely to be more disabling than loss to the same extent of the other, non dominant limb.
Loss of a thumb is more disabling than loss of a finger, because many day-to-day tasks depend on an adequate grasp between finger and thumb. Loss of a thumb or of a single finger is however unlikely to result in care needs unless there are added complications such as arthritic changes involving the hands.

In some cases the use of simple aids can help the person manipulate common household utensils.

Care needs may be associated with fitting a prosthesis, and in the case of a functional prosthesis a period of training in its use is likely to be needed.

Mobility Considerations
Mobility will rarely be affected, but there may be balance problems, particularly if large parts of both upper limbs are absent.

Lower Limb Amputations
Levels can vary from the loss of the tip of a toe to amputation through the hip joint, or even including the removal of part of the pelvis (hemipelvectomy).

Occasionally, complications may arise, such as swelling (oedema) of the stump, infection, friction which may lead to blisters and sore areas, or skin problems which rarely may be related to materials within the prosthesis. Bony spurs or re-growth of bone or neuromas (painful nerve swellings) may develop at the stump leading to a need for it to be refashioned surgically. Following any of these complications and surgery, it may be necessary to leave the prosthetic limb off - continued use could lead to worsening of the condition. The prosthesis may need so be redesigned or adapted once healing has occurred.

It is normal for the person to feel that the lost limb is still there (phantom sensation) and occasionally this may be painful (phantom pain). Pain in the residual limb may arise as a result of painful swelling at the end of cut nerves (neuroma). In addition to problems with the residual limb there may be problems in other areas such as the back or the remaining limb. In particular, peripheral vascular disease severe enough to lead to amputation is likely to affect the remaining limb also. The onset of arthritis may be accelerated due to extra dependence on the remaining limb.

Sometimes, long term (10 - 15 years after amputation) sequelae may arise due to twisting of the spine (scoliosis) causing chronic back pain, balance problems, chronic irritation of the stump and the earlier onset of arthritis in the weight-bearing limb.

Activities of Daily Living (ADLs)
ADLs may be associated with help in fitting the prosthesis, care for the stump, and dealing with complications. Except in very young and very elderly people, such needs are likely to be minimal. Usually, the higher the level of amputation, the greater the needs are.
Until the person adapts to the prosthesis help may be needed to get in and out of bed, out of a bath and going upstairs and downstairs. The length of time over which help will be needed will vary from person to person with age and general health. Adaptation is more difficult in elderly people and they may also have the problem of arthritis in the other joints. If the person has had both legs amputated, then their care needs may be greatly increased.

**Mobility Considerations**

Following the majority of amputations in otherwise fit persons, a prosthesis is fitted once the wound has healed, and the person is trained to walk, using aids such as a stick or walking frame as necessary.

The functional level achieved will depend on a number of factors: the age, physical and mental fitness of the person; their motivation; the level of amputation and construction of the stump; and the availability of rehabilitation programmes. A young person, otherwise fit, will usually regain useful mobility following a period of rehabilitation of anything from one month to a year. Rehabilitation will be delayed by the presence of complications or obesity.

Some people, particularly elderly persons and those with bilateral above knee (A/K) amputations, never learn to become independently mobile, and remain wheelchair users.

The level of amputation will affect functional achievement. In cases of hemipelvectomy or amputation through the hip joint, although prostheses are satisfactory, they tend to be heavy. Walking is likely to be extremely fatiguing, and the quality of walking will be less than that of a person whose amputation is at a lower level. In above-knee amputations, provided the stump is of adequate length, it is possible in most cases to fit a prosthesis. A person with an amputation below knee (B/K) level can normally be fitted with a prosthesis. Amputation of the forefoot or toes may require no more than the fitting of special footwear.

Balance problems may occur with amputation at any level, even the toes, especially the great toes. Such problems however are normally short term. Balance problems may be increased if the remaining limb is damaged or diseased.

In cases of particular difficulty, advice from a Departmental Medical Services doctor may prove useful.

**How long will the needs last?**

Needs will vary with many factors, including age, general health, reason for amputation, level of amputation and the presence of other disabilities.
Following amputation, there is often a "grief" reaction to the loss of the limb and, if this is particularly severe in an individual, the rehabilitation process may be prolonged and counselling will be required.

- Amputation - lower limb/s
- Amputation - upper limb/s
- Amputation – upper & lower limb/s

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Over 65**

**New amputees**
Adapting to a new amputation is more difficult over age 65, this relates to the underlying indication for amputation not just the age of the claimant. In this age group the indication is usually ischaemic or diabetic peripheral vascular disease. This group often have associated cardiovascular disease and physical deconditioning (loss of fitness). They often do not have the strength and flexibility to learn to walk on a prosthesis. This is because the work of walking with a prosthesis is much greater than walking normally; higher level amputations require more effort than lower level ones. For many, rehabilitation to walking with a prosthesis will not be possible and mobilising with a wheelchair will be the goal of rehabilitation.

People who are otherwise fit and well can learn to walk after amputation over age 65 and the life span of an otherwise healthy amputee is normal.

**Existing amputees**
Although amputations from trauma and congenital limb deficiency are rare in the UK they give rise to a relatively large proportion of the amputee population because of their good prognosis. This group will have been mobilising with prostheses for many years. Arthritis, stump problems or the sheer effort of walking may limit their walking ability in later years despite a high level of adaptation, fitness and skill.
What you need to know about Anaemia

What is Anaemia?
- Read more about Vitamin B12 deficiency
- Read more about Iron deficiency anaemia

For information about other types of anaemia Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around as a result of Anaemia and…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Symptoms of anaemia in most individuals are mild, and do not result in any significant disability, with functional impairment…. Read more about ADL & mobility needs.

How long will the needs last?
Symptoms of anaemia in most individuals are mild with functional impairment being minimal in the majority of cases…. Read more about award duration.

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.
Linked pages :-
- Ageing
- Falls
- Frailty
What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around as a result of Anaemia and therefore further evidence would not usually be required in most cases. However, for Sickle Cell Anaemia, each case will need to be assessed on its merits. Further information may be needed from sources such as the General Practitioner, Hospital Consultant, Nurse Specialist or Health Care Professional examination report.

Activities of Daily Living and Mobility needs
Symptoms of anaemia in most individuals are mild, and do not result in any significant disability, with functional impairment being minimal in the majority of cases. Specifically, affected individuals would normally be able to carry out all activities of daily living, and there would normally be no significant restriction of self care activities.

A minority of cases will have disability. Severe anaemia, particularly in the elderly, may result in symptoms of cardiac failure, when exertional breathlessness may be more severe, resulting in some impairment of various activities of daily living.

Anaemia as a secondary complication of other disease processes, e.g., Rheumatoid Arthritis, will also not cause any significant impairment of function in the majority of people, and disability will be as a consequential effect of the primary condition.

Each case will need to be assessed on its merits. Further information may be needed from sources such as the General Practitioner, Hospital Consultant, Nurse Specialist or Health Care Professional examination report.

Anaemias of uncertain origin
Anaemia, which is mild or moderate in degree, may develop secondary to various well recognised conditions, e.g. severe chronic infections, rheumatoid arthritis, chronic renal failure, liver cirrhosis, and malignant disease. The anaemia in these conditions does not usually cause any significant symptoms, and disability in these circumstances is as the result of the associated medical condition.

How long will the needs last?
• In auto-immune haemolytic anaemia, the prognosis is more serious than in the hereditary form, death in haemolytic crisis being more frequent. The effect of blood transfusion, high dose steroids, and splenectomy are not as satisfactory as in the hereditary disease. Immunosuppressive therapy or thymectomy (removal of the thymus gland) may have to be considered with failure of first line therapy.
• Haemolytic anaemia occurs occasionally in association with a variety of other diseases such as chronic leukaemia, liver cirrhosis, malignant disease, syphilis and tuberculosis.

• Transfusion with incompatible blood will result in destruction of the infused cells, and the production of an acute haemolytic anaemia, with resulting severe systemic reactions.

Symptoms of anaemia in most individuals are mild with functional impairment being minimal in the majority of cases. Affected individuals would normally be able to carry out all activities of daily living, and there would normally be no significant restriction of self-care activities. Anaemia as a secondary complication of other disease processes e.g. Rheumatoid Arthritis will also not cause any significant impairment of function in the majority of people, and disability will be as a result of the primary condition. Severe anaemia may be more pronounced, resulting in some impairment of various activities of daily living.

**Note:** Sickle cell anaemia is not covered by this guidance.

<table>
<thead>
<tr>
<th>Type of Anaemia</th>
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</thead>
<tbody>
<tr>
<td>Aplastic anaemia</td>
</tr>
<tr>
<td>B12 (pernicious) / folate deficiency anaemia</td>
</tr>
<tr>
<td>Iron deficiency anaemia</td>
</tr>
<tr>
<td>Other anaemia / type not known</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Asthma

Back to A - Z

What is Asthma?
Asthma is a long-term condition that can cause a cough, wheezing and breathlessness. The severity of the symptoms varies... Read more about NHS Choices - asthma.

What evidence is available?
The claimant and/or their carer should be able to provide the majority of information required to obtain a clear picture of needs. However, if further details are needed, the General Practitioner or the Asthma Nurse is the best source of information.

Activities of Daily Living and Mobility needs
The following tables present pen pictures of customers' likely mobility and care needs at varying levels of... Read more about ADL & mobility needs.
Linked pages -:
Medical Research Council Dyspnoea scale details

How long will the needs last?
In occupational asthma, early treatment, and removal of the person from the precipitating cause may effect a cure... Read more about award duration.

Over 65s
It is estimated that around 6-10% of older people have asthma, and it may genuinely present as a new illness, or... Read more about effects in the over 65 age group.

Activities of Daily Living and Mobility needs
The following tables present pen pictures of customers' likely mobility and ADL needs at varying levels of functional severity mild, moderate and severe:
## Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>Mild asthma is an intermittent condition, which causes breathlessness, leading to intermittent lack of exercise and activity tolerance. Though the person may be very breathless at times, the modern treatment available now would normally control symptoms. The attacks are likely to be short-lived and infrequent.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>Walking would normally be unlimited, i.e. well over 1 mile, except on the infrequent occasions when an exacerbation occurs, and this would only last for a few hours at the most controlled by inhalers. They may sometimes experience slight breathlessness on exertion, (i.e. when hurrying).</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>Daily life would normally be unaffected and the person could live independently and normally between attacks. Therefore, a person with mild functional restriction would normally be able to attend to all his/her own daily activities of self-care (bathing, dressing attending to his/her hygiene needs, and preparing a main meal for him/herself). Even when they have an attack they last for a short time, adequately controlled by inhalers.</td>
</tr>
</tbody>
</table>
## Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>Moderate asthma is an intermittent condition, which causes breathlessness, leading to intermittent lack of exercise and activity tolerance. For some of the time, most days, people with moderate asthma would be wheezy and breathless, with symptoms being most noticeable at the beginning and end of the day. They would normally be intermittently wheezy at night.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>A person with moderate functional restriction would normally be able to walk well over half a mile (800 metres) on the flat, though they may become breathless on hills and stairs. However, they should manage this at a slower than usual pace. At this stage, the affected person would normally be likely to take a bronchodilator (such as “ventolin”) before expected exercise. During an attack, walking distance could be severely affected but his would normally be for a minority of the time.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>The degree of breathlessness would not be severe enough to affect the ability to bath, dress, and attend to hygiene needs and preparing and cooking a main meal. During exacerbations, this ability will be compromised, but only for a few days at the most. They would normally be well controlled with medication and the person would normally be able to administer their own medication.</td>
</tr>
</tbody>
</table>
## Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>Severe limitation of exercise, and activity tolerance. Acute exacerbations will occur on top of this. A person with severe asthma will normally be wheezy and breathless all the time.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>A person with severe functional restriction would not normally be able to walk 50 metres slowly, on the flat, without stopping for breath. They could not normally keep up with another person of the same age and sex, while walking on level ground.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>Any task, which requires physical activity, is likely to take longer due to severe breathlessness. Help may therefore, be required with bathing, dressing, getting round the house and going up and down the stairs, etc. They may not be able to prepare and cook a main meal, due to difficulty lifting a hot pan. They would not normally be able to manage one flight of stairs, without having to stop and have a rest. The affected person would normally be able to administer his/her own medication during an attack unaided. At night he/she would normally be able to use medication and call for attention if needed.</td>
</tr>
</tbody>
</table>

**How long will the needs last?**

In occupational asthma, early treatment, and removal of the person from the precipitating cause may effect a cure.
Apart from that, asthma is a chronic but variable condition. Modern asthma treatment is capable of eliminating, or significantly reducing asthma symptoms. The majority of attacks or flare-ups are short-lived and normally do respond to treatment. A minority of cases are “brittle” and treatment is less effective. Such cases should be discussed with the Departments Medical Services provider.

Once treatment has been stabilised, the condition will normally remain static, and the care and mobility needs are not likely to change.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Duration of assessment of severe asthma</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>Assessed as severe for less than 5 years</td>
<td>3 year award</td>
</tr>
<tr>
<td></td>
<td>Assessed as severe for more than 5 years</td>
<td>Indefinite period</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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Asthma in people over 65

It is estimated that around 6-10% of older people have asthma, and it may genuinely present as a new illness, or the person may have had it for many years.

Because the diagnosis and treatment of asthma in the elderly can be more complicated than in those who are younger, asthma tends to be under-diagnosed and under-treated and indeed may present late, with worse asthma symptoms, as older people may not perceive the feeling of breathlessness so well, and may just believe breathlessness is a normal consequence of ageing.

The elderly asthmatic is more likely to have worse symptoms, more likely to be hospitalised, and more likely to die, because of late presentation, diagnosis, and treatment, and potential interactions of asthma medications with other drugs.

The presentation may not be typical [e.g. of breathlessness at night (paroxysmal nocturnal dyspnoea) rather than wheeze], and though the elderly asthmatic is less likely to have associated allergies and eczema, he/she is likely to have co-existing conditions, including cardiac conditions, which can confuse the picture.

The very medications, which are normally used to treat asthma can have serious side effects which can worsen the elderly asthmatic’s general
condition and quality of life. They are more likely to suffer from a racing heart, tremor and even angina from beta agonists (such as Salbutamol). Theophylline takes a long time to clear from the blood.

Because the elderly asthmatic is likely to be taking other medications for other conditions, there is more likelihood of drug interactions, and treatment goals may have to be modified, because of this, as well as the person's general condition, and older people are more likely to be taking beta blockers or non-steroidal anti-inflammatory medication, which can make asthma worse.

Adverse side effects can occur when elderly people are put on steroids, as they may become confused or even psychotic, and further osteoporosis may occur in already weak bones.

Older people are more likely to have problems with using metered-dose inhalers, if they have physical impairments [e.g. stroke, arthritis, visual impairments, tremor, or problems with co-ordination]; or mental impairment [such as cognitive impairment]. In these cases, a device to aid metered-dose delivery, a spacer device, or breath-actuated device may be needed.

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What you need to know about Autistic Spectrum Disorders (ASD)

What is an Autistic spectrum disorder?
Autism and Asperger syndrome are both part of a range of related developmental disorders known as autistic spectrum disorders (ASD).... NHS Choices - ASD.

What evidence is available?
It may be difficult to obtain recent medical evidence for adults with autistic spectrum disorder, when they have limited contact with.... Read more about evidence sources.

Activities of Daily Living and Mobility needs
Some people with high functioning autism will have care and mobility needs. Others will have lower levels of need and.... Read more about ADL & mobility needs.

How long will the needs last?
Although adolescents with these conditions progress in their education and are able to acquire a variety of daily living skills as they mature, it is unlikely that.... Read more about award duration.

Over 65s
There are no specific features yet reliably identified and recorded for the elderly.

What evidence is available?
It may be difficult to obtain recent medical evidence for adults with autistic spectrum disorder, when they have limited contact with their general practitioners or hospital services, since their general health is satisfactory. However for older teenagers and young adults some reports and previous assessments, including those made by educational psychologists, may be available in their medical records or from the school or college they are attending -:
Special Education Needs (SEN)

Note: These reports should be accompanied by medical evidence wherever possible.

They may also have been assessed by speech and language therapists, occupational therapists, social workers and other health care professionals who provide services for people with learning disabilities living in the
community. Copies of reports may be obtained from community teams, social services or local authorities. This applies to those living at home and in residential accommodation. Customers or their carers may also have copies of these assessments or care plans. Adults with Autistic Spectrum Disorder who have associated mental health disorders may have been referred to community mental health teams and psychiatric clinics, from which reports can be requested.

An assessment by a Health Care Professional is appropriate when disabilities are stable and long standing, and when other sources of evidence are not available, or give insufficient detail to ascertain the overall level of functional impairment.

Activities of Daily Living and Mobility needs

**Autistic spectrum disorder and normal or above average intelligence**

Some people with high functioning autism will have ADL and mobility needs. Others will have lower levels of need and are likely to be able to deal with self care and bodily functions, and to be able to prepare a simple meal. Some will live independently; some will need a more structured environment within a family, or with support from carers. A structured routine organized by another person may be important in enabling them to maintain personal hygiene and proper nutrition. Assistance with communication may be needed in some situations. For example some people would be unable to cope with a domestic emergency, or major change of routine. In such situations they might need help in communicating with strangers or outside organizations.

**Autistic spectrum disorder with mild to moderate learning disability**

Within this grouping there will be a wide spectrum of disabling effects that may require help from others. Some will live in supported accommodation and some will live at home, usually with carers. They are likely to need help or encouragement to wash, dress, prepare food etc. They may need to be advised to wear clothes appropriate to the season and to eat a varied and nutritious diet. It may be necessary to discourage aimless and repetitive behaviours and to encourage participation in appropriate activities. Some may be vulnerable to financial and sexual exploitation. Medication may need to be given and supervised. They often need help to communicate with others e.g. unfamiliar people, to avoid social isolation and to deal with correspondence and financial matters. Some may need to be watched over to prevent damage to surroundings or maintain a safe environment, and to discourage challenging behaviour. The care provided allows them to live within a structured environment and routine, whereby they are able to maximise their abilities to carry out tasks of daily living. They are often likely to need guidance in both familiar and unfamiliar places, even if they are able to manage short trips on known routes e.g. to a local shop. Some may be vulnerable to exploitation or exhibit disturbed or anti social behaviour when out. Communication with strangers may
pose great difficulty, and they would be unable to ask for help or
directions, or to respond to directions in a meaningful fashion.
Some individuals may have difficulty communicating with others when out
of doors. They may show unusual or unacceptable behaviour such as
shouting, for example, if routine journeys are disrupted or altered.

**Autistic spectrum disorder with severe learning disability**

Many adults with this degree of impairment will live in supported or
residential accommodation with a high degree of help and support from
care workers. Some will live at home with family. They will need help with
most aspects of personal care to maintain nutrition and prevent self
neglect. Attention will be required to discourage repetitive or aimless
behaviours, and to encourage participation in appropriate activities. They
may need watching over to prevent potentially dangerous behaviours or
activities such as running off, or to deal with disruptive or challenging
behaviour. Associated problems like epilepsy or other physical disabilities
will increase the requirement for help and supervision including the
administration of medication.
The ability to walk is likely to be unimpeded in the absence of
neuromuscular problems affecting the lower limbs. But they will be unable
to find their way out of doors without help from some one else.

### How long will the needs last?

Although adolescents with these conditions progress in their education
and are able to acquire a variety of daily living skills as they mature, it is
unlikely that there will be much substantial change in their abilities in
adulthood. Adults with moderate/severe autism are unlikely to be able to
live independently or be employed. Those with high functioning autism,
including Asperger syndrome, may acquire jobs, but their condition
impedes their ability to secure or retain employment without support. Jobs
secured may be of a lower level than their educational ability, and people
may be unable to remain in a job for prolonged periods of time.
Learning disability runs a life long course with little change.
Once care and mobility needs have been established they are unlikely to
improve and a life award should be considered.
However, intellectual or physical deterioration can occur in later life and
may result in increasing care and mobility needs.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asperger’s syndrome</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Autism</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration
disabling effects and the duration of disabling effects must be based on
the particular circumstances of the individual claimant.
# What you need to know about Anxiety Disorders

**What is an Anxiety Disorder?**
- Read more on [NHS Choices - Agoraphobia](https://www.nhs.uk/conditions/agoraphobia/)
- Read more on [NHS Choices - Generalised Anxiety disorder](https://www.nhs.uk/conditions/generlised-anxiety-disorder/)
- Read more on [NHS Choices - Panic disorder](https://www.nhs.uk/conditions/panic-disorder/)
- Read more on [NHS Choices - Phobias](https://www.nhs.uk/conditions/phobias/)

For information about other types of anxiety disorder Decision Makers are advised to discuss with the Departments Medical Services provider.

**What evidence is available?**
The claimant and/or carer should be able to provide the information required to accurately assess.... [Read more about evidence sources](#).

**Activities of Daily Living and Mobility needs**
When evaluating claims of anxiety and fear the Decision Maker needs to decide in the first instance whether the customer is.... [Read more about ADL & mobility needs](#).

**How long will the needs last?**
For first episodes of an Anxiety Disorder, the prognosis is uncertain for the first 6 to 12 months... [Read more about prognosis and duration](#).

**Over 65s**
Isolated anxiety disorders, including agoraphobia are unusual in people over 65. When they occur, they are usually.... [Read more about effects in the over 65 age group](#).

**What evidence is available?**
The claimant and/or carer should be able to provide the information required to accurately assess mobility and care needs. However, if further details are needed, the [Specialist Nurse [CPN], Consultant](https://www.nhs.uk/conditions/panic-disorder/) or [General Practitioner](https://www.nhs.uk/conditions/panic-disorder/) is an appropriate source of information.
Activities of Daily Living and Mobility needs

General Information
When evaluating claims of anxiety and fear the Departmental Decision Maker needs to decide in the first instance whether the customer is describing normal sensations or emotions occurring in everyday situations. If the symptoms appear to be part of an anxiety disorder or other mental health disorder, the Departmental Decision Maker will have to decide from the evidence whether the symptoms are of sufficient severity and pervasive nature that the resultant functional impairment would give rise for a need for help with care, getting around or supervision.

People who have a genuine severe anxiety related condition would have consistent disability when considering their activities of daily living. For example a person who is unable to go to the doctors surgery would also be expected to be unable to attend leisure activities.

The following tables present pen pictures of customers’ likely mobility and care needs at varying levels of functional severity - mild, moderate and severe:

Back to top of section
Mild Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>The following would normally be characteristic of a person with mild functional restriction. They may include mild or intermittent symptoms of anxiety, (perhaps precipitated by a life event), worry, mild irritability, mild sleep disturbance and tiredness or mild physical symptoms such as sweating and a dry mouth.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person should not have difficulty safely finding their way around unfamiliar places outdoors although those especially with agoraphobia may feel reassured if accompanied. However, should the companion not be present, the affected person is unlikely to be unable to find their way around outdoors.</td>
</tr>
</tbody>
</table>
People with mild functional restriction would not normally have any significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities. Attention to bodily functions is unlikely to be affected by social phobia. Although very distressing at the time for the person involved, panic disorder is unlikely to put the person or others at risk of danger. Episodes are short lived, and even if frequent during the day are unlikely to prevent the person attending to their own personal care.

The disabling effects of simple phobias are restricted to situations in which the person comes into contact with the object causing acute anxiety, or manoeuvres, which the person undertakes to avoid the stimulus. Simple phobias do not give rise to a need for help with personal care of for supervision out of doors in unfamiliar places. There is no need for supervision in social situations, since there is no risk of danger to the individual. The person would be able to find their way around in unfamiliar places without help, since there is no confusion, impairment of judgement or difficulty in thinking.

People with agoraphobia are unlikely to have any need for help with personal care. Although people may suffer anxiety symptoms while out, those with less severe symptoms are able to go out and carry out normal tasks like shopping. They have no need for supervision since they are not confused, their memory is normal and concentration is usually normal and unimpaired.
Also their ability to communicate with others is not impaired.

Moderate Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>The following would normally be characteristic of a person with a moderate functional restriction. They may include more severe and chronic symptoms or frequent episodes of severe anxiety. Worry and apprehension, which are difficult to control. Irritability and poor concentration. More severe physical symptoms such as palpitations, dizziness, trembling, hyperventilation [over breathing] and more severe sleep disturbance.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person should not have difficulty safely finding their way around unfamiliar places outdoors although those especially with agoraphobia may feel reassured if accompanied. Should the companion not be present, the affected person is unlikely to be unable to find their way around outdoors. However, a person with a moderate or severe functional restriction due to Depressive Illness together with associated Agoraphobia may have difficulty finding their way around unfamiliar places and may require support.</td>
</tr>
<tr>
<td>ADL</td>
<td>People with moderate functional restriction would not normally have any significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities. Attention to bodily functions is unlikely to be affected by social phobia. People with a moderate functional restriction would not normally exhibit significant self-neglect. Although very distressing at the time for the person involved, panic disorder is unlikely to put the person or others at risk of danger. Episodes are short lived, and even if frequent during the day are unlikely to prevent the person attending to their own personal care. The disabling effects of simple phobias are restricted to situations in which the person comes into contact with the object causing acute anxiety, or manoeuvres, which the person undertakes to avoid the stimulus. Simple phobias do not give rise to a need for help with personal care or for supervision out of doors in unfamiliar places. There is no need for supervision in social situations, since there is no risk of danger to the individual. The person would be able to find their way around in unfamiliar places without help, since there is no confusion, impairment of judgement or difficulty in thinking. People with agoraphobia are unlikely to have any need for help with personal care. Although people may suffer anxiety symptoms while out, those with less severe symptoms are able to go out and carry out normal tasks like shopping. They have no need for supervision since they are not confused, their memory is</td>
</tr>
<tr>
<td>Severe Functional Restriction</td>
<td></td>
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<tr>
<td>-------------------------------</td>
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<tr>
<td>normal and concentration is usually normal and unimpaired. Also their ability to communicate with others is not impaired.</td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
</tr>
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<td>---------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Disabling Effects</td>
<td>The following would normally be characteristic of a person with a severe functional restriction. They may include very severe and chronic symptoms or frequent episodes of severe anxiety, worry and apprehension that are difficult to control or irritability and poor concentration. More severe physical symptoms such as palpitations, dizziness, trembling, hyperventilation [over breathing]. More severe sleep disturbance, perhaps de-personalisation and de-realisation. They may be extremely limited in their social function and are likely to avoid almost all contact and never leave their homes. They may be unable to attend social events and leisure activities.</td>
</tr>
<tr>
<td>Mobility</td>
<td>The person may have difficulty finding their way around unfamiliar places and may require guidance as would a person with a moderate or severe functional restriction due to Depressive illness together with associated Agoraphobia or severe Anxiety. For people with agoraphobia alone, a minority of people have severe disease. Some never leave the house at all, even with a companion, or only go out very occasionally to special events or appointments with an escort. It may be difficult for such people to receive an assessment of their condition and appropriate treatment, unless the mental health team can provide these in the first instance in the person’s home.</td>
</tr>
</tbody>
</table>
ADL

People with a severe functional restriction would not normally have such significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities e.g. washing, dressing and maintaining acceptable standards of hygiene and nutrition. People with a severe functional restriction would not normally exhibit significant self-neglect. Nor is it likely that the condition would put the person or others at risk of danger.

How long will the needs last?

For first episodes of an Anxiety Disorder, the prognosis is uncertain for the first 6 to 12 months and it would be reasonable to award for a limited period whilst awaiting the outcome of response to treatment.

Similarly, for infrequent repeated episodes it would be reasonable to award for a limited period initially whilst awaiting the outcome of response to treatment.

Generalised Anxiety Disorder - How long will the needs last?

For first episodes of an Anxiety Disorder, the prognosis is uncertain for the first 6 to 12 months and it would be reasonable to award for a limited period whilst awaiting the outcome of response to treatment.

Similarly, for infrequent repeated episodes it would be reasonable to award for a limited period initially whilst awaiting the outcome of response to treatment.

Generalised Anxiety Disorder is a chronic condition. Spontaneous remission is rare and exacerbations are common.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Customers under 50 years of age-:</td>
<td>Less than 5</td>
<td>2 year award</td>
</tr>
<tr>
<td>Generalised Anxiety Disorder</td>
<td>years</td>
<td></td>
</tr>
<tr>
<td>Customers over 50 years of age-:</td>
<td>More than 5</td>
<td>5 year award</td>
</tr>
<tr>
<td></td>
<td>years</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Less than 5</td>
<td>2 year award</td>
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<tr>
<td></td>
<td>years</td>
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</tbody>
</table>
Generalised Anxiety Disorder

Customers under 50 years of age: Other anxiety disorder / type not known

Customers over 50 years of age: Other anxiety disorder / type not known

Panic Disorder - How long will the needs last?

The course is usually chronic, with remissions and relapses. With treatment, up to half of patients with panic disorder may be symptom-free after 3 years.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Customers under 50 years of age: Panic Disorder</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td>Customers over 50 years of age: Panic Disorder</td>
<td>More than 5 years</td>
<td>5 year award</td>
</tr>
</tbody>
</table>

Phobias - How long will the needs last?

Simple (Specific) phobias
If a simple (specific) phobia persists into adult life, then it usually follows a chronic course. Exposure treatment can achieve long-term cure in about half of patients with specific phobias.

Complex phobias
In complex phobias e.g. a social phobia, the condition is life-long and unremitting if untreated, and there is a substantial rate of relapse even after prolonged treatment. About a third of patients will enjoy a complete remission during long-term follow-up.
Agoraphobia - How long will the needs last?

Untreated, agoraphobia typically runs a chronic course.

Treatment seems to be most effective if instituted early in the development of the disorder, when the person is encouraged to return to the situation, which provokes the symptoms. Although people may continue to experience some mild anxiety, they are able to function normally again with treatment e.g. go shopping alone. Relapse is common but people should be offered further treatment if this occurs. People however with established symptoms lasting over one year have a poorer prognosis. These who have the condition over 5 years are likely to have life long problems, even with prolonged treatment.

20% of patients with agoraphobia eventually achieve spontaneous remission.
90% of patients with agoraphobia will experience significant improvement with treatment.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
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</thead>
<tbody>
<tr>
<td>Customers under 50</td>
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<tr>
<td>years of age:-</td>
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<tr>
<td>Agoraphobia</td>
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<td></td>
<td>Less than 5 years</td>
<td>2 year award</td>
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<tr>
<td></td>
<td>More than 5 years</td>
<td>5 year award</td>
</tr>
<tr>
<td>Customers over 50</td>
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<tr>
<td>years of age:-</td>
<td></td>
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</tr>
<tr>
<td>Agoraphobia</td>
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<tr>
<td></td>
<td>Less than 5 years</td>
<td>2 year award</td>
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<tr>
<td></td>
<td>More than 5 years</td>
<td>Indefinite award</td>
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<tr>
<td></td>
<td>More than 5 years</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

Simple (specific) phobias

Customers over 50 years of age:-
Simple (specific) phobias

Customers under 50 years of age:-
Complex phobias

Customers over 50 years of age:-
Complex phobias
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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**Anxiety disorders in people over 65**

Isolated anxiety disorders, including agoraphobia are unusual in people over 65. When they occur, they are usually associated with a depressive illness.

Agoraphobia may, however, sometimes occur following an acute physical illness, despite a good recovery from the underlying physical condition.

Treatment is similar to that for a younger age group, with some minor differences. For example, as many people with anxiety states have a co-existing depressive illness, the use of sedative antidepressants may be useful.

Back to top of section
What you need to know about mechanical Back Pain

What is mechanical Back pain?
Most people (60-80% of the world's population) will experience back pain at some point in their lifetime. 85-90% of all.... Read more about Back pain.

What evidence is available?
The claimant and/or carer are unlikely to be able to provide the information required to clearly distinguish between .... Read more about evidence sources.

Activities of Daily Living and Mobility needs
During an acute bout of mechanical back pain, sudden onset of pain may render an individual temporarily ....... Read more about ADL and mobility needs.

How long will the needs last?
The prognosis for complete recovery in mechanical back pain is excellent. By the end of 6 weeks, 90% of both new and..... Read more about award duration.

Over 65's
The prevalence of back pain declines slightly after the age of 65. It is commoner in women. Severity, chronicity and ...... Read more about effects in the over 65 age group.

Mechanical Back Pain
Mechanical Back Pain is also called by a number of other medical terms. These are -:

• Non-specific back pain
• Simple backache
• Spondylosis (without pathological/neurological changes)
• Lumbar spondylosis or spondylitis (without pathological/neurological changes)
• Osteoarthritis of spine (without pathological/neurological changes)
• Lumbago
• Back strain or sprain
• Spasm of back
- Back pain
- Chronic back pain
- Degenerative back problem or disease
- Muscular back pain

Most people (60-80% of the world’s population) will experience back pain at some point in their lifetime. 85-90% of all episodes of back pain are non-specific or mechanical in nature.

Mechanical means that the source of the pain may be in the spinal joints, vertebrae or soft tissues. However, in the vast majority of cases of mechanical back pain it is not possible to identify a pathologically definable problem. That is, no structural abnormality of the back can be found on examination or x-ray to account for the symptoms.

Multiple studies have shown that spinal abnormalities are as common in symptom free individuals as they are in those who have back pain. These incidental findings may include:

- Non-specific degenerative changes
- Bulging inter-vertebral discs
- Desiccated discs
- Soft tissue and/or bony abnormalities

Specialised investigations such as Computerised Tomography (CT) and Magnetic Resonance Imaging (MRI) scans have also failed to identify a cause for MBP.

Many alarming abnormalities in the lumbar spine and associated structures have been discovered in symptom free people with normal back function on MRI/CT imaging. Mechanical back pain is therefore best described as non-specific.

Once an individual has experienced their first episode of mechanical back pain, although the episode itself is usually self-limiting and resolves quickly, there is an increased risk of further back pain episodes.

Risk factors for recurrent back pain include:

- Smoking
- Previous pain syndromes (e.g. Fibromyalgia)
- Poor socio-economic status
- Psychological distress at presentation
- Dissatisfaction with employment
- Heavy manual work

Back to top of section
What evidence is available?

Mechanical Back Pain

The claimant and/or carer are unlikely to be able to provide the information required to clearly distinguish between Mechanical Back Pain and Specific Back Pain and to accurately assess resulting mobility and care needs diagnostic details should be obtained from the General Practitioner or Consultant.

Activities of Daily Living and Mobility considerations – Mechanical back pain

<table>
<thead>
<tr>
<th>Mechanical Back Pain</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category</strong></td>
<td><strong>Description</strong></td>
</tr>
<tr>
<td>Disabling Effects</td>
<td>During an acute bout of mechanical back pain, sudden onset of pain may render an individual temporarily immobile on each occasion. These episodes of severe pain and restriction are likely to be infrequent and of short duration and are unlikely to last longer than 1-2 days. Pain usually quickly subsides to a much lower level and usually completely resolves, the majority being completely symptom free in 1-2 weeks. Only 5% of the total will still experience discomfort at 12 weeks but will normally have minimal functional limitations. Individuals with chronic low back pain may experience some difficulty in bending the lower back. The affected individual should be encouraged to maintain a positive mental attitude and return promptly to employment and normal activities/lifestyle. This is important in maintaining independence and reducing unnecessary reliance on others. Similarly, as mechanical back pain does not lead to neurological or other problems in the lower limbs, mobility should not be restricted. MBP is, however a common cause of Fibromyalgia.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Walking would not normally be adversely affected. The person would normally be able to walk normal distances with no significant impairment of gait or speed. No guidance or supervision needs are anticipated.</td>
</tr>
<tr>
<td>ADL</td>
<td>The person would normally be able to carry out self-care tasks without help. Specifically they would normally be able to sit, rise, bend down using the hips and knees and get in and out of bed in the usual fashion. They would normally be able to prepare a main meal for</td>
</tr>
</tbody>
</table>
themselves. People with this condition would not normally suffer from falls and supervision and watching over would not be required.

Note:
In a small proportion of cases MBP can cause disability. The main distinguishing feature in such cases is a marked and ongoing problem with pain. This has 2 main aspects:

- Difficulty in coping with pain.
- Problems with pain management.

A multidisciplinary team approach in the management of such cases is essential, together with early intervention. Evidence that the individual is having significant difficulties in coping with pain and that referral to a Pain Management Clinic is necessary supports the claimed limitations of lifestyle due to MBP.

How long will the needs last?

Mechanical Back Pain

The prognosis for complete recovery in mechanical back pain is excellent. By the end of 6 weeks, 90% of both new and recurrent episodes of mechanical back pain are symptom free, with the majority of these resolving fully in 1-2 weeks. A further 5% recover within 12 weeks.

The remaining 5% develop persistent pain leading to chronic low back pain. The development of chronic low back pain however does not equate with disability. As a general rule, individuals with chronic (longstanding and persistent) back pain have minimal care needs or mobility restrictions. In a small percentage of cases, psychological and psychosocial factors lead to the development of a disabled lifestyle.

Most people with a herniated cervical disc (about 80-90%) improve significantly with conservative treatment. Only about 10% require surgical treatment, and most people make a full recovery and return to work within a month or two. A small minority of those receiving surgery do go on to have chronic symptoms such as persistent pain and upper extremity weakness and numbness.

MBP is most unlikely to cause any significant long-term care or mobility needs. People with this type of back problem almost always learn methods and strategies in order to adapt and overcome their difficulties (e.g. rising from bed, stooping, dressing and preparing a main meal). They will actively refuse help, which is known to worsen their pain (e.g. being pulled up from sitting or from lying in bed, or being turned over in bed).

It should only be rarely that the Departmental Decision Maker considers that entitlement due to Mechanical Back Pain is appropriate. It is strongly
suggested that each case is discussed with Medical Services to confirm entitlement and to decide upon the duration of award.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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Back pain in people over 65
The prevalence of back pain declines slightly after the age of 65. It is commoner in women. Severity, chronicity and disability may worsen with age although the results of studies are inconsistent.

Although the majority have non-specific back pain, most of which is due to degenerative disease, the incidence of specific back pain rises in comparison to younger people.

Treatment of non-specific back pain.

Treatment of non-specific back pain is similar to that in younger people with some minor exceptions.

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What you need to know about specific Back Pain

What is specific Back pain?
- Read more on NHS Choices - Ankylosing Spondylitis
- Read more on Cauda equina
- Read more on NHS Choices - Kyphosis
- Read more on NHS Choices - Slipped disc
- Read more on Spinal Stenosis
- Read more on NHS Choices - Spondylolisthesis
- Read more on NHS Choices - Scoliosis
- Read more on Tumours & specific back pain

For information about other specific back pain disorders Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
The claimant and/or carer are unlikely to be able to provide the information required to accurately assess..... Read more about evidence sources.

Activities of Daily Living and mobility needs
People with this level of restriction would normally have some pain and discomfort in the...... Read more about ADL & mobility needs.

How long will the needs last?
Prognosis and duration of disabling effects will vary according to the condition. The outlook for the majority of ..... Read more about award duration.

Over 65's
The prevalence of back pain declines slightly after the age of 65. It is commoner in women. Severity, chronicity and..... Read more about effects in the over 65 age group.
What evidence is available?

Specific Back Pain

The claimant and/or carer are unlikely to be able to provide the information required to accurately assess mobility and care needs. Further details should be obtained from the Consultant, Physiotherapist, Occupational Therapist or General Practitioner.

Activities of Daily Living and Mobility considerations - Specific back pain

Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with this level of restriction would normally have some pain and discomfort in the lower back and possibly in the buttocks and thighs as well. They may experience discomfort from tightening of the neck or back muscles. Their discomfort is likely to be more noticeable on physical activity, but these periods of increased discomfort are likely to be infrequent and of short duration.</td>
</tr>
<tr>
<td>Mobility</td>
<td>People with such a restriction would normally be able to walk several hundred metres at a normal or near normal speed. They would be unlikely to suffer from falls. If an acute flare up occurs, mobility may be more severely affected but this would be for the minority of the time. There would be no need for guidance or supervision outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>People with this level of functional restriction would normally be able to safely manage all aspects of their personal care. More difficulty with personal care tasks may arise if flare-ups occur, but this will be for the minority of the time. Specifically there would normally...</td>
</tr>
</tbody>
</table>
be no significant difficulty in getting out of a normal height chair, getting in and out of bed and the bath, rising from the toilet and coping with personal hygiene or climbing stairs safely. There would normally be no significant difficulty in dressing, using appropriate aids where necessary, or with feeding, washing, shaving and aspects of main meal preparations such as lifting pans and peeling vegetables. Some difficulty may be experienced in bending. However, if good hip and knee movements are present, bending can be achieved even with minimal back movements by bending at the hips and knees. People with such a condition would not normally suffer from falls and there would be no requirement for supervision and watching over.

**Moderate Functional Restriction**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with this level of functional restriction are likely to experience pain and discomfort in their neck or lower back for most of the time. The pain may radiate into one buttock predominantly and travel down that leg below the knee into the foot and toes. The leg pain is often accompanied by numbness and tingling on the affected side in the specific region supplied by the nerve root. They may also experience discomfort from tightening of the back muscles. In the case of cervical prolapse (herniation), pain may radiate from the neck to the arm, and is often associated with numbness and tingling.</td>
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</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>People with such a restriction will be able to walk at least a few hundred metres at a normal or near normal speed. They should be able to walk with a mild limp, and they would be unlikely to suffer from falls. There would be no need for guidance or supervision outdoors.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>People with this level of functional restriction could have difficulty coping with some activities of daily life in particular dressing their lower garments e.g. trousers and socks due to bending difficulties but technical aids are available to overcome this if present. They would normally be able to carry out other personal care tasks such as rising from a normal height chair, getting into and out of bed and the bath and climbing stairs. However, despite the presence of pain or discomfort, functional limitations in performing these activities are likely to be minimal in the majority of cases. If the upper limbs are affected, aspects of main meal preparation such as</td>
</tr>
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</table>
lifting pans and peeling vegetables would normally be possible, albeit with some discomfort. Simple aids such as a light saucepan are helpful to overcome any difficulties. There is likely to be some restriction of spinal movements, e.g. limitation of forward flexion and extension of the back, and reduced sideways (lateral) flexion on one side. However, if good hip and knee movements are present, bending can be achieved even with minimal back movements by bending at the hips and knees. People with such a condition would not normally suffer from falls and there would be no requirement for supervision and watching over.

<table>
<thead>
<tr>
<th>Severe Functional Restriction</th>
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<tbody>
<tr>
<td>Category</td>
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<tr>
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</tr>
<tr>
<td><strong>Disabling Effects</strong></td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
</tr>
<tr>
<td><strong>ADL</strong></td>
</tr>
</tbody>
</table>
have difficulties with dressing, particularly with their lower garments e.g. trousers, socks due to bending difficulties. There may be considerable difficulty with other personal care tasks, such as rising from a normal height chair, climbing stairs and aspects of main meal preparations such as lifting pans, and bending to a traditional oven to insert and remove items. Due to leg weakness on one side, loss of sensation and possible foot drop, a risk of falls may be present. There may be a requirement for supervision and watching over if falls occur even with the use of walking aids. If affected on both arms there may be marked problems with dressing, preparing a main meal and toileting. If however only one side is involved, only bimanual tasks are affected.

**How long will the needs last?**

**Specific Back Pain**

Prognosis and duration of disabling effects will vary according to the condition. The outlook for the majority of individuals with specific back pain is good with fifty percent (50%) of cases recovering fully within six weeks.

The remainder will develop longer lasting back pain, and may also have leg pain and/or other symptoms on one side. These symptoms may become longstanding and persistent (chronic), but this does not equate with disability.

Many individuals with a prolapsed disc, even when nerve root entrapment is present, will normally have mild disability. The majority of individuals would normally be self-caring and should be encouraged to participate in as active a lifestyle as possible.

The majority will have minimal or mild care needs or mobility restrictions.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ankylosing Spondylitis</td>
<td>Less than 5 years</td>
<td>3 year award</td>
</tr>
<tr>
<td></td>
<td>More than 5 years</td>
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<tr>
<td>Condition</td>
<td>Less than 5 years</td>
<td>More than 5 years</td>
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<td>--------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Spondylolisthesis</td>
<td>More than 5 years</td>
<td>Less than 5 years</td>
</tr>
<tr>
<td>Spondylosis/Spondylitis (OA) (if pathological/neurological changes present)</td>
<td>More than 5 years</td>
<td>Less than 5 years</td>
</tr>
<tr>
<td>Spinal stenosis</td>
<td>More than 5 years</td>
<td>Less than 5 years</td>
</tr>
<tr>
<td>Structural abnormalities of the spine e.g.</td>
<td>More than 5 years</td>
<td>Less than 5 years</td>
</tr>
<tr>
<td>Kyphosis</td>
<td>N/A</td>
<td>Less than 5 years</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>N/A</td>
<td>More than 5 years</td>
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<tr>
<td>Other specific back pain / type not known</td>
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<tr>
<td>Cauda Equina</td>
<td>More than 1 year</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>Dislocation</td>
<td>More than 1 year</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>Slipped disc disorders e.g.</td>
<td>N/A</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>Prolapsed Intervertebral Disc (PID)</td>
<td></td>
<td>More than 1 year</td>
</tr>
<tr>
<td>Prolapsed Cervical Disc</td>
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<tr>
<td>Lordosis</td>
<td>N/A</td>
<td>Less than 5 years</td>
</tr>
<tr>
<td>Spinal osteochondrosis</td>
<td>More than 5 years</td>
<td>Less than 5 years</td>
</tr>
<tr>
<td>Sprain or strain of spine / pelvis (as a result of major trauma e.g. RTA</td>
<td>More than 1 year</td>
<td>Less than 1 year</td>
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<tr>
<td>or a fall from height etc)</td>
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<tr>
<td>Vascular and nerve compression</td>
<td>More than 5 years</td>
<td>Less than 5 years</td>
</tr>
<tr>
<td>Vertebral subluxation</td>
<td>More than 5 years</td>
<td>Less than 5 years</td>
</tr>
</tbody>
</table>

**Specific back pain and surgery**

In all cases where surgery is undertaken and entitlement is appropriate, Award for 1 year
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back pain in people over 65
The prevalence of back pain declines slightly after the age of 65. It is commoner in women. Severity, chronicity and disability may worsen with age although the results of studies are inconsistent.

Although the majority have non-specific back pain, most of which is due to degenerative disease, the incidence of specific back pain rises in comparison to younger people.

Degenerative disease of the spine
With advancing age, these changes are universal. However, even though the majority of the population have X ray evidence of degenerative disease of the spine by age 65, there is poor correlation with symptoms.

Spondylolisthesis is the forward movement of one vertebral body over the vertebral body beneath it. In older people the most common cause is degenerative change in the spine. It is usually an incidental X ray finding and does not usually cause a clinical problem. Symptoms, if present are usually non-specific and nerve root entrapment is uncommon. Occasionally it can cause narrowing of the spinal canal resulting in spinal stenosis.

Degenerative disease of the spine predisposes to spinal stenosis and prolapsed inter-vertebral disc (see relevant sections).

Metabolic bone disease
Osteoporosis is the metabolic bone disease of greatest clinical and economic significance in the elderly (see relevant section).

Paget’s disease (osteitis deformans) occurs in 3 percent of elderly people. It is caused by increased bone turnover. The resulting bone is larger than normal but is mechanically weak. It is usually asymptomatic. The most commonly affected bones are the skull, pelvis, femur and tibia and the lumbar spine. Any symptoms that occur depend upon the bones affected. Symptoms arise from:

- Deformities and fractures in the weakened bone.
- Nerve compression by the expanding bone (for example the auditory nerve, resulting in deafness).
- Cardiac failure due to an increased blood supply to the affected bone.
Back pain due to Paget's disease may be treated with analgesics, but may warrant treatment with specific medication such as calcitonin and bisphosphonates (for example, etidronate).

**Ankylosing Spondylitis**
In the elderly, advanced spinal disease may result in fused or “bamboo” spine, spinal fracture, or spondylodiscitis, all of which result in significant reduction of spinal mobility.

Treatment includes physiotherapy, exercise, education and non-steroidal anti-inflammatory medication (NSAIDs) as this reduces discomfort and the risk of permanent deformity.

**Neoplasm (Tumour/cancer)**
The incidence of back pain caused by neoplasm increases with age. In one study, 7 percent of people with back pain over the age of 50 were found to have a neoplastic cause, either primary or secondary, compared with no cases of neoplasm in people under the age of 50.

**Infection**
Although uncommon, these are more common as a cause of back pain in the elderly.

People with infections of the spine are usually generally unwell. Treatment is usually with the relevant antibacterial agent, usually antibiotics.

**Cauda Equina syndrome**
This rare condition is a severe neurological disorder that normally results from a prolapsed disc. It can lead to incontinence and even paraplegia, and is often a medical emergency.

The cauda equina is Latin for “horse’s tail” and describes the bundle of nerve roots at the end of the spinal cord. The spinal cord ends at the upper region of the lumbar spine and becomes a bundle of individual nerve roots like a horse’s tail, which continue along the spinal canal. The cauda equina is the continuation of these nerve roots in the lumbar region.

Cauda equina syndrome most commonly results from a central disc prolapse in the lumbar region. It is accompanied by a range of symptoms, the most important features are:

- rapidly worsening neurological signs and symptoms in a person with a known lumbar disc prolapse.
- bilateral leg pain (sciatica) and neurological signs (muscle weakness and sensory loss).
- saddle (or caudal) anaesthesia [unable to feel anything in the body area that would normally sit on a saddle].
- urinary or bowel incontinence.

Prompt surgical treatment is indicated for cauda equina syndrome, ideally within 48 hours of the onset of the syndrome. Delay may result in permanent neurological damage with functional limitations. If left untreated, cauda equina syndrome can result in paraplegia.

**Spinal Stenosis**

This is a condition where there is narrowing of the spinal canal. This may be caused by recurrent disc prolapse and subsequent loss of disc height, or by arthritis of spinal (facet) joints where bony outgrowths (osteophytes) impinge on the spinal canal.

Due to spinal canal narrowing, nerve root pain and paraesthesia (sensory impairment with numbness and tingling) occur. These symptoms usually commence in later life, usually after 50 years of age, and are characterised by back and leg pain brought on by physical activity, and relieved slowly by rest.

Bending forwards also relieves symptoms, as this activity opens the spinal canal. Individuals with spinal stenosis commonly report that their symptoms are eased by walking uphill, or on climbing stairs, or by leaning on a supermarket trolley, as these activities involve bending the spine.

**Disabling Effects**

As a general rule, many individuals with spinal stenosis will have symptoms that develop slowly over time; minimal or mild care and mobility needs would normally be present. Such individuals would normally be self-caring. Mobility would not normally be significantly restricted in the majority of cases. A minority of cases develop rapidly worsening symptoms and functional limitations, with severe restriction of walking tolerance.

**Treatment**

Most individuals with spinal stenosis, where the person’s symptoms are mild or of short duration will be offered non-operative therapy. This consists of a combination of short periods of bed rest, controlled physical activity, physiotherapy, non-steroidal anti-inflammatory drugs, pain relief medication and epidural injections. Not all of these may be required in every case.

A minority of individuals will have severe incapacitating nerve root pain in one or both legs and severe back pain on activity (known as spinal claudication, ‘neurogenic intermittent claudication’ or ‘psuedoclaudication’). These symptoms are often accompanied by absent reflexes, muscle weakness and loss of sensation in the legs. Such cases are referred for consideration of surgery, when a laminectomy is the treatment of choice. This spinal operation is often successful in fully resolving the person’s symptoms.
Tumours (Cancer) and Specific Back Pain

Tumours affecting bone can be either Primary, arising from the bone itself, or secondary satellite deposits called Metastases arising from a distant non-bony tumour. The following tumours commonly metastasise to bone:

- bronchus
- thyroid
- breast
- kidney
- prostate
- malignant melanoma
- multiple myeloma

Primary bone tumours are far less common than metastases, and present with local pain and swelling. Treatment will depend upon the type of tumour, but usually involves surgery followed by radiotherapy and chemotherapy.

The majority of spinal pain arising from tumours is due to metastases. These satellite deposits invade the bone (and other tissues) and alter the function of that tissue or put pressure on surrounding tissues and structures. This may result in a variety of symptoms. Back pain from metastases can result from the cancer growing inside non-expandable bone, or from pressure on nerves and/or other surrounding structures.

Metastatic bone disease typically presents with bony pain, pathological fractures or spinal cord compression syndrome. Most tumours weaken bone by producing substances, which encourage bone re-sorption. The weakened bone is thus more likely to fracture than normal bone, (a pathological fracture), and due to the presence of the cancer is less likely to heal.

Disabling effects

Spinal cord compression syndrome occurs when the tumour compresses the spinal cord or the nerve roots in the spinal canal. This causes pain and loss of function of the nerves (neurological deficit). Such a person may develop severe mobility restrictions and may have difficulty getting into and out of bed and the bath, rising from a chair, dressing and undressing, preparing a main meal and attending to toilet needs. Under these circumstances there may be care needs both day and night.

The longer a person has a neurological deficit, the less likely normal nerve function will return. Urgent surgical decompression of the spinal canal may be indicated, along with other treatments to inhibit the cancer, and control pain. If performed promptly, this may restore much functional ability and decrease care and mobility needs.
Management of metastatic bone disease

The most effective way to treat metastases is with anti-tumour therapy, e.g. radio or chemotherapy. Where this is ineffective, efforts should be concentrated on the following:

Control of pain:

- Pain relief medication.
- Non Steroidal Anti Inflammatory Drugs (NSAIDs).
- Nerve blocks.

Treatment of local lesions:

- Surgical fixation of fractures, if possible.
- Spinal cord decompression.

Drugs to inhibit bone re-sorption:

A cure may not normally be possible with advanced metastatic bone disease, and the above measures may be palliative in their intent (i.e. designed to relieve symptoms rather than cure the disease). Palliative therapy can often improve quality and length of life, but with this level of disease a claim under the Special Rules would not be unreasonable.

Pain Management Clinic

Not to be confused with Pain Clinics, which are usually run by anaesthetists and aim to treat the pain.

Pain Management Clinics are run by a professional multidisciplinary team, usually consisting of a psychologist, physiotherapist, nurse and doctor. Pain management programmes are offered to people who have chronic pain of at least 6 months duration and where all other appropriate treatments have been undertaken. Referral from a GP or local hospital is required, and an initial assessment is carried out by the clinic to confirm suitability for the programme before a place will be offered.

The programme lasts between 8-10 weeks and consists of small groups who meet weekly for a half - day session. Usually this is conducted on a non - residential basis, but in severe cases a residential option may be offered.

A variety of methods are employed by the multidisciplinary team. The basis of the programme is aimed at introducing coping strategies, which help individuals manage their pain and improve their quality of life. This will include psychological, physical and practical techniques, known as Cognitive Behavioural Therapy (CBT).
What you need to know about Bipolar disorder

Back to A-Z

What is Bipolar disorder?
Bipolar disorder – known in the past as manic depression – is a condition that affects your moods, which can. Read more on NHS Choices - bipolar disorder.

What evidence is available?
The claimant may not be a reliable source of information therefore the carer should be able to provide the information required to…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Mild Functional Restriction - Symptoms of anxiety and panic arising from the disorder would be unlikely to…. Read more about ADL & mobility needs.

How long will the needs last?
Although recovery from an individual episode of mania or depression can be expected, the long-term prognosis for…. Read more about award duration.

Over 65s
The incidence of bipolar disorder in people over 65 is similar to that in younger people. It accounts for between…. Read more about effects in the over 65 age group.

What evidence is available?

The claimant may not be a reliable source of information therefore the carer should be able to provide the information required to accurately assess mobility and care needs. However, if further details are needed, the Specialist Nurse or Consultant Psychiatrist is an appropriate source of information.

The claimant may be supported by the Care Programme Approach (CPA) and hold written information outlining the level of external support required, which is a useful first source of further medical evidence.
# Activities of Daily Living and Mobility needs

## Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>Symptoms of anxiety and panic arising from the disorder would be unlikely to be prominent or cause any functional limitation. Limb function would be normal.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>People with mild functional restriction would, for example normally have no difficulty finding their way around outdoors, because they do not usually experience any confusion, inattention, memory loss, or impaired judgement.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>People with mild functional restriction would normally be able to care for themselves by maintaining personal hygiene, preparing meals etc. They would have little or no functional limitations on a day-to-day basis and their mood would be normal and they would be alert and orientated with no evidence of confusion, memory loss, poor concentration, disordered thinking, or impaired judgement. They would not require supervision or watching over to prevent abnormal behaviour.</td>
</tr>
</tbody>
</table>
Moderate Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with moderate functional restriction who manifest hypomanic symptoms may become overactive, agitated, inattentive, noisy, have bizarre ideas, delusions and disordered thinking such that they are unable to initiate and complete the usual tasks of daily living. Sleep patterns may be disrupted with unacceptable or antisocial behaviour occurring at night. Aggressive, hostile and violent behaviour may develop. Insight into their medical condition may be limited and the need for treatment denied. Self - neglect, social isolation, and social withdrawal may occur in moderate bipolar disorder when depressive symptoms are predominant Confusion, incoherent speech, decreased memory, and impaired judgement may be present. Symptoms of anxiety and panic disorder may also occur as part of the illness. Limb function would be normal.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>People with moderate functional restriction would display inattention, confusion, poor concentration, incoherent speech, memory loss, impaired judgement and anxiety and panic disorder, which would indicate that they may need guidance or supervision outdoors. Bizarre and anti-social behaviour may be a problem out of doors.</td>
</tr>
</tbody>
</table>
| People with moderate functional restriction, if in the hypomanic phase, would need to be encouraged to get up at an appropriate time, wear suitable clothes, maintain personal hygiene, prepare and eat regular meals, go to bed and remain there at night. If depressed they would need encouragement to initiate and complete tasks of daily living e.g. they may need to be told and encouraged to get up, wash, dress, and prepare meals in order to maintain a reasonable standard of hygiene and nutrition. They might have to have support mechanisms in place to maintain a stable routine for the person to prevent relapse and exacerbations of symptoms or need to be reminded and encouraged to attend a day centre, hospital or psychiatric clinic appointments or attend for regular blood tests if taking lithium.
If depressed they may need to be encouraged to participate in social and leisure activities to reduce social withdrawal and isolation or need help with communication, correspondence, and financial matters including prevention of reckless spending. Someone to supervise their medication and some supervision indoors due to inattention, decreased concentration, confusion, incoherent speech, memory loss, impaired judgement and bizarre/anti social behaviour. They may need protection from financial or sexual exploitation. |
Severe Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with severe functional restriction who manifest severe symptoms of mania may become very overactive, very agitated, inattentive, noisy, have bizarre ideas, delusions, hallucinations and highly disordered thinking. Sleep patterns may be disrupted and unacceptable or antisocial behaviour occurs throughout the night as well as by day. They may fail to eat or drink at all and can potentially collapse with exhaustion. Aggressive, hostile and violent behaviour may develop. Insight into their medical condition may be limited and the need for treatment denied. Self-neglect, social isolation, and social withdrawal may occur in moderate bipolar disorder when depressive symptoms are predominant. Confusion, incoherent speech, decreased memory, and impaired judgement may be present. Symptoms of anxiety and panic disorder may also occur as part of the illness. Limb function would be normal.</td>
</tr>
<tr>
<td>Mobility</td>
<td>People with severe functional restriction would display inattention, confusion, incoherent speech, memory loss and impaired judgement, which is likely to indicate that they would need guidance or supervision outdoors. They may exhibit anti-social, bizarre or occasionally hostile or aggressive behaviour, which is also likely to require guidance or supervision outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>People with severe functional restriction, if in the manic phase would need to be encouraged to get up at an appropriate time, wear suitable clothes, maintain personal hygiene, prepare and eat regular meals, go to bed and remain there at night. If depressed encouragement would be needed to initiate and complete tasks of daily living e.g. they may need to be told and encouraged to get up, wash, dress, and prepare meals in order to maintain a reasonable standard of hygiene and nutrition. Regular contact to prevent self-neglect and a decline into apathetic behaviour. If not encouraged, the person may lie in bed all day and do nothing, or engage in aimless, repetitive activities. They would need to be reminded and encouraged to attend a day centre, hospital or psychiatric clinic appointments and to attend for regular blood tests if taking lithium. If depressed, encouragement to participate in social and leisure activities to reduce social withdrawal and isolation would be required and help with communication, correspondence, and financial matters including prevention of reckless spending. To have support mechanisms in place to maintain a stable routine for the person to prevent relapse and exacerbations of both manic and depressive symptoms. Supervision from a carer to reduce risk of self-harm. Encouragement to eat or drink. Supervised medication including attendance for medication by injection in some cases. Supervision to deal with the consequences of bizarre, antisocial, hostile and aggressive</td>
</tr>
</tbody>
</table>
behaviours. They may need protection from financial or sexual exploitation.

**How long will the needs last?**

Although recovery from an individual episode of mania or depression can be expected, the long-term prognosis for people with bipolar disorders is poorer than might be anticipated. Long-term studies (25 years) show that on average a person with bipolar disorder will have ten further episodes of mood disturbance. The time interval between episodes tends to shorten with increasing numbers of episodes and increasing age. Although treatment of an individual episode of mania or depression symptoms may be relatively effective, people continue to have disabling symptoms affecting daily life, social interaction and ability to work.

For a person who is making a reasonable recovery from a single episode of hypomania or severe depression it may be appropriate to make a limited award. Those people who relapse infrequently, perhaps every 3 to 5 years, and in whom the evidence shows that the mental state is normal between relapses might also be eligible for a limited award.

People who have a history of recurrent episodes, and in whom symptoms of abnormal mood exist most of the time, despite treatment with appropriate medication, should be considered for an indefinite award.

The following features are likely to indicate long-term disability:

- Recurrent episodes of mania and depression.
- Decreasing interval between episodes of relapse.
- History of multiple hospital admissions.
- History of admission under the Mental Health Act.
- In sheltered or supervised accommodation.
- Long-term prescription of mood stabilising drugs such as lithium.
- Treated with ECT.
- Rapid cycling disorder.

### Impairment

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset, frequency of relapses &amp; mental state between relapses</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bipolar disorder</td>
<td>- Less than 5 years or More than 5 years and one relapse in a 3 year period</td>
<td>5 year award</td>
</tr>
</tbody>
</table>
• More than 5 years and mental state normal between relapses.

• More than 5 years and more than one relapse in a 3 year period or

• More than 5 years and mental state not normal between relapses.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Bipolar disorders in people over 65

The incidence of bipolar disorder in people over 65 is similar to that in younger people. It accounts for between 5 and 10 percent of affective illness in old age.

The symptoms are similar to those found in a younger age group, but in older people it is more likely that a depressive episode will occur immediately after a manic episode.

Treatment is similar to that for a younger age group, with some minor differences. For example, because older people are more sensitive to medication, lithium blood levels should be monitored with particular care and the level should be kept at the lower end of the therapeutic range.
What you need to know about Bladder cancer

Back to A - Z

What is Bladder cancer?
Bladder cancer is caused by an abnormal tissue growth, known as a tumour, which grows and spreads inside the bladder. Read more on NHS Choices - bladder cancer.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even... Read more about evidence sources.

Activities of Daily Living and Mobility needs
Disabling effects of bladder cancer are variable and depend on how advanced disease has become, what treatment is.... Read more about care & mobility needs.

How long will the needs last?
This is the commonest type of bladder cancer and has the best long term outcome. About 75% of people.... Read more about award duration.

Over 65s
There are no special features in the elderly.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a ‘Care plan’ from social services

Hospital
Specialist doctors -:
- Oncologist
- Physician
- Haematologist

**Specialist nurses have many different job titles :-**
- Clinical Nurse Specialist
- Stoma care nurse
- Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

**Professions Allied to Medicine :-**
- Physiotherapist
- Occupational Therapist
- Social worker
- Counsellor
- Psychologist

Also refer to the ‘Symptomatic treatments’ page.

**Hospice**

Hospice Specialists :-:

- Palliative Care Physician
- Macmillan Nurse
- Clinical Nurse Specialist
- Social worker
- Physiotherapist
- Occupational Therapist
- Counsellor

[Back to top of section]

**Activities of Daily Living and Mobility needs**

Disabling effects of bladder cancer are variable and depend on how advanced disease has become, what treatment is possible and whether recovery is expected or not. There are three different categories used in care and mobility guidance for bladder cancer and are:

- Superficial bladder cancer
- Invasive bladder cancer
- Advanced or metastatic bladder cancer

**Superficial**

There are usually no care or mobility needs associated with superficial bladder cancer or its treatment.
Invasive Care
The symptoms of this condition are not disabling and the aim of treatment of this condition is to return a person to full health. If someone is receiving treatment it is unlikely that there will be enduring care needs once recovery from surgery or radiotherapy treatment is complete. If any award is made to cover disabling effects during the treatment period it should be of limited duration. The exception to this is

• Where other disabilities mean that a person cannot manage their own continence or urostomy without help in which case a life award should be made to reflect that urinary diversion is permanent, an example of this would be severe rheumatoid hands affecting manual dexterity or mobility problems.
• Where enduring but rare side effects of chemotherapy or radiotherapy treatment occur.

If cancer has returned after treatment for invasive bladder cancer - follow Advanced or Metastatic bladder cancer guidance below.

Mobility
There are usually no enduring mobility problems associated with this condition.

Advanced or Metastatic Care
They may experience any of the common disabling effects of metastatic cancer such as those caused by brain, liver and bone metastases. For those who have developed metastatic disease after cystectomy they may have difficulty managing their urostomy through fatigue, particular problems for them may be dealing with larger heavier night bags used to collect urine and dealing with laundry associated with leaks. A further problem may be the added burden of extra tubes and equipment associated with nephrostomy tubes (this is a catheter inserted through the back - into the kidney when the urine outflow from the kidney is blocked) – a kidney which is blocked like this may be very painful. This is in addition to the general effects of metastatic disease.

Mobility
A particular problem for people with bladder cancer may be lymphoedema of the lower limbs which has a profound effect on the ability to walk.

How long will the needs last?

Superficial
This is the commonest type of bladder cancer and has the best long term outcome. About 75% of people diagnosed have this sort of bladder cancer.
Invasive

It is recommended that if treatment is not being given for any reason and if needs are identified an indefinite award is made.
If treatment is being given, any award made should be limited to the length of treatment and a reasonable period of recovery.
In the typical case a return to health is expected once recovery from treatment has taken place.

Advanced or Metastatic

Average survival with supportive treatment only is 2-4 months. With maximal treatment including cisplatin based chemotherapy this can be extended to 12-14 months with 20% of people treated like this living for 3 years or more.
No long term improvement in condition is expected, this is a terminal illness.

<table>
<thead>
<tr>
<th>Stage of cancer</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Superficial</td>
<td>N/A</td>
</tr>
<tr>
<td>Invasive :-:</td>
<td></td>
</tr>
<tr>
<td>Treatment being given</td>
<td>Length of treatment period plus a reasonable recovery period</td>
</tr>
<tr>
<td>No treatment being given</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Advanced / Metastatic</td>
<td>Indefinite</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Bladder & urinary tract disorders

What is a Bladder or Urinary tract disorder?
- Read more about Benign Prostatic hyperplasia (prostate enlargement)
- Read more about bladder (urinary) incontinence
- Read more about bladder (urinary) infections
- Read more about Hydronephrosis
- Read more about Prostatitis
- Read more about Pyelonephritis (Kidney infection)
- Read more about a Renal (Kidney) stone
- Read more about Gonorrhoea and Non-gonocccocal urethritis (NGU)

For information about other types of bladder or urinary tract disorder Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
Self-assessment is the prime source of evidence and in most cases the needs will be clear from ..... Read more about evidence sources.

Activities of Daily Living and Mobility needs
Most congenital abnormalities of the urinary tract are diagnosed at birth and they are all correctable either by ..... Read more about ADL and mobility needs.

How long will the needs last?
Many of the urological problems that present are treatable or corrected by surgery. For instance ..... Read more about award duration.

Over 65s
The presentation, signs and symptoms and disabling effects are likely to be the same in the over- 65 age group. There is likely to be a higher incidence of benign prostatic hyperplasia in this group.

What evidence is available?
Self-assessment is the prime source of evidence and in most cases the needs will be clear from the claim pack. The claim pack should however be checked to see who has completed it and that it is an accurate and reliable description of their problems.
If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it should provide good evidence.

**Hospital Factual Report**
In cases of acute and chronic disorders, a Consultant Urologist would normally have been involved in the diagnosis, management and treatment of the individual. In the case of stones, the admission may have been urgent and there should be relevant hospital records available. The absence of any documented history of a specialist consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required.

**General Practitioner Factual report**
Conditions such as acute infections would usually be treated by the GP. Also, the General Practitioner would normally have made the initial referral of the claimant to the Consultant (if a referral has been made) and would normally be aware of the results of tests, treatment and current medication. Therefore a GPFR is often most useful in these cases.

**HCP examination report**
A Health Care Professional examination report would be likely to be necessary when :-

- The person claims significant disability (equivalent to a moderate or severe condition),
- In the absence of supporting evidence from the GP or Hospital Specialist,
- If no corroborative evidence has been able to be obtained, or
- If it is the only means whereby the claimant’s needs can be clarified.

**Medical Services**
The Medical Services doctor may be asked to request relevant information such as test results from the GP or Hospital Consultant and to interpret test results and other information. Complex claims may also be referred to Medical Services for discussion.

**Activities of Daily Living and Mobility needs**
Most congenital abnormalities of the urinary tract are diagnosed at birth and they are all correctable either by treatment or by surgery. For example, reflux is treated in children by long-term antibiotics. They may also grow out of it or the ureters are re-implanted by operative procedure.

Many conditions are treatable or surgically correctable where relevant.

If a person is mentally competent, and has normal use of his/her limbs, urinary incontinence, and other conditions such as stricture can be managed by self-catheterisation, intermittent catheterisation, indwelling
catheter with a bag (via the urethra or suprapubic) and/ or the use of incontinence pads.

The only situations in which care / mobility needs may be appropriate are -:

- Functional incontinence caused by a severe mental health condition such as dementia or severe psychosis.
- Advanced cancer of the prostate or bladder, for example. Click on the links for details of Bladder cancer guidance and Prostate cancer guidance. Back to top of section

How long will the needs last?
Many of the urological problems that present are treatable or corrected by surgery.

For instance, infection such as pyelonephritis and bladder, urethral or prostate infection are treatable by antibiotics.

Conditions such as stones in the ureter or bladder, for instance, will be treated by the stone passing naturally or being removed surgically.

Conditions such as stricture of the urethra, hydronephrosis/hydroureter and benign prostatic hypertrophy can be treated surgically.

In the case of malignancy, this may or may not be curable. Click here for Bladder cancer guidance and Prostate cancer guidance.

A person with incontinence, as long as they are mentally competent, can normally manage it independently. However, if they have other conditions limiting mobility or manual dexterity for example, they may not be able to cope independently.

In summary, there are very few situations where there are disabling effects arising from urological conditions, two exceptions being incurable malignancy and functional incontinence (where the background factor is a severe mental health condition).

Note:
The ‘qualifying period’ and ‘prospective test’ would not normally be satisfied with urological disorders, as treatment and recovery would normally be complete before the end of this period.

<table>
<thead>
<tr>
<th>Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benign prostatic hyperplasia (prostate enlargement)</td>
</tr>
<tr>
<td>Bladder calculus (Bladder stone)</td>
</tr>
<tr>
<td>Bladder (urinary) incontinence -:</td>
</tr>
<tr>
<td>Stress incontinence</td>
</tr>
<tr>
<td>Urge incontinence</td>
</tr>
</tbody>
</table>
Urinary overflow
Other / type not known
Blockage / stricture of the Urethra
Cystitis (Bladder infection) & other UTIs
Gonorrhoea & Non-gonocccocal urethritis (NGU)
Hydronephrosis / Hydroureter
Prostatitis
Pyelonephritis (Bacterial infection of the kidneys)
Renal (Kidney) stone / Obstruction
Trauma to the urethra
Ureteric colic (stone in the ureter)

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about Blood disorders

What is a Blood disorder?
- Read more about Haemophilia A & B
- Read more about Von Willebrand’s disease (VWD)

For information about other types of blood disorder Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
Anyone with haemophilia, clotting factor deficiency or von Willebrand’s disease, however mild, will have access to…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Mild functional restriction - clotting factor replacement is only required after significant injury or trauma. It is not…. Read more about care & mobility needs.

How long will the needs last?
People born before 1970 are likely to have disabling problems related to joint damage and multiple joints are likely to…. Read more about award duration.

Over 65s
People born before the 1970s are likely to have had many bleeding episodes prior to the introduction of…. Read more about effects in the over 65 age group.

What evidence is available?
Anyone with haemophilia, clotting factor deficiency or von Willebrand’s disease, however mild, will have access to a Comprehensive Haemophilia Care Centre. People with moderate and severe haemophilia are likely to use the centre along with anyone with mild haemophilia and haemophilia related joint problems. Often the centre will be used for all health needs not only those related to haemophilia. This is because haemophilia complicates any type of medical treatment – e.g. dentistry. A range of professionals will be involved with care and these include the treating haematologist, the specialist nurse, specialist physiotherapist and social worker.
The consultant or specialist nurse at the centre will be a good source of information on severity of haemophilia and clotting replacement therapy required.

The specialist physiotherapist will be the best source of information on mobility and joint problems. Anyone with such problems is likely to have had a joint scoring assessment. Joint score information for the lower limbs may be enough to confirm reduced mobility. If difficulties with care related to upper limb joint damage are claimed, further medical evidence in the form of a factual report in addition to joint scores is recommended. If neurological problems are claimed, either of these sources will be able to provide evidence of disabling effects.

Activities of Daily Living and Mobility needs

Mild Functional Restriction
Moderate Functional Restriction
Severe Functional Restriction

Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likely treatment</td>
<td>Clotting factor replacement is only required after significant injury or trauma. It is not required frequently enough to require home supplies and self treatment. Mobility will depend on whether there is joint damage to the lower limbs. The probability of this will depend on the customer’s age. A small proportion of people with mild haemophilia born before 1970 have significant joint damage from untreated bleeds that occurred before clotting factor treatment was available. Joint damage is not likely to be widespread and in this group joint replacement, particularly knee replacement can improve mobility. This is because in many cases most of the other joints are healthy, having not been affected by bleeding episodes.</td>
</tr>
<tr>
<td>Mobility</td>
<td>ADL Personal care may be difficult if the elbow or shoulder is significantly affected and range of movement in both these joints is poor. This is rare and is only likely in adults born before 1970. In these cases, help may be required with personal hygiene, dressing, meal preparation and administration of treatment.</td>
</tr>
</tbody>
</table>
Supervision by others does not prevent bleeds or prevent adults with normal cognitive function from sustaining injuries. Adults are able to recognise the onset of bleeding and seek help or self-treat.

**Moderate Functional Restriction**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likely treatment</td>
<td>Likely to self administer clotting factors on an as required basis.</td>
</tr>
</tbody>
</table>
Mobility will depend on whether there is joint damage to the lower limbs. The probability of this will depend on their age. People born before 1970 will have significant joint damage from untreated bleeds that occurred before clotting factor treatment was available. People born from 1970 onwards may have some joint damage depending on their frequency of their bleeding and the number of significant bleeds into joints they have had over the years.

If mobility is restricted, this will be because of pain related to arthritis in the hips, knees and ankles. Joint replacement of individual joints will relieve pain from arthritis and prevent further bleeding into that joint but will not improve range of movement or mobility. This is because other joints are affected. If a ‘fixed flexion’ deformity of the knee or hip is present then mobility is especially likely to be reduced, a flexion deformity effectively shortens the affected leg and affects gait. In someone with multiple damaged joints, this places further strain on other joints and increases the risk of bleeding when walking.

People with moderate haemophilia born more recently are likely to have very little joint damage. This is because clotting factor treatment can be administered at the onset of bleeding at home before a significant amount of blood has collected in the joint.

ADL

Personal care may be difficult if the elbow or shoulder is significantly affected and range of movement in both these joints is poor. This is much less common than mobility problems due to lower limb involvement. It is particularly likely in adults born before 1970.

Supervision by others does not prevent bleeds or prevent adults with normal cognitive function from sustaining injuries. Adults are able to recognise the onset of bleeding and seek help or self-treat.
### Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likely treatment</td>
<td>Likely to be on self administered prophylactic (preventative) clotting factor treatment at home. This involves several injections a week as described under treatment. The majority of adults are able to administer this themselves. Bleeding episodes are recognised early and extra clotting factors administered as described so preventing further joint damage form uncontrolled bleeding.</td>
</tr>
</tbody>
</table>
Mobility will depend on whether there is joint damage to the lower limbs. The probability of this will depend on their age. People born before 1970 are likely to have significant joint damage from untreated bleeds that occurred before clotting factor treatment was available. People born from 1990s onwards may have no or minimal joint damage as large bleeds into joints have been effectively prevented by prophylactic treatment. People born after 1986 may also have received prophylactic (preventative) treatment and be mobile. The majority will have some joint damage. Mobility is likely to be restricted because of pain on walking related to arthritis in the hips, knees and ankles. Joint replacement of individual joints will relieve pain from arthritis and prevent further bleeding into that joint but will not improve mobility or range of movement. This is because other joints are affected and they will still be painful on walking e.g. ankle pain becomes more noticeable after knee replacement. If flexion deformity of the knee or hip is present than mobility is especially likely to be reduced, a flexion deformity effectively shortens the affected leg and affects gait. In someone with multiple damaged joints this places further strain on other joints and increases the risk of bleeding when walking. People born before 1980 are likely to have multiple affected joints and mobility problems.

ADL

Personal care may be difficult if the elbow or shoulder is significantly affected and range of movement in both these joints is poor. This is much less common than mobility problems due to lower limb involvement. It is particularly likely in adults born before 1970. In these cases help may be required with personal hygiene, dressing, meal preparation and administration of treatment.

Supervision by others does not prevent bleeds or prevent adults with normal cognitive function from sustaining injuries.
Adults are able to recognise the onset of bleeding and seek help or self-treat.

**How long will the needs last?**

<table>
<thead>
<tr>
<th>Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haemophilia A</td>
</tr>
<tr>
<td>Haemophilia B (Christmas disease)</td>
</tr>
<tr>
<td>Von Willebrand’s disease</td>
</tr>
<tr>
<td>Clotting disorder - Other / type not known</td>
</tr>
</tbody>
</table>

**Haemophilia**

People born before 1970 are likely to have disabling problems related to joint damage and multiple joints are likely to be affected.

People born before 1991 may have contracted one of the blood borne diseases associated with clotting factor replacement.

Younger people may have no or minimal joint damage because they have received prophylactic (preventative) clotting factor treatment from a young age thereby reducing bleeds and long-term damage. Prophylactic therapy was not used throughout the UK until the mid to late 1990s. Anyone born before then may have disabling problems related to joint damage. People with haemophilia born since then are unlikely to have significant joint damage unless they have an inhibitor.

**Mild Functional restriction**

Care and mobility needs related to neurological damage are indefinite and so indefinite awards are recommended.

As joint damage is less widespread in this group, joint replacement can significantly improve mobility. Awards should be reviewed after hip or knee replacement surgery. Joint replacement in the upper limbs will not significantly improve function and awards made related to upper limb arthritis and deformity should be indefinite.

**Moderate Functional restriction**

Care and mobility needs related to neurological and joint damage are indefinite and so indefinite awards are recommended.

**Severe Functional restriction**

Care and mobility needs related to neurological and joint damage are indefinite and so indefinite awards are recommended.
**Von Willebrand’s disease**

The majority of people will have mild disease. In some cases, drug treatment to reduce bleeding will be necessary. No care or mobility needs are anticipated in this group.

In more severe cases, where treatment with clotting factors is required to control either spontaneous bleeding or bleeding after trauma or surgery, there may be joint damage or neurological damage as in haemophilia. Assessment of care and mobility needs in these cases should be carried out as for haemophilia.

Supervision by others does not prevent bleeds or prevent adults with normal cognitive function from sustaining injuries. Adults are able to recognise the onset of bleeding and seek help or self-treat.

Where needs arise because of neurological impairment or joint damage related to episodes of bleeding follow the guidance for haemophilia. Care needs are likely to be indefinite for neurological and multiple joint damage.

**Development of Inhibitors**

Indefinite awards are recommended whether treatment for inhibitor is effective or not. This is because damage caused by uncontrolled bleeding is a permanent effect even though the cause of it (inhibitor) may have been effectively treated. Care and mobility needs related to neurological damage are indefinite and joint replacement does not improve mobility or range of movement.

**Other clotting factor deficiencies**

These are rare conditions and the effects will be variable. When assessing mobility, evidence of neurological impairment and joint damage related to bleeding should be assessed as for haemophilia.

Indefinite awards are recommended.

**Female haemophilia carriers**

No care or mobility needs are anticipated.

**All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.**

**Over 65**

People born before the 1970s are likely to have had many bleeding episodes prior to the introduction of clotting factors treatment. They are likely to have significant and widespread joint damage related to previous bleeding episodes even if bleeding is well controlled now. Mobility is likely to be significantly reduced and they may be unable to walk at all due to
flexion deformities of the lower limb joints. They may require help with personal care and administration of treatment due to the effects of severe arthritis on the joints of the upper limb. They may have neurological problems related to past episodes of bleeding or a blood borne virus related to clotting factor treatment in 1970’s and 1980’s. Needs are likely in this group, indefinite awards are recommended.

Back to top of section
# What you need to know about Bone marrow transplants

## What is a Bone marrow transplant?
Bone marrow is a spongy material found in the hollow centres of some bones. It is important as it contains…. [Read more about bone marrow transplants.](#)

## What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even…. [Read more about evidence sources.](#)

## Activities of Daily Living and Mobility needs
Needs are related to both treatment and the disease. During the period immediately after transplant the patient will be…. [Read more about ADL & mobility needs.](#)

## How long will the needs last?
Anyone undergoing a bone marrow or stem cell transplant is going to develop care needs for a period…. [Read more about award duration.](#)

## Over 65s
People over 65 are unlikely to have Peripheral Blood Stem Cell Transplant (PBSCT) or Bone Marrow Transplant unless…. [Read more about effects in the over 65 age group.](#)

## What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A [hospital factual report](#) will contain this information.

### Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a ‘Care plan’ from social services
Hospital
Specialist doctors -:
• Oncologist
• Physician
• Haematologist

Specialist nurses have many different job titles -:
• Clinical Nurse Specialist
• Stoma care nurse
• Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
• Physiotherapist
• Occupational Therapist
• Social worker
• Counsellor
• Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
• Palliative Care Physician
• Macmillan Nurse
• Clinical Nurse Specialist
• Social worker
• Physiotherapist
• Occupational Therapist
• Counsellor

Activities of Daily Living and Mobility needs

Care
Needs are related to both treatment and the disease. During the period immediately after transplant the patient will be in isolation in hospital. After discharge they will have been advised about their diet and may need help from someone else with food preparation. They are likely to need help to travel to the hospital if they are at home. Normal everyday activities like chatting on the telephone and reading are likely to be very exhausting and they may require a lot of sleep. Severe fatigue may make activities of daily living difficult. Help with activities of daily living from someone else may be required because of pain, fatigue or breathlessness.
During this period and for some months afterwards as they recover they are likely to remain severely immunosuppressed to a greater or lesser extent.

**Mobility**

Severe fatigue and reduced exercise tolerance related to any of the following may reduce the ability to walk:

- Chemotherapy treatment
- Anaemia

People who are immunocompromised will be advised to avoid crowded public places. Fatigue may mean that travel for example to hospital is difficult and a carer may need to accompany them.

**How long will the needs last?**

Anyone undergoing a bone marrow or stem cell transplant is going to develop care needs for a period. Treatment and recovery for those who successfully undergo bone marrow transplant or stem cell transplant is likely to take 1 to 2 years. Recovery is more likely to be prolonged in those who have had an allograft, those who have had salvage chemotherapy prior to transplant and those who are having treatment for myeloma.

**1or 2 year time limited awards are recommended in most cases.**

At review there may be on going needs related to the enduring side effects of chemotherapy treatment or needs related to relapsed disease following transplant – in either case indefinite awards related to current needs are recommended.

No ongoing needs are anticipated for the majority of people whose Peripheral Blood Stem Cell Transplant (PBSCT) or Bone Marrow Transplant has been successful.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Over 65**

People over 65 are unlikely to have Peripheral Blood Stem Cell Transplant (PBSCT) or Bone Marrow Transplant unless they are extremely healthy for their age. There are no special features.
What you need to know about Bowel cancer

What is Bowel cancer?
Bowel cancer is a general term for cancer that begins in the large bowel. Depending on where in the bowel the cancer starts. Read more on [NHS Choices - bowel cancer](https://www.nhs.uk/conditions/bowel-cancer/).

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Disabling effects of bladder cancer are variable and depend on how advanced disease has become, what treatment is…. Read more about ADL & mobility needs.

How long will the needs last?
Once treatment is complete, the chances of recurrent disease depend on the aggressiveness and spread of…. Read more about award duration.

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Over 65s
There are no special features in the elderly.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A [hospital factual report](https://www.nhs.uk/conditions/bowel-cancer/) will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
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- Physician
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- Stoma care nurse
- Macmillan Nurse

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- Counsellor

**Activities of Daily living and Mobility needs**

The design of stomas has improved dramatically in recent years, as have the appliances to go with them. Problems of smell and leak are much less common. It would be extremely unusual for a stoma to be fashioned if the patient couldn’t physically take care of it themselves. If needs are claimed in relation to stoma care because of other disabilities supporting medical evidence of disability should be obtained.
Typically people with bowel cancer are able to attend to their care needs and have no difficulty getting around.

However problems with care and mobility are likely to arise when someone:

- Has metastasis or recurrent disease
- Already has or develops other disabilities which compound the effects of bowel cancer or its treatment

Help with personal care for the purposes of DLA is typically not required during or after potentially curative treatment of colorectal cancer. Help with personal care will be required in the first few days after surgery. If a stoma is fashioned as part of the surgery help may be required for some weeks until the person gets used to managing it for them selves. A stoma care nurse will normally provide specialist support at home (visits and phone calls) for the first few weeks and be available in future should problems develop.

Care will not be required for the majority of the time during chemotherapy although during treatment weeks another person will probably need to help out with cooking, shopping and other tasks because of treatment side effects.

The exception to this may be people having very intensive treatment for rectal cancer. It can be appreciated that people having preoperative radiotherapy to the pelvis for up to 6 weeks followed by major surgery and possibly a 6-9 month course of chemotherapy after surgery are likely to have a prolonged period of fatigue and general debility. If severely affected by fatigue in the early period of treatment this is only likely to get worse and care needs may be identified.

If severe fatigue is present, it is likely that tasks can be physically completed but that any task requiring concentration or effort over a period of more than a few minutes will lead to extreme exhaustion and the need for rest and recovery.

Tasks such as dressing and preparing food are likely to fall into this category if they take more than a few minutes. Fatigue is particularly likely to affect ability to prepare food when exacerbated by problems such as mouth ulceration, nausea or loss of appetite related to treatment. There may be no motivation to prepare food in these circumstances and care in the form of encouragement to eat and drink as well as food preparation may be required.

Walking distance and exercise tolerance are likely to be reduced compared to normal, but stamina to walk for a few minutes e.g. 100 m from a hospital car park to a hospital ward or clinic will be maintained. There would normally be no need for physical support and no guidance or supervision needs would be present.

How long will the needs last?
Once treatment is complete, the chances of recurrent disease depend on the aggressiveness and spread of the original tumour cells. The spread of tumours through the bowel wall is measured very carefully under the microscope and a Dukes’ grading given. These measurements are used to make decisions on whether chemotherapy after surgery is necessary and predict the likelihood of the cancer coming back. 5 year survival is 50% over all but varies a lot according to Dukes' stage at diagnosis.

**Stages A and B**
People with Dukes' A and B stage tumours are likely to be cured of their disease.

**Stages C and D**
People with Dukes' C stage are more likely to have recurrence and people with Dukes' D stage have metastatic spread.

If care and mobility needs are identified these are likely to be on-going when related to--:

- recurrent or metastatic disease
- other disabilities unrelated to bowel cancer

Improvement is likely if needs are related to treatment of primary disease. Debility related to treatment is not usually much more than 6 months. However the treatment of rectal cancer is prolonged and needs identified in the early part of treatment are likely to persist through until recovery.

**Rectal cancer**
Awards of one year to 18 months are recommended to coincide with recovery from treatment of rectal cancer.

<table>
<thead>
<tr>
<th>Impairment</th>
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</thead>
<tbody>
<tr>
<td>Bowel Cancer including:</td>
</tr>
<tr>
<td>• Caecal cancer</td>
</tr>
<tr>
<td>• Colon cancer</td>
</tr>
<tr>
<td>• Sigmoid cancer</td>
</tr>
<tr>
<td>• Rectal cancer</td>
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<tr>
<td>• Anal cancer</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

[Back to top of section]
What you need to know about Brain tumours

What is a Brain tumour?
A brain tumour is a growth of cells in the brain that multiply in an abnormal, uncontrollable way. However, it is not always cancerous. Read more about brain tumours.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Needs are likely to arise because of neurological impairments caused or exacerbated by either the effects of the tumour or. Read more about ADL & mobility needs.
Linked pages :- Deeming Provisions

How long will the needs last?
There are around 100 different types of brain tumour and prognosis is highly variable between them. For this reason. Read more about award duration.
Linked pages :- Deeming Provisions

Over 65s
There are no special features. Over all, survival is substantially lower in older people.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
• General Practitioner - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
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- Occupational Therapist
- Counsellor

**Activities of Daily Living and Mobility needs**

**Treatment of primary tumours**

Needs may arise from either the
• Effect of the tumour
• Effects of treatment

Needs are likely to arise because of neurological impairments caused or exacerbated by either. Most primary tumours will be treated with surgery or surgery followed by radiotherapy or radiotherapy and chemotherapy. The primary tumour may be completely or partially removed. Most people will have had a craniotomy – the recovery from this type of surgery is described under treatment. In an uncomplicated case, where there was no or minimal neurological impairment before surgery, recovery would be expected to take up to 3 months.

If a neurological impairment is present on diagnosis, the impairment may get temporarily worse because of the treatment. Recovery may take much longer than 3 months. Some improvement in impairment is likely with recovery and will be aided by neuro-rehabilitation.

Care
Care needs may arise due to physical or behavioural neurological impairments.

Physical problems may include problems with limb or trunk movement ranging from clumsiness/unsteady balance to paralysis. There may be paralysis or loss of sensation on one side of the body (hemiplegia), similar to a person who has had a stroke. If the upper limbs are affected help may be required with activities of daily living. Severe problems with balance and weakness are likely to make self care, particularly dressing difficult. Preparing food with balance problems is potentially dangerous. Sudden onset of visual impairment in addition to the other symptoms of a brain tumour are likely to create or exacerbate care needs. Fits are a common symptom and supervision may be required until fits can be controlled with appropriate medical treatment.

Behavioural problems may include reduced or absent sense of danger as well as inappropriate or distressing behaviour. Patients often lack motivation and planning strategies for daily activities. Short term memory loss is a frequent feature of brain tumours and their treatment. When behavioural problems are present regular supervision will be necessary. Symptoms may get worse during treatment but may improve afterwards over several months. Improvement may continue gradually over several years but usually plateaus after maximal rehabilitation.

Mobility
Mobility may be affected in several ways by neurological impairments:

• Hemiplegia - loss of movement/clumsiness to either side of the body
• Altered sensation to either side of the body
• Perceptual neglect of one side of the body
• Difficulties with balance
• Poor concentration
• Central sensory deficits such as blindness or visual field defects and hearing problems. To consider H/R Mobility Severely Visually Impaired (SVI) or deaf/blind deeming provision criteria, click on the link Deeming Provisions.

- Behavioural problems

People with weakness, sensory problems and balance problems may have difficulty walking. They may require assistance or assistive devices and/or equipment to enable safe mobility and independence. Severe problems with balance may also make walking difficult or dangerous even though they have normal strength and movement in their legs. People with sensory problems may require guidance and supervision if their deficit is severe.

People with behavioural or cognitive problems may require guidance and supervision because of one of the following

• Loss of awareness of danger
• Memory loss
• Inappropriate behaviour

People with difficult to control or uncontrolled epilepsy may require guidance and supervision in both the home and unfamiliar places. 30% of people with brain tumours do not achieve complete control of their epilepsy.

Symptoms may get worse during treatment and can improve afterwards over several months. Improvement may continue gradually over several years but not always completely resolve, particularly memory loss, which can actually continuously worsen following completion of primary treatment.

**Recurrent brain tumours**

Brain tumours usually recur because they are either highly malignant or they were in an inaccessible area of the brain and could not be completely removed. Further treatment is likely to be able to control symptoms and slow further progression down; but impairments are less likely to improve. If needs are identified because of neurological or cognitive impairment indefinite awards are recommended.

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**How long will the needs last?**

| Impairment | Tumours – benign – other / type not known | Brain and spinal cord – cancer of |
Primary brain tumours
There are around 100 different types of brain tumour and prognosis is highly variable between them. For this reason guidance on award duration is provided by tumour diagnosis in the table below. In order to use the table the correct histological diagnosis must be known. This information is most likely to be available from the Clinical Nurse Specialist, treating neurosurgeon, treating neuro-oncologist or the GP. Accurate information on impairment is most likely to be available from the Clinical Nurse Specialist or GP.

For many tumours awards are recommended for one year in the presence of neurological deficits if needs are identified. This is because function may improve significantly over time especially with neurorehabilitation. For example a person may learn how to walk again or their personality may substantially return to normal. Review at one year assesses residual impairment once neurorehabilitation is complete. Once recovery is complete needs may be absent or reduced. In cases where disease progresses despite treatment needs are likely to increase.

Recurrent brain tumours
If needs are identified indefinite awards are recommended.

Types of adult brain tumours with information on prognosis.
Grade of tumour indicates whether a tumour is benign (G40) or malignant (C51) and if malignant how aggressively it will behave.

<table>
<thead>
<tr>
<th>Name of brain tumour</th>
<th>Features</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Astrocytic tumours</strong></td>
<td></td>
</tr>
<tr>
<td>There are several different types of astrocytoma. This type of tumour occurs more frequently in people who have had radiation treatment to the head.</td>
<td></td>
</tr>
<tr>
<td>Pilocytic astrocytoma (WHO grade 1)</td>
<td>This is a slow growing type of tumour that has a good prognosis, it is often curable. The main treatment is surgery very occasionally followed by radiation therapy. If needs are identified 1 year time limited awards are recommended. Recovery is expected in the typical case.</td>
</tr>
<tr>
<td>Diffuse astrocytoma/low-grade diffuse astrocytoma (WHO grade 2) including 3 different subtypes:</td>
<td></td>
</tr>
<tr>
<td>- Fibrillary astrocytoma</td>
<td>These tumours typically affect young adults and are treatable. The mean survival time after surgical treatment is 6-8 years. If needs are identified 1 year time limited</td>
</tr>
<tr>
<td>- Gemistocytic astrocytoma</td>
<td></td>
</tr>
</tbody>
</table>
Protoplasmic astrocytoma awards are recommended, if needs persist on review indefinite awards are recommended. It is recognised that gemistocytic astrocytomas have a worse prognosis and are treated like anaplastic astrocytomas.

Anaplastic or malignant astrocytoma (WHO grade 3) Typically affects people around the age of 40. These tumours can be treatable but not curable. Typically they progress to glioblastoma which is a higher grade tumour within about 2 years. The main treatment is surgery followed by radiation therapy. Young people whose initial treatment successfully removes all of the tumour are most likely to do well; although removal of all the tumour with clear margins is unusual. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended.

Glioblastoma/ malignant glioma/glioblastoma multiforme (WHO grade 4) includes 3 different sub-types:
- Giant cell glioblastoma
- Small cell glioblastoma
- gliosarcoma

This is the commonest type of brain tumour – around 20% of all brain tumours. It is one of the most aggressive human cancers and median survival is less than one year. 2 year survival is 5-10%. Radiotherapy can prolong median survival from 14 weeks to 38 weeks but may not reverse any disabilities. Rapidly progressive disability is likely, needs are likely. Indefinite awards are recommended in all cases.

Pleomorphic xanthoastrocytoma is very rare it usually affects young adults. Recurrence
free survival rates of 71% at 5 years and 61% at 10 years are reported. If needs are identified 1 year time limited awards are recommended. Recovery can be expected in the typical case. Very slow growing treatable tumour that mainly affects people with tuberous sclerosis (a rare genetic disorder). If needs are identified 1 year time limited awards are recommended. Recovery is expected in the typical case, however there may be ongoing needs unrelated to the brain tumour in this group.

Subependymal giant cell astrocytoma (SEGA) (WHO grade 1)

Oligodendroglial tumours: there are two types of this tumour see below – this group has a median postoperative survival time of 3 to 10 years. This type of tumour is likely to be treated with radiotherapy or chemotherapy and survival is good if response to treatment is complete.

Oligodendroglioma (low grade, WHO grade 2))

Well differentiated tumour that often responds well to treatment, recovery is possible in the typical case. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended. Poorly differentiated tumour with a worse outcome than low grade oligodendroglioma. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended.

Anaplastic oligodendroglioma (WHO grade 3).

Mixed gliomas

Oligoastrocytoma (low grade, WHO grade 2)

Median survival time with treatment of 6 years. If needs are identified 1 year time limited awards are
Anaplastic Oligoastrocytoma (WHO grade 3)

These are high grade tumours with outcomes similar to other malignant astrocytomas. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended.

**Ependymal tumours**

<table>
<thead>
<tr>
<th>Tumour Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myxopapillary ependymoma (WHO grade 1)</td>
<td>Commonly affects people aged between 30 and 40. Commonly affects the lower end of the spinal cord – survival is excellent. Recovery is expected in the typical case. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended.</td>
</tr>
<tr>
<td>Subependymoma (WHO grade 1)</td>
<td>Usually affects middle aged and elderly men – usually cured by surgery. Recovery is expected. Needs unlikely. If needs are identified 1 year time limited awards are recommended.</td>
</tr>
<tr>
<td>Ependymoma (WHO grade 2)</td>
<td>Affects young adults. 5 year median survival 57% and 10 year median survival 45%. Can occur in the spine and cause paraplegia that is permanent. Recovery from initial treatment is expected in the typical case. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended.</td>
</tr>
<tr>
<td>Anaplastic ependymoma (WHO grade 3)</td>
<td>Prognosis is possibly worst in very young people. If needs are identified 1 year time limited awards are recommended.</td>
</tr>
</tbody>
</table>
Neuroepithelial tumours of uncertain origin

Astroblastoma
Affects young adults. Very rare. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended.

Choroid glioma of the third ventricle
Rare and slow growing but difficult to treat. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended.

Gliomatosis cerebri
Rare. Widely infiltrating aggressive tumour with median survival of less than one year. Rapidly progressive disability is likely, needs are likely. Indefinite awards are recommended in all cases.

Neuronal and mixed neuronal-glial tumours

Gangliocytoma
Ganglioglioma
Anaplastic ganglioglioma
Dysembryoplastic neuroepithelial tumour
Central neurocytoma
Cerebellar liponeurocytoma
(lipomatous medulloblastoma)
All of these tumours are very rare. The main treatment is surgery sometimes followed by radiation therapy. If needs are identified 1 year time limited awards are recommended. Seek medical advice on individual cases.

Embryonal tumours

Medulloblastoma
Affects young adults, 5 year survival is between 50% and 70%. Recovery from initial treatment is expected in the typical case. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended.
**Choroid plexus tumours**

<table>
<thead>
<tr>
<th>Tumour Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Choroid plexus papilloma</td>
<td>Often cured by surgery. 5 year survival around 100%. Recovery expected in the typical case.</td>
</tr>
<tr>
<td>Choroid plexus carcinoma</td>
<td>2 year survival less than 40%. Recovery from initial treatment can be expected in the typical case. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended.</td>
</tr>
</tbody>
</table>

**Pineal parenchymal tumours**

<table>
<thead>
<tr>
<th>Tumour Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pineocytoma</td>
<td>Affects young adults. 5 year survival 88%. If needs are identified 1 year time limited awards are recommended. Recovery is expected in the typical case.</td>
</tr>
<tr>
<td>Pineoblastoma</td>
<td>5 year survival 58%. Recovery from initial treatment is expected in the typical case. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended.</td>
</tr>
<tr>
<td>Pineal parenchymal tumours of indeterminate differentiation</td>
<td>Variable outcome. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended.</td>
</tr>
</tbody>
</table>

**Meningeal tumours**

- **Meningioma grade I**
  - Cured by surgery in 80-90% of cases. If needs are identified 1 year time limited awards are recommended. Recovery is expected in the typical case.

- **Meningioma grade II**
  - Cured by surgery in 60-70% of cases. If needs are identified 1 year time limited...
<table>
<thead>
<tr>
<th>Condition</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meningioma grade III/anaplastic Meningioma</td>
<td>Median survival of less than 2 years. If needs identified an indefinite award is recommended.</td>
</tr>
<tr>
<td>Haemangiopericytoma</td>
<td>Responds well to initial treatment but recurs in 90% of cases over 15 years. Recovery from initial treatment is expected in the typical case. If needs are identified 1 year time limited awards are recommended, if needs persist on review indefinite awards are recommended. Indefinite awards recommended on recurrence.</td>
</tr>
<tr>
<td>Melanocytic lesions</td>
<td>Poor prognosis. If needs identified an indefinite award is recommended.</td>
</tr>
<tr>
<td>Pituitary tumours</td>
<td></td>
</tr>
<tr>
<td>Benign adenomas of the pituitary gland</td>
<td>Around 80% of this group experience resolution of symptoms with treatment. Needs unlikely, recovery expected. Good long term prognosis. Rarely visual field problems will persist after treatment. May require hormone replacement.</td>
</tr>
<tr>
<td>Carcinomas of the pituitary gland</td>
<td>Median survival of around 2 years. If needs identified an indefinite award is recommended.</td>
</tr>
<tr>
<td>Craniopharyngoma</td>
<td>Good prognosis with combined modality treatment (surgery and radiotherapy). 10 year recurrence free survival of 60-90%. Needs depend on initial deficits (visual, hypothalamic). If needs are identified 1 year time limited awards are recommended, if needs persist on review</td>
</tr>
</tbody>
</table>
Capillary haemangioblastoma

- Indefinite awards are recommended.
- Good prognosis. Most commonly occurs in association with a genetic disorder called von Hippel-Lindau disease. Recovery is expected in the typical case, however there may be ongoing needs unrelated to the brain tumour in this group.

Schwannoma/neurilemoma/neurinoma

- Usually benign tumour often cured by surgery. If needs are identified 1 year time limited awards are recommended. Recovery is expected in the typical case.

You may need to consider whether H/R Mob SVI deeming provisions are satisfied. Click on the link Deeming Provisions. – visual impairment DP

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about Breast cancer

Back to A - Z

What is Breast cancer?
Breast cancer is the most common cancer in the UK. About 46,000 women get breast cancer in…. Read more about breast cancer.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Early breast cancer - there are unlikely to be any long term care and mobility needs after treatment for early breast cancer…. Read more about ADL & mobility needs.

How long will the needs last?
Time-limited awards are recommended in early breast cancer and locally advanced breast cancer, if needs are identified…. Read more about award duration.

Over 65s
There is no specific guidance for over 65’s.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a ‘Care plan’ from social services

Hospital
Specialist doctors -:
• Oncologist
• Physician
• Haematologist

Specialist nurses have many different job titles -:
• Clinical Nurse Specialist
• Stoma care nurse
• Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
• Physiotherapist
• Occupational Therapist
• Social worker
• Counsellor
• Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
• Palliative Care Physician
• Macmillan Nurse
• Clinical Nurse Specialist
• Social worker
• Physiotherapist
• Occupational Therapist
• Counsellor

Activities of Daily Living and Mobility needs

Early breast cancer - there are unlikely to be any long term care and mobility needs after treatment for early breast cancer. The exceptions to this include -:

• enduring but rare side effects of chemotherapy
• Significant lymphoedema of the arm (<1%)
• Radiation induced brachial Plexopathy (RIBP) - rare

In the rare situation where an award is appropriate during treatment of early breast cancer, the award should last for the duration of treatment and then be reviewed. When disabling effects related to rare side effects such as Radiation induced brachial Plexopathy (RIBP) are claimed, indefinite
awards are recommended – corroborating medical evidence will be available.

Locally advanced breast cancer that responds to treatment may have no residual disabling effects however it may not be clear at presentation who will respond to treatment and who will not. Those who do not respond are likely to have a very poor prognosis and may be terminally ill from the outset. Time limited awards of 12-18 months are recommended if needs are identified.

Metastatic breast cancer may have no disabling effects whilst under control with treatment. If not controllable or if it escapes control, disabling effects are likely to increase in both number and severity. Specific complications of breast cancer including spinal cord compression and fungating tumour are likely to be disabling in themselves and be associated with significant fatigue and debility. No improvement in function is likely to occur.

**Back to top of section**

**How long will the needs last?**

Time-limited awards are recommended in early breast cancer and locally advanced breast cancer, if needs are identified. In locally advanced breast cancer that does not respond to treatment needs are likely to persist, if needs are ongoing at renewal indefinite awards are recommended.

In recurrent or metastatic breast cancer indefinite awards are recommended if needs are identified.

Indefinite awards are also recommended for enduring side effects of treatment such as significant lymphoedema, enduring effects of chemotherapy and Radiation Induced Brachial Plexopathy – clear medical evidence of such effects should be available.

**Impairment**

Breast cancer

*All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.*
What you need to know about Cardiac Arrhythmias

What is a Cardiac Arrhythmia?
- Read more about Atrial Fibrillation
- Read more about Supraventricular tachycardia
- Read more about Heart Block
- Read more about a Pacemaker implantation

For information about other heart rhythm disorders Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
Self-assessment is the prime source of evidence, but the claim pack should be checked to see who has completed it, and that it is an accurate and reliable description of their problems.

If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.

Activities of Daily Living and Mobility needs
The main disabling effects of arrhythmia are transient as the arrhythmia may be intermittent and can usually be well managed.

How long will the needs last?
Arrhythmias may cause a lot of symptoms or no symptoms. Benign arrhythmias for which no treatment is needed usually cause no long-lasting effects.

Over 65s
As people get older they are more likely to have a cardiac arrhythmia which may be associated with a higher risk of serious complications.

What evidence is available?
Self-assessment is the prime source of evidence, but the claim pack should be checked to see who has completed it, and that it is an accurate and reliable description of their problems.
Medical Services

Hospital Factual Report
In all cases of moderate and severe cardiac disease a Consultant Cardiologist, and a Specialist Cardiac Nurse would normally have been involved in the diagnosis, management and treatment of the individual. Indeed the absence of any documented history of a Cardiology consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required.

If the person has undergone a successful catheter ablation, cardioversion, insertion of a pacemaker or defibrillator or other procedure, they will be followed up in the hospital Outpatient Department, and this will be the best source of information for his/her residual needs.

The Cardiac Rehabilitation Nurse
The Cardiac Rehabilitation Nurse is a Specialist nurse, who works in close contact with the Cardiologist, and is part of the Cardiac Rehabilitation Team.

She/he is closely involved with the patient, from the start of the hospital stay, and, as well as attending to the physical needs of the patient, is crucial in advising, and supporting the patient.

Heart failure patients suffer from an enormous impact on their confidence in their ability to do things, and a large proportion of them suffer from depression, and the Specialist Nurse is there to support them. She/he also can act as an intermediary between the Consultant (and the rest of the team), and the patient, giving advice on medication, dose adjustments, lifestyle, social issues and so on. He/she is also in a position to tell the patient about their illness, and discuss things like prognosis, which may be worrying the patient, as well as being an important issue.

This contact is kept up after the patient is discharged, for both medical and psychological reasons; and phone contact, for reassurance of the patient, may take place several times a week, in cases of severe heart failure. At late-stage or end-stage disease, the patient may contact the nurse many times, because of the need for psychological, financial or social support, and for advice on managing often quite complex treatment regimes. Obviously, the amount of contact varies, with the severity of the condition, and the readiness of the patient to seek help.

The Specialist Nurse can also act as a go-between for the patient, GP and Consultant co-ordinating and adjusting the treatment options.

Therefore, this role is recognized as being extremely important for the well-being of the patients and more and more hospitals use their services on a permanent basis.
General Practitioner Factual report
The General Practitioner would normally have made the initial referral of the claimant to the Cardiologist, and would normally be aware of the results of tests, and current medication. The general practitioner may not have such detailed knowledge of the claimant’s needs, if he/she are more frequently managed by the Consultant Cardiologist, and the Specialist Cardiac Nurse, (who are more likely to have detailed knowledge of exercise tolerance, and the disabling effects of the condition).

If there is no specialist health professional involvement or evidence cannot be obtained from them, then a factual report from the claimant’s own doctor would be more appropriate.

HCP examination Report
An HCP examination report would be likely to be necessary when the person claims significant disability (equivalent to a moderate or severe condition), but there is no supporting evidence from the GP or hospital Specialist; if no corroborative evidence has been able to be obtained; or if it is the only means whereby the claimant’s needs can be clarified.

Medical Services
The Medical Services doctor may be asked to request relevant information such as test results from the GP or Hospital Consultant, and to interpret test results and other information.

Activities of Daily Living and Mobility needs

Disabling Effects
The main disabling effects of arrhythmia are transient as the arrhythmia may be intermittent and can usually be well controlled by:

- Medication,
- Electrical Cardioversion (ECV),
- Pacemaker,
- Surgical ablation of the conduction system.

In such cases, the disabling effects are not likely to be significant.

However, the underlying cause of the arrhythmia or consequences of the arrhythmia such as a stroke or heart failure may cause disabling effects. If evidence suggests that the customer has heart failure or has had a stroke, which may have resulted from an arrhythmia then go to either Heart Failure guidance or Stroke guidance.

How long will the needs last?
Arrhythmias may cause a lot of symptoms or no symptoms.
Benign arrhythmias for which no treatment is needed usually cause minimal functional impairment.

Everyone will have an arrhythmia at some time in their life, the vast majority are not symptomatic, and are usually incidental findings, such as on monitoring.

The consequence of arrhythmias may be none or they may be life – threatening.

Any mobility and care needs are likely to be the result of secondary effects of the arrhythmia such as stroke or heart failure. If evidence suggests that the customer has heart failure or has had a stroke, which may have resulted from an arrhythmia then go to either Heart Failure guidance or Stroke guidance.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atrial fibrillation / Flutter</td>
<td>Less than 2 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 2 years</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Cardiac arrhythmia causing heart failure</td>
<td>N/A</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Cardiac arrhythmia causing stroke</td>
<td>Less than 2 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 2 years</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Cardiac arrhythmia – Implantable defibrillator / Pacemaker fitted</td>
<td>Less than 2 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 2 years</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Heart block</td>
<td>Less than 2 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 2 years</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Other cardiac arrhythmia / type not known</td>
<td>Less than 2 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 2 years</td>
<td>Indefinite</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant. Back to top of section

**Arrhythmias in people over 65**

- As people get older they are more likely to have a cardiac arrhythmia which may be associated with a substantial risk to health.

- This is often as a result of the process of ageing and changes related to disease, such as ischaemic heart disease, and changes to the heart’s structure.

- The symptoms may be vague – falls, dizziness, fatigue, blackouts, confusion etc.
• Atrial fibrillation or flutter is the most common arrhythmia in the elderly. With atrial fibrillation, (as in all ages), stroke prevention (by the use of anticoagulant medication) is very important.

• Bundle branch block is common in the elderly.

• It is not normal for an older person to have bradycardia (slow heartbeat) and it is normally indicative of an underlying conduction disturbance, which may need pacemaker treatment.

• Tachycardia (fast heartbeat) is less well tolerated in the older person and can precipitate low blood pressure (hypotension), angina and heart failure.

• The management of arrhythmia in an older person is basically the same as for people of other age groups but an underlying cause should always be borne in mind.

• An older person may already be on anti-arrhythmic drugs, (which in themselves may cause an arrhythmia) and is likely to be on other medication; potential drug interactions have to be considered.

Back to top of section
What you need to know about Cardiomyopathy

What is Cardiomyopathy?
Cardiomyopathy is a disease of the heart muscle caused by damage to, or a change in, the heart muscle structure itself. Read more about Cardiomyopathy.

Decision Makers are advised to discuss with the Departments Medical Services provider

What evidence is available?
Self-assessment is the prime source of evidence but the claim pack should be checked to see who has completed it and.... Read more about evidence sources.

Activities of Daily Living and Mobility needs
The main disabling effects of cardiomyopathy are a consequence of the illness such as heart failure or angina due to.... Read more about ADL & mobility needs.

How long will the needs last?
Dilated Cardiomyopathy - prognosis is hugely variable. Life expectancy is likely to be reduced, especially if heart failure symptoms.... Read more about award duration.

Over 65s
There is an increased incidence of ischaemic dilated cardiomyopathy in elderly patients, (10% of people who develop.... Read more about effects in the over 65 age group.

What is Cardiomyopathy?
Cardiomyopathy is a disease of the heart muscle caused by damage to, or a change in, the heart muscle structure itself.

As a consequence, the heart muscle’s pumping ability is affected and other alterations of function may also take place.

Cardiomyopathy may present by:

- The symptoms it causes,
- An incidental finding during examinations or screening.
The patient may suffer profound psychological consequences, on being given the diagnosis.

Cardiomyopathy can be classified into 4 main types: -

- Dilated cardiomyopathy,
- Hypertrophic cardiomyopathy,
- Restrictive cardiomyopathy,
- Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC).

**Dilated Cardiomyopathy**

This is the most common form of cardiomyopathy. The muscle of the left ventricle, and sometimes the right ventricle, becomes weak and slack, so even though the heart is bigger (“enlarged” or “dilated”) it cannot pump as effectively.

**Hypertrophic Cardiomyopathy**

In this type of cardiomyopathy, the walls of the heart become thickened (hypertrophy) and stiff. The heart does not fill properly, and this may lead to heart failure, and in some people there is obstruction to the outflow of blood from the left ventricle to the aorta, leading to symptoms on exertion. There may be leaking of the mitral valve of the heart. There is a small risk of sudden death, which varies from patient to patient.

**Restrictive Cardiomyopathy (“Infiltrative”)**

This is a rare condition and causes “stiffness” of the heart because of a stiffening of the walls of the ventricles. This impedes filling of the heart. Many of the features of restrictive cardiomyopathy are similar to those of hypertropic cardiopathy.

**Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)**

This disease has been recently acknowledged and is a disease of the heart muscle which usually affects the right ventricle more than the left ventricle. Heart muscle cells are replaced by scarring and fat cells. The right ventricle usually becomes weakened and arrhythmias may occur.

In some forms of cardiomyopathy, clots form in the heart, and may break off and travel to other parts of the body (as emboli). If an embolus blocks a blood vessel to the brain, a stroke may result.

If evidence suggests that the customer has heart failure, which may have resulted from cardiomyopathy then follow [Heart Failure guidance](#).

If evidence suggests that the customer has had a stroke, which may have resulted from valvular heart disease then follow [Stroke guidance](#).
**What evidence is available?**

Self-assessment is the prime source of evidence but the claim pack should be checked to see who has completed it and that it is an accurate and reliable description of their problems. If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.

- **Hospital Factual Report**
- **The Cardiac Rehabilitation Nurse**
- **General Practitioners Factual Report**
- **HCP Examination Report**
- **Medical Services**

**Hospital Factual Report**

In all cases of moderate and severe cardiac disease a Consultant Cardiologist and a Specialist Cardiac Nurse would normally have been involved in the diagnosis, management and treatment of the individual. Indeed the absence of any documented history of a Cardiology consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required. If a person has undergone a successful heart transplant, the claimant will be followed up in the hospital Outpatient Department, and this will be the best source of information for his/her residual needs.

**The Cardiac Rehabilitation Nurse**

The Cardiac Rehabilitation Nurse is a [Specialist Nurse](#), who works in close contact with the Cardiologist, and is part of the Cardiac Rehabilitation Team.

She/he is closely involved with the patient, from the start of the hospital stay, and, as well as attending to the physical needs of the patient, is crucial in advising and supporting the patient.

Heart failure patients suffer from an enormous impact on their confidence in their ability to do things and a large proportion of them suffer from depression and the Specialist Nurse is there to support them. She/he also can act as an intermediary between the Consultant (and the rest of the team) and the patient, giving advice on medication, dose adjustments, lifestyle, social issues and so on. He/she is also in a position to tell the patient about their illness and discuss things like prognosis, which may be worrying the patient, as well as being an important issue.

This contact is kept up after the patient is discharged, for both medical and psychological reasons; and phone contact, for reassurance of the patient, may take place several times a week, in cases of severe heart failure. At late - stage or end - stage disease, the patient may contact the nurse many times because of the need for psychological, financial or social support and for advice on managing often quite complex treatment regimes. Obviously, the amount of contact varies with the severity of the condition and the readiness of the patient to seek help.
The Specialist Nurse can also act as a go - between for the patient, GP and Consultant co-ordinating and adjusting the treatment options. Therefore, this role is recognized as being extremely important for the well-being of the patients and more and more hospitals use their services on a permanent basis.

**General Practitioner Factual report**

The [General Practitioner](#) would normally have made the initial referral of the claimant to the Cardiologist and would normally be aware of the results of tests and current medication. The general practitioner may not have such detailed knowledge of the claimant’s needs if he/she is more frequently managed by the Consultant Cardiologist and the Specialist Cardiac Nurse, (who are more likely to have detailed knowledge of exercise tolerance and the disabling effects of the condition). If there is no specialist health professional involvement or evidence cannot be obtained from them, then a factual report from the claimant’s own doctor would be more appropriate.

**HCP examination Report**

An [HCP Examination report](#) would be likely to be necessary when the person claims significant disability (equivalent to a moderate or severe condition), but there is no supporting evidence from the GP or hospital Specialist; if no corroborative evidence has been able to be obtained; or if it is the only means whereby the claimant’s needs can be clarified.

**Medical Services**

The [Medical Services](#) doctor may be asked to request relevant information such as test results from the GP or Hospital Consultant and to interpret test results and other information.

**Activities of Daily Living and Mobility needs**

**Disabling Effects**

The main disabling effects of cardiomyopathy are a consequence of the illness such as heart failure or angina due to inadequate blood supply to the heart muscle even where the coronary arteries are healthy. The main disabling effects are due to heart failure. If evidence suggests that the customer has heart failure, which may have resulted from cardiomyopathy then follow [Heart Failure guidance](#).

In some forms of cardiomyopathy, clots form in the heart, and may break off and travel to other parts of the body (as emboli). If an embolus blocks a blood vessel to the brain, a stroke may result. If evidence suggests that the customer has had a stroke, which may have resulted from cardiomyopathy then follow [Stroke guidance](#).
How long will the needs last?
The following gives details of the medical course of each type of cardiomyopathy.

Dilated Cardiomyopathy
Prognosis is hugely variable. Life expectancy is likely to be reduced, especially if heart failure symptoms are present. Dilated cardiomyopathy is the most common reason for heart transplant.

Hypertrophic Cardiomyopathy
- Prognosis is variable, but often there is a slow deterioration; many patients are symptomless for much of their lives.
- Sudden death may occur at any age, but the annual mortality is highest in children and adolescents (up to 6%). It usually occurs during or just after strong physical activity. About 4% of people, overall, with hypertrophic cardiomyopathy die each year.
- An Implantable Cardioverter Defibrillator (ICD) is felt to be an effective treatment for the prevention of sudden death and therefore should be offered to high-risk cases. This is because it is thought that ventricular arrhythmias are the cause of many cases of sudden death.
- Amiodarone is used in less risky cases of sudden death.
- Death from chronic heart failure is less common.
- No pharmacological treatment will change the clinical course of the disease, though symptoms (such as in atrial fibrillation and heart failure) may be alleviated.

Restrictive Cardiomyopathy
This disease usually occurs in elderly patients. Life expectancy is reduced. Heart Transplantation may be indicated, but for young patients only.

Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)
Prognosis is hugely variable because of the different degrees of severity of the disease. Many people are virtually unaffected but some are more seriously affected and may be at risk of sudden death. The condition may progress or it may improve.

If evidence suggests that the customer has heart failure, which may have resulted from cardiomyopathy then follow Heart Failure guidance.

If evidence suggests that the customer has had a stroke, which may have resulted from cardiomyopathy then follow Stroke guidance.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiomyopathy causing Heart Failure</td>
<td>N/A</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Cardiomyopathy causing Stroke</td>
<td>Less than 2</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>years</td>
<td></td>
</tr>
</tbody>
</table>
More than 2 years  Indefinite
Cardiomyopathy –
Other complications
N/A  Indefinite

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Cardiomyopathy in people over 65

There is an increased incidence of ischaemic dilated cardiomyopathy in elderly patients, (10% of people who develop dilated cardiomyopathy are likely to be over 65 years). This is because of diffuse coronary artery disease; the heart muscle is deprived of blood supply, and the end result is scar tissue replacing the ischaemic muscle with hypertrophy of the remaining muscle to compensate.

Restrictive cardiomyopathy may occur as a result of the deposition of amyloid protein in the heart, and amyloidosis is more common in older people.

Hypertrophic Cardiomyopathy occurs in about 4% of older people, and this figure may be an underestimate.

Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC) usually affects younger people.
What you need to know about Carpal tunnel syndrome

Back to A - Z

What is Carpal tunnel syndrome?
Carpal tunnel syndrome (CTS) is a relatively common condition that causes pain, numbness and a burning or..., Read more on NHS Choices - carpal tunnel syndrome.

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore..., Read more about evidence sources.

Activities of Daily Living and Mobility needs
The median nerve is responsible for sensation in most of the palm of the hand, apart from the area under the..., Read more about ADL & mobility needs.

How long will the needs last?
Whilst there would normally be no significant restriction of self-care activities, a minority of cases will..., Read more about award duration.

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages:
Ageing
Falls
Frailty

What evidence is available?

There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required in most cases.

However, in the minority of cases where disability may have occurred (see ADL and Mobility needs), then it may be necessary to request a factual report from the customer's own General Practitioner.
Activities of Daily Living and Mobility needs

- The median nerve is responsible for sensation in most of the palm of the hand, apart from the area under the little finger, and for certain thumb movements – i.e. lifting the thumb vertically away from the palm, (abduction), and moving the thumb across the palm of the hand towards the little finger (opposition).
- Loss of function of the median nerve due to carpal tunnel syndrome will give rise to varying degrees of impairment of manual dexterity, particularly activities involving pinch or key grip.
- Many individuals with carpal tunnel syndrome will experience mild and intermittent symptoms in the early stages of the condition. The dominant hand is usually affected first, tends to develop the worst symptoms and may be the only hand affected. However, Carpal Tunnel Syndrome can affect both hands. Even though the worst symptoms are normally experienced in the dominant hand, the degree of functional impairment would normally be minimal in the majority of cases. Specifically such individuals would normally be able to dress and undress unaided, and be able to manipulate small objects, such as buttons and zips, although there is a tendency to drop items. Aspects of main meal preparation including peeling and chopping vegetables and lifting pans are unlikely to be significantly impaired.
- There would normally be no significant restriction of self-care activities.
- A minority of cases will have disability. This tends to occur where the condition is longstanding and treatment has not been sought. In such cases severe muscle wasting at the base of the thumb occurs together with marked loss of sensation of most of the palm of the hand. This causes considerable difficulties with manual dexterity.

How long will the needs last?

Whilst there would normally be no significant restriction of self-care activities, a minority of cases will have disability. In cases where significant nerve damage and muscle wasting at the base of the thumb has occurred, full recovery is unlikely.

<table>
<thead>
<tr>
<th>Impairment</th>
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</thead>
<tbody>
<tr>
<td>Carpal Tunnel syndrome</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Cervical cancer

What is Cervical cancer?
Cervical cancer is an uncommon type of cancer that develops in a woman’s cervix. The cervix is the entrance to…. Read more on NHS Choices - cervical cancer.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
The majority of women will receive curative treatment for early stage disease and return to health with no…. Read more about ADL & mobility needs.

How long will the needs last?
In the rare situation where care and mobility needs are identified because of treatment of stage 1, 2 or 3 cervical cancer…. Read more about award duration.

Over 65s
There are no special features.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a ‘Care plan’ from social services
Hospital
Specialist doctors -:
• Oncologist
• Physician
• Haematologist

Specialist nurses have many different job titles -:
• Clinical Nurse Specialist
• Stoma care nurse
• Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
• Physiotherapist
• Occupational Therapist
• Social worker
• Counsellor
• Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:

• Palliative Care Physician
• Macmillan Nurse
• Clinical Nurse Specialist
• Social worker
• Physiotherapist
• Occupational Therapist
• Counsellor

Activities of Daily Living and Mobility needs

The majority of women will receive curative treatment for early stage disease and return to health with no disabling effects. Some may develop long term side effects of treatment.

Stage 1 and 2 disease
• Five year survival from stage 1 disease is about 80-95%. Five year survival from stage 2 disease is 60-90%. Long term side effects of treatment are infertility and early menopause. Because this group has
good long term survival they are likely to develop proportionately more of the long term side effects from their radiotherapy treatment.

- There are unlikely to be any long term care and mobility needs after initial treatment. The exception to this is the enduring but rare side effects of chemotherapy and long term effects of pelvic radiotherapy. Needs are likely to arise when disease recurs.

**Stage 3 disease**

- Five year survival from stage 3 disease is 30-50%. Long term disabling effects include the side effects of radiotherapy particularly on the bladder and bowel which may develop some years after treatment. Recurrent disease is common and may occur quite soon after treatment of initial disease – up to date medical evidence from the treating hospital will be important.

**Stage 4 disease**

- Stage 4A disease means the cancer has spread to other organs in the pelvis, there are likely to be disabling effects including problems with the bowel and bladder related to invasion by cancer. Treatment is likely to include chemotherapy, radical radiotherapy and/or major surgery. Radical treatment for advanced disease typically has more side effects than treatment of early disease. Long term survival is poor.
- Stage 4B disease means metastases have occurred, any of the disabling effects of metastatic disease may be present, she may be terminally ill. 5 year survival is about 16%.

**Metastatic disease and recurrent disease after treatment of any stage of cervical cancer.**

This person is likely to be terminally ill although the expected survival may be longer than six months. There may be disabling effects from metastatic disease anywhere in the body including:

- Liver metastases – these may cause fatigue and in the later stages, mental confusion, abdominal swelling or pain and jaundice
- Lung metastases or malignant pleural effusion – may cause very disabling breathlessness reducing mobility to a few yards.
- Brain metastases – these may cause fits, personality change, confusion, difficulties with balance, walking and self care
- Bone metastases – pain and pathological fractures

Problems specifically related to advanced cervical cancer or its treatment may include:

- Lymphoedema of the lower limbs, this is likely to affect ability to walk.
- Pelvic pain syndromes
- Problems with the bowel or bladder following radiotherapy treatment, including urinary and faecal incontinence; women who have had pelvic exenteration may have one or two stomas to care for.

[Back to top of section]
How long will the needs last?

In the rare situation where care and mobility needs are identified because of treatment of stage 1, 2 or 3 cervical cancer, the award should last for the duration of treatment as typically improvement is expected. If treatment side effects do not improve when treatment stops or develop some years later, disabling effects are likely to persist. In stage 4 and recurrent disease needs are likely to increase over time.

- Stage 0 cervical cancer – there are cancerous cells on the cervix but not invasive cancer
- Stage 1 cervical cancer – there is a small invasive cancer in the cervix only
- Stage 2 cervical cancer – the cancer has spread to involve the upper part of the vagina as well as the cervix
- Stage 3 cervical cancer – the cancer has spread to the side wall of the pelvis or down to the lower part of the vagina
- Stage 4 cervical cancer – the cancer has spread into the bladder or rectum or distant organs such as the liver

<table>
<thead>
<tr>
<th>Cancer stage</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stages 1, 2 or 3</td>
<td>Period of treatment plus reasonable recovery period</td>
</tr>
<tr>
<td>Stage 4, and Recurrent disease</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

[Back to top of section]
What you need to know about Chronic Fatigue Syndrome (CFS) / Myalgic Encephalomyelitis (ME)

What is CFS/ME?
Chronic fatigue syndrome (CFS) causes persistent fatigue (exhaustion) that affects everyday life and doesn't go away with…. Read more on NHS Choices - CFS/ME.

What evidence is available?
Useful sources of further evidence include Consultant, Physiotherapist, Occupational therapist, General practitioner…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
The disabling effects of CFS/ME in individuals is variable. The following describes the typical problems with…. Read more about ADL & mobility needs.

How long will the needs last?
People with mild illness may recover spontaneously, or with some general advice or a limited treatment programme over…. Read more about award duration.

Over 65s
CFS/ME is predominantly a disease of young adults.

What evidence is available?
Useful sources of further evidence include -:
- Hospital Consultant
- Physiotherapist
- Occupational therapist
- General Practitioner
- Health Care Professional

Activities of Daily Living and Mobility needs
The disabling effects of CFS/ME in individuals is variable. The following describes the typical problems with daily living activities for the majority of the time.
## Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>The ability to walk long distances may be reduced, but the person is likely to be able to walk short distances on an unrestricted basis most of the time. Their judgment, thought processes and means of communicating are not affected to the extent that they would be unable to find their way around in familiar and unfamiliar places.</td>
</tr>
<tr>
<td>ADL</td>
<td>The person would normally to be able to wash, dress, bathe, use the toilet, get up and downstairs without difficulty. The ability to plan a meal is not impaired and the tasks involving in preparing and cooking food are unlikely to be restricted in any way.</td>
</tr>
</tbody>
</table>

## Moderate Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>The ability to walk more than 100 metres consistently may be restricted in moderate cases, but severe restriction of walking is unlikely. Their judgment, thought processes and means of communicating are not affected to the extent that they would be unable to find their way around in familiar and unfamiliar places.</td>
</tr>
<tr>
<td>ADL</td>
<td>Those with a moderate level of functional restriction would be expected to be able to manage some personal care and preparation of food without help from another person most of the time. Tasks may take longer than normal and may need to be followed by a period of rest. Although the level of fatigue and symptom severity may vary during the day or from day to day, the ability to maintain personal hygiene and nutrition is likely to be unimpaired.</td>
</tr>
</tbody>
</table>

**Severe Functional Restriction**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>Such claimants may be severely restricted in their ability to walk. There may a requirement for supervision either at home or out of doors as a result of significant cognitive impairment, but it would be uncommon.</td>
</tr>
<tr>
<td>ADL</td>
<td>People with a severe level of functional restriction, who spend most of the day in bed or otherwise immobile, and who may have clinically evident muscle wasting, may well need help with personal care and preparing food.</td>
</tr>
</tbody>
</table>
How long will the needs last?

People with mild illness may recover spontaneously, or with some general advice or a limited treatment programme over the course of the following six months. These people are likely to be treated in a general practice setting.

People with established CFS/ME of moderate severity lasting one to two years or more are likely to need a more extensive management programme, as described above, lasting 6 to 12 months or more. Most people who are able to attend hospital for treatment are likely to make a significant improvement with appropriate management. Some people will recover fully, but others will not achieve their previous level of functioning. Some may not improve. Those who recover may be at risk of recurrence. Those who improve are at risk of relapse. In many patients, disability and quality of life can be improved, sometimes to a significant extent.

Severe cases are less likely to recover completely or benefit substantially from a management programme.

Indicators of a good prognosis are: -

- Male sex,
- A definite history of an acute viral illness like glandular fever at the onset,
- Mild disability and few symptoms,
- Clinical features showing a pattern of evolution towards functional recovery,
- Early diagnosis aimed at eliminating associated physical disorders and/or identifying psychiatric illness along with other complicating psychological or social factors,
- A management approach which may encompass physical, psychological and social elements that allows a stepwise approach to functional improvement using rehabilitation.

Indicators of a poor prognosis are: -

- Onset of symptoms without any clear precipitating factor,
- Clinical features characterised by severe and unremitting symptoms,
- Severe and persistent disability,
- A management approach that overemphasises the importance of either complete rest or which advocates a rapid return to pre-illness levels of physical activity,
- Those with co-morbid significant medical conditions or mood disorders,
- A complex background of adverse psychological and social factors.
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about Chondromalacia patella

What is Chondromalacia patella?
Sudden pain in one of the knees is usually the result of overusing the knee or suddenly injuring it. In many…. Read more on NHS Choices - knee pain.

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and Mobility needs
Mobility may be restricted as a result of pain, however, with treatment and avoiding the activities, which increase pain…. Read more about ADL & mobility needs.

How long will the needs last?
Mobility may be restricted as a result of pain however, with treatment and avoiding the activities which increase pain…. Read more about award duration.

Over 65s
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Linked pages :-
Ageing
Falls
Frailty

Activities of Daily Living and Mobility needs

- Mobility may be restricted as a result of pain, however, with treatment and avoiding the activities, which increase pain, this should be minimal. Sometimes a stick may be used to help weight-bearing but this is unusual.

- Over time and with a sensible exercise regime full recovery should occur.

- People with this condition are unlikely to be at risk of falling or prone to falls.
How long will the needs last?

Mobility may be restricted as a result of pain however, with treatment and avoiding the activities which increase pain, this should be minimal.

Sometimes a stick may be used to help weight-bearing but this is unusual.

Over time and with a sensible exercise regime full recovery should occur.

People with this condition are unlikely to be at risk of falling or prone to falls.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about Liver cirrhosis

What is Liver cirrhosis?
Cirrhosis is scarring of the liver as a result of continuous, long-term liver damage. Scar tissue replaces…. Read more on [NHS Choices - liver cirrhosis](https://www.nhs.uk/conditions/liver-cirrhosis/).

What evidence is available?
Most people with cirrhosis will have had the diagnosis made in hospital and will be followed up in hospital clinics…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Following diagnosis, while symptoms are mild or minimal the person is unlikely to have any functional limitations…. Read more about ADL & mobility needs.

How long will the needs last?
Cirrhosis often develops insidiously over many years with the person having few or no symptoms. Once established…. Read more about award duration.

Over 65s
The size and function of the liver deteriorates with ageing. In general liver diseases in the elderly carry a….. Read more about effects in the over 65 age group.

What evidence is available?
Most people with cirrhosis will have had the diagnosis made in hospital and will be followed up in hospital clinics. Reports can be obtained from Consultants or specialist nurses working in gastro-enterology or specialist liver clinics. People with early or mild disease may be predominantly under the care of their general practitioners. Some with cirrhosis who misuse alcohol may not attend their hospital visits for monitoring. It may be possible to obtain some information on their physical condition from the community alcohol teams who care for their psychological health.

It may be helpful to seek advice from Medical Services if the diagnosis of the condition causing cirrhosis is not clear. Treatment options and prognosis are determined to a significant extent by the underlying disease.
Activities of Daily Living and Mobility needs
Following diagnosis, while symptoms are mild or minimal the person is unlikely to have any functional limitations. As the condition progresses with increasing impairment of liver function, muscle weakness, fatigue, weight loss and poor overall physical condition, individuals may have difficulties in washing, dressing, climbing stairs, preparing food and walking, and a propensity to fall. Late complications of liver failure that impair cognitive function (e.g. drowsiness, disorientation, abnormal behaviour) may lead to a need for supervision.

If evidence shows that Cirrhosis is due to Alcohol misuse, then also consult the Alcohol misuse guidance for additional information.

How long will the needs last?
Cirrhosis often develops insidiously over many years with the person having few or no symptoms. Once established the outlook tends to be unpredictable; it depends on the underlying disease process. Repeated hospital admissions for treatment of complications are associated with a poor outlook. In those who continue to consume alcohol the prognosis is very poor (65% mortality within 5 years). Some people who undergo liver transplantation will have a good outlook. Development of hepato-cellular carcinoma has a poor prognosis.

If evidence shows that Cirrhosis is due to Alcohol misuse, then also consult the Alcohol misuse guidance for additional information.

If evidence shows that the customer has liver failure, then go to the Liver Failure guidance.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
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</thead>
<tbody>
<tr>
<td>Alcohol induced cirrhosis</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Autoimmune cirrhosis</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Other cirrhosis / type not known</td>
<td>Indefinite</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Cirrhosis of the liver in people over 65
The size and function of the liver deteriorates with ageing. In general liver diseases in the elderly carry a worse prognosis than in the younger age. However the clinical features and treatment of the liver impairments are similar in both age groups.

Back to top of section
What you need to know about Claw or Hammer toes

What are Claw/Hammer toes?
Foot pain is a common problem with a wide range of possible causes. If it is severe or persistent,…. NHS Choices - foot pain.

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and Mobility needs
With appropriate footwear and, if necessary, supports, mobility should not be affected by this condition. If surgery has…. Read more about ADL & mobility needs.

How long will the needs last?
If surgery has taken place there are various routines depending on the surgeon’s preference. Sometimes patients may…. Read more about award duration.

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.
Linked pages -:
Ageing
Falls
Frailty

Activities of Daily Living and Mobility needs

With appropriate footwear and, if necessary, supports, mobility should not be affected by this condition.

If surgery has taken place there are various routines depending on the surgeon’s preference. Sometimes patients may have to stay off their foot for several weeks, and therefore mobility will be restricted during this time.

How long will the needs last?
If surgery has taken place there are various routines depending on the surgeon's preference. Sometimes patients may have to stay off their foot for several weeks, and therefore mobility will be restricted during this time.

Once healing has taken place, walking can be resumed as normal.

<table>
<thead>
<tr>
<th>Impairment</th>
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</thead>
<tbody>
<tr>
<td>Claw / Hammer toes</td>
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</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

[Back to top of section]
What you need to know about Chronic Obstructive Pulmonary Disease (COPD)

Back to A - Z

What is Chronic obstructive pulmonary disease (COPD)?
Chronic obstructive pulmonary disease (COPD) is the name for a collection of lung diseases including chronic bronchitis, emphysema and.... Read more on NHS Choices COPD

What evidence is available?
The claimant and / or carer should be able to provide the information required to accurately assess mobility and.... Read more about evidence sources.

Activities of Daily Living and Mobility needs
Mild functional restriction - the person normally has little or no symptoms. They would normally have wheeziness and.... Read more about ADL & mobility needs.
Linked pages :-
Medical Research Council Dyspnoea scale details

How long will the needs last?
Chronic Obstructive Airways Disease (COAD) and Emphysema are chronic progressive disorders characterised by.... Read more about award duration.

Over 65s
Because COAD and Emphysema are slowly progressive conditions, they are more common in older people, especially.... Read more about effects in the over 65 age group.

What evidence is available?
The claimant and / or carer should be able to provide the information required to accurately assess mobility and care needs. However, if further details are needed the General Practitioner, Consultant or Specialist Respiratory nurse is an appropriate source of information. Medical Services doctors are always available for interpretation of test results or discussion of claims where there is insufficient evidence.

Activities of Daily Living and Mobility needs
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>The person normally has little or no symptoms. They would normally have wheeziness and breathlessness on a less than daily basis and would usually only suffer from a mild “smoker’s cough”, producing some mucoid sputum. They may become breathless on moderate, prolonged or heavy exertion.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with mild restriction would normally be able to walk an unlimited distance, at a normal pace and manner on level ground, and manage hills or slopes. There would be no need for guidance and supervision whilst outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>Daily living would normally be unaffected, with the patient being able to attend to all daily activities of self-care without any difficulty. This includes bathing, dressing, attending to hygiene and toilet needs, and being able to prepare and cook a main meal. He/ she would normally be able to climb one flight of stairs. They would not normally be at risk of falls. Occasionally, the person may have an episode of chest infection, which may cause some difficulty with exercise tolerance, but this would only occur for the minority of the time.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>The person would normally suffer from wheeziness and breathlessness for part of each day. Because he/ she would normally be breathless on extra activity, he/ she would have to take things more slowly. He/ she could also be</td>
</tr>
</tbody>
</table>
incapacitated by exacerbations (chest infections), where cough and breathlessness are increased, but this is for the minority of the time.

| **Mobility** | A person with moderate restriction would normally be unable to keep up with others when walking on the level. However, he/she may be able to walk up to 100 to 200 metres, as long as he/she walks at a slow pace. There would be no need for guidance and supervision while out of doors. |
| **ADL** | A person with moderate restriction would normally have breathlessness as a noticeable and troublesome symptom. However, this would not normally affect such activities as rising from a bed or chair, bathing, dressing, attending to toilet needs, and being able to prepare and cook a main meal to a significant degree. These people are susceptible to chest infections especially following a cold, and for a few days, or weeks, this could cause him/her to be very breathless and he/she may normally need assistance with some of these activities at this time. Normally, a customer would be breathless climbing one flight of stairs (that is, on mild or ordinary exertion) but they would be able to manage this activity at their own pace. However, during periods of chest infection they would have greater difficulty in climbing a flight of stairs but this would not be for most of the time. People with this condition would not normally be susceptible to falls. |

<p>| <strong>Severe Functional Restriction</strong> |  |</p>
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>Cognitive function would not usually be affected therefore the person is mentally able to cope, on the whole. However, in those who are retaining CO2 (carbon dioxide), cognitive function may be impaired. Because</td>
</tr>
</tbody>
</table>
of inability to eat normally, there usually is severe weight loss or malnutrition. Patients suffering from very severe disease would have severe breathlessness on minimal exertion and be on oxygen for several hours a day (unless in CO2 retention i.e. when there is a presence of more than the normal amount of carbon dioxide in the blood tissues). Oxygen is not prescribed in these circumstances.

<table>
<thead>
<tr>
<th>Mobility</th>
<th>A person with severe restriction would normally experience severe breathlessness on walking any distance. He/she would not normally be able to walk more than 50 metres at the most, at a very slow pace. There may be a risk of falls.</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL</td>
<td>A person with severe restriction would normally require assistance in all aspects of daily self-care, such as getting in or out of a bed, chair, or the bath, washing, dressing, including lower garments and fastenings, attending to toilet needs, and some aspects of preparing and cooking a main meal such as bending to an oven and carrying and lifting hot saucepans because of severe breathlessness on minimal exertion. He/she would normally not be able to get him/herself comfortable in bed without assistance. In addition, the person would not normally be able to manage one flight of stairs. Some of the time, communication may be affected, because of severe breathlessness, and the person may not be able to cope with aspects of their medical treatment, such as the administration of oxygen, without assistance. The person would normally need assistance in eating and drinking. There may be a risk of falls and the person would not normally be capable of rising independently from a fall.</td>
</tr>
</tbody>
</table>
Click on the link below for details of the Medical Research Council (MRC) Dyspnoea scale:  
http://www.gp-training.net/protocol/respiratory/copd/dyspnoea_scale.htm

How long will the needs last?

Chronic Obstructive Airways Disease (COAD) and Emphysema are chronic progressive disorders characterised by airflow limitation. They are essentially progressive conditions, which worsen with time, especially if the person continues to smoke.

Pulmonary rehabilitation (to achieve optimum fitness) can reduce symptoms and improve function. Controlled oxygen therapy for more than 15 hours a day has been shown to increase survival significantly.

Smoking cessation is the single most effective intervention to reduce the risk of further development. Cessation of smoking may slow the decline in lung function to normal levels of decline in a relatively short time. This would not affect the prognosis of moderate and severe disease because the damage is done, but may improve the prognosis in mild disease.

The prognosis in moderate and severe COPD therefore, is likely to be life-long with consequent care and mobility needs, which will not improve as the disease is progressive and the person is likely to gradually deteriorate.

COAD, chronic bronchitis and emphysema

At first the only symptom for many years may be a “smoker’s cough”.

This symptom progresses to cough with sputum, wheeze and breathlessness. Chest infections occur more and more regularly with colds causing the production of purulent sputum. These infections increase in severity and duration until a cough is constantly present.

With progression of the disease, the person experiences increasing breathlessness on exertion.

With advanced disease, breathlessness becomes severe and occurs at rest and normally affects all aspects of daily life. At end-stage disease, the person is bed-bound or chair-bound and likely to be on oxygen for several hours a day. It is a chronic, slowly progressive disorder with little variation over a period of time.

Bronchodilator therapy may help the degree of airflow obstruction to some extent as most patients have some degree of asthmatic-type responsiveness to bronchodilators. 20-30% of patients improve somewhat when given a course of steroids and inhaled corticosteroids may be indicated. Long-term oral corticosteroid treatment should normally be avoided.
The disease is regarded as being progressive, with a continuous steady decline in lung function.

**Emphysema**

The best predictor of survival is the FEV1 after bronchodilator use.

Emphysema gradually develops over a number of years.

People with emphysema have great difficulty in exhaling (breathing out). Symptoms such as shortness of breath (sometimes associated with wheeze) occur initially on exertion and then as the disease progresses with little exertion and ultimately at rest. The person eventually may not be able to carry out basic activities in a normal fashion. With advanced disease, breathlessness becomes severe and occurs at rest and normally affects all aspects of daily life. At end-stage disease, the person is bed-bound or chair-bound and likely to be on oxygen for several hours a day.

It is a chronic, slowly progressive disorder with little variation over a period of time.

Bronchodilator therapy may help those who have a tendency to airways constriction.

Some patients improve somewhat when given a course of steroids and inhaled corticosteroids may be indicated. Long-term oral corticosteroid treatment should be avoided.

**No medication has been shown to restore lost lung function.**

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic bronchitis</td>
<td></td>
</tr>
<tr>
<td>Chronic Obstructive Airways Disease (COAD)</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Emphysema</td>
<td></td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Over 65**

**COAD, chronic bronchitis and emphysema**

Because Chronic Obstructive Airways Disease (COAD) and Emphysema are slowly progressive conditions, they are more common in older people, especially those with a significant smoking history.
• Stopping smoking, even in later life, is likely to improve life expectancy and slow the rate of decline of lung function.

• The conditions can be under-diagnosed and under-treated and may present late, as older people may not perceive the feeling of breathlessness so well, and may just believe that breathlessness is a normal consequence of ageing; alternatively, the presentation may not be typical, as they may experience breathlessness at night, rather than wheeze.

• With moderate to severe disease, there is an increased energy output, and people thus affected require an increased calorie intake (by at least 50%) in the form of carbohydrate and fat.

• Poor nutrition is more likely to occur in the elderly, (because of isolation, mobility problems, reduced cognitive function, or communication problems, for example). The elderly therefore, are likely to be more severely affected than a younger person, and more at risk of deterioration in their general condition.

• The adverse side effects that may occur with the use of steroids are of even more relevance in the elderly; for example, they may easily become confused or even psychotic, and if they already have existing osteoporosis, it could be worsened, and there may be an increased risk of fracture of the hip.

• The treatment in the elderly is the same.

**Emphysema**

• Inadequate assessment of a person’s emphysema, which may occur as a result of his/ her reduced cognitive function, or communication problems, may lead to their not receiving adequate and appropriate treatment, such as long-term oxygen therapy.

• Pulmonary rehabilitation, which involves a multidisciplinary approach, aims to improve functional capacity as much as possible, especially in the elderly, who are particularly likely to benefit from a programme of exercise, oxygen therapy, improved nutrition, and information about their condition.
What you need to know about Crohn’s disease

Back to A - Z

What is Crohn’s disease?
Crohn’s disease is a long-term condition that causes inflammation of the lining of the digestive system. Read more about Crohn’s disease.

What evidence is available?
General practitioners are able to provide reports for people with mild disease whose exacerbations respond readily to standard drug therapies or who are in remission. People with perianal problems such as abscesses and fistulas may attend practice or community nurses for regular treatment and dressings. People with Crohn's disease which relapses regularly and those with more severe disease, attend Gastroenterology clinics for regular monitoring. Care will be shared with surgical colleagues when operations are needed to treat complications. Reports may be obtained from Consultants and Specialist Gastroenterology Nurses working in these clinics.

Activities of Daily Living and Mobility needs
People in remission, people with mild disease and those whose exacerbations respond quickly to medication are. Read more about ADL & mobility needs.

How long will the needs last?
Some people have mild symptoms and exacerbations resolve quickly with medication. Up to 10% have a prolonged. Read more about award duration.

Over 65s
Elderly people with moderate or severe Crohn’s disease may also have considerable care needs. They may need. Read more about effects in the over 65 age group.

What evidence is available?

General practitioners are able to provide reports for people with mild disease whose exacerbations respond readily to standard drug therapies or who are in remission. People with perianal problems such as abscesses and fistulas may attend practice or community nurses for regular treatment and dressings.

People with Crohn's disease which relapses regularly and those with more severe disease, attend Gastroenterology clinics for regular monitoring. Care will be shared with surgical colleagues when operations are needed to treat complications. Reports may be obtained from Consultants and Specialist Gastroenterology Nurses working in these clinics.
Activities of Daily Living and Mobility needs
People in remission, people with mild disease and those whose exacerbations respond quickly to medication are unlikely to have any long term functional restrictions affecting their ability to walk or provide self care.

Some people with disease of moderate severity may be restricted in their ability to stand, bend/kneel and walk around due to abdominal pain and the effects of complications such as fistulas. These individuals are likely to be taking more potent drugs, have frequent exacerbations of abdominal pain and diarrhoea and be attending hospital regularly. Some may need help with dressings and treatments from nurses. They may be restricted in their ability to self-care, including preparation of meals if symptoms last for some months or fail to respond to standard drug regimes. It is unlikely however that walking would be severely restricted since lower limb function is normal. Anxiety and concern about diarrhoea and needing to locate a toilet when out are not considered to be an indication that guidance or supervision are necessary.

People with the most severe disease are constitutionally unwell, have low body weight, evidence of malnutrition, decreased muscle bulk and persistent pain. These individuals have progressive disease with complications that have failed to respond to both medical treatments and surgery. They are likely to need help with self care and some will have considerable restriction in walking.

Further details on NHS Choices -:
Bowel Incontinence
Back to top of section

How long will the needs last?
Some people have mild symptoms and exacerbations resolve quickly with medication.

Up to 10% have a prolonged remission with minimal effects on long term health.

However 75% of cases have recurrent episodes of varying severity lasting over many years. About one eighth have progressive disease without remission.

Ultimately 2% are considered to have very severe disease with debilitating pain, weight loss, poor general health and development of complications. They often fail to respond to any of the standard drug therapies.

At the present time no medical or surgical treatment is considered to be curative.
Overall the excess mortality due to active disease is approximately double that of the general population.

Crohn’s disease is recognised to predispose to cancers of the small and large intestines.

In cases where there is severe unremitting disease with weight loss, poor general health and complications there is unlikely to be any improvement in the Care and Mobility needs.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Over 65**

Elderly people with moderate or severe Crohn’s disease may also have considerable care needs.

They may need help to:-

- move around the house
- get upstairs
- get on and off the toilet
- with personal hygiene, dressing, and bathing.
- using pads and waterproof pants to control faecal incontinence if diarrhoea is persistent or limited mobility slows down access to the toilet.

Frail elderly, especially if underweight or subject to poor nutrition/malabsorption, will need assistance with medication, encouragement to maintain adequate nutrition and fluid intake, and may also be prone to falls.
What you need to know about Middle Ear infection - Otitis Media
Back to A - Z

What is a Middle ear infection - Otitis media?
Most ear infections occur in infants aged 6-18 months, though anyone can get an ear infection. For reasons that....Read more on NHS Choice - Otitis Media.

What evidence is available?
Other than the exceptions detailed in the ADL and mobility needs section, there would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and Mobility needs
The main symptom of Otitis media is the persistent discharge from the ear. The patient will need to…. Read more about ADL & mobility needs.

How long will the needs last?
Otitis media generally responds well to treatment although this may have to be continued over…. Read more about award duration.

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.
Linked pages :-
Ageing
Falls
Frailty

Activities of Daily Living and Mobility needs
The main symptom of chronic suppurative otitis media is the persistent discharge from the ear. The patient will need to carry out regular cleansing of the external ear and may need to apply drops several times a day.
Regular visits to surgery or a hospital outpatients department may be needed for cleansing of the ear canal (aural toilet) until the discharge has dried up.
In the majority of cases needing only simple management of the condition there should be no need for help with personal bodily functions unless the person suffers another condition affecting the ability to manage the problem. In such cases any needs would form part of the requirements of the associated condition and should be assessed in that context.
Complications such as hearing loss may produce a need for help with communication and learning. The specific functional effects of hearing loss are covered as a separate topic.

Tinnitus can be a distressing symptom for some but unless it is severe or precipitates a psychological condition such as anxiety or depression it should not produce any care needs in its own right. The care needs of any psychological problems should be assessed on their own merit.

Uncomplicated chronic suppurative otitis media should not produce factors that adversely affecting walking ability. In complicated cases where the organs of the vestibular balance organs are affected there is a potential for mobility to be disrupted by episodic vertigo (giddiness) but this again would need to be assessed on its own merit.

Children with chronic suppurative otitis media or indeed recurrent acute otitis media may develop behavioural disorders associated with pain or hearing loss but needs generated by abnormal behaviour also would have to be considered as a separate entity.

**Variability**

Chronic suppurative otitis media tends to run a protracted course over several months with episodes of acute infection sometimes being superimposed on the clinical picture.

Apart from short term problems generated by the acute illness there should be no significant variation in the condition or level of care needed.

**How long will the needs last?**

Chronic suppurative otitis media generally responds well to treatment although this may have to be continued over several months. Significant complications of acute or chronic suppurative otitis media include brain abscess or infection in the temporal bone of the skull but these occur in only a very small number of cases.

The overall prognosis for all forms of otitis media is excellent.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

[Back to top of section]
What you need to know about Depression/Depressive disorder

What is Depression/Depressive disorder?
Depression is more than simply feeling unhappy or fed up for a few days. We all go through spells of feeling down, but…. Read more on [NHS Choices - depression](https://www.nhs.uk/conditions/depression/).

What evidence is available?
The claimant and / or carer should be able to provide the necessary information to enable assessment of mobility and…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Mild functional restriction - the person may have low mood that is characteristically worse in the evening than…. Read more about ADL & mobility needs.

How long will the needs last?
The average length of a depressive episode is about 6 months but about 25% of people have episodes lasting more than…. Read more about award duration.

Over 65s
Depression is common in the elderly. However, the first onset of depressive illness becomes less…. Read more about effects in the over 65 age group.

What evidence is available?
The claimant and / or carer should be able to provide the necessary information to enable assessment of mobility and care needs. However, if further details are needed, the Specialist Nurse or Consultant is an appropriate source of information.

The claimant may be supported by the Care Programme Approach (CPA) and hold written information outlining the level of external support required, which is a useful first source of further medical evidence.

Activities of Daily Living and Mobility needs
The following tables present pen pictures of customers’ likely mobility and care needs at varying levels of functional severity
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
</table>
| Disabling Effects | The person may have -:  
• Low mood that is characteristically worse in the evening than in the morning.  
• Lack of energy, interest and irritability.  
• Associated anxiety, phobias and obsessional symptoms may also be present and they may experience difficulty going to sleep or periods of wakening during the night. |
| Mobility          | People would normally have no difficulty finding their way around outdoors because they do not usually experience any confusion, inattention, memory loss or impaired judgement. There would be no physical restriction of walking ability. |
| ADL               | People would normally be expected to care for themselves by maintaining personal hygiene and preparing meals etc. They would have little or no functional limitation on a day-to-day basis arising from any symptoms nor would they need supervision or watching over to prevent abnormal or untoward behaviour. |
Moderate Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
</table>
| Disabling Effects | People with a moderate restriction will display 2 out of 3 of the following :-  
- Depressed mood  
- Loss of enjoyment  
- Fatiguability  

 and  

 at least 4 of the following :-  
- Reduced concentration and attention  
- Reduced self esteem and self confidence  
- Ideas of guilt and unworthiness  
- Bleak and pessimistic views of the future  
- Ideas of self harm or suicide  
- Disturbed sleep  
- Reduced appetite  

 However, people with a moderate restriction **would not** normally exhibit :-  
- Significant self neglect  
- Psychotic symptoms such as hallucinations and delusions  
- Significant slowing of movements or agitation  |
| Mobility      | Agoraphobia, physical inertia and apathy may require someone to encourage the moderately depressed person to get out and about. Those people with associated agoraphobia or severe anxiety may have difficulty finding their way around unfamiliar places and may require support. |
| ADL | The following care requirements would normally be reasonably required -:  
|     | • Encouragement to prepare a cooked main meal.  
|     | • Encouragement to go out and engage in social activities.  
|     | • Encouragement to take medication, but this is likely to be limited to once or twice a day.  

**Note:** In the great majority of cases any evident care needs will only be for a limited period, which is unlikely to exceed several months during any one episode.
Severe Functional Restriction
<table>
<thead>
<tr>
<th><strong>Category</strong></th>
<th><strong>Description</strong></th>
</tr>
</thead>
</table>
| **Disabling Effects** | They may have -:
- Severely depressed mood
- Prominent biological symptoms such as loss of appetite weight and sleep disturbance
- Severe agitation or significant slowing of movements.

There may also be -:
- Significant impairment of concentration and memory possibly resulting in confusion, psychotic symptoms such as delusions of guilt, worthlessness or poverty, persecutory hallucinations and significant social withdrawal.
- Insight is likely to be limited. |
| **Mobility** | If there is significant impairment of concentration, insight, judgement or memory or psychosis or psychomotor retardation present, there may be a need for guidance or supervision.  

Apart from the rare occurrence of depressive stupor, (motionless and mute) there would be no physical restriction of walking ability. People with depressive stupor will be hospitalized and usually respond to treatment within a period of weeks. |
If there is significant impairment of concentration and motivation and/or presence of psychosis or psychomotor retardation the customer may require -:

- Help to plan and prepare a main meal.
- They would normally also need prompting to go to bed, use the toilet, deal with incontinence, maintain hygiene and appearance, wash and dry, use the bath and shower, dress, move around indoors, use the stairs, get in and out of a chair, eat and drink and use medication or medical treatment.
- Help with communication may be required and there may be an increased risk of suicide. (For further information please see section on self-harm).

### How long will the needs last?

The average length of a depressive episode is about 6 months but about 25% of people have episodes lasting more than a year and about 10-20% develop a chronic unremitting course.

It is not possible to specify with accuracy the duration of any individual depressive episode, as people with severe disability usually respond well to treatment.

For infrequent repeated episodes it would be reasonable to award for a limited period initially whilst awaiting the outcome of response to treatment.

In the great majority of cases any evident care needs will only be for a limited period, which is unlikely to exceed several months during any one episode.

There is evidence that the prognosis is worse in older people.

### Criteria that indicate chronicity in depressive Illness

The following are associated with an increased likelihood that depression will be chronic -:

- Increased severity
- Longer duration
- Older age (especially over 60)
<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Customers under 50 years of age -:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive Illness</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td>(disorder)</td>
<td>More than 5 years</td>
<td>5 year award</td>
</tr>
<tr>
<td>Customers over 50 years of age -:</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td>Depressive Illness</td>
<td>More than 5 years</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>(disorder)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post Natal Depression</td>
<td>N/A</td>
<td>1 year award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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**Depressive illness in people over 65**

Depression is common in the elderly. However, the first onset of depressive illness becomes less common after the age of 60 and rare after the age of 80.

The incidence of suicide increases with age and suicide in the elderly is usually associated with depressive illness.

Clinical features are similar to those in younger people, but some symptoms are more prominent in the elderly and these include:

- Retardation and agitation,
- Cognitive impairment,
- Delusions (False beliefs that are unshakeable) concerning poverty and physical illness. Occasionally there are nihilistic delusion such as the belief that the body is empty, non existent or not functioning.
- Hallucinations may be accusatory or obscene.

Depressive symptoms may not be conspicuous and the person may present with hypochondriasis, anxiety or confusion.

A small proportion may present with pseudodementia i.e. they have difficulty with concentrating and remembering but formal testing of memory demonstrates no significant deficit.

The prognosis for depressive illness in the elderly is poorer than that for younger people. About 85 percent display considerable improvement within a few months. The other 15 percent do not recover completely.

Of the 85 percent that initially recover:
One third remain completely well,
One third have further depressive episodes with complete remission between episodes,
One third become chronically disabled by depression.

Poor outcome is associated with:
Onset over the age of 70,
Long duration of illness,
Associated physical illness,
Poor recovery from previous episodes,
Associated organic brain pathology,
Poor compliance with treatment,
Serious coincidental life events,

The principles of treatment are the same as that for younger adults. Certain modifications are required in the elderly, for example, physical disorders should be effectively treated; ECT is more frequently used and is an effective treatment of severe depressive illness in the elderly; Antidepressant medication dose should be specifically tailored and life long treatment should be considered following the first episode of depressive illness.

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What you need to know about Diabetes

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What is Diabetes?
Diabetes is a long-term condition caused by too much glucose, a type of sugar, in the blood. It is also known as... Read more on NHS Choices - diabetes.

What evidence is available?
If considering entitlement to H/R Mobility component under the Severely Visually Impaired (SVI) provisions, the following... Read more about evidence sources.

Activities of Daily Living and Mobility needs
In the case of diabetic patients, with mild functional restriction, the aim of treatment is to have good glycaemia control... Read more about ADL & mobility needs.

How long will the needs last?
There is no cure for Diabetes. The condition is managed by insulin, tablets or diet. The only problem with self-care in a small... Read more about award duration.

Over 65s
Non-Insulin Dependent Diabetes Mellitus (NIDDM) often, but not always presents in older people. The prevalence of... Read more about effects in the over 65 age group.

What evidence is available?
Note: If considering entitlement to H/R Mobility component under the Severely Visually Impaired (SVI) provisions, the following evidence source must be used:

The Consultant Ophthalmologist will be able to provide information about symptoms, signs, investigations including assessment of vision, treatment/management, and is likely to have information about resulting disability or needs.

Other evidence sources
Self-assessment is the prime source of evidence, but the claim pack should be checked to see who has completed it, and that it is an accurate and reliable description of their problems.
If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.

Sources of Further Evidence in Diabetes are:
- The Specialist Diabetic Nurse
- Hospital Factual Report
- General Practitioner Factual Report
- HCP Examination Report
- Medical Services

The Specialist Diabetic Nurse
The Specialist Diabetic Nurse is a Specialist nurse, who works in close contact with the Consultant Diabetologist, and is part of the Diabetic Team.

He/she is closely involved with the patient, from the start of attendance at the hospital clinic, and, as well as attending to the physical needs of the patient, is crucial in advising, and supporting the patient. The Diabetic Specialist Nurse may have more contact with the patient, than the Consultant, through informal contact and phone calls, (especially in the cases of teenagers and young adults, who do not wish to have too much contact with the hospital).

Some diabetic patients suffer from depression, and the Specialist Nurse is there to support them, and refer onwards, to a Psychologist or Psychiatrist, if necessary. She also can act as an intermediary between the Consultant (and the rest of the team), and the patient, giving advice on medication, dose adjustments, lifestyle, social issues and so on. He/she is also in a position to tell the patient about their illness, and discuss things like prognosis, which may be worrying the patient, as well as being an important issue.

This contact is kept up after the patient is discharged, for both medical and psychological reasons; and phone contact, for reassurance of the patient, may take place frequently. Obviously, the amount of contact varies, with the severity of the condition, and the readiness of the patient to seek help.

The Specialist Nurse can also act as a go-between for the patient, GP and Consultant co-ordinating and adjusting the treatment options.

Therefore, this role is recognised as being extremely important for the well-being of the patients and more and more hospitals use their services on a permanent basis.

Hospital Factual Report
In all cases of moderate and severe diabetic disease a Consultant Diabetologist, and a Specialist Diabetic Nurse would normally have been involved in the diagnosis, management and treatment of the individual. In the presence of established complications, there will be involvement with a Consultant Cardiologist, Consultant Vascular Surgeon, Consultant
Nephrologist, Consultant Ophthalmologist, and/or Consultant Neurologist, (depending on the degree and type of complications). The absence of any documented history of a Consultant consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required. If a person has undergone a successful operation or procedure, such as a Percutaneous Transluminal Coronary Angioplasty (PTCA), a Coronary Artery Bypass Graft (CABG), angioplasty of peripheral artery, cataract operation, laser treatment for retinopathy, dialysis or renal transplant, the claimant will be followed up in the hospital Outpatient Department, and this will be the best source of information for his/her residual needs.

**General Practitioner Factual report**

The Practitioner would normally have made the initial referral of the claimant to the Diabetologist, and would normally be aware of the results of tests and current medication. The general practitioner may not have such detailed knowledge of the claimant’s needs if he/she is more frequently managed by the Consultant Diabetologist, and the Specialist Diabetic Nurse, (who are more likely to have detailed knowledge of the disabling effects of the condition).

If there is no specialist health professional involvement or evidence cannot be obtained from them, then a factual report from the claimant’s own doctor would be more appropriate.

**HCP examination Report**

An [HCP examination report](#) would be likely to be necessary when the person describes multiple complications for, which factual reports provide inadequate evidence to enable the assessment of functional restrictions; or if it is the only means whereby the claimant’s needs can be clarified.

**Medical Services**

The Services doctor may be asked to request relevant information such as test results from the GP or Hospital Consultant and to interpret test results and other information.

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## Activities of Daily Living and Mobility needs

### Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>In the case of diabetic patients, with mild functional restriction, the aim of treatment is for patients to have good glycaemia control. They can manage their own monitoring and treatment, (including hypo’s), and do not suffer from complications.</td>
</tr>
<tr>
<td>Mobility</td>
<td>There should be no difficulty in walking, and no difficulty in getting about in an unfamiliar area.</td>
</tr>
<tr>
<td>ADL</td>
<td>Such a person would normally be able to look after all aspects of self - care with regard to bodily functions (such as bathing and showering, dressing, attending to his/her own toilet needs, planning, preparing and cooking a main meal, and going up and down stairs.) Without vision complications he/she should also be able to check and administer his/her own insulin. He/she normally would have warning of “hypo’s”, (hypoglycaemic episodes – low blood sugar), and be in a position to take the necessary steps to avoid or curtail them.</td>
</tr>
</tbody>
</table>
Moderate Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>In such a person, with moderate functional restriction due to their diabetes, some complications affecting vision, cardiovascular (e.g. the heart), peripheral vascular (e.g. the blood vessels in the legs) or neurological systems (e.g. the nerves, and nerve pathways), may be present. At this stage, renal (kidney) effects would not be likely to be obvious or debilitating. The person should be able to monitor and treat his/ her own disease, unless vision is affected to a severe extent. They would normally be able to cope with hypo’s themselves.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>The person may be affected by angina and/or peripheral vascular disease and/or reduced foot sensation, to some degree. However, he/she would normally be able to walk more than 100 metres on the flat, without stopping. Some individuals may have problems with reading signs, but on the whole, a person with diabetes with moderate disabling effects would normally be able to get about, unaided, in an unfamiliar place, as they can ask for directions.</td>
</tr>
</tbody>
</table>
| ADL | A person with moderate restriction should be able to look after his/her self-care needs, relating to bodily functions, as vision would not be significantly affected to impact on general care, such as dressing, bathing/showering, attending to toilet needs or planning and cooking a main meal. Cardiovascular and vascular effects on exertion, and neurological impairment, at this stage, would not be enough to seriously affect the above activities.

There is a chance that a person with a visual impairment might need a visual aid for reading labels and recipes, and checking medication strength and levels in the syringe, but this depends on the individual's disablement. Normally, he/she should be able to manage stairs, but may have to take them more slowly, and stop and rest, either halfway, or at the top.

Such a person would normally recognise hypoglycaemia (low blood sugar), and have a sugar source available to take at all times, in case of such an event. Night hypoglycaemia can be avoided as much as possible, in these people, by their checking their blood glucose level before going to bed, and having a snack if necessary. |
Severe Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>A person with severe functional restriction may display evidence of long-term raised blood sugar, and fats, as well as proteinuria. Conversely, they may have good control at the present time, but be suffering from severe complications, (because of poor glycaemic control in the past). Such a person is likely to be suffering from significant complications affecting one or all of the following systems. 1) the heart (coronary artery disease, leading to angina requiring treatment), 2) the peripheral blood vessels, especially in the legs, leading to narrowing of the vessels, and poor circulation of the feet or legs, 3) the nerve pathways especially affecting the lower limbs, making the patient susceptible to damage to these areas, without being aware, 4) eye complications causing vision to be affected, 5) kidney complications, causing diabetic nephropathy, which may progress to kidney (renal) failure. He/She may need assistance with monitoring, and treatment of his/her condition, and may not be aware of the onset of hypo’s.</td>
</tr>
<tr>
<td>Mobility</td>
<td></td>
</tr>
<tr>
<td>-----------------</td>
<td></td>
</tr>
<tr>
<td>Each person would need to be assessed according to how the diabetes has affected that person.</td>
<td></td>
</tr>
<tr>
<td>If the person has angina and/or narrowing of the arteries in the legs (leading to cramp on walking), or nerve damage leading to pins and needles and weakness in the legs), they might be only able to manage a walking distance of 30 metres or less.</td>
<td></td>
</tr>
<tr>
<td>With amputation (s) he/she may be confined to a wheelchair, and not be able to walk at all. If he/ she has (or is getting used to) a prosthesis, walking may be quite severely compromised, at least for a few months.</td>
<td></td>
</tr>
<tr>
<td>A person with severe visual effects resulting from the condition may have great difficulty in getting around out of doors unaided, may not be able to read street or road signs, and in fact may be registered blind. They may also satisfy the H/R Mobility criteria under the Severely Visually Impaired (SVI) deeming provisions. Click on the link <a href="#">H/R Mobility Severely Visually Impaired (SVI) deeming provisions</a>.</td>
<td></td>
</tr>
</tbody>
</table>
Each person would need to be assessed according to how the diabetes has affected that person.

He/she would normally still be able to dress him/herself, but may need assistance getting out of the bath, or helping with showering, if there is significant problems with the nerve pathways in the feet, or indeed, amputations. He/she may need assistance with testing their own blood and reading the result, with administering insulin and with checking and taking tablet medication, if vision is significantly affected.

If the heart and/or peripheral circulation in the legs is affected, he/she may have difficulty managing stairs without assistance. If amputations of one or both legs have occurred, he/she may need assistance on the stairs, as they may not have adjusted well to a prosthetic limb, or using stairs may not be an option at all, except by stair lift.

### How long will the needs last?

- There is no cure for Diabetes. The condition is managed by insulin, tablets or diet.
- The only problem with self-care in a small number of people with uncomplicated diabetes is hypoglycaemic attacks without warning. This is more likely to occur with longstanding diabetes, as neuropathy may mask the symptoms. Usually good glycaemic control can be achieved within 6 months, but if this persists, there is unlikely to be any improvement, where this has been present for 2 years.
- The main disabling effects for diabetes are due to complications affecting the eyes, large and small blood vessels, and the kidneys. The prognosis will then depend on the complication.
If evidence shows that the customer has ischaemic heart disease as a result of Diabetes, then also consult the Ischaemic Heart disease guidance for additional information.

If evidence shows that the customer has peripheral neuropathy as a result of Diabetes, then also consult the Peripheral Vascular disease guidance for additional information.

If evidence shows that the customer has retinopathy / cataracts as a result of Diabetes, then also consult the Vision guidance for additional information.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes – type 1 (insulin dependent)</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 5 years</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Diabetes – type 2 (insulin or non-insulin dependent)</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 5 years</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Diabetes – type not known / other</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 5 years</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Diabetes with renal complications and awaiting renal transplant surgery</td>
<td>N/A</td>
<td>2 year award</td>
</tr>
<tr>
<td>Diabetes with peripheral neuropathy</td>
<td>N/A</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Diabetes with ischaemic heart disease on a waiting list for surgery (Angioplasty / CABG)</td>
<td>N/A</td>
<td>1 year award</td>
</tr>
<tr>
<td>Diabetes with ischaemic heart disease - no surgery planned</td>
<td>N/A</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Diabetes with visual complications - Cataracts</td>
<td>N/A</td>
<td>1 year award</td>
</tr>
<tr>
<td>Diabetes with visual complications – Retinopathy</td>
<td>N/A</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>You may need to consider whether H/R Mob SVI deeming provisions are satisfied. Click on the link to Deeming Provisions.</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Diabetes with any complications and no surgery planned for any</td>
<td>N/A</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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Diabetes in people over 65

- Non-Insulin Dependent Diabetes Mellitus (NIDDM) often, but not always presents in older people.
- The prevalence of diabetes rises with increasing age and affects around 20% of those over 65 years in the UK, up to 50% in some ethnic groups and the obese. Of these, half will be unaware that they have diabetes.
- There are an increasing number of older insulin-dependent diabetics who were diagnosed when young; some have survived with few or no complications.
- Many older people with diabetes are recognised late for various reasons and diagnosis may be made as an incidental finding when routine screening tests are carried out. This is partly because the renal threshold for glucose is raised (so the classical symptoms of polyuria and glycosuria occur later) and the thirst mechanism is reduced (so the symptom of excessive drinking is delayed).
- The mortality rate for older people with diabetes is more than twice that of non-diabetic people of the same age mainly because of the increase in cardiovascular disease especially in those with Type 2 Diabetes.
- Older people, especially those who have had diabetes for more than 20 years have a reduced awareness of the symptoms of hypoglycaemia (if treated with insulin or sulphonylurea medication) and therefore are at greater risk.
- Because of the development of complications with diabetes over time older person with diabetes are more likely to have complications than younger persons:
  - After 20 years, almost all patients with IDDM have some retinopathy
  - After 20 years, 30% develop nephropathy
- Around 30% of diabetic patients develop neuropathy; it is related to the duration of the diabetes and the degree of control.
- Secondary diabetes is more common in older people.

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What you need to know about Dislocations

What is a Dislocation?
- Read more on NHS Choices - shoulder dislocation

For information about other sites of dislocation Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
Extent of functional problems depends on the dislocation, and the amount of damage done to other tissues such as the muscles and nerves. Medical Services advice may need to be sought in such cases.

Activities of Daily Living and Mobility needs
This depends on the dislocation, and the amount of damage done to other tissues such as the muscles and nerves. ... Read more about ADL & mobility needs.

How long will the needs last?
In a dislocation to a fit young person, progress is likely to be rapid and full function will normally return fairly quickly. ... Read more about award duration.

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.
Linked pages :-
Ageing
Falls
Frailty

Activities of Daily Living and Mobility needs
This depends on the dislocation, and the amount of damage done to other tissues such as the muscles and nerves. Medical Services advice may need to be sought in such cases. In a dislocation to a fit young person, progress is likely to be rapid and full function will normally return fairly quickly.

It may take longer where there is more damage to surrounding tissues and in an older person.
However, in general, the prognosis is good and full function would be expected.

**How long will the needs last?**

- In a dislocation to a fit young person, progress is likely to be rapid and full function will normally return fairly quickly.
- It may take longer where there is more damage to surrounding tissues and in an older person.
- However, in general, the prognosis is good and full function would be expected.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

[Back to top of section]
What you need to know about Dissociative disorders

What is a Dissociative disorder?
Dissociative disorders are disorders where there is a disruption of the normal integration of consciousness, memory, identity or perception of the environment. Read more about dissociative disorders.

Discuss with Medical Services.

What evidence is available?
In cases of moderate and severe Dissociative disorders it is highly probable that a consultant psychiatrist will have. Read more about evidence sources.

Activities of Daily Living and Mobility needs
People with a mild functional restriction are likely to be under GP care only, live independently in the community & have been. Read more about ADL & mobility needs.

How long will the needs last?
The prognosis for Dissociative disorders varies. The prognosis is generally related to the duration of symptoms, the longer. Read more about award duration.

Over 65s
Dissociative disorders are less common in the elderly. The principles of treatment are the same as for younger people although it may be more difficult for them to obtain appropriate treatment.

What are dissociative disorders?
Dissociative disorders are disorders where there is a disruption of the normal integration of consciousness, memory, identity or perception of the environment.

The cause of dissociative disorders is not known but it is thought that they develop as a protection against remembering life-threatening traumatic life events and those threatening to bodily integrity such as abuse, rape, war and natural disasters. There may be a genetic component as there is an increased incidence in relatives of people with the condition.
What evidence is available?
In cases of moderate and severe dissociative disorders it is highly probable that a Consultant Psychiatrist will have been involved in the management and treatment of the individual. Indeed the absence of any documented history of a psychiatric consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required.

Activities of Daily Living and Mobility Considerations

Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a mild functional restriction are likely to -:</td>
</tr>
<tr>
<td>Mobility</td>
<td>They would normally have no physical difficulty in getting around.</td>
</tr>
<tr>
<td>ADL</td>
<td>They should not normally exhibit significant self-neglect.</td>
</tr>
</tbody>
</table>

Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a moderate functional restriction are likely to -:</td>
</tr>
<tr>
<td>Mobility</td>
<td>They may have difficulty finding their way around unfamiliar places and may require guidance.</td>
</tr>
<tr>
<td>ADL</td>
<td>They are not likely to require supervision to prevent potentially dangerous behaviours or activities.</td>
</tr>
</tbody>
</table>
Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a severe functional restriction are likely to:</td>
</tr>
<tr>
<td></td>
<td>• Attend psychiatric day hospital</td>
</tr>
<tr>
<td></td>
<td>• Live in residential care or long term hospital care or if living at home been assessed as requiring 12 to 24 hour supervision</td>
</tr>
<tr>
<td></td>
<td>• Have been advised by an HCP or DVLA that they are not safe to drive or their licence has been revoked by DVLA</td>
</tr>
<tr>
<td>Mobility</td>
<td>They would normally have no physical difficulty in getting around.</td>
</tr>
<tr>
<td></td>
<td>They may have difficulty finding their way around unfamiliar places and may require guidance.</td>
</tr>
<tr>
<td>ADL</td>
<td>They may require prompting with a variety of day to day activities, depending upon the severity of their symptoms.</td>
</tr>
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How long will the needs last?

The prognosis for dissociative disorders varies. The prognosis is generally related to the duration of symptoms – the longer the symptoms have been present, the worse the prognosis. Dissociative amnesia and dissociative fugue often respond quickly to treatment if of short duration. Dissociative identity disorder and depersonalisation disorder tend to require many years of treatment. Treatment of chronic conditions is generally only partially effective.

Initially therefore, a short term award of 2 years should be considered.

Thereafter, an indefinite award should be considered.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award period</th>
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<tbody>
<tr>
<td>Dissociative disorders</td>
<td>First award period - 2 year award</td>
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<tr>
<td></td>
<td>Further award period - indefinite</td>
</tr>
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All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Diverticular disease/Diverticulitis

Back to A - Z

What is Diverticular disease/Diverticulitis?
Diverticular disease and diverticulitis are two related digestive conditions. Symptoms of diverticular disease include…. NHS Choices - diverticular disease/diverticulitis.

What evidence is available?
General practitioners are able to provide up to date information about people whose symptoms are stable and well…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
People with asymptomatic diverticular disease found during investigations for other abdominal conditions have no functional…. Read more about ADL & mobility needs.

How long will the needs last?
People with recurrent symptoms of abdominal pain and changes of bowel habit are usually able to manage their condition with…. Read more about award duration.

Over 65s
Some elderly frail individuals may take longer to recover and need help with dressing, personal hygiene, moving…. Read more about effects in the over 65 age group.

What evidence is available?
General practitioners are able to provide up to date information about people whose symptoms are stable and well controlled with medication. They can also confirm recovery from surgical operations. People with recurrent and more complex disease attend hospital outpatients including gastroenterology, surgery and geriatric clinics.

Reports may be obtained from doctors and specialist nurses working in these clinics. Specialist stoma nurses can provide up to date information on people with temporary or permanent colostomies. Some people at home recovering from surgery and those with colostomies, receive treatment and advice from community (district) nurses.
Activities of Daily Living and Mobility Considerations

People with asymptomatic diverticular disease found during investigations for other abdominal conditions have no functional restrictions and pursue normal life styles.

Similarly those with intermittent symptoms or episodes of acute diverticulitis that respond readily to standard treatment, are unlikely to have any long term functional restrictions necessitating help from others. The abdominal pain experienced is usually intermittent or episodic and does not affect the function of the lower limbs or restrict walking.

Most people who undergo surgery for complications can be expected to recover after some weeks or months.

Most adults with a temporary or permanent colostomy can be trained to manage it themselves within days or weeks. People with poor manual dexterity, visual impairment, abnormal cognitive function (e.g. dementia) may need colostomy care from another on a long-term basis.

Click on the link for details of :-

Bowel Incontinence
Back to top of section

How long will the needs last?

People with recurrent symptoms of abdominal pain and changes of bowel habit are usually able to manage their condition with attention to diet and medication.

10 – 25% may develop episodes of acute diverticulitis, and it is not known why this happens in some rather than others. Acute diverticulitis usually responds to treatment with fluids, antibiotics and analgesics within a few days or a week.

After an initial attack the yearly risk of having another episode is 3%. About 50% of recurrences occur within a year and 90% in five years. However people with symptomatic disease and people who experience episodes of acute inflammation are unlikely to have adverse outcomes and can lead a normal life style without undue restriction.

Following surgery for complications most people make a good recovery after some weeks or months. Those who require extensive surgery or more than one operation may take longer to recover fully.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
Over 65
Some elderly frail individuals may take longer to recover and need help with dressing, personal hygiene, moving around at home, help with the toilet, long term help with using a colostomy, attention to diet and supervision of medication etc.

Elderly people who have had extensive and complex surgery may experience long-term debility.

Back to top of section
What you need to know about Drug induced liver disease

What is Drug induced liver disease?
A large number of prescribed drugs, other medicinal substances and toxins can damage the liver. ... Read more about drug induced liver disease
Discuss with Medical Services.

What evidence is available?
It is usually the case that people with drug induced liver disease will have been diagnosed and treated in hospital. ... Read more about evidence sources.

Activities of Daily Living and Mobility needs
People who recover fully once the liver toxic drug is withdrawn are unlikely to have any long-term functional limitations. ... Read more about ADL & mobility needs.

How long will the needs last?
Early identification of a drug as the cause of liver disease and its removal often leads to recovery from the liver damage with ... Read more about award duration.

Over 65s
The size and function of the liver deteriorates with ageing. In general liver diseases in the elderly carry a worse prognosis than in the younger age. However the clinical features and treatment of the liver impairments are similar in both age groups.

What is Drug - induced liver disease?
A large number of prescribed drugs, other medicinal substances and toxins can damage the liver. In most cases the hepato-toxic effect is idiosyncratic and cannot be predicted; in certain cases the drug or substance is known to damage the liver and the effect is dose dependent. Toxic effects can be avoided in the latter circumstances by prescribing low doses and withdrawing the drug as soon as problems arise. Herbal remedies and illegal drugs such as cocaine and ecstasy can cause liver damage.

Some people appear to be more susceptible to drug hepato-toxicity than others. There may be increased susceptibility with age. It is estimated that between 0.1 and 3% of hospital admissions are due to adverse drug
reactions affecting the liver. A small number of drug reactions cause fatal liver disease.

If evidence shows that the customer has liver failure, which may have resulted from drug-induced liver disease then go to Liver Failure guidance.

If evidence shows that the customer has cirrhosis, which may have resulted from drug-induced liver disease then go to Cirrhosis guidance.

What evidence is available?
It is usually the case that people with drug induced liver disease will have been diagnosed and treated in hospital. Reports can be obtained from Consultants or specialist nurses working in liver clinics.

When an individual has made a good recovery from an episode of drug induced liver damage, it may be most helpful to obtain a general practitioner factual report. This report will confirm that there are no residual problems.

Activities of Daily Living and Mobility needs
People who recover fully once the liver toxic drug is withdrawn are unlikely to have any long-term functional limitations. Recovery usually occurs within months although sometimes it can take up to two years.

Although people may complain of fatigue and general malaise during this time, these symptoms are unlikely to be so disabling that help is needed with personal care or walking is significantly restricted.

How long will the needs last?
Early identification of a drug as the cause of liver disease and its removal often leads to recovery from the liver damage with a good prognosis. Resolution of symptoms and jaundice takes place over weeks or months although sometimes it can take up to two years.

Acute toxicity with fulminant hepatic failure can be fatal. However in those who respond to treatment, the liver is often able to recover fully with no adverse long-term effects.
Individuals who develop chronic hepatitis due to drug damage may have a variety of more serious outcomes that become apparent over some years. These include the development of cirrhosis and progressive liver failure.

If evidence shows that the customer has chronic hepatitis, which may have resulted from drug-induced liver disease then go to Viral hepatitis guidance.

If evidence shows that the customer has cirrhosis, which may have resulted from drug-induced liver disease then go to Cirrhosis guidance.

If evidence shows that the customer has liver failure, which may have resulted from drug-induced liver disease then go to Liver Failure guidance.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
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<tbody>
<tr>
<td>Drug induced liver disease causing chronic hepatitis</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Drug induced liver disease causing cirrhosis</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Drug induced liver disease causing liver failure</td>
<td>Indefinite</td>
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</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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What you need to know about Dyspeptic disorders

What is a Dyspeptic disorder?
- Read more about a Stomach ulcer
- Read more about a Hiatus Hernia
- Read more about Gastro-oesophageal Reflux Disease (GORD)
- Read more about Dyspepsia (Indigestion)
- Read more about a Femoral hernia repair

For information about other dyspeptic disorders Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
Uncomplicated cases of stomach ulceration are likely to be under the care of general practitioners. Endoscopy for diagnosis and follow up is usually carried out in a hospital clinic. Medical reports may be obtained from doctors and specialist nurses in gastroenterology clinics, and from surgical departments if complications have led to more complex interventions.

Activities of Daily Living and Mobility needs
In most cases of stomach ulceration, drug therapy affects a cure and all symptoms resolve. Recurrent symptoms or .... Read more about ADL & mobility needs.

How long will the needs last?
In most cases symptoms due to stomach ulceration resolve rapidly with drug treatment, within days or .... Read more about award duration.

Over 65s
Elderly people who have had a hospital admission and/or surgery for stomach ulcer complications might take some months to.... Read more about effects in the over 65 age group.

What evidence is available?
Uncomplicated cases of stomach ulceration are likely to be under the care of general practitioners. Endoscopy for diagnosis and follow up is usually carried out in a hospital clinic. Medical reports may be obtained from doctors and specialist nurses in gastroenterology clinics, and from surgical departments if complications have led to more complex interventions.
Activities of Daily Living and Mobility needs

In most cases of stomach ulceration, drug therapy affects a cure and all symptoms resolve. Recurrent symptoms or exacerbations of symptoms, invariably respond to further drug treatment. People with stomach ulceration lead normal lives without any long-term functional restrictions on a daily basis. They would not be restricted in their ability to walk or to care for themselves. Adults who have undergone surgery for stomach ulcer complications would be expected to recover within a few weeks and return to full function with a normal prognosis.

How long will the needs last?

In most cases symptoms due to stomach ulceration resolve rapidly with drug treatment, within days or weeks. Recurrent dyspepsia or exacerbations of pain usually respond to a further course of tablets. Symptoms can also be controlled on a long-term basis with antacids or courses of protein pump inhibitors.

Following hospital admission and/or surgery for complications such as bleeding or perforation a full recovery and return to normal function can be expected. Where drugs such as NSAIDs have been implicated in stomach ulceration, no recurrence is likely if these classes of medication are avoided in the future. If these drugs are necessary for pain relief, for example in the more severe types of arthritis (rheumatoid arthritis), additional prescription of a protein pump inhibitor (PPI) medication reduces the likelihood of stomach ulceration and its complications.

<table>
<thead>
<tr>
<th>Impairment</th>
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<tbody>
<tr>
<td>Hiatus Hernia</td>
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<tr>
<td>Gastro-Oesophageal Reflux disease (GORD)</td>
</tr>
<tr>
<td>Stomach ulcer / Duodenitis</td>
</tr>
<tr>
<td>Gastric ulcer / Gastritis</td>
</tr>
<tr>
<td>Peptic Ulcer</td>
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<tr>
<td>Helicobacter Pylori Infection</td>
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</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Over 65

Elderly people who have had a hospital admission and/or surgery for stomach ulcer complications might take some months to recover fully. However since drug treatment for the condition is successful in controlling recurrence, they would be unlikely to have any long-term functional restrictions arising solely from peptic ulceration.

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What you need to know about Dystonia

What is Dystonia?
Dystonia is a medical term that describes a range of movement disorders that causes involuntary spasms and contractions.…. Read more on NHS Choices - dystonia.

What evidence is available?
Dystonia is usually managed in a hospital setting by a Consultant Neurologist who may specialise in ‘movement disorders’…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Blepharospasm - the vast majority of people with blepharospasm will control their condition with regular botulinum toxin injections.…. Read more about ADL & mobility needs.

How long will the needs last?
Blepharospasm - this condition is likely to stabilise after a few years and neither improve or get worse. Regular treatment will…. Read more about award duration.

Over 65s
There are no special features.

What evidence is available?
Dystonia is usually managed in a hospital setting by a Consultant Neurologist who may specialise in ‘movement disorders’ although this is rare for focal dystonia. Medical evidence from the neurologist will be the best source of evidence of a diagnosis of dystonia.

The exception to this is spasmodic dysphonia or laryngeal dystonia. This type of dystonia is likely to be managed by an Ear, Nose and Throat (ENT) specialist rather than a neurologist
Activities of Daily Living and Mobility needs

Focal dystonias

Blepharospasm
The vast majority of people with blepharospasm will control their condition with regular botulinum toxin injections. No care or mobility needs would be anticipated. Likely difficulties for this group include recurrent symptoms as their botulinum toxin wears off, these are unlikely to be as severe as prior to initial treatment but may cause difficulties driving.

For a small number of people who have not responded to botulinum toxin and in whom other treatments have been ineffective there may be disabling effects related to the effect of the condition on vision. There are likely to be difficulties with self care or mobility around the home. Cooking and travelling outside the home are likely to be difficult if vision is significantly impaired.

Oromandibular dystonia (cranial dystonia)
This condition affects speech and ability to eat by making these activities difficult and socially awkward. A minority of people will control their condition with regular botulinum toxin injections. No care or mobility needs would be anticipated. Likely difficulties for this group include recurrent symptoms as their botulinum toxin wears off; these are unlikely to be as severe as prior to initial treatment. If the condition cannot be controlled by treatment there will be no care or mobility needs. However the nature of the condition may lead to social isolation, depression or other mental health condition. In these cases assessment of needs should be made on the mental health condition.

Spasmodic dysphonia or laryngeal dystonia
There are typically no care or mobility needs associated with this condition, although it may have necessitated a change in employment if severe. Although the voice may be very quiet or sound strangled, it is still possible to communicate. However the nature of the condition may lead to social isolation, depression or other mental health condition. In these cases assessment of needs should be made on the mental health condition.

Spasmodic torticollis or cervical dystonia
The majority of people will control their condition with regular botulinum toxin injections. No care or mobility needs would be anticipated. Likely difficulties for this group include recurrent symptoms as their botulinum toxin wears off; these are unlikely to be as severe as prior to initial treatment. People with more disabling symptoms or those that do not respond to botulinum toxin injections are likely to try drug treatment. If this treatment also fails then surgery including selective peripheral denervation and deep brain stimulation may be tried. The nature of the condition may lead to social isolation, depression or other mental health condition. This is
more likely if chronic pain is present. In these cases assessment of needs should be made on the mental health condition.

In a severe case there may be needs related to physical symptoms. Medical evidence of such disability must be provided. Examples include:

- Where posture is very contorted and there are spinal complications such as radiculopathies and accelerated Spondylosis.
- fixed postures (particularly if the head is fixed down onto the chest or fixed in extension (looking up above)
- the condition cannot be controlled by any treatment

**Hemifacial spasm**

The vast majority of people will control their condition with regular botulinum toxin injections. No care or mobility needs would be anticipated even if the condition is not controlled. Likely difficulties for this group include recurrent symptoms as their botulinum toxin wears off, these are unlikely to be as severe as prior to initial treatment but may cause difficulties driving. Spasms may interfere with speech but not prevent it. Recurrent botulinum toxin injections eventually may give rise to wasting of the muscles of the face making it look asymmetrical. The nature of the condition and its effect on appearance may lead to loss of employment, social isolation and depression – the effects of the condition on mental health may give rise to needs.

**Writer’s cramp or hand dystonia**

This condition has no effect on mobility. The dystonia may affect activities of self care; for example washing would be unaffected but there may be difficulty doing up buttons and tying laces in a very severe case especially where tremor is also a feature. Similarly the ability to prepare food may be compromised if the condition is severe -e.g. holding a knife to chop vegetables. In the majority of cases these activities not directly related to writing will not be or minimally be affected by the dystonia and there will be no care needs. Writer’s cramp can impinge significantly on occupations where writing is a major part of the work load.

The exception to this, in a mild condition, will be where self care requires a higher level of manual dexterity than is usual because of other medical problems or disabilities. Examples of this will include any type of stoma including a colostomy, urostomy, laryngectomy stoma etc where small dressings may need to be cut and manipulated into position. The type of activities affected are those which require two hands, one used to hold something steady and the other used to perform the activity. Indwelling catheters and attached night drainage bag for example require the use of both hands to screw small connections into place, these actions may be impossible with a dystonia of the forearm. Complex medication needs such as the following – indwelling catheters and lines, injections, the use of home nebuliser and oxygen equipment may be affected in a severe case.
Generalised dystonias

Idiopathic Torsion dystonia

Adults with this condition are likely to have developed generalised dystonia during childhood. The condition commonly affects the legs from the beginning and immediately affects walking ability. Abnormal spasmodic movements of the legs make taking steps very exhausting and difficult and remaining balanced with uncontrolled movements is also difficult. Within a few years walking more than half a mile may be impossible and gradually the distance walked independently reduces as spasms become more frequent and severe. Speed of walking is much reduced from onset. Severe disability is usual within about 10 years. Such people may be able to mobilise short distances and get into a wheelchair but will need a wheelchair when outside the house. Spasms of the upper limb and trunk may make self care very difficult if not impossible. For example lifting the arm to brush the hair may always result in abnormal movements and help may be required with washing and personal grooming for this reason. Help with personal care is less likely to be needed in people who have some response to drug treatment.

DBS surgery may be considered or used. This surgery may considerably improve movements and improve ability to walk and self care to the level where no help with care or mobility is required. DBS takes some time to improve function as adjustments to stimulation to improve function are made over time. Personal adjustment after a period of severe disability also takes time.

Rare dystonias

Myoclonus dystonia

There are typically no care or mobility needs associated with this condition.

Tardive dystonia

In the majority of cases stopping the causative drug will reverse the condition and movement return to normal over several months. If the condition has been present for more than a year it is unlikely to dramatically improve. The disabling effects will depend on which part or parts of the body are affected and how effective treatment is at controlling or reducing the movements. For facial tics affecting the eyes and mouth only see blepharospasm and Oromandibular dystonia. In a severe case the trunk, neck, arm and leg muscles are affected and the condition is more like a generalised dystonia, it may affect walking, balance or use of the upper limbs for self care or other activities. The condition is highly visible to others, the nature of the condition and its effect on appearance may lead to loss of employment, social isolation and depression – the effects of the condition on mental health may give rise to needs. If there is concurrent mental illnesses please refer to mental health guidance.

Tardive dyskinesia

The most effective treatment is to stop the causative drug as soon as possible. Symptoms will often disappear if this is done quickly enough.
Abnormal movements may be present 24 hours a day, with constant jerking twitching and grimacing movements of the face in addition to fidgeting of the hands and upper limbs. The movements may disturb sleep. Communication is affected because the abnormal movements interfere with facial expression. The condition is highly visible to others, the nature of the condition and its effect on appearance may lead to loss of employment, social isolation and depression – the effects of the condition on mental health may give rise to needs. If there is concurrent mental illnesses please refer to mental health guidance.

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**How long will the needs last?**

**Focal dystonias**

**Blepharospasm**
This condition is likely to stabilise after a few years and neither improve or get worse. Regular treatment will be required to preserve useful vision. If treatment fails at any point then needs are likely to arise in a severe case.

**Oromandibular dystonia (cranial dystonia)**
This condition is likely to stabilise after a few years and not improve or get worse. In a minority of cases it will be reasonably controlled with regular treatment. If uncontrolled, needs may arise from the effect of the condition on mental health.

**Spasmodic dysphonia or laryngeal dystonia**
Even when severe there are no care or mobility needs associated with this condition. Needs may arise from the effect of the condition on mental health.

**Spasmodic torticollis or cervical dystonia**
This condition is likely to get worse over several years and stabilise. Those cases with significant pain that are uncontrolled by treatment are most likely to have needs and these needs are likely to persist. Those with milder symptoms who are of young age and are not likely to have needs are most likely to recover from the condition, although permanent remission is rare.

**Hemifacial spasm**
This dystonia behaves like other dystonias, it get worse over several years and then becomes stable. In most cases it can be controlled with regular botulinum toxin injections and rarely curative surgery is used. Without surgery ongoing treatment is needed to control symptoms. The condition does not tend to go away by itself.

**Writer’s cramp or hand dystonia**
This condition tends to persist, particularly if severe. If needs are identified either because a person has personal care needs requiring manual
dexterity or because the condition is exceptionally severe these are likely to be enduring.

The next sections cover other types of dystonia, which are less common but which can be very disabling.

Generalised dystonias

Idiopathic (primary) generalised Torsion dystonia
This condition is enduring and is unlikely to respond well enough to drugs for walking to be resumed. There may be needs associated with mental health problems related to having a severe physical disability in addition to any physical needs identified. Significant change in level of disability is unlikely unless Deep Brain Stimulation surgery is undertaken. It may take a long time after such surgery for maximal reduction in disability to be achieved. If DBS is used disability is likely to be reduced in most cases and dramatically so in many with resumption of normal walking ability and the ability to use the upper limbs normally with minimal or mild Dystonic movements. A stable condition is likely to be reached around 2 years after surgery.

Dopa-responsive dystonia-parkinsonism (Segawa's Syndrome)
The partial condition responds very well to drug treatment with levodopa. In the typical case there is likely to be severe disability prior to diagnosis that resolves with diagnosis and treatment. Long term effective treatment with none of the expected side effects associated with levodopa is anticipated.
The homozygous type severe case is likely to be and remain severely disabled with mental retardation, seizures and enduring physical and mental impairment related to severe developmental delay.

Rare dystonias

Myoclonus dystonia
This condition stabilises after a few years. Other dystonia conditions may develop later in life in addition to Myoclonus.

Tardive dystonia
This condition usually resolves when the causative drug is stopped. If not stopped the condition gets progressively worse and may be permanent. The condition is unlikely to improve very much once present for a year.

Tardive dyskinesia
This condition usually resolves when the causative drug is stopped. If not stopped the condition gets progressively worse and may be permanent. The condition is unlikely to improve very much once present for a year.
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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What you need to know about Eating disorders

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<td>• Read more on <a href="#">NHS Choices - Binge eating</a></td>
</tr>
<tr>
<td>• Read more on <a href="#">NHS Choices - Bulimia Nervosa</a></td>
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</table>

For information about other Eating disorders Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
Self-assessment is the prime source of evidence, but the claim pack should be checked to see who has completed it.…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Function is usually well preserved in people with Anorexia Nervosa (AN) and Bulimia Nervosa (BN). If the disorders are…. Read more about ADL & mobility needs.

How long will the needs last?
About half of people with Anorexia Nervosa (AN) recover completely….. About 50% of people with Bulimia Nervosa make a full…. Read more about award duration.

Over 65s
Eating disorders are uncommon in the elderly, although rare cases have been reported in people over the age of 65…. Read more about effects in the over 65 age group.

What evidence is available?
Self-assessment is the prime source of evidence, but the claim pack should be checked to see who has completed it. If the form has been filled in by the customer, due to the nature of their condition, it might not necessarily be an accurate or reliable description of their problems.

If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.
The DM should bear in mind that the completion of the corroborative statement by a mental health professional does not necessarily mean that they endorse what has been said in the claim pack.

In all cases of moderate and severe eating disorders it is highly probable that a Consultant Psychiatrist will have been involved in the management and treatment of the individual. Hospital factual reports should therefore be obtained if required. Although the absence of any documented history of a psychiatric consultation should raise doubts about the nature and/or severity of the given diagnosis, please note that people with eating disorders usually deny problems and may avoid medical contact, especially psychiatric care. Therefore a HCP Examination report should be considered for a person with a moderate or severe eating disorder with no recent documented evidence (GP or hospital) of risk factors.

An HCP Examination report may be helpful if the person has physical problems

Other sources of information include the following:

**Community Mental Health Team**

The community mental health team provides a multidisciplinary team approach. The team will include psychiatrists, community psychiatric nurses, occupational therapists and social workers working in close collaboration with social service departments. One member of the team may co-ordinate the care and is known as the Care Co-ordinator.

**Care co-ordinator**

When the customer is being supported by a community mental health team the care co-ordinator on that team will be the preferred source of further evidence.

They have lead responsibility for the delivery of the care plan and so they can give details of the support that the customer has been assessed as needing. They will also know whether the customer is being helped by an Assertive Outreach or Crisis Resolution team.

**Day Centre and Psychiatric Day Hospital**

Attendance at a day centre (not on hospital site) or psychiatric day hospital (on hospital site) is likely to indicate severe disability.

These are therapeutic environments for evaluation, diagnosis and treatment of patients with mental health problems. They are staffed by psychiatric nurses, and there is input from all other members of the community mental health team. Attendance presents an alternative for patients whose condition requires intensive treatment, but do not need to be hospitalised.
Community Psychiatric Nurse (CPN)
A customer may be in regular contact with a CPN who will have assessed their care requirements. Advice is given about the amount of psychiatric nursing required and the administration of drugs.

The CPN will be in contact with other mental health professionals. They are well placed to provide detailed evidence about the customer’s needs.

NHS Care Programme Approach (CPA) care plan
When the customer is in contact with mental health services there will be a care plan under the NHS Care Programme Approach. The care plan will include information on health and social care as well as domestic support and is reviewed regularly.

The customer is given their own copy, which could be requested, as it will contain useful evidence of needs.

Social Services care plan
Social Services departments may be approached for help by someone with mental health problems. A community care assessment by a social worker/care manager will be arranged and a care plan produced.

The care plan will include details of the customer’s day-to-day living and the support provided. A copy can be obtained from the customer.

Mental Health Social Worker
Where a mental health social worker has been appointed to support a customer they will have information about the customer’s ability to cope with everyday living.

Subject to consent to approach them being given, the mental health social worker will be able to provide some useful evidence about the customer’s needs.

Accommodation manager
When the customer is living in supported accommodation then the type and level of support provided could be helpful in determining their need for help.

A phone call to the accommodation manager could provide useful evidence.

Crisis Resolution Team
The customer may have been supported during a crisis by the Crisis Resolution Team. The teams are mainly comprised of CPNs, who would make urgent visits, day or night to anyone who is thought to be in need of hospitalisation.
The idea is to provide intensive treatment at home instead. The Crisis Resolution Team would be well placed to provide details of the customer’s condition.

**General practitioner factual report**

If there is no specialist mental health professional involvement or evidence cannot be obtained from them, then it may be necessary to request a factual report from the customer’s own doctor.

The GP may have only limited knowledge of customer’s mental health problems, even when there is no one else involved.

**Activities of Daily Living and Mobility needs**

Function is usually well preserved in people with Anorexia Nervosa (AN) and Bulimia Nervosa (BN). If the disorders are mixed e.g. AN and BN, the symptoms tend to be worse. If there is co-morbidity with diabetes medical risks are exponentially increased.

Functioning may be very impaired in the presence of severe obsessive compulsive disorder (OCD) symptoms and may potentially make a mild or moderate condition more severe. Females who are pregnant or care for infants may need extra assistance. Driving is not recommended for people with a BMI <15 as concentration and attention may be impaired.

In AN most people are physically capable of feeding themselves, but they may require prompting to do so. If the person’s weight loss becomes extreme and they become severely ill, they require intensive attention to feeding and maintaining normal body chemistry. Such people will usually be admitted to hospital. People with AN, unless weight loss is extreme, would not normally be expected to have any mobility needs.

In BN because weight loss is usually absent, care needs are likely to be significantly less than for AN.
### Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
</table>
| **Effects** | People with a mild functional restriction are likely to:  
  - Not be receiving psychiatric care or supervision  
  - Be at low physical risk |
| **Mobility** | They would normally have no physical difficulty in getting around.  
  They should not have difficulty finding their way around unfamiliar places and should not require guidance. |
| **ADL** | They should not normally exhibit significant self-neglect.  
  They should not normally have any significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities. |
### Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
</table>
| **Effects** | People with a moderate functional restriction are likely to:  
- Be at moderate physical risk |
| **Mobility** | They would normally have no difficulty walking several hundred metres. They should not have difficulty finding their way around unfamiliar places and should not require guidance. |
| **ADL** | They may require encouragement to eat and plan and prepare a meal. They should not normally have any significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities. |

### Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
</table>
| **Effects** | People with a severe functional restriction:  
- Are likely to be at severe physical risk  
- May have severe OCD symptoms or co-morbid medical conditions, for example, diabetes  
- May be at high risk of self harm |
| **Mobility** | Walking distance may be severely restricted due to muscular weakness secondary to dehydration and salt imbalance. Salt imbalance may also cause muscle spasms, fits and faints. Renal failure may occur in severe cases. The distance that they are able to walk will be determined by the degree of muscular weakness which will vary from person to person. They should not have difficulty finding their way around unfamiliar places and should not require guidance. |
| **ADL** | They are likely to require encouragement to eat and plan and prepare a meal. They are likely to have a significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities. They are likely to require observation to stop compensatory behaviours, for example exercise or vomiting. |
How long will the needs last?

**Anorexia Nervosa (AN)**
About half of people with Anorexia Nervosa (AN) recover completely, a quarter improve and a quarter develop a chronic eating disorder.

Mortality has been reported as up to 5% over 4 to 5 years, but as high as 10% in the long term. Just over two third of deaths are due to the effects of starvation and one third are by suicide.

Education is disrupted, with attendance at school reduced by more than 50%. Vocational functioning is also impaired, with 21% of people still relying on state benefits 10 -15 years after the onset of the illness. Social isolation is common, social communication skills are poor and social networks are small.

Good prognosis is associated with an early age at onset and a short interval between the onset of symptoms and the beginning of treatment. Poor prognosis is associated with vomiting, bulimia, profound weight loss, long duration of illness, co-morbid psychiatric illness and psychosocial problems.

**Bulimia Nervosa (BN)**
About 50% of people with Bulimia Nervosa make a full recovery, 30% make a partial recovery and 20% continue to be symptomatic.

Good prognosis is associated with a shorter duration of illness, younger age of onset and higher socio-economic status. Poor prognosis is associated with borderline personality disorder, concurrent substance misuse, low motivation for change and a history of obesity.

An increase in mortality rate has been reported for Bulimia Nervosa (9 times the normal population risk).

In view of the potential for improvement, if the condition has been present for less than 5 years, a 2 year award should be considered. If the condition has been present for more than 5 years, a 5 year award should be considered.

**EDNOS (Eating disorder not otherwise specified)**
The course and prognosis of EDNOS is similar to that of the disorder it most closely resembles i.e. AN or BN.

In view of the potential for improvement, if the condition has been present for less than 5 years, a 2 year award should be considered. If the condition has been present for more than 5 years, a 5 year award should be considered.

In view of the potential for improvement in each type of eating disorder suggested award duration is -:
<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexia nervosa</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 5 years</td>
<td>5 year award</td>
</tr>
<tr>
<td>Bulimia nervosa</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 5 years</td>
<td>5 year award</td>
</tr>
<tr>
<td>Eating Disorder Not Otherwise Specified (EDNOS)</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 5 years</td>
<td>5 year award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Over 65**

Eating disorders are uncommon in the elderly, although rare cases have been reported in people over the age of 65. Although the clinical features and treatment are similar to those in people under 65, because the condition is uncommon in the elderly, diagnosis may be delayed.
What you need to know about Eczema (atopic)

Back to A - Z

What is Eczema?
Eczema is a condition that causes the skin to become itchy, red, dry and cracked. It is a long-term, or chronic, condition. Read more on NHS Choices - atopic eczema.
For information about other types of eczema Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
In rare cases of resistant eczema, particularly those where there is long standing damage to the skin from friction or scratching, healing does not occur and longer term difficulty with manual dexterity may be evident. These patients are usually under specialist care and evidence of persistent functional disability needs to be sought and each case considered in on its own merits.

Activities of Daily Living and Mobility needs
Eczema is usually a mild intermittent condition with minimal function effects for the majority of the time. During flare-ups of.... Read more about ADL & mobility needs.

How long will the needs last?
For those whose atopic eczema persists into adulthood, the condition is likely to be permanent. Likewise allergic skin.... Read more about award duration.

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.
Linked pages -:
Ageing
Falls
Frailty

What evidence is available?
In rare cases of resistant eczema, particularly those where there is long standing damage to the skin from friction or scratching, healing does not occur and longer term difficulty with manual dexterity may be evident. These patients are usually under specialist care and evidence of persistent functional disability needs to be sought and each case considered in on its own merits.

Activities of Daily Living and Mobility needs
Eczema is usually a mild intermittent condition with minimal function effects for the majority of the time.
During flare-up of eczema the patient experiences discomfort and irritation that may interfere with sleep. Eczema of the hands, particularly when there is significant fissuring or cracking of the skin, may cause temporary impairment of manual dexterity with difficulty doing up buttons or using implements. Eczema affecting the feet may make standing and walking uncomfortable for a short period until the rash subsides.

Creams or ointments may need to be applied to areas that the patient is unable to reach and help may be needed with this. However in most cases the attack would be expected to last no more than 3-4 weeks at this level of severity and in the recovery phase, although there may be residual skin rash, there should be no loss of ability to deal with personal functions or the ability to walk. In rare cases of resistant eczema, particularly those where there is long standing damage to the skin from friction or scratching, healing does not occur and longer term difficulty with manual dexterity may be evident. These patients are usually under specialist care and evidence of persistent functional disability needs to be sought and each case considered in on its own merits.

**Variability**

Eczema usually follows a pattern of exacerbation (flare-up) and remission (recovery) with periods between attacks when the skin is apparently normal. Attacks can last for several weeks at a time often with several months between. Repeated contact with irritants or sensitizers may induce exacerbations and the patient would be expected to be able to take action to avoid contact with known precipitating factors.

In some cases, particularly in atopic eczema, there may be a chronic low grade rash although this rarely would be expected to cause functional disability.

**How long will the needs last?**

For those whose atopic eczema persists into adulthood, the condition is likely to be permanent. Likewise allergic skin sensitisation is likely to persist for life. Irritant eczema should resolve and the skin should heal permanently once the source of irritation has been removed and the acute condition treated. In some cases where irritation has been prolonged or the condition neglected the inflammation of the skin can become chronic with continuous symptoms needing ongoing treatment.

However, in most cases exacerbations would be expected to last no more than 3-4 weeks and although there may be residual skin rash, there should be no loss of ability to deal with personal functions or the ability to walk.

With good management and reasonable care to avoid precipitating factors, most cases of eczema should be controlled with minimal resulting disability.
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about Endometrial (uterine) cancer

What is Endometrial (uterine) cancer?
Cancers of the uterus (womb) usually begin in the cells that make up the lining of the uterus (called the endometrium). Read more on NHS Choices - endometrial cancer.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even. Read more about evidence sources.

Activities of Daily Living and Mobility needs
The majority of women will receive curative treatment for early stage disease and return to health with no. Read more about ADL & mobility needs.

How long will the needs last?
In the rare situation where care and mobility needs are identified because of treatment of stage 1, 2 or 3 endometrial. Read more about award duration.

Over 65s
There are no special features associated with this age group.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- General Practitioner - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- Community or District Nurse - will have information on any home care or outreach package in place as this is coordinated through the practice.
- Social worker - customer may have a ‘Care plan’ from social services

Hospital
Specialist doctors -:
Specialist nurses have many different job titles :-
  - Clinical Nurse Specialist
  - Stoma care nurse
  - Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine :-
  - Physiotherapist
  - Occupational Therapist
  - Social worker
  - Counsellor
  - Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
  Hospice Specialists :-:
  - Palliative Care Physician
  - Macmillan Nurse
  - Clinical Nurse Specialist
  - Social worker
  - Physiotherapist
  - Occupational Therapist
  - Counsellor

Activities of Daily Living and Mobility needs
The majority of women will receive curative treatment for early stage disease and return to health with no disabling effects. Some may develop long term side effects of treatment.

Stage 1 and 2 disease
Long term side effects of treatment are infertility and early menopause. There are unlikely to be any long term care and mobility needs after treatment. The exception to this is the enduring but rare side effects of chemotherapy, pelvic lymphadenectomy (removal of the lymph nodes around the uterus) or radiotherapy. Needs are likely to arise when disease recurs.
Stage 3 disease
Long term disabling effects include the rare enduring side effects of chemotherapy. Side effects of radiotherapy may develop some years after treatment. Recurrent disease is fairly common and may occur only a few months after treatment of initial disease – up to date medical evidence from the treating hospital will be important.

Stage 4 disease
Most of these people are terminally ill. Those that are fit enough to have surgery are likely to go on to have chemotherapy or radiotherapy and are those with the best outcome in this group. A proportion may have many of the problems of metastatic disease group at the outset.

Problems specific to endometrial cancer include -:
- Lymphoedema of the lower limbs.
- Pelvic pain syndromes.
- Problems with the bowel or bladder following radiotherapy treatment, these may affect continence of either and occasionally the formation of a stoma such as a colostomy or ileostomy if the lower bowel or rectum is affected by the cancer may be necessary.

Metastatic and recurrent disease
There may be disabling effects from metastatic disease anywhere in the body including -:
- Liver metastases – these may cause fatigue and in the later stages, mental confusion, abdominal swelling or pain and jaundice.
- Lung metastases or malignant pleural effusion – may cause very disabling breathlessness reducing mobility to a few yards.
- Brain metastases – these may cause fits, personality change, confusion, difficulties with balance, walking and self care.
- Bone metastases – pain and pathological fractures.

How long will the needs last?
In the rare situation where care and mobility needs are identified because of treatment of stage 1, 2 or 3 endometrial cancer, any award made should last for the duration of treatment as typically improvement is expected. In stage 4 and recurrent disease needs are likely to increase over time.

Stage 1 and 2 disease
Five year survival from stage 1 disease is about 95%.
Five year survival from stage 2 disease is 80-90%.

Stage 3 disease
Five year survival from stage 3 disease is 50-60%.

Stage 4 disease
Five year survival for stage 4 disease is about 26%.
Most of these people are terminally ill.

**Metastatic and Recurrent disease**

This person is likely to be terminally ill although the expected survival may be longer than six months.

The majority of women have early stage disease but some of these women will experience recurrence of their endometrial cancer. After treatment endometrial cancer may recur either as a growth in the pelvis or more usually somewhere else in the body. For those with locally advanced disease like stage 4 disease, recurrence is very likely even when primary treatment is successful. The aim of treatment in stage 4 disease is to control the disease for as long as possible.

<table>
<thead>
<tr>
<th>Cancer stage</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stages 1, 2 or 3</td>
<td>Period of treatment plus reasonable recovery period</td>
</tr>
<tr>
<td>Stage 4, Metastatic and Recurrent disease</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

[Back to top of section]
What is Endometriosis?
Endometriosis is a common condition in which small pieces of the womb lining (the endometrium) are found outside. Read more on NHS Choices - endometriosis.
What is Epilepsy?
Epilepsy affects the brain and causes repeated seizures, also known as fits. Epilepsy affects around 456,000 people in.... Read more on NHS Choices - epilepsy

What evidence is available?
The claimant and / or carer should be able to provide the information required to accurately assess mobility.... Read more about evidence sources.

Activities of Daily Living and Mobility needs
In general, only the most severely affected people with epilepsy will qualify for an award i.e. those with either frequent or.... Read more about:
- ADL & mobility needs.
- Living with Epilepsy
- Nocturnal seizures

How long will the needs last?
In looking at prognosis and duration of disabling effects, it is helpful to divide seizures into idiopathic i.e. those without any.... Read more about:
- Award duration
- Living with Epilepsy
- Nocturnal seizures

Over 65s
The annual incidence of seizure disorders (epilepsy) in those over 60 years is rising, and 25% of new cases of epilepsy.... Read more effects in the over 65 age group.

What evidence is available?
The claimant and / or carer should be able to provide the information required to accurately assess mobility and care needs. However, if further details are needed, the General Practitioner or Consultant is an appropriate source of information.
Activities of Daily Living and Mobility needs

In general, only the most severely affected people with epilepsy will qualify for an award, (i.e. those with either frequent or severe fits causing injury, those who have no warning or have a dangerous and prolonged post-ictal phase).

Epilepsy affects each person in a different way. In some cases, supervision or attention may be required to prevent the risk of harm and injury during a seizure. To determine this risk, the following questions should be asked to build a complete picture of the customer’s epileptic condition and the way that condition affects their lifestyle.

Once this information is known, DLA / AA legislation can then be applied to the customer’s circumstances.

Note: None of the following questions on their own provide all the information needed to assess the risk of harm and the need for supervision / attention.

<table>
<thead>
<tr>
<th>Question</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is the frequency of seizures?</td>
<td>This begins to provide part of the overall picture. This is important as some types of seizure produce very specific seizure characteristics. Some people experience more than one type of seizure. This will help with the consideration of risk.</td>
</tr>
<tr>
<td>2. What type of seizure / seizures are experienced?</td>
<td>This information helps to consider the need for any supervision or attention in connection with the seizure.</td>
</tr>
<tr>
<td>3. Is a useful warning of a seizure experienced and if so is it recognised and remembered?</td>
<td>Again, this assists in determining the level of risk and deciding what supervision / attention is needed to avoid or reduce that risk. Injuries sustained may be bruising or tongue biting to fractures or head injury.</td>
</tr>
<tr>
<td>4. What is the history and nature of any injuries sustained during the seizure?</td>
<td>Again, this will help to determine the level of risk and the supervision / attention needed to avoid or reduce that risk. Post-epileptic behaviour can last from a few minutes to days.</td>
</tr>
</tbody>
</table>

Similar considerations are made by Occupational Health physicians in relation to employment and by the DVLA regarding safety to drive as detailed in the link below.
Other considerations might be -:

- Does the customer drive?
- Are seizures experienced during the day and / or night?
- Is the parent caring for a young child under the age of three?
- Has the customer had an episode of unexplained ‘Status Epilepticus’ in the past 12 months?

The above information will help with the consideration of entitlement and / or duration of award.

Click on the link for details of -:

Living with Epilepsy
Nocturnal seizures
Back to top of section

**How long will the needs last?**

In looking at prognosis and duration of disabling effects, it is helpful to divide seizures into idiopathic (seizures without any known cause) and secondary (where there is an underlying cause).

The success in preventing seizures with Anti-Epileptic Drugs (AEDs) varies depending upon the type of seizure. With idiopathic seizures, there is a good chance that AEDs will control the condition. However, seizures caused by underlying brain disease may be more difficult to control.

Suggested factors for the development of chronic, poorly controlled epilepsy include:

- Presence of additional disabling conditions
- Partial epilepsy
- More than one seizure type
- Long duration of active seizures
- Frequent seizures at onset

<table>
<thead>
<tr>
<th>Type</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generalised seizure (with status epilepticus in last 12 months) :-</td>
<td>Episode within the last year</td>
<td>1 year award</td>
</tr>
<tr>
<td>Absence seizure (Petit mal)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Atonic seizure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clonic seizure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Myoclonic seizure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tonic seizure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tonic-clonic seizure (Grand mal)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>primary or secondary</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Partial seizure (with status epilepticus in last 12 months -):

- Complex partial seizure
- Complex partial seizure evolving to generalised tonic-clonic seizure
- Simple partial seizure
- Generalised seizure (without status epilepticus in last 12 months) -:
- Absence seizure (Petit mal)
- Atonic seizure
- Clonic seizure
- Myoclonic seizure
- Tonic seizure
- Tonic-clonic seizure (Grand mal) primary or secondary
- Partial seizure (without status epilepticus in last 12 months) -:
- Complex partial seizure
- Complex partial seizure evolving to generalised tonic-clonic seizure
- Simple partial seizure
- Non epileptic attack disorder (pseudoseizure)
- Seizure (Epilepsy) - unclassified

Episode within the last year 1 year award

Less than 2 years 2 year award

More than 2 years 5 year award

Less than 2 years 2 year award

More than 2 years 5 year award

N/A  N/A

Less than 2 years 2 year award

More than 2 years 5 year award

All information must be taken into account when considering the duration of disabling effects, and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Click on the links for details of -:
- Living with Epilepsy
- Nocturnal seizures
- Back to top of section

Seizure disorders in people over 65

The annual incidence of seizure disorders (epilepsy) in those over 60 years is rising, and 25% of new cases of epilepsy occur over the age of...
65. The cause of epilepsy can be identified in more than 50% of older patients.

The incidence of secondary epilepsy in the elderly has now risen to more than 100 per 100,000, and the main causes of secondary epilepsy are: cerebro-vascular disease (around 50% of cases), brain tumour, injury and bleeding on the brain (sub-dural haematoma), and degenerative conditions of the central nervous system, including Alzheimer’s Disease.

Strokes are more likely to occur in older people, and in the first year following a stroke, 5% have seizures. Because of the common factor of cerebro-vascular disease in this older age group, 3% of stroke patients also have a history of fits.

Older people have a lower threshold for developing seizures in response to a stimulus than younger people, and there is an increased likelihood of relapse.

As well as differing in causation, incidence and prevalence from those of young adults or children, seizures in the elderly differ in presentation, and predominant types of fit. It is harder to differentiate for instance between a faint (syncope) and a fit in the elderly; and complex partial status epilepticus may present as confusion.

Older people are more at risk of losing their quality of life and independence with epilepsy, and are more susceptible to injury and broken limbs because of their increased general frailty, osteoporosis, and relative immobility, for example.

All anti-epileptic medications have side effects, and, with an older person, several factors are particularly important, including his/ her state of health, the presence of other conditions, (such as heart failure) and other medication which the patient is taking. However, it is possible to control 70% of fits in the older age group.

Many elderly people are still driving, and the same driving regulations apply.

**Living with Epilepsy**

- Introduction
- Behaviour and emotions
- Driving and recreation
- Education and employment
- Pregnancy and motherhood
- Daily living
- Caring for a child under 3 years of age
Introduction

The vast majority of people with epilepsy are able to live full lives with no disability in between attacks. Approximately 80% can be significantly helped by current therapies and may go months or years between seizures with 70% being seizure free on Anti-Epileptic Drugs (AEDs). However, there is a 2 to 3 fold increase in sudden death, which is unexplained and unpredictable. With some types of seizures, there is a risk of head injury or aspiration of vomit into the lungs, which can, on occasions be fatal.

Epilepsy can and does affect a small proportion of people and their friends and families by influencing other factors, which may seriously impact on their activities of daily life. For example, some people may require someone else there all the time because they experience fits without any warning and/or exhibit dangerous post-epileptic behaviour.

People with prolonged seizures or severe seizures that are resistant to treatment have, on average, a shorter life expectancy and an increased risk of cognitive impairment. This is particularly the case if the seizures developed early in childhood.

Behaviour and emotions

It is not uncommon for people with epilepsy to develop behavioural and emotional difficulties. Such individuals may avoid social contact in school, employment, or other settings.

All people with epilepsy have an increased risk of poor self-esteem, depression and suicide, and may live with an ever-present fear that they will have another seizure.

Driving and recreation

By law, people with epilepsy must stop driving and notify the DVLA (Drivers and Vehicle Licensing Agency).

In the U.K. a Group 1 (car or motorcycle) licence cannot be held unless the following legal criteria are met.

The regulations state:

- A person who has suffered an epileptic attack whilst awake must refrain from driving for 1 year from the date of the attack before a driving licence may be issued.
- A person who has suffered a single epileptic attack whilst asleep must also refrain from driving for 1 year from the date of the attack.
- If seizures have occurred only during sleep for a period of at least 3 years, and no attacks whilst awake have occurred, then a Group 1 driving licence may be held.
- The DVLA advises patients not to drive during a period of drug withdrawal, and for 6/12 after the withdrawal has been completed.
• In any event, the driving of a vehicle by such a person should not be likely to cause danger to the public.

For vocational and truck drivers the regulations are even stricter, (i.e. a 10 year period of freedom must be established during which there is no anticonvulsant use).

Stringent regulations also apply to the armed forces, aircraft pilots, sea captains, divers and similar activities.

The correct diagnosis of a seizure or other attack at any age is therefore of major social and legal importance.

In the UK it is the responsibility of the affected individual to inform the DVLA.

If treatment (AEDs) is withdrawn, the DVLA recommends that driving should cease whilst the AEDs are being withdrawn, and for a period of 6 months following withdrawal. If the person has a seizure, then the normal regulations apply.

In law if within a 24 hour period, more than one epileptic attack occurs, these are treated as a “single event” for the purpose of applying the epilepsy regulations for driving. An episode of Status Epilepticus would be considered, as a solitary seizure and the driving licence would be withdrawn for 1 year.

Education and employment
Most children with epilepsy attend mainstream schools. Many children with epilepsy have no other major condition, and the seizures are well controlled.

Some children with epilepsy have other major conditions (such as learning difficulties) and may require special schooling. This accounts for up to 25% of children with epilepsy.

Pregnancy and motherhood
Women with epilepsy need special treatment, and active advice with regard to contraception and becoming pregnant.

Some of the AEDs used to treat epilepsy are associated with birth defects. This risk is slightly higher than 4 - 6% compared with the background risk of 1-3%.

Many patients with epilepsy, who become pregnant, stop their medication because of the potential side effects of the medication on the unborn baby. This may increase the seizure frequency.
Pregnancy often makes epilepsy worse, because there are complex biochemical changes in the body, in pregnancy, which may increase seizure frequency, or change the effectiveness of the medication.

Epilepsy may present for the first time in pregnancy.

**Daily living**

A number of factors are likely to influence the effects of epilepsy on daily living and therefore any care or mobility needs. No single factor can be decisive.

The vast majority of people with epilepsy are able to live full lives with little disability in between attacks. They cannot generally be considered as being in substantial danger. Though the medications which they take may not affect the majority of people’s ability to care for themselves and get around, they may be affected to some degree by side effects, such as mental sluggishness, depression, tremors, rashes, spots, hypertrophy of the gums, blood disorders to name a few.

A risk of seizure occurrence does not in itself mean that a person needs attention or supervision.

In some types of seizures, the person may be incontinent during the seizure. However, unless other conditions are present e.g. learning difficulties or problems with manual dexterity, the person will usually be able to deal with this themselves.

It is a small minority who will require attention or supervision to any significant degree due to complicating conditions or where the epilepsy cannot be adequately controlled.

**Caring for a child under 3 years of age**

A parent with epilepsy who is caring for a young child may pose a risk to that child. When assessing that risk, the following should be taken into account: -

- The nature of the fits
- Whether there is any useful warning of an impending fit
- Any dangerous post fit behaviour
- The frequency of the fits
- Age of the child

If it is considered there is a significant risk the person with epilepsy may need supervision to prevent them injuring the child during a seizure.

**Nocturnal (night-time) seizures**

Some seizures occur at night, and for some people seizures occur only at night.
Once a person is in bed, they are not at risk of falling and injuring themselves. The danger of choking or being suffocated by a pillow is extremely small and special pillows are available on the market to reduce this possibility to a minimum. Alternatively, the person may choose not to use a pillow.

There are also other adaptations which could be made to the room, such as the use of a low bed.

With some types of epilepsy, confused or automatic behaviour may lead to the danger of wandering or other behaviour, which may lead to harm to the person. In these circumstances, it would be sensible for appropriate precautions to be taken, such as having another person in the house and minimizing hazards.

It should be sufficient that someone is present in the house with the person, as there would not usually be a need for another person to remain awake observing the person in case they had a fit.
What you need to know about Fainting (syncope)

Back to A - Z

What is Fainting?
Fainting is a sudden, temporary loss of consciousness that usually results in a fall. Healthcare professionals often use the term. Read more on NHS Choices - fainting.

What evidence is available?
Where there is a need to seek clarification of care / mobility needs, then it may be necessary to request a factual report from the customer’s own GP.

Activities of Daily Living and Mobility needs
Fainting, by definition, results in a transient period of unconsciousness and therefore carries a degree of risk of injury. Read more about ADL & mobility needs.

How long will the needs last?
In young persons with no evidence of underlying cardiac disease and no known cause for the syncope, the prognosis. Read more about award duration.

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linking -:
Ageing
Falls
Frailty

Activities of Daily Living and Mobility needs
Fainting, by definition, results in a transient period of unconsciousness and therefore carries a degree of risk of injury from falling or the effects of losing consciousness while in a potentially hazardous situation such as when driving or working at height.

However, a simple faint is usually an isolated episode and should not result in the need for restriction of activities or any specific help or supervision out with that needed at the time of the attack. Simple faints can occur repeatedly in susceptible individuals, usually in predictable situations and even so should not result in a functional abnormality.

Solitary episodes of fainting with no evidence of an underlying cause would not result in restriction of driving.
Where attacks are frequently recurrent as in situational fainting, or where they are associated with significant underlying disease, the risks of harm and the need for help or supervision will need to be considered based on the more general guidelines for assessing episodic loss of consciousness. Continued frequent attacks of fainting may well impact on quality of life and perceptions of well-being.

In a study of a large series of cases the incidence of serious injury such as fracture was 6% and that of minor injury such as abrasion or bruising was 29%.

Fainting poses an accepted risk for frail elderly people due to age related physiological changes in heart rate, blood pressure and cerebral blood flow, as well as the effects of co-existing conditions and is commonly associated with falls. The incidence of fainting is 6% in the older adult (>70 yrs) with a prevalence of 10%, although these figures may underestimate the risk as incidents of falling may not be reported as fainting.

Where there is underlying disease the functional effects of that condition would need to be evaluated in their own right.

Variability
The condition is episodic and therefore inherently variable. In simple fainting there should be no impairment of function between episodes and any difficulties are limited to the immediate period of the episode. When fainting accompanies an existing condition the ongoing effects of that condition will influence any variability.

How long will the needs last?
In young persons with no evidence of underlying cardiac disease and no known cause for the syncope the prognosis is good. Many people experience only a solitary episode although around 30% may experience a further episode within 2 years. Some may get attacks in predictable situations such as during periods of anxiety or when unwell with a viral infection but generally the condition is infrequent and unpredictable.

The prognosis of syncope resulting from another condition depends on the treatment and underlying prognosis of that condition.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about Fractures

What is a fracture?
- Read more on NHS Choices - fractured hip
- Read more on NHS Choices - fractured rib
- Read more on NHS Choices - broken arm/wrist
- Read more on NHS Choices - broken collarbone
- Read more on NHS Choices - broken toe
- Read more on NHS Choices - broken nose

For information about other fracture sites Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
The immediate effects of a fractured bone may cause significant functional restrictions. In many cases, such restrictions…. Read more about ADL & mobility needs.

How long will the needs last?
The repair of a fracture is a continuous and gradual process. The amount of time taken for a fracture to unite depends upon…. Read more about award duration.

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages -:
Ageing
Falls
Frailty

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required in most cases.

However, where there are complications (see ADL and Mobility needs), then it may be necessary to request a factual report from the customer’s own General Practitioner.

**Activities of Daily Living and Mobility needs**

The immediate effects of a fractured bone may cause significant functional restrictions. In many cases, such restrictions are unlikely to persist beyond three months. This period allows for the majority of fractures to heal (unite) and for general physical recovery to take place.

- In a minority of cases, the fractured bones do not knit together (non-union) and recovery of function may be delayed. Surgery may be required to assist the healing process.
- Some fractures are complicated by infection. Established bony infection (osteomyelitis) may be very difficult to treat and result in longstanding disability. Such individuals may also be generally unwell.
- Delayed healing may also occur where the fractured bone has a single blood supply, such as the lower third of the tibia, and the neck of femur. In some cases a fracture may occur through a joint, damaging the joint structure. If possible, such fractures should be treated by operation.
- Secondary osteoarthritis often complicates a fracture through a joint, and full recovery of function may not occur. In such cases, care and/or mobility needs may occur.

**Osteoporosis**

From middle age onwards, bones gradually become less dense and are more liable to fracture. This is a normal part of the ageing process.

Osteoporosis is a condition where this process of bone thinning is greatly accelerated. Osteoporotic bones are brittle and are much more likely to fracture. The healing of osteoporotic fractures is not impaired, so any resultant disability may not last more than a few weeks or months. This is often the case in the younger person. However in the elderly, who have sustained repeated fractures and progressive collapse of the spine, no significant improvement in disability is likely.

**How long will the needs last?**

The repair of a fracture is a continuous and gradual process. The amount of time taken for a fracture to unite depends upon the type of fracture and which bones are affected. However, as a general rule, fractures need to be immobilised for between two to eight weeks. Following this, gentle exercises and movements are important, to build up bone and muscle
strength. Physiotherapy may be required to assist this process. As a general rule, a return to about full function within 3 months usually occurs.

The healing of osteoporotic fractures is not impaired, so any resultant disability may not last more than a few weeks or months. This is often the case in the younger person. However in the elderly, who have sustained repeated fractures and progressive collapse of the spine, no significant improvement in disability is likely.

If a fracture has occurred, and this is the reason for the functional restrictions, the fracture should heal within 6 months.

<table>
<thead>
<tr>
<th>Impairment</th>
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<tbody>
<tr>
<td>Fracture complications -:</td>
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<tr>
<td>Compartment syndrome</td>
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<tr>
<td>(Volkmann’s ischaemia)</td>
</tr>
<tr>
<td>Sudek’s atrophy</td>
</tr>
<tr>
<td>Fracture complication – Other / type not known</td>
</tr>
<tr>
<td>Fracture/Injuries/Dislocation -:</td>
</tr>
<tr>
<td>Lower limb - Fracture of Pelvis – Fracture of Spine – Fracture of Thorax - Fracture of</td>
</tr>
<tr>
<td>Upper limb - Fracture of</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Gallstones

What is a Gallstone?
Gallstones are small stones, usually made of cholesterol, that form in the gallbladder. In most cases they do not cause any….
[Read more on NHS Choices - gallstones.]

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required in most cases.

Activities of Daily Living and Mobility needs
Most people with gallstones have no symptoms and therefore no functional disability i.e. 'silent gallstones'. Some may….
[Read more about ADL & mobility needs.]

How long will the needs last?
Gallstones do not resolve spontaneously and once formed will persist throughout the rest of life. If treated by medication or….
[Read more about award duration.]

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.
Linked pages -:
- Ageing
- Falls
- Frailty

Activities of Daily Living and Mobility needs

- Most people with gallstones have no symptoms and therefore no functional disability ('silent gallstones'). Some may experience minor symptoms of indigestion, particularly following a meal with a high content of fat.
- Problems can occur when either the gallbladder becomes inflamed or infected (cholecystitis) or when a stone or part of a stone is dislodged and passes into the bile ducts. These cause acute symptoms relating to systemic effects of infection, biliary colic or obstruction and need urgent treatment.
• Following treatment of acute symptoms recovery would be expected to be good with no residual disability. Occasionally people may experience recurrent attacks of biliary colic if definitive treatment to remove the stones has not been completed. Between attacks, apart from the possible need to make minor adjustments to diet for the majority of the time, the person should be able to live a normal life.

• In acute cholecystitis the patient is acutely ill until the condition resolves either spontaneously or with treatment. The attack may be short-lived with spontaneous recovery in 2-3 days. If it does not recover spontaneously or the condition rapidly deteriorates the patient will probably need to be admitted to hospital.

• Episodes may occur infrequently and between attacks the person would be normal with no ongoing disability apart from perhaps the need for some dietary adjustment. Some patients may experience only a single episode with no further problems.

• In chronic cholecystitis symptoms can recur regularly but there would again be no ongoing loss of function between episodes other than possibly some vague abdominal pain associated with meals.

How long will the needs last?
Gallstones do not resolve spontaneously and once formed will persist throughout the rest of life. If treated by medication or lithotripsy, there is subsequent a risk of further stone formation.

When treated by removal of the gallbladder the problem should be resolved although in susceptible individuals there remains a small risk of further stones forming within in the bile ducts themselves.

Chronic cholecystitis tends to run a prolonged course until treated definitively. Apart from some of the more vague symptoms, which cause only mild effect on lifestyle, it is the frequency and severity of episodes of acute cholecystitis that determines the need for specific treatment.

The after effects of laparoscopic cholecystectomy are minimal with the person able to resume a normal life within a few weeks. Recovery from open cholecystectomy takes longer with at least six weeks for primary wound healing and up to three months to regain full function of the abdominal muscles.

Symptoms are generally episodic in nature and variability relates only to the frequency of acute episodes. Most only last a few days and the patient should not suffer continuing disability between episodes. If these recur regularly then definitive treatment to resolve the problem is indicated.

Complications following surgery or secondary effects of gallbladder disease on function of the liver or pancreas may prolong the illness but where there is evidence of such problems then each case would need to be considered on its own merits.
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Gout

What is Gout?
Gout is a type of arthritis, in which crystals of sodium urate produced by the body, can form inside joints. The most common....Read more on NHS Choices - gout.

What evidence is available?
There would normally be no lasting significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and Mobility needs
During an acute attack, a person may be confined to bed or chair, or may be severely restricted in their activities. Such…. Read more about ADL & mobility needs.

How long will the needs last?
During an acute attack, a person may be confined to bed or chair, or may be severely restricted in their activities…. Read more about award duration.

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages -:
Ageing
Falls
Frailty

Activities of Daily Living and Mobility Considerations

During an acute attack, a person may be confined to bed or chair, or may be severely restricted in their activities. Such severe restriction will be of extremely short duration, as effective treatment exists to relieve pain and inflammation within hours. Even if untreated, an acute attack of gout will settle on its own, and the joint will return to normal with no functional limitations.

Functional limitations from longstanding gout are rare due to effective treatment.
How long will the needs last?
During an acute attack, a person may be confined to bed or chair, or may be severely restricted in their activities. Such severe restriction will be of extremely short duration, as effective treatment exists to relieve pain and inflammation within hours. Even if untreated, an acute attack of gout will settle on its own, and the joint will return to normal with no functional limitations.

Functional limitations from longstanding gout are rare due to effective treatment.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about Hearing Impairment (Deafness)

Back to A - Z

What is Impaired hearing (Deafness)?

- Read more on NHS Choices - Hearing Impairment (Deafness)
- Read more on NHS Choices - Meniere's Disease
- Read more on NHS Choices - Labyrinthitis

For information about other specific conditions causing Hearing Impairment Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?

In the first instance, the claimant and/or the carer should be able to provide the information required, but if further information is needed, Read more about evidence sources.

Activities of Daily Living and Mobility needs

Although the following is based upon audiometric results, it should be noted that for an individual, the amount of.... Read more about ADL & mobility needs.

Linked pages:
Deeming provisions

How long will the needs last?

For people with recent onset of hearing loss, from whatever cause, in view of the potential response to treatment, the prognosis is.... Read more about award duration.

Linked pages:
Deeming provisions

Over 65s

The symptoms and management of hearing loss in the elderly are similar to those in a younger age group. However, if.... Read more about effects in the over 65 age group.

What evidence is available?

Note: If considering entitlement to H/R Mobility component under the Severely Visually Impaired (SVI) provisions, the following evidence source must be used:

The Consultant Ophthalmologist will be able to provide information about symptoms, signs, investigations including assessment of vision,
treatment/management, and is likely to have information about resulting disability or needs.

Note: If the Consultant Ophthalmologist doesn’t have up to date information, consider arranging for an eyecare examination.

In the first instance the claimant and/or the carer should be able to provide the information required, but if further information is required an Audiology or General Practitioner may be an appropriate source. However, a general practitioner does not usually have significant or specialist knowledge of the claimant’s hearing loss and resulting needs. A more appropriate source may be a Social Worker (especially one who specialises in working with deaf and hard of hearing people), a Hearing Therapist, a Teacher of the Deaf, or Professionals involved in arranging or delivering communication support to the claimant (such as a Disability Adviser at a college or university, or a BSL interpreter that the client uses regularly).

In certain circumstances (e.g. deaf / blind cases), it may be appropriate for the Decision Maker to request an Audiological report (a technical assessment) to establish the extent of deafness in a customer.

**Activities of Daily Living and Mobility needs**

Although the following is based upon audiometric results, it should be noted that for an individual, the amount of hearing disability in everyday life cannot be accurately predicted from audiometric test results. The tabulated results are only broadly true for the subgroup as a whole.

Even where hearing function itself is concerned, the pure tone audiogram measures only one of several aspects. It shows the sensitivity of the ear at different frequencies but does not show reduced discrimination between frequencies, for example. This is another common aspect of sensorineural hearing loss and further affects the ability to follow what people are saying.

Interpretation of an audiogram is complex, for example the audiogram does not measure hearing but hearing loss, the hearing loss is on a logarithmic scale so a 20db loss is not half a 40db loss. The DM really needs to consider communication difficulty in addition to straight hearing loss. For example a person will also use visual signs such as lip movements to understand another person.

Therefore all information must be taken into account when considering a claim.
Mild Functional Restriction – Hearing loss 21 – 40 dB but see disabling effects below

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>Within this range a hearing aid may be required depending upon the frequencies affected by the hearing loss, the persons’ occupation and whether they have a dual sensory disability. They will be unlikely to require communication aids, to lip read or use manual communication (BSL). They will have speech that can be understood by strangers and will be able to hear and understand a normal voice at 1 metre. Background noise may be intrusive.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>The ability to walk is likely to be unimpeded. They are unlikely to have difficulty finding their way around unfamiliar places and are likely to be able to ask for and hear directions. They are likely to be aware of common hazards.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>The resulting disability is unlikely to affect their ability to independently carry out activities of daily living. They are likely to be able to identify common hazards in the home.</td>
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</tbody>
</table>
Moderate Functional Restriction – Hearing loss 41 – 70 dB but see disabling effects below
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>They are likely to gain benefit from amplification either from a hearing aid or by external devices. They may rely on a combination of amplified sound and lipreading. They will have speech that can be understood by strangers and will be able to hear and understand a normal voice at 1 metre with appropriate amplification. Background noise will have a notable affect in understanding speech.</td>
</tr>
<tr>
<td>Mobility</td>
<td>The ability to walk is likely to be unimpeded. They are unlikely to have difficulty finding their way around unfamiliar places and are unlikely to require guidance. However, they may not be able to hear traffic and other hazards adequately, for example to enable them to be aware of a hazard approaching outside their field of vision. They may also have difficulty with judging the direction, distance, or velocity of the source of the sound. However, in the absence of other factors such as a learning disability, significant visual problem or mental health problems, this may be compensated for by increased visual awareness and by taking a little extra time.</td>
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</tbody>
</table>
They are likely to be able to attend to tasks of personal care. However, they may have problems with communication and may need a variety of types of communication support. The most common are lipspeakers, speech-to-text reporters, and notetakers. Communication support may be provided professionally or informally, for example by family or friends with the requisite abilities. They are likely to be able to identify common hazards in the home with appropriate amplification.

<table>
<thead>
<tr>
<th>Severe Functional Restriction - Hearing loss 71 dB or more but see disabling effects below</th>
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<tbody>
<tr>
<td>Note that this includes people with severe and profound hearing loss.</td>
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<table>
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<tr>
<th>Category</th>
<th>Description</th>
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<tr>
<td>Disabling Effects</td>
<td>They will be more dependent on communication devices such as a textphone or videophone than those with a moderate condition. They are likely to lip read, but if BSL is the person’s first language, they may have no or limited lipreading skills. They are likely to use manual communication if the onset of hearing loss was before the development of language skills (pre-lingual deafness). Prelingually deaf adults may also have difficulties with written English. They may be eligible for a cochlear implant, but this is unsuitable for many deaf adults, particularly those who are prelingually deaf. They will be unable to hear and understand a raised voice at 1 metre. (Although in ideal conditions with aids they may be able to hear a raised voice, this may be adversely affected by background noise). Speech may be affected such that they may not be understood clearly by strangers.</td>
</tr>
</tbody>
</table>
Mobility

The ability to walk is likely to be unimpeded. These people will be unable to hear speech and may rely on lip reading or British Sign Language (BSL) if they are skilled in these methods, however they will still have problems with communication unless accompanied by a BSL interpreter. In addition, they may not be able to hear traffic and other hazards adequately, for example to enable them to be aware of a hazard approaching outside their field of vision. They may also have difficulty with judging the direction, distance, or velocity of the source of the sound. Those who are prelingually deaf may have unintelligible speech and if the person cannot read or write, may not be able to find their way about on unfamiliar routes. People with this level of functional restriction may have difficulty finding their way around unfamiliar places and may require guidance outdoors. However, in the absence of other factors such as a learning disability, significant visual problem or mental health problems, this may be compensated for by increased visual awareness and by taking a little extra time. They may also satisfy the H/R Mobility criteria under the Severely Visually Impaired (SVI) or the deaf/blind deeming provisions. Click on Deeming provisions and consult the Vision guidance.
| ADL | They are likely to be able to attend to tasks of personal care. However, they will have problems with communication and will be unable to hear speech and may rely on lip reading or British Sign Language (BSL) if they are skilled in these methods. BSL users need to use a BSL interpreter for the translation of spoken English to BSL and vice versa. If they have difficulties with written English they may also need translation of the written word to BSL and vice versa. Those who do not use BSL may need a variety of other types of communication support. The most common are lipspeakers, speech-to-text reporters, and notetakers. Communication support may be provided professionally or informally, for example by family or friends with the requisite abilities. There are many environmental aids available, which may help in some situations. |

If there is any doubt about the level of functional restriction seek medical services advice.

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**How long will the needs last?**

For people with recent onset of hearing loss, from whatever cause, in view of the potential response to treatment, the prognosis is uncertain for the first 12 months and it would be reasonable to award for a limited period whilst awaiting the outcome of response to treatment.

For people who have had recent surgical interventions, such as Cochlear Implants, Middle Ear Implants and Bone Anchored Hearing Aids, the response to treatment varies. Therefore, a review after 12 months should be undertaken and further medical evidence obtained at that time.

For people with hearing loss of onset in childhood, or onset more than 5 years ago, a long-term award may be considered. However, further medical evidence should first be obtained to confirm that a specialist unit has carried out an assessment and that no medical or surgical intervention is considered appropriate.
Factors such as the physical health, mental state and any other co-existing disablement may impair and prolong the period of learning and rehabilitation in an individual case.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
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<tbody>
<tr>
<td>Conductive hearing loss -:</td>
<td></td>
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<tr>
<td>• Otitis Media with effusion (OME)</td>
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<td><strong>previously known as</strong> Chronic Secretory</td>
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<tr>
<td>Otitis Media</td>
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<tr>
<td>• Chronic Suppurative Otitis Media</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Conductive hearing loss due to Trauma</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td>• Otitis externa - chronic</td>
<td>More than 5 years</td>
<td>Indefinite award</td>
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<tr>
<td>• Otosclerosis</td>
<td></td>
<td></td>
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<tr>
<td>• Other causes of conductive hearing loss / type not known</td>
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<tr>
<td>Hearing loss - mixed</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td>• Hearing loss - mixed</td>
<td>More than 5 years</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Sensorineural hearing loss -:</td>
<td></td>
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<tr>
<td>• Deafness – congenital / Pre lingual</td>
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</tr>
<tr>
<td>• Labyrinthitis</td>
<td>Less than 5 years</td>
<td>2 year award</td>
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<tr>
<td>• Menieres disease</td>
<td>More than 5 years</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>• Presbyacusis</td>
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<tr>
<td>• Sensorineural hearing loss due to Trauma</td>
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</tr>
<tr>
<td>• Sensorineural hearing loss - Other causes of / type not known</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease affecting hearing &amp; balance - Other / type not known -:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The most common hearing conditions are covered by this guidance. Some of the more unusual conditions not covered may have care / mobility needs depending on the degree of hearing loss. Medical Services advice should be obtained in these cases.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing impairment with visual impairment -:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>You may need to consider whether the H/R Mob Severely Visually Impaired (SVI) deeming provisions are satisfied. See <a href="#">Deeming Provisions</a> and consult the Vision guidance.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>You may need to consider whether the deaf/blind deeming provisions are satisfied. See <a href="#">Deeming Provisions</a> and consult the Vision guidance.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
Hearing Impairment in people over 65

The symptoms and management of hearing loss in the elderly are similar to those in a younger age group. However, if the onset of hearing loss was sudden, the period of adaptation is likely to take longer in the elderly and in some circumstances they may never adapt.

Back to top of section
What you need to know about Heart (Cardiac) failure

What is Heart failure?
- Read more on NHS Choices - Heart (Cardiac) failure
- Read more on NHS Choices - Heart transplant
- Read more on NHS Choices - Heart & Lung transplant

What evidence is available?
In all cases of moderate and severe cardiac disease a Consultant Cardiologist and a Specialist Cardiac Nurse….

Activities of Daily Living and Mobility needs
Mild functional restriction - the person with mild heart failure is likely to have some shortness of breath on greater than…. Read more about ADL & mobility needs.
Linked pages:
- Functional classification
- Medical Research Council Dyspnoea scale

How long will the needs last?
The prognosis is worse with increasing age and probably in males. Prognosis in heart failure depends on the severity of the…. Read more about award duration.

Over 65s
Heart (Cardiac) Failure is predominantly a disease of older persons, it occurs in 1 in 10 of the over 65’s & 5% to 10% of people in…. Read more about effects in the over 65 age group.

What evidence is available?
Self-assessment is the prime source of evidence but the claim pack should be checked to see who has completed it and that it is an accurate and reliable description of their problems.

If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.
- Hospital Factual Report
- The Cardiac Rehabilitation Nurse
Hospital Factual Report

In all cases of moderate and severe cardiac disease a Consultant Cardiologist, and a Specialist Cardiac Nurse would normally have been involved in the diagnosis, management and treatment of the individual. Indeed the absence of any documented history of a Cardiology consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required. If a person has undergone a successful heart transplant, the claimant will be followed up in the hospital Outpatient Department, and this will be the best source of information for his/ her residual needs.

The Cardiac Rehabilitation Nurse

The Cardiac Rehabilitation Nurse is a Specialist nurse, who works in close contact with the Cardiologist and is part of the Cardiac Rehabilitation Team.

She/he is closely involved with the patient, from the start of the hospital stay, and, as well as attending to the physical needs of the patient, is crucial in advising, and supporting the patient.

Heart failure patients suffer from an enormous impact on their confidence in their ability to do things and a large proportion of them suffer from depression and the Specialist Nurse is there to support them. She/he also can act as an intermediary between the Consultant (and the rest of the team) and the patient, giving advice on medication, dose adjustments, lifestyle, social issues and so on. He/she is also in a position to tell the patient about their illness and discuss things like prognosis, which may be worrying the patient, as well as being an important issue.

This contact is kept up after the patient is discharged, for both medical and psychological reasons; and phone contact, for reassurance of the patient, may take place several times a week, in cases of severe heart failure. At late - stage or end - stage disease, the patient may contact the nurse many times because of the need for psychological, financial or social support and for advice on managing often quite complex treatment regimes. Obviously, the amount of contact varies with the severity of the condition and the readiness of the patient to seek help.

The Specialist Nurse can also act as a go - between for the patient, GP and Consultant co-ordinating and adjusting the treatment options.

Therefore, this role is recognized as being extremely important for the well - being of the patients and more and more hospitals use their services on a permanent basis.
General Practitioner Factual report

The General Practitioner would normally have made the initial referral of the claimant to the Cardiologist and would normally be aware of the results of tests and current medication. The general practitioner may not have such detailed knowledge of the claimant’s needs if he/she is more frequently managed by the Consultant Cardiologist and the Specialist Cardiac Nurse, (who are more likely to have detailed knowledge of exercise tolerance and the disabling effects of the condition).

If there is no specialist health professional involvement or evidence cannot be obtained from them, then a factual report from the claimant’s own doctor would be more appropriate.

HCP examination Report

An HCP examination report would be likely to be necessary when the person claims significant disability (equivalent to a moderate or severe condition), but there is no supporting evidence from the GP or hospital Specialist; if no corroborative evidence has been able to be obtained; or if it is the only means whereby the claimant's needs can be clarified.

Medical Services

The Medical Services doctor may be asked to request relevant information such as test results from the GP or Hospital Consultant and to interpret test results and other information.

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### Activities of Daily Living and Mobility needs

#### Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>The person with mild heart failure is likely to have some shortness of breath on greater than ordinary exertion (such as running for a bus, running upstairs). See <a href="#">Functional classification</a>.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>They would normally be able to walk 500 metres or more on the flat. There would be no need for guidance or supervision.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>These people are breathless on extra exertion. Therefore they are likely to be somewhat breathless on running for a bus or running upstairs but still would normally be able to do this. A person with mild heart failure should, however be able to manage to look after all their own bodily functions without assistance. That is, bathing, dressing, attending to his/her own toilet needs and planning, preparing and cooking a main meal for one person.</td>
</tr>
</tbody>
</table>
## Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>With moderate heart failure, the affected person would normally be breathless on doing mild (ordinary) exertion.  See <a href="#">Functional classification</a>.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>They would normally be breathless on mild exertion, but would normally be able to walk more than 100-200 metres, at a slower than usual pace. They avoid inclines, normally and limit their activity, according to their capability.  There would be no need for guidance or supervision.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>He/she would still be likely to be able to carry out daily activities at a slower than normal pace. The condition may fluctuate.  He/she would normally be able to bath and dress/undress him/herself without assistance but may at times need help getting out of the bath.  He/she should be able to manage his/her own toilet needs and plan, prepare and cook a main meal for one.  He/she would normally have to take stairs slowly and would normally be likely to stop for a brief time on the stairs.  At night he/she would normally not be able to lie flat but would normally sleep propped up on 2 or 3 pillows.  Attention at night for assistance with toilet needs is not likely to be usual.</td>
</tr>
</tbody>
</table>
Severe Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>A person with severe heart failure would normally have severe functional limitations and be breathless on slight (minimal) exertion or at rest. See <a href="#">Functional classification</a>. A condition called acute Pulmonary Oedema may occur and is life - threatening. He/she would normally have been admitted to hospital, within the previous 12 months, because of deterioration of health.</td>
</tr>
<tr>
<td>Mobility</td>
<td>He/she would not normally be able to make more than 20-30 yards, on the flat, before developing extreme breathlessness and could only manage stairs with extreme difficulty, hills being out of the question. There would be no need for guidance or supervision.</td>
</tr>
</tbody>
</table>
| ADL | Severe heart failure has a huge and overwhelming impact on daily life. A person with severe heart failure would normally move around very slowly and frequently be housebound. They would normally require help with most aspects of self-care, i.e. getting in and out of bed, getting dressed and undressed, bathing and getting to and on and off the toilet. Also because of breathlessness and fatigue a person with a severe condition (though likely to be able to plan and prepare part of a meal while sitting) would not normally be able to lift a pan of boiling water safely and would be too breathless to bend to get something out of the oven.

At night, with severe heart failure, he/she would not normally be able to lie flat and would normally sleep propped up on several pillows and the affected person would normally be likely to need assistance to rearrange pillows and to get in and out of bed to use a toilet or commode. However, if a bottle is placed conveniently within reach a person would normally be able to use a bottle but not to empty it.

Click on the link below for details of the Medical Research Council Dyspnoea scale :-
http://www.gp-training.net/protocol/respiratory/copd/dyspnoea_scale.htm

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**How long will the needs last?**
The prognosis is worse with increasing age and probably in males.

Prognosis in heart failure depends on the severity of the disease and the presence of complications, such as arrhythmias. Higher concentrations of B-type natriuretic peptide (BNP) are commonly associated with increased risk of death and other adverse cardiovascular events.
It also depends on what has caused the heart failure in the first place.

- 10% of patients, with mild to moderate heart failure die within a year,
- Over 50% of patients with severe heart failure die within the first year after diagnosis.
- Advanced heart failure is regarded as fitting into the New York Heart Association (NYHA) classification of class 3 to class 4 symptoms.

Patients with severe heart failure are prescribed Metolazone (a Thiazide diuretic).

Patients in the terminal stage of the disease are prescribed Diamorphine.

**Prognosis in the Older Person**

The 5-year survival rate for older persons with established heart failure is less than 50% - that is worse than for most forms of cancer. Advanced heart failure in older persons carries a one-year mortality rate of 25% to 50%.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac / Heart Failure</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Heart Failure in people over 65**

Cardiac Failure is predominantly a disease of older persons:

- It occurs in 1 in 10 of the over 65’s.
- 5% to 10% of people in their 80’s are affected.

Both the incidence and prevalence of chronic cardiac failure are rising, because of better care of coronary events, and hence better survival, more emphasis on preventative medicine, with respect to vascular risk factors in the ageing population, and more older people in the population (currently, around one quarter of the population is over 60 in the UK, but by 2030, this will have risen to one third).

The causes are usually coronary heart disease, especially in the Caucasian population, whereas hypertension (high blood pressure) is likely to be a predisposing factor in the Afro-Caribbean population. Older patients with chronic heart failure are more likely to be female, with pre-existing high blood pressure, and preserved left ventricular function; diastolic dysfunction is also a prominent feature, especially those with a history of high blood pressure.
Other causes of heart failure in older patients are:

- Degenerative heart valve disease,
- Arrhythmias,
- Pulmonary hypertension (e.g. as a result of COPD – chronic obstructive pulmonary disease),
- High cardiac output states (e.g. as a result of anaemia, Paget’s Disease and thyroid disease),
- Cardiomyopathy.

Diagnosis may be difficult, because of other co-existing disease, possible multiple medications and their effects, and complicating factors such as dementia.

Because of age-related changes in the cardiovascular and other organ systems in the older person, there is the likelihood of increased severity of symptoms, possible complication in the management, and a worsened prognosis, as well as the increased likelihood of developing cardiac failure. Also, the dosage of many of the medications including those for cardiac failure should be the lowest effective dose, because kidney and liver function may be reduced, older patients often receive multiple drugs for multiple conditions, and there are drug interactions and adverse effects of which to be aware.

Chronic cardiac failure is an important cause of chronic disability in older adults with physical and psychological effects of:

- Breathlessness,
- Poor exercise tolerance,
- Reduction in activity,
- Isolation,
- Depression and anxiety,
- Possible poor cognitive state.

The management of cardiac failure in older patients is similar to that of younger patients; however cardiac failure in the older person is best treated using a co-ordinated multidisciplinary team approach. A full medical management plan should follow Consultant Cardiologist assessment and involve the GP and/or a Specialist Cardiac Failure Nurse at a heart failure follow-up clinic or a day hospital with particular facilities for older people, and/or those who are frail.

Important factors, which would be monitored, are:

- Medication supervision and adjustment of medication according to the NICE Guidelines (National Institute for Health and Clinical Excellence), bearing in mind side-effects and drug interactions,
• Lifestyle factors, such as nutrition, alcohol intake, exercise (Tai Chi has documented physical and psychosocial benefits and is used in some cardiac rehabilitation programmes),
• Treating the cause, if possible (for example, corrective operation for aortic stenotic valvular disease or treatment for atrial fibrillation),
• Addressing social factors, including isolation, inability to attend follow-ups, the need for social support or a carer,
• Cognitive assessment and assessment for depression. (Frequently used tests are the Mini Mental State Examination, the Abbreviated Mental Test Score, the Clock Drawing and Mini-Cog and the Geriatric Depression Scale).

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Functional classification of Cardiac disease

| The New York Heart Association Functional Classification of Cardiac Disease |
|-----------------------------|--------------------------------------------------|
| Class 1                     | No functional limitation.                        |
| Class 2                     | Symptoms on extra exertion i.e. mild heart failure. |
| Class 3                     | Symptoms on ordinary physical activity i.e. moderate heart failure. |
| Class 4                     | Symptoms at rest or on minimal exertion i.e. severe heart failure and severe functional limitation. |

This classification is now in common use.
What you need to know about Human Immunodeficiency Virus (HIV) & Acquired Immune Deficiency Syndrome (AIDS)

What is HIV & AIDS?
HIV is a virus most commonly caught by having unprotected sex or by sharing infected needles to inject drugs. HIV stands for…. Read more on NHS Choices - HIV & AIDS.

What evidence is available?
People with HIV should be under the care of a multidisciplinary team, usually in a hospital based specialist centre which…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Mobility and care needs may arise from any of the conditions associated with HIV. It should be noted that, although the CD4 count…. Read more about ADL & mobility needs.
How long will the needs last?
Without treatment, about 50% of people infected with HIV will become ill and die from AIDS over about 10 years. The mortality…. Read more about award duration.

Over 65s
HIV and AIDS are affecting an increasing number of people over the age of 50. The clinical features are similar to those in…. Read more about effects in the over 65 age group.

What evidence is available?
People with HIV should be under the care of a multidisciplinary team, usually in a hospital based specialist centre which is responsible for initiating and monitoring antiretroviral (ART) and other therapy. Therefore, if further medical evidence is required, and the person is under the care of a Consultant, a hospital factual report should be sent.

If the person is under the care of the General Practitioner alone, a GP factual report should be sent. In some circumstances the GP may be unaware of the diagnosis if the person is under the care of the hospital and has requested that the GP is not informed of the diagnosis.
Activities of Daily Living and Mobility needs

Mobility and ADL needs may arise from any of the conditions associated with HIV.

It should be noted that, although the CD4 count is an important indicator of a person’s wellbeing, all factors should be taken into account. For example, people on treatment may have a CD4 count >350/µl but may be significantly debilitated due to either severe side effects of treatment or HIV associated conditions.

Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a mild restriction are likely to have:</td>
</tr>
<tr>
<td></td>
<td>• CD4 count &gt;350/µl. They are likely to be asymptomatic although they may have enlarged lymph glands.</td>
</tr>
<tr>
<td></td>
<td>• CD4 count &gt;200/µl with relatively non disabling problems such as:</td>
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<tr>
<td></td>
<td>Sexually transmitted diseases</td>
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<td></td>
<td>Mouth conditions</td>
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<tr>
<td></td>
<td>Skin conditions</td>
</tr>
<tr>
<td></td>
<td>Minor side effects of medication</td>
</tr>
<tr>
<td>Mobility</td>
<td>The ability to walk is unlikely to be impeded and they would normally be able to find their way around in unfamiliar places.</td>
</tr>
<tr>
<td>ADL</td>
<td>The resulting disability is unlikely to affect their ability to independently carry out activities of daily living.</td>
</tr>
</tbody>
</table>
## Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a moderate restriction are likely to have a CD4 count &gt;100 and &lt; 200 /µl. The resulting disability depends upon the condition present and the response to treatment. For example, the following conditions may have varying effects on mobility and the ability to carry out activities of daily living:</td>
</tr>
</tbody>
</table>
|                     | • Respiratory e.g. pneumonia or tumour  
|                     | • Neurological e.g. neuropathy  
|                     | • Tumours e.g. advanced visceral Kaposi’s sarcoma  
|                     | • Constitutional symptoms  
|                     | • Gastrointestinal e.g. diarrhoea  
|                     | • Haematological problems e.g. anaemia  
|                     | • Psychiatric or social disabilities resulting from HIV or its treatment                                                                                                                                   |
|                     | Each case will therefore need to be assessed individually.                                                                                                                                                   |
| Mobility            | The ability to walk may be impeded and they may not be able to find their way around in unfamiliar places, but this depends upon the associated condition and response to treatment.                                |
| ADL                 | The resulting disability may affect their ability to independently carry out activities of daily living, but this depends upon the associated condition and response to treatment.                                    |
### Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with a severe restriction are likely to have a CD4 count &lt; 100 /µl associated with:-</td>
</tr>
<tr>
<td></td>
<td>• Advanced carcinoma</td>
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<td></td>
<td>• HIV encephalopathy</td>
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<tr>
<td></td>
<td>• Primary cerebral lymphoma</td>
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<td></td>
<td>• Progressive multifocal leucoencephalopathy (PML)</td>
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<td></td>
<td>• Systemic non-Hodgkins Lymphoma (NHL)</td>
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<td></td>
<td>• Visual impairment due to Cytomegalovirus retinitis</td>
</tr>
<tr>
<td></td>
<td>• Uncontrollable diarrhoea</td>
</tr>
<tr>
<td></td>
<td>• Psychiatric or social disability resulting from HIV or its treatment</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>The ability to walk is likely be impeded and they may not be able to find their way around in unfamiliar places.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>The resulting disability is likely to affect their ability to independently carry out activities of daily living.</td>
</tr>
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</table>

**How long will the needs last?**

Without treatment, about 50% of people infected with HIV will become ill and die from AIDS over about 10 years.

The mortality for HIV positive people has fallen from about 30% per year to about 2% since the introduction of HAART. The average survival of a person starting HAART is now probably 20 years or more. One study from Denmark has shown that a newly infected person at age 25 is now expected to live to 57.5 years or 63.9 years if not co-infected with hepatitis C. This compares with a life expectancy for a non-HIV infected person of 76.2 years.

**If evidence shows that the customer has HIV / AIDS with Hepatitis C then go to** [Viral Hepatitis](#) **guidance for additional information.**

A poorer prognosis in HIV positive people starting treatment i.e. an increased probability of progression to AIDS is associated with :-

- A lower CD4 count and higher plasma viral load
- Advanced age
• Infection through injecting drug use

People with the most favourable prognostic factors are estimated to have a 3.5% chance of progression to AIDS or death within 3 years -:

• aged < 50 years old
• not infected through injection drug use
• viral load < 100 000 copies/ml
• CD4 cell count > 350 /µl on initiation of HAART

People with the most unfavourable prognostic factors are estimated to have a 50% chance of progression to AIDS or death within 3 years -:

• Severe seroconversion illness
• aged ≥ 50 years old
• infected through intravenous drug use
• viral load ≥ 100 000 copies/ml
• CD4 cell count < 50 /µl on initiation of HAART
• Inability to take HAART/ART or poor compliance
• Drug resistant virus
• Other poor social circumstances

Once the claimant’s condition has deteriorated to the extent that care and mobility needs are established it is likely that there will be a subsequent deterioration, perhaps leading to death. However, the progress of the illness may not become clear until two years after the onset of the diagnosis of advanced HIV.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Duration of symptoms</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advanced HIV / AIDS</td>
<td>Present for less than 2 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>Present for more than 2 years</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>AIDS dementia complex (HIV encephalopathy)</td>
<td>N/A</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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**HIV and AIDS in people over 65**

HIV and AIDS are affecting an increasing number of people over the age of 50. The clinical features are similar to those in younger people but the diagnosis may not be entertained until later on in the illness. Treatment of
HIV and AIDS in the elderly is similar to those in people under the age of 65. Disease progression and mortality rates are higher in the elderly. 

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What you need to know about Hodgkin’s lymphoma

What is Hodgkin’s lymphoma?
Lymphoma is a cancer of the lymphatic system. The lymphatic system is made up of a series of vessels and glands, known as lymph. Read more on NHS Choices - lymphomas.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even. Read more about evidence sources.

Activities of Daily Living and Mobility needs
The majority of people will undergo standard chemotherapy as their first line treatment for Hodgkin lymphoma; some people. Read more about ADL & mobility needs.

How long will the needs last?
First line treatment - in the rare situation where an award is appropriate during treatment with standard chemotherapy, the. Read more about award duration.

Over 65s
There are no special features. Over all survival is not as high in older people.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- General Practitioner - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- Community or District Nurse - will have information on any home care or outreach package in place as this is coordinated through the practice.
- Social worker - customer may have a ‘Care plan’ from social services

Hospital
- Specialist doctors -
- Oncologist
Specialist nurses have many different job titles -:
- Clinical Nurse Specialist
- Stoma care nurse
- Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
- Physiotherapist
- Occupational Therapist
- Social worker
- Counsellor
- Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
- Palliative Care Physician
- Macmillan Nurse
- Clinical Nurse Specialist
- Social worker
- Physiotherapist
- Occupational Therapist
- Counsellor

Activities of Daily Living and Mobility needs
The majority of people will undergo standard chemotherapy as their first line treatment for Hodgkin lymphoma; some people will not respond to the treatment and move on to ‘salvage chemotherapy’ followed by high dose chemotherapy and Peripheral Blood Stem Cell Transplant (PBSCT) or bone marrow transplant. Care and mob guidance is divided into two groups -:
- Relapsed Hodgkin lymphoma
- First line treatment of Hodgkin Lymphoma

First line treatment of Hodgkin Lymphoma
A return to health is expected in the typical case. There are unlikely to be any long term care and mobility needs after treatment. The exception to this are the enduring but rare side effects of chemotherapy
Relapsed Hodgkin lymphoma
This group are likely to undergo salvage chemotherapy followed by high dose chemotherapy and Peripheral Blood Stem Cell Transplant (PBSCT) or bone marrow transplant. Treatment and recovery for those who successfully undergo this treatment is likely to take 18 months to 2 years. During this period they are likely to have periods of being immunosuppressed and be advised to avoid crowded public places. Episodes of severe fatigue may endure for many months related to chemotherapy treatment and anaemia. Some will be unwell and have care or mobility needs for about 3-6 months - during the transplant and transplant recovery period. Others will develop needs related to chemotherapy side effects during standard chemotherapy, if this happens and they progress straight to high dose chemotherapy needs are likely to last through the first course and into the transplant period. Recovery from the transplant is likely to be more prolonged in this group and may take a year. The main cause of needs is likely to be severe chemotherapy related fatigue.

If high dose chemotherapy has already been used then other types of chemotherapy may be to be given to control disease and symptoms, in this case ongoing needs may relate to symptoms of disease as well as treatment.

Mobility
Severe fatigue and reduced exercise tolerance related to any of the following may reduce the ability to walk

- Chemotherapy treatment
- Anaemia
- Disease effects e.g. lung involvement causing breathlessness

People who are immunosuppressed may be advised to avoid public places at busy times.

Activities of Daily Living
Severe fatigue may make activities of daily living difficult. Help with activities of daily living from someone else may be required because of pain, fatigue or breathlessness.

How long will the needs last?

First line treatment
In the rare situation where an award is appropriate during treatment with standard chemotherapy, the award should last for the duration of treatment and then be reviewed.
Relapse

The five year survival of people who have had one relapse of lymphoma is 50%-60%; Needs are likely to be identified in this group, time limited awards with review are recommended to cover duration of treatment and recovery. 40-50% will die as a result of first relapse and survivors are likely to have ongoing needs. Up to date medical evidence will be vital at any review of award.

People whose disease relapses a second or third time do less well and in this group long term or life awards are more appropriate – some may be terminally ill.

Long term side effects some years after successful treatment

Any needs arising from these are likely to be long term and life awards are recommended.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about High Blood Pressure (Hypertension)

Back to A - Z

What is High blood pressure (Hypertension)?
Known as the 'silent killer', high blood pressure rarely has obvious symptoms. Around 30% of people in England have high….

What evidence is available?
Except where there are complications, there would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and Mobility needs
The majority of hypertensives are asymptomatic and do not have a functional disability. Malignant hypertension, which is rare, may…. Read more about ADL & mobility needs.

How long will the needs last?
The majority of hypertensives are asymptomatic and do not have functional restrictions. It is the complications of hypertension such as…. Read more about award duration.

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages -:
Ageing
Falls
Frailty

Activities of Daily Living and Mobility needs
The majority of hypertensives are asymptomatic, and do not have a functional disability.

Malignant hypertension, which is rare, may be symptomatic, and these people would be ill, and would normally be admitted to hospital. However, generally, they are treated, and return home, after a short period of time, unless they have had a stroke.

When the hypertension has led to conditions such as heart failure, heart attack, stroke, retinal damage etc, the patient may have the disabling
effects of these resultant conditions, and the focus should be on these conditions, not the hypertension. Therefore, it is the complications of hypertension that lead to the disability.

**How long will the needs last?**

The majority of hypertensives are asymptomatic and do not have functional restrictions. It is the complications of hypertension such as heart failure, heart attack, stroke, retinal damage etc that lead to functional restrictions. Appropriate guidance should be accessed if such complications are causing functional restrictions.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

[Back to top of section]
What you need to know about Irritable Bowel Syndrome (IBS)

Back to A - Z

What is IBS?
IBS (irritable bowel syndrome) is a common condition of the digestive system and can cause bouts of stomach cramps, bloating, diarrhoea and …. Read more on NHS Choices - IBS.

What evidence is available?
General practitioners are able to provide confirmation of the diagnosis and details of any drug treatments prescribed. Some people…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Irritable bowel syndrome does not cause any significant functional restrictions that restrict walking or lead to a need for…… Read more about ADL & mobility needs.
Linked pages:
Bowel Incontinence

How long will the needs last?
People may experience symptoms for many years without adverse long-term effects. 40% are helped by explanation of the condition…. Read more about award duration.

Over 65s
There are no specific features in the elderly.

What evidence is available?
General practitioners are able to provide confirmation of the diagnosis and details of any drug treatments prescribed. Some people attend gastroenterology clinics, and hospital reports may be helpful in respect of diagnosis confirming normal investigations.

Activities of Daily Living and Mobility needs
Irritable bowel syndrome does not cause any significant functional restrictions that restrict walking or lead to a need for help with self-care. Although most people with frequent diarrhoea and urgency of defaecation will need to get to the toilet quickly, the condition does not usually cause faecal incontinence. They would have no difficulty in finding their way around out of doors and locating a toilet if required.
Click on the link for details of :-
Bowel Incontinence

How long will the needs last?
People may experience symptoms for many years without adverse long-term effects. 40% are helped by explanation of the condition combined with simple remedies. In one study 65% of people were symptom free at five years.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about Coronary (Ischaemic) Heart Disease (CHD)

What is Coronary (Ischaemic) Heart Disease (CHD)?
Coronary heart disease (CHD) is the UK's biggest killer, around one in five men and one in seven women die from the disease.... Read more on [NHS Choices - coronary heart disease](#).

What evidence is available?
Self-assessment is the prime source of evidence. If the claim pack has been completed on behalf of the customer, by someone.... Read more about evidence sources.

Activities of Daily Living and Mobility needs
Mild functional restriction - people with mild restriction from angina are well most of the time as the attacks are intermittent.... Read more about ADL & mobility needs.
Linked pages: [Medical Research Council Dyspnoea scale details](#)

How long will the needs last?
Coronary or ischaemic heart disease is a progressive disease, but the prognosis has improved with effective therapy, and with.... Read more about award duration.

Over 65s
There are various effects of ageing in the cardiovascular system, which include a slightly enlarged heart, which does not.... Read more about effects in the over 65 age group.

What evidence is available?

General
Self-assessment is the prime source of evidence.

If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.
The DM should bear in mind that the completion of the corroborative statement by a Health Care Professional does not necessarily mean that they endorse what has been said in the claim pack.

In all cases of severe illness it is highly probable that a consultant and/or physician will have been involved in the management and treatment of the individual. Indeed the absence of any documented history of a hospital medical consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required.

An HCP examination report may be helpful.

Links for information on other sources where further evidence can be obtained.

General Practitioner
Consultant
Specialist Nurse
Back to top of section
## Activities of Daily Living and Mobility needs

### Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with mild restriction from angina are well most of the time as the attacks are intermittent and usually only occur with greater than ordinary exertion. The attacks are quickly resolved by GTN (glyceryl trinitrate) spray or tablets.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Walking would normally be unlimited, provided it is done at the speed expected for that person’s age, and level of fitness. Guidance or supervision needs are unlikely to be present.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with mild restriction from angina would not normally experience pain and/or breathlessness, with the exertion required for self-care activities, such as bathing, dressing, attending to his/her hygiene needs and preparing a main meal for him/her. There would normally be no need for supervision, on a daily basis, either in or out doors.</td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
</tr>
<tr>
<td>-------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with moderate restriction from angina are susceptible to an attack if they “push themselves” beyond normal exertion levels. Therefore, their angina attacks are intermittent, but occur at a level of moderate exertion. Normally they would often be likely to use preventative GTN (glyceryl trinitrate) before anticipated exercise or stress, and avoid exertion such as inclines, walking briskly, hurrying up stairs, going out in cold weather, and large meals. They may impose quite severe restrictions on their own activities, for fear of angina.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>He/she would normally be able to walk a distance of a few hundred metres, at a steady, or slightly reduced pace, using GTN spray preventatively, if necessary. He/she may have problems keeping up with another person of the same age. Guidance or supervision needs are unlikely to be present.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>A person with moderate restriction from angina would not normally experience pain and breathlessness with self-care activities, although preventative GTN may sometimes be needed, e.g. to get up, bathe, dress, use the toilet unaided, and prepare and cook a simple meal. He/she may need to take GTN spray before going upstairs, but would normally be able to go up one flight of stairs, without GTN, albeit at a reduced pace. He/she would not normally need supervision, in or out of doors.</td>
</tr>
</tbody>
</table>
Severe Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>A person with severe restriction from angina would normally experience angina on minimal exertion, such as dressing and drying self after a bath or shower, and the angina may be associated with breathlessness.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with severe restriction from angina would normally only be able to walk between 50 to 100 metres, without stopping, at a normal pace, due to angina and/or breathlessness. These people, for fear of angina, often impose quite severe restriction on all daily activities, on themselves. There will be a minority of people however, with severe IHD who are able to walk less than 50m. A report should be obtained from a consultant or medical services advice sought in such cases. Guidance or supervision needs are unlikely to be present.</td>
</tr>
<tr>
<td>ADL</td>
<td>Most people with severe restriction from angina would normally be able to undertake self-care tasks, slowly but unaided. Prophylactic (preventative) GTN may be needed. They would normally be unable to climb one flight of stairs, without needing to stop and rest for a few minutes, and would normally take GTN spray either as a preventative measure, before doing so, or to relieve angina, afterwards. There are a minority of people with very severe angina, who would need assistance with self-care tasks, and because they would normally have a severe restriction in physical activity, could not manage stairs. These people would normally be in hospital.</td>
</tr>
</tbody>
</table>
How long will the needs last?

Coronary or ischaemic heart disease is a progressive disease, but the prognosis has improved with effective therapy, and with good surgical treatment. Modifications to lifestyle such as stopping smoking, changing diet and increasing exercise also reduce risk and improve prognosis.

The type of intervention depends upon whether the extent of coronary artery disease is single vessel, 3 vessel or left main stem vessel. Prognosis for high-risk patients with multi-vessel disease or main vessel disease or impaired left ventricular function is improved by surgery. In fact those who have had successful surgery or Percutaneous Transluminal Coronary Angioplasty (PTCA) are subsequently normally free of angina and have a good quality of life.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angina - awaiting PTCA or CABG surgery</td>
<td>1 year award</td>
</tr>
<tr>
<td>Angina - no surgery awaited / planned</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Myocardial infarction - awaiting PTCA or CABG surgery</td>
<td>1 year award</td>
</tr>
<tr>
<td>Myocardial infarction - no surgery awaited / planned</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Other coronary heart disease / type not known -</td>
<td>1 year award</td>
</tr>
<tr>
<td>awaiting PTCA or CABG surgery</td>
<td></td>
</tr>
<tr>
<td>Other coronary heart disease / type not known -</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>no surgery awaited / planned</td>
<td></td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Coronary (Ischaemic) Heart Disease in people over 65

Ageing—general comments

There are various effects of ageing in the cardiovascular system, which include: -

1. A slightly enlarged heart, which does not pump as efficiently during exercise.
2. Stiffer arteries
3. Isolated systolic hypertension (where the blood pressure rises when the heart contracts).
Heart disease and the Elderly

The prevalence of risk factors for heart disease increases with increasing age, and coronary artery disease is clinically evident in 20% of those over 80 years. However, the symptoms of ischaemic heart disease in the elderly may present differently, (breathlessness rather than chest pain, or "silent angina" in diabetics). Elderly people may modify their lifestyle to avoid the onset of angina, may be used to having chest pains for a long period of time, (and not seeking help), and may present later with a heart attack, than younger people.

In the elderly, co-existing conditions such as anaemia and thyroid disease, heart failure and arrhythmias are common and may worsen angina.

In the elderly, angina may be caused by another condition (aortic stenosis – a tight aortic valve), and this should be considered as a cause, and ruled out, when angina is investigated.

Preventative measures and lifestyle changes with the aim of lowering risk factors are just as important in the elderly, but medication should be introduced gradually, and in lower doses because of the risk of adverse side effects and drug interactions.

Angioplasty and CABG can and should be used as treatment measures, but the risks of mortality, and side effects from the procedures are increased, and the benefits have to be weighed against the risks, in elderly people. Diffuse disease may be present, and not amenable to procedures.

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What you need to know about Kidney cancer

Back to A - Z

What is Kidney cancer?
Cancer of the kidney is a relatively common type of cancer. Symptoms of kidney cancer include blood in your urine, constant…. Read more on NHS Choices - kidney cancer.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Treatment of stage 1, 2 or 3 renal cancer - the majority of people in this group will have had surgery as treatment of their time …. Read more about ADL & mobility needs.

How long will the needs last?
Kidney cancer be staged using the number staging or TNM staging systems. The table shows the equivalent stages of both…. Read more about award duration.

Over 65s
Although kidney cancer is more common in older people, there are no special features.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a 'Care plan' from social services
Hospital
Specialist doctors -:
• Oncologist
• Physician
• Haematologist

Specialist nurses have many different job titles -:
• Clinical Nurse Specialist
• Stoma care nurse
• Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
• Physiotherapist
• Occupational Therapist
• Social worker
• Counsellor
• Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
• Palliative Care Physician
• Macmillan Nurse
• Clinical Nurse Specialist
• Social worker
• Physiotherapist
• Occupational Therapist
• Counsellor

Activities of Daily Living and mobility needs

Treatment of stage 1, 2 or 3 renal cancer

The majority of people in this group will have had surgery as treatment of their disease. The recovery time form these operations are up to 12 weeks. There are not usually any long term side effects of this type of surgery except those listed under surgery in the treatment section. Chemotherapy is sometimes used in the treatment of transitional cell cancer but not renal cell cancer; it may prolong recovery to 8-9 months or rarely give rise to enduring side effects. Recovery of normal function is
expected in the typical case. Radiotherapy is rarely used so the long term side effects of these treatments are unlikely to be a problem for this group.

**Stage 4, advanced or recurrent renal cancer after treatment of any stage of the disease**

The majority of people are terminally ill; the median survival for this group is 10 months with treatment. The five year survival is 10%.

They may experience any of the following symptoms related to their kidney cancer:

- **Haematuria** (blood in the urine)
- **Anaemia**, this may be recurrent due to repeated bleeding and causes extreme fatigue and difficulty walking around
- **Pain** from invasion by the tumour and 'clot colic' this is pain from blockage of the ureter by blood clots and can be severe

There may be disabling effects from metastatic disease anywhere in the body including:

- **Liver metastases** – these may cause fatigue and in the later stages, mental confusion, abdominal swelling or pain and jaundice
- **Lung metastases or malignant pleural effusion** – may cause very disabling breathlessness reducing mobility to a few yards.
- **Brain metastases** – these may cause fits, personality change, confusion, difficulties with balance, walking and self care
- **Bone metastases** – pain and pathological fractures – this is a common cause of serious disability in this group.

Note: This guidance does not cover Wilms tumour (a type of childhood kidney cancer) and any such cases in adults must be discussed with Medical Services.

**How long will the needs last?**

Kidney cancer be staged using the number staging or TNM staging systems. The table below shows the equivalent stages of both systems and the likely outcome of treatment by stage of disease.

Note: This guidance does not cover Wilms tumour (a type of childhood kidney cancer) and any such cases in adults must be discussed with Medical Services.
<table>
<thead>
<tr>
<th>Number stage</th>
<th>Equivalent TNM stage</th>
<th>Expected outcome of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1 – the tumour is small and has not spread out from the kidney</td>
<td>T1 N0 M0</td>
<td>Treatment is often curative and a return to health is expected</td>
</tr>
<tr>
<td>Stage 2 – the tumour is large but has not spread outside the kidney</td>
<td>T2 N0 M0</td>
<td>Treatment is often curative and a return to health is expected</td>
</tr>
<tr>
<td>Stage 3 – the cancer has spread outside the kidney into the adrenal gland, the renal vein or into one lymph node near the kidney</td>
<td>T3a N0 M0 and T3b N0 M0</td>
<td>T3a N0 M0 and T3b N0 M0 Treatment is often curative and a return to health is expected</td>
</tr>
<tr>
<td></td>
<td>T1 or T2 or T3 and N1 M0 T3 N0 M0 T3a N1 M0 T3b N1 M0 T3c N0 or N1 M0</td>
<td>TNM stages in this group are rarely cured by treatment, a return to health after treatment often occurs but disease tends to recur.</td>
</tr>
<tr>
<td>Stage 4 – the cancer is locally advanced – has invaded surrounding structures or has metastasised</td>
<td>T4 N0 or N1 M0 Any T and N2 M0 Any T any N and M1</td>
<td>This group has a poor outcome; unless metastasis is very limited and treated by surgery – see ‘operations for metastatic disease’ in the treatment section.</td>
</tr>
</tbody>
</table>

Once treatment of early disease is complete typically there are no long term disabling effects.
Advanced disease and recurrent disease have a poor outcome and most will be terminally ill. Needs are likely to increase over time and recovery is not expected. Indefinite awards are recommended.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Period of Award</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stages 1 to 3 (see table above)</td>
<td></td>
</tr>
<tr>
<td>If treatment of early disease completed.</td>
<td>1 year award</td>
</tr>
<tr>
<td>Stages 3 (see table above) &amp; 4</td>
<td></td>
</tr>
<tr>
<td>If disease is advanced / recurrent</td>
<td>Indefinite Award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Kidney (Renal) disorders

What is a Kidney (Renal) disorder?
- Read more on NHS Choices - Kidney (Renal) dialysis
- Read more on NHS Choices - Chronic Kidney (Renal) failure
- Read more on NHS Choices - Glomerulonephritis
- Read more on NHS Choices - Kidney (Renal) infection
- Read more on NHS Choices - Kidney stones (Renal calculus)
- Read more on NHS Choices - Kidney (Renal) transplant
- Read more on NHS Choices - Nephrotic synome
For more information about other types of kidney disorders Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
Self-assessment is the prime source of evidence and in most cases the needs will be clear from the claim pack, but the claim pack should be checked to see who has completed it, and that it is an accurate and reliable description of their problems.

Activities of Daily Living and Mobility needs
Kidney Dialysis Patients - all family members are affected, patients and families must learn to incorporate new treatments and….
Read more about ADL & mobility needs.
Linked page: Renal Dialysis - Deeming Provisions

How long will the needs last?
The overwhelming majority of people with chronic kidney disease (CKD) are under the care of general practitioners and do not need…. Read more about award duration.

Over 65s
Kidney function normally declines with age, not only because the kidneys get smaller but also because of reduced efficiency of…. Read more about effects in the over 65 age group.

What evidence is available?
Self-assessment is the prime source of evidence and in most cases the needs will be clear from the claim pack, but the claim pack should be checked to see who has completed it, and that it is an accurate and reliable description of their problems.
If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it should provide good evidence.

**Hospital Factual Report**

In cases of acute and chronic kidney disorders, renal transplant and dialysis, a [Consultant Nephrologist](#) and a [Specialist Renal Nurse](#) would normally have been involved in the diagnosis, management and treatment of the individual. Indeed the absence of any documented history of a specialist consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required.

**General Practitioner Factual report**

The [General Practitioner](#) would normally have made the initial referral of the claimant to the Consultant, and would normally be aware of the results of tests, treatment and current medication. If there is no specialist health professional involvement, or if evidence cannot be obtained from them, then a factual report from the claimant’s own doctor would be more appropriate.

**HCP Examination Report**

A [HCP Examination report](#) would be likely to be necessary when the person claims significant disability (equivalent to a moderate or severe condition), but there is no supporting evidence from the GP or Hospital Specialist; if no corroborative evidence has been able to be obtained; or if it is the only means whereby the claimant’s needs can be clarified.

**Medical Services**

The [Medical Services doctor](#) may be asked to request relevant information such as test results from the GP or Hospital Consultant, and to interpret test results and other information.

**Activities of Daily Living and Mobility needs**

- [Kidney Dialysis Patients](#)
- [Chronic Kidney Disease Patients](#)
- [Unsuccessful Kidney Transplant Patients](#)

**Kidney Dialysis Patients**

**Introduction**

All family members are affected, patients and families must learn to incorporate new treatments and changes to their lifestyles. This change to lifestyle can lead to behavioural and psychological illness.
There are limitations to travel and holidays. Some patients continue to work. Working however is often difficult due to the treatment restrictions and a person’s lack of general well being.

Renal patients are required to restrict their dietary and fluid intake, and fluid restriction can be 500mls per day. Dietary restrictions are dependant on a person’s individual blood results. Examples of restricted foods are fruit, chocolate, coffee, dairy products, alcohol.

There is normally a requirement for transport to and from the Hospital. This can be provided by Patient transport Ambulance service, which results in long waiting times for patients before and after dialysis treatment. Some patients will be able to drive their own cars following treatment this is dependant on their general well being.

**Haemodialysis**

Haemodialysis is a very robust treatment, which makes the patient feel very tired. This is because of huge fluxes in their metabolism. Haemodialysis takes place in a dialysis suite situated either in hospital or in the patient’s own home.

During haemodialysis the person is immobile and dependent on others for his/her needs, and requires monitoring for indications of the effectiveness of the treatment and signs of any complications. Changes in blood pressure are usually recorded regularly throughout the period of haemodialysis.

Because of rapid changes which can occur in blood pressure and in the movements of salts and/or water into and out of the body during dialysis, and the risks of danger these may pose, there is a reasonable need for continual supervision during the periods of haemodialysis.

**Peritoneal Dialysis**

In a person who is otherwise physically and mentally well, attention or supervision would not normally be necessary. However, many patients who undergo Continuous Ambulatory Peritoneal Dialysis (CAPD) and Ambulatory Peritoneal Dialysis (APD) are elderly. Most people with CAPD increasingly require the input of helpers. They may basically be independent, but in many situations, help is required from family members.

The requirement for dialysis will reduce a person’s physical independence.

In the many cases complicated by extremes of age, blindness, mental impairment, or severe physical weakness preventing the lifting of the bags of fluid it is unlikely that the affected individual will be able to complete the process without a great deal of help. In these cases, the complicating condition as well as the dialysis will have an effect on the overall care and mobility needs.
The occurrence of the following disabilities in those undergoing CAPD or APD will likely require assistance from another one or more times a day:

(i) Severe physical frailty from any cause (e.g. Anaemia, which is common in renal failure); help may be needed with the lifting of the bags, which can be heavy - bags used in APD hold approximately 12 litres of fluid whereas those used in CAPD hold only 3-4 litres of fluid.

(ii) Blindness: the bags must be checked to make sure they are clear. Clouding may be a sign of infection or fibrin formation. The latter can block the connecting tubes and is dealt with by an injection of heparin into the bag.

(iii) Loss of manual dexterity: the changes of the bags needs considerable manual dexterity and must be carried out under meticulous aseptic (germ free) conditions. The function of the hands is very important. Persons with moderate to severe arthritis of the hands (e.g. Rheumatoid arthritis) may well not be able to perform the actions without the assistance of another person.

(iv) Extremes of age: the very young and the very old may well need assistance with the changing of the bags.

(v) Learning difficulties: This must be a consideration, however, in some centres, patients with learning difficulties undergo training in PD when they are accepted onto the PD programme. Therefore they may not necessarily require assistance or supervision; each case would need to be assessed on its merits.

Night attention is not normally needed on account of dialysis alone as the dialysing fluid is left in the abdominal cavity overnight, changes taking place during the day.

The dialysis machines have become smaller, but they are heavy and will require transporting in their travelling cases. This is a consideration in the frail, elderly and weak.

**Mobility Considerations**

Those doing well on dialysis should be able to walk, but around 50% of patients will not be able to walk 100 metres.

All these cases will need to be assessed on their merits.

**Chronic Kidney Disease Patients**

Some patients may not even know that they have the condition or may not have extensive needs arising as a result of the condition. Others will experience significant and disabling weakness and fatigue.

If chronic kidney disease progresses to end-stage renal failure, treatment requiring dialysis or transplantation will be necessary to sustain life, and
the care and mobility needs will be that of a person undergoing dialysis or who has had a transplant.

**Unsuccessful Kidney Transplant Patients**
If a person has chronic graft rejection, there will be a slow decline in renal function more than 3 months after transplantation, not responding to treatment. It will be obvious after a three month period post-transplant whether further treatment in the form of dialysis is needed. These patients will experience significant and disabling weakness and fatigue. A return to dialysis will be needed while a new transplant is awaited, however a new transplant may not be forthcoming for a considerable time. The treatment can vary between haemodialysis, peritoneal dialysis, and transplant, and each method of treatment can be revisited more than once. The care and mobility needs of the individual therefore will be dependant on what sort of treatment the person is having at the time.

Click on the link for details of -:
Kidney Dialysis - Deeming Provisions
Back to top of section

**How long will the needs last?**
The overwhelming majority of people with chronic kidney disease (CKD) are under the care of general practitioners and do not need to be seen by secondary or tertiary hospital services.

There is no specific waiting list for dialysis.

Following transplantation, acute rejection is seen in between 10 and 30% of transplant recipients and usually presents with declining renal function within the first 3 months.


<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Renal failure</td>
<td>1 year award</td>
</tr>
<tr>
<td>Chronic renal failure -: awaiting transplant</td>
<td>3 year award</td>
</tr>
<tr>
<td>Chronic renal failure -: not awaiting transplant</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Successful renal transplantation</td>
<td>N/A</td>
</tr>
<tr>
<td>Renal transplant with rejection of transplanted kidney – awaiting re-transplant</td>
<td>5 year award</td>
</tr>
<tr>
<td>Renal transplant with rejection of transplanted kidney – not awaiting re-transplant</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Interstitial Nephritis</td>
<td>Depends on underlying disease</td>
</tr>
</tbody>
</table>
Nephrotic syndrome  
Glomerulonephritis  
Renal calculus (Kidney Stone)  
Other kidney disease / type not known  

Depends on underlying disease  
N/A  
N/A  
Depends on underlying disease

**Renal dialysis - deeming provision**

**Renal dialysis (which fulfils the deeming provision criteria)**  
Indefinite award of M/R Care component

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Over 65**

Kidney function normally declines with age, not only because the kidneys get smaller but also because of reduced efficiency of the individual components in the kidney. However, the kidneys can usually deal with the workload, unless stressed by extra factors then the ageing kidney has a reduced capacity to manage stress. The main causes of renal failure in the elderly are hypertension, diabetes mellitus and atherosclerosis.

Kidney failure in the elderly can cause a significant decline in independence and physical wellbeing.

Chronic renal failure is a disease of older people but their age should not be an obstacle to treatment as long as overall health allows.

**Kidney Dialysis – Deeming Provisions**

Two groups of people with renal failure and undergoing dialysis treatment two or more times a week may be considered as “deemed” to satisfy one or more of the medical criteria of the middle rate care component of Disability Living Allowance or the lower rate of Attendance Allowance. These are —:

4. Those undergoing a type of dialysis, which normally requires the attendance or supervision of another person during the period of dialysis.

5. Those who because of the particular circumstances of their case in fact require another person, during the period of dialysis, to attend in connection with their bodily functions or to supervise them in order to avoid substantial danger.

There are however exceptions to the above as set out below :-:
A person cannot be deemed to satisfy either the day condition or the night condition if the renal dialysis

6. Is carried out under the NHS and
7. Is out-patient treatment and
8. Is carried out
   3.1 In a hospital or similar institution and
   3.2 With the assistance or supervision of any member of the hospital staff

These people may have other care and mobility needs, which also have to be taken into account when the overall needs are assessed.
What you need to know about Laryngeal (larynx) cancer

What is Laryngeal cancer?
Cancer of the larynx, also known as laryngeal cancer, is an uncommon type of cancer that develops inside the tissue of the….

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Activities of Daily Living and Mobility needs
Localised disease - most treatments for laryngeal cancer last less than 3 months. For example radiotherapy and recovery or….

How long will the needs last?
Localised disease - rarely, needs may be identified due to chemotherapy related side effects which are expected to last for….

Over 65s
Although this disease is more common in the over 65s, there are no special features. Older people often do not return to their previous level of fitness after major surgery.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a ‘Care plan’ from social services
Hospital
Specialist doctors -:
- Oncologist
- Physician
- Haematologist

Specialist nurses have many different job titles -:
- Clinical Nurse Specialist
- Stoma care nurse
- Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
- Physiotherapist
- Occupational Therapist
- Social worker
- Counsellor
- Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
- Palliative Care Physician
- Macmillan Nurse
- Clinical Nurse Specialist
- Social worker
- Physiotherapist
- Occupational Therapist
- Counsellor

Activities of Daily Living and Mobility needs
- Speech and people who have had a Partial Laryngectomy
- Speech and people who have had a Subtotal Laryngectomy
- Speech and people who have had a total laryngectomy
- Caring for a tracheostomy
- Mobility
- Swallowing and diet
- Musculoskeletal problems
- Psychological Effects
Localised disease

Most treatments for laryngeal cancer last less than 3 months. For example radiotherapy and recovery or recovery from surgery. The exception to this is chemotherapy when it is given by itself over 6 cycles. If chemotherapy alone is being given, this treatment is likely to be palliative rather than curative. Side effects related to this treatment that result in needs during the first cycles are only likely to get worse through the treatment, a time limited award may be appropriate to cover this period. Rarely there may be the enduring side effects of chemotherapy treatment. Rarely there may be ongoing difficulties with swallowing which require special feeding ranging from soft diet to gastrostomy feeding.

Most people with laryngeal cancer are likely to be mobile and self caring at 3 months post treatment, if needs are present they are likely to be related to:

- the ability to speak
- having a tracheostomy

These difficulties are described in detail. The best source of evidence for assessment of needs will be the speech and language therapist who has most recently treated the claimant.

Speech and people who have had a Partial Laryngectomy

A person who has had this treatment will not have a permanent tracheostomy and will be able to speak with the remains of their larynx; it may take several months to become confident speaking to strangers. Their voice is likely to be weaker and hoarser than before. Likely difficulties include tiring of the voice when speaking for long periods and some difficulty being heard in noisy environments such as pubs, parties and shops. This is likely to be a significant problem for people who need their voices at work e.g. teachers, actors. Rarely tongue movement which makes many of the sounds of speech may be affected by treatment – this is likely to leave a person with a speech impediment as well as a weak voice. This often responds well to speech therapy but there may be a long period during which speech is unintelligible to strangers and confidence is lost.

There may be problems with swallowing in the months after surgery; this may occasionally involve aspirating or accidentally breathing in or choking on food whilst swallowing. Often this problem improves with time and patients will be taught techniques to enable safer swallowing. If this problem is persistent it is likely to be a cause of embarrassment and may lead to social isolation. If help or supervision is required because of aspiration at mealtimes this is a care need. Aspiration is likely to be persistent if it is still a problem 12 months after surgery. Should the problem result in frequent difficulties or recurrent chest infections then in consultation with the patient and their family, further treatment in the form of a total laryngectomy may be offered.
**Speech and people who have had a Subtotal Laryngectomy**

After this surgery part of the larynx remains which enables a person to speak with an altered quiet hoarse voice. It may take months to become confident speaking to strangers. A tracheostomy will be in place and needs to be cared for. This may be temporary but as breathing becomes more confident may be removed. Likely difficulties include tiring or fatiguing of the voice when speaking for long periods and some difficulty being heard in noisy environments such as pubs, parties and shops. This is likely to be a significant problem for people who need their voices at work e.g. teachers, actors. Rarely, tongue movement which makes many of the sounds of speech may be affected by treatment – this is likely to leave a person with a speech impediment as well as a weak voice. This often responds well to speech therapy but there may be a long period during which speech is difficult or unintelligible to strangers and confidence is lost.

There may be problems with swallowing in the months after surgery; this may involve aspirating or accidentally breathing in food whilst swallowing. Often this problem improves with time and there are techniques to enable safer swallowing which can be learnt. If this problem is persistent it is likely to be a cause of embarrassment and may lead to social isolation. If help or supervision is required because of aspiration at mealtimes this is a care need. Aspiration is likely to be persistent if it is still a problem 12 months after surgery.

**Speech and people who have had a total laryngectomy**

A person who has their whole larynx removed is called a total laryngectomee. They have no larynx at all to speak with and will need to learn to speak again. There are several ways of speaking without a voice box:

- **Oesophageal speech** – a person swallows air and speaks (vocalises) by burping it back out again using resonance in the back of the throat (the pharynx) to make sounds. They may manage one word at a time within 6 weeks and be speaking in short sentences (3 – 4 words) within 6 months. Often even people who speak really well using the technique speak more slowly than normal. The length of each sentence will be dependent upon the amount of air “burped back”. Continued improvement in speech is likely for the first year. This type of speech is tiring at first and sounds very different to normal speech; it may be difficult for strangers to understand. Practical problems include making themselves heard and understood speaking over the telephone and in noisy environments - particularly to strangers. Psychological problems may develop because of the inability to express emotion through the voice by moderating pitch or speak for long enough to express feelings or needs. It is possible to develop good speech using this technique but this is the exception rather than the rule, social isolation is common.

- **Speech Valves** – there are various types of one way valves which connect the oesophagus to the trachea. The sound is the same as oesophageal speech but the air doesn’t have to be swallowed it comes through the one-way valve from the trachea to the oesophagus from the
lungs. The hole is called a tracheo-oesophageal puncture (TEP). Mostly someone using one of these will have to close their tracheostomy by putting a finger over it every time they want to speak but some of them are ‘hands free’. The names of the valves are:
Blom-Singer
Provox
Groningen
Problems are common with these valves; some people will not manage with them and have to use oesophageal speech or other speech aid.
Common problems include -:
Leakage through the valve of fluid into the trachea and lungs – this causes coughing.
Candida infection around the valve – this is the main cause of leakage, regular anti-fungal drugs may be taken to control it.
Leakage of the valve at the end of its life – they last around 6 months – the valve needs to be replaced usually at the hospital. When this occurs there will be problems including coughing and inability to speak until valve is changed.
Dislodged valve – the valve may be inhaled rather than just falling out.
Foreign bodies in the lung can cause severe ‘aspiration’ pneumonia if not removed straight away and the hole for the valve can close within a few minutes of dislodging meaning further surgery to put a new one in or adopting a new technique for speech.
Some of these valve problems can be minimised or reduced if the patient or their relative can learn how to replace the valve themselves but not everyone can do this and periods of coughing, loss of speech and trips to the hospital may be a real burden.

The effort of speaking with one of these is less than for oesophageal speech and the voice achieved can be louder. It takes time and practice to develop good speech using a valve. The disadvantages are that saliva can leak into the trachea and lungs through the valve and they require more care and attention in terms of keeping them clean through the day. Under normal circumstances the valve needs cleaning twice a day with a special brush. More frequent cleaning is required if the person has a cough or a cold. When the valve blocks a person cannot speak, this may happen regularly. Speech is usually possible 6-8 weeks after surgery and improves over the first year.

This type of voice sounds very different to normal speech; it may be difficult for strangers to understand. Practical problems include making themselves understood to strangers and speaking over the telephone. Having to place a finger over the stoma in the neck to speak draws other people’s attention to the neck and can make a person feel more abnormal and self conscious. Psychological problems may develop because of the inability to express emotion through the voice by moderating pitch or speak for long enough to express feelings or needs. It is possible to develop good speech using this technique but not everyone can do this, social isolation is common.
Electronic larynx - this is an electronic vibrating device which is held against the neck to enable speech. It can take up to a year to be able to use the device well enough to make strangers understand and the voice sounds mechanical. Practical problems include making themselves understood to strangers and speaking over the telephone. Psychological problems may develop because of the inability to express emotion through the voice by moderating pitch or speak for long enough to express feelings or needs. Whispering is not possible either. As one hand has to hold the device for speech, only one hand is free during speech. This makes it impossible to speak whilst driving, eating, preparing food etc. This is a less tiring method of speaking without a larynx and is often the option of last resort; the mechanical ‘robotic’ voice can be very off-putting. Strangers may react very negatively to the voice particularly on the telephone and this is embarrassing and upsetting. Social isolation is common.

About 20-30% of laryngectomees do not communicate using the above methods, this is usually because caring for the valve was very frustrating and difficult or they disliked the sound of the new voice. People who do not have a voice have to attract attention first - by waving, clapping or tapping someone on the shoulder, they articulate words silently, make gestures, write or use picture charts. Communication difficulties are likely to cause terrible frustration and sometimes severe anxiety as the easiest and quickest means of summoning help when they are in distress is lost.

Caring for a tracheostomy

A tracheostomy is a hole in the neck that a person breathes through instead of breathing through the mouth; the hole may be called a tracheostomy or a laryngectomy stoma. The airway is not connected to the mouth unless there is a one way speech valve in place. Nearly everyone needs some help caring for the tracheostomy and encouragement to eat and drink in the early months after surgery. A tracheostomy will leak mucus and become crusted over without care. Some people may need to change bedding and /or nightwear during the night due to excess mucus production. The hole can block with crust or mucus over 24 hours or sooner if a person has a cold. Blocking of the stoma is potentially life threatening. A person may need to attend to their stoma every few hours to keep it clean. This involves cleaning the stoma. Crusts need to be removed from the stoma to prevent blockage. Most people use cotton buds and tweezers to remove crustling.

They may need to wear a device to keep the stoma open and clear: a ‘tube’ or a ‘vent’ or ‘stoma button’ as well as a protective dressing over the stoma. This stoma button needs to be removed and cleaned regularly. The stoma needs to be protected from water e.g. during bathing, showering or the rain. Most people are able to manage themselves e.g. by wearing a shower shield. Protecting the stoma from the rain is difficult for those who cannot lift up their arms to hold an umbrella in the air because of neck surgery. Most people are also able to cough up mucus through their stoma most of the time and do not need home suction.
Rarely a humidifier or home suction may be needed to keep the stoma functioning – travelling away from home is likely to be restricted if this type of equipment is needed. If mucus is a problem and coughing is difficult the stoma may block from time to time – this is an emergency and will normally mean a carer has to be available to perform suction when the laryngectomee cannot breathe.

**Mobility**

The nose and throat provide important protection and airflow resistance to the lower airways which help to keep the alveoli open and protected from cold and dryness. Closure of the vocal cords assists the effort of coughing considerably and also the ability to perform certain activities such as straining to lift a heavy object and straining to open the bowels. Consequently lifting heavy items, straining to open the bowels and coughing up mucus are much harder than they were before. Techniques can be learnt to overcome the coughing difficulty but not the other difficulties. Secondly, the lower airways are much more open to irritants and damage and chronic lung problems on top of frequent coughs and colds and the need to protect the stoma may result. In order to prevent chronic lung damage humidification and filtration of air are necessity. Most patients wear a HME (heat and moisture exchanger) to conserve heat and moisture during expiration (breathing out), then returning it to the inspired air. Examples of HME’s are -:

- Buchanan bibs
- Laryngofoam
- Deltanex protectors, etc

People who have had a laryngectomy are more likely to have Chronic Obstructive Airways Disease and if breathlessness is severe or exercise tolerance much reduced walking is likely to be affected.

**Swallowing and diet**

Many people may have swallowing difficulties post-laryngectomy. Some people may need to liquidise food, make it semi-solid, or cut food up into very small pieces. Extra attention to proper and careful swallowing may be necessary. This may make mealtimes prolonged, and the person may have to reheat food during a meal. Some people develop stricturing (tightening) of the neo-pharynx (reconstructed throat), making swallowing difficult and sometimes resulting in regurgitation problems during meals. Periodic stretching of the stricture under general anaesthetic may sometimes be required in order to continue with oral feeding.

Acid reflux is a common problem. Patients may experience reflux of stomach contents into the mouth and throat, and this may be worse when bending forwards, or when lying down. Sleeping propped up in bed may be necessary, as may lifestyle and dietary modifications, and some may require medicine such as ranitidine, omeprazole (Losec) to control this reflux.
Smell and taste are also greatly diminished, as air no longer flows through the nose and throat. Olfaction (sense of smell) plays a crucial role in the ability to appreciate the flavour of food. Therefore, so called ‘neck breathers’ have a decreased enjoyment of eating. In addition to this, olfaction is important for monitoring the safety of the environment. Thus, the laryngectomee will not be alert to the smell of fire, gas leaks and the presence of toxins in food that has spoilt.

**Musculoskeletal problems**

Shoulder dysfunction – loss of shoulder function is a potentially distressing consequence of neck dissection. This may cause a significant loss of shoulder flexion and abduction, and shoulder pain and drooping may also be a problem. This restricted range of movement of the shoulder, and loss of function can impact on all activities of daily living related to shoulder function; for example, washing, dressing, combing hair, writing, reaching for objects above shoulder level, reaching into cupboards, hanging out washing, etc. Severe pain in the neck and shoulder(s) may also occur as a consequence; and this pain often increases when moving the shoulder and lying on the affected shoulder. Neck tightness, stiffness, loss of sensation in the neck, or a feeling of constriction and restricted range of movement may also be a problem. This can impact on everyday activities, such as turning the head to watch for traffic and other dangers. The appearance of the neck may also lead to psychological problems.

**Psychological Effects**

Particular problems for people who have had laryngectomy in addition to the general psychological effects of cancer (see general notes) are related to quality of life which may be severely impaired:

- Embarrassment because of altered voice or inability to speak
- Ability to swallow and enjoy food with others
- Cosmetic effect of having a hole in the throat, altered appearance of neck after neck dissection
- Effects on taste and smell,

They may become socially reclusive without help and support.

**Advanced, Recurrent or Metastatic Cancer**

A person who has had treatment for advanced laryngeal cancer may have any of the problems related to speech or care of a tracheostomy. In addition to those problems there may be any of the symptoms of metastatic disease.

[Back to top of section]
How long will the needs last?

Localised disease
Rarely, needs may be identified due to chemotherapy related side effects which are expected to last for up to 6 months and a time limited award is recommended to cover this period.

Speech problems
There are likely to be severe difficulties with communication for anyone having surgery to remove part of or the entire larynx. For some these difficulties will persist. If surgery was less than eighteen months ago some improvement in communication is likely and a time limited award is recommended. If surgery was more than eighteen months ago and there are still needs related to communication a life award is recommended.

Tracheostomy care
When a person has other medical problems which are not expected to improve – perhaps restricted movement of the upper limbs or dexterity of the hands and is unable to self care for their stoma within a few months of surgery a life award is recommended. Similarly a person who is unable to cough and clear their stoma or who requires suction by a carer for blockages or to remove mucus to facilitate breathing more than a few months after surgery is likely to have ongoing needs and a life award is recommended.

Advanced or Metastatic Cancer
Life awards are recommended.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Learning disability

What is a Learning disability?
This guidance refers to a number of different conditions and syndromes, some of which cause both mental and physical disability. This guidance covers…… Read more on NHS Choices - Learning disability

What evidence is available?
The claimant is generally not in a position to be able to provide the information required to accurately assess…… Read more about evidence sources.
Linked pages:
Further sources of evidence

Activities of Daily Living and Mobility needs
The following would normally be characteristic of a person with a mild functional restriction…… Read more about ADL & mobility needs.

How long will the needs last?
Remember, this guidance refers to a number of different conditions and syndromes, some of which cause…… Read more about award duration.

Over 65s
People over 65 may experience the following problems: If the parents are the carers, they may find this increasingly…… Read more about effects in the over 65 age group.

What evidence is available?
The claimant is generally not in a position to be able to provide the information required to accurately assess mobility and care needs. The necessary details are best obtained from the Carer, Consultant, Specialist Nurse or Occupational Therapist.

It may be difficult to obtain recent medical evidence for adults with a learning disability, when they have limited contact with their general practitioners or hospital services, since their general health is satisfactory. However for older teenagers and young adults some reports and previous assessments, including those made by educational psychologists, may be available in their medical records or from the school or college they are attending :-: 
• **Special Education Needs (SEN)**

Note: These reports should be accompanied by medical evidence wherever possible.

They may also have been assessed by speech and language therapists, occupational therapists, social workers and other health care professionals who provide services for people with learning disabilities living in the community. Copies of reports may be obtained from community teams, social services or local authorities. This applies to those living at home and in residential accommodation. Customers or their carers may also have copies of these assessments or care plans.

An assessment by a Health Care Professional is appropriate when disabilities are stable and long standing, and when other sources of evidence are not available, or give insufficient detail to ascertain the overall level of functional impairment.

Click on the link for details of -:
[Further Evidence sources](#)
[Back to top of section](#)

**Activities of Daily Living and Mobility needs**

**Mild Functional Restriction**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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</table>
| Disabling Effects| The following would normally be characteristic of a person with a mild functional restriction.  
• Mild learning disability and -:  
  - GP care only  
  - No behavioural problems  
  - Lives in unsupervised accommodation  
  - Attended mainstream school  
  - Employed with no support  
  - No legal protection in place  
  - No associated physical, psychiatric or other problems. |
| Mobility         | A person with mild functional restriction would not be expected to have physical difficulties with walking. Nor would they require guidance or supervision outdoors. |
| ADL              | People with a mild restriction should be able to live independently, though they may need help in coping with housing and employment, family responsibilities, planning complex activities or when under unusual stress. |
Consequently they would not normally be expected to have attention or supervision needs.

**Moderate Functional Restriction**

<table>
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<tr>
<th>Category</th>
<th>Description</th>
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</thead>
</table>
| **Disabling Effects** | The following would normally be characteristic of a person with a moderate functional restriction.  
• Moderate learning disability and :-  
Multidisciplinary community team care  
No behavioural problems  
Require intermittent supervision, i.e. can be left alone for prolonged periods of time  
Attended mainstream school with statement  
Supported employment  
No legal protection in place  
There may be associated problems that include :-  
• Visual impairment  
• Hearing impairment  
• Motor disabilities  
• Epilepsy |
| **Mobility**     | The ability to walk is likely to be unimpeded in the absence of neuro-muscular problems affecting the lower limbs.  
They are likely to require guidance and supervision when finding their way around outdoors as they may be vulnerable to exploitation, demonstrate disturbed or antisocial behaviour and have difficulty in communicating with strangers. |
| **ADL**          | They are likely to require attention with prompting to wash, dress, prepare food, wear appropriate clothes and eat a proper diet. Also to partake in appropriate activities, to take medication and deal with correspondence and financial matters.  
They are not likely to require assistance with most aspects of bodily functions.  
They may need supervision to prevent |
potentially dangerous behaviours or activities.

### Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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| Disabling Effects | The following would normally be characteristic of a person with a severe functional restriction.  
  - Severe or profound learning disability  
  - Multidisciplinary community team care  
  - Severe or profound learning disability  
  - Behavioural problems  
  - Require regular supervision every day  
  - i.e. can only be left alone for very brief periods of time  
  - Attended special school  
  - Unable to work  
  - Legal protection in place that includes:  
    - Court of Protection  
    - Guardianship order  
    - Appointee  
    - Section 25 Supervised Discharge  
  - There may be associated problems that include:  
    - Severe visual impairment  
    - Severe hearing impairment  
    - Severe motor disabilities  
    - Poorly controlled epilepsy  
    - Incontinence  
    - Schizophrenia or other severe and enduring mental illness  
    - Severe behavioural problems  
    - Dementia |
| Mobility          | The ability to walk is likely to be unimpeded in the absence of neuro-muscular problems affecting the lower limbs.  
  - They are likely to require guidance and supervision when finding their way around outdoors as they may be vulnerable to exploitation, injury on busy roads, demonstrate disturbed or antisocial behaviour and have difficulty in communicating with strangers. |
| ADL               | They are likely to require regular attention to assist with most aspects of bodily functions and with prompting to |
wash, dress, prepare food, wear appropriate clothes and eat a proper diet. Also to partake in appropriate activities, to take medication and deal with correspondence and financial matters. They are likely to need supervision to prevent potentially dangerous behaviours or activities.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
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<tbody>
<tr>
<td>Learning disability i.e. Down’s syndrome, Fragile X syndrome &amp; Learning disability - Other / type not known</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

**How long will the needs last?**

Remember, this guidance refers to a number of different conditions and syndromes, some of which cause both mental and physical disability. This guidance covers the mental impairment aspect of the overall disability only. Appropriate guidance must be referred to where there is also any physical impairment.

Learning disability runs a life long course with little change.

Once care and mobility needs have been established they are unlikely to improve and a life award should be considered. However, intellectual or physical deterioration can occur in later life and may result in increasing care and mobility needs.

A young adult assessed appropriately in childhood as having a moderate learning disability is unlikely to develop fully independent living skills and a child classified as having a severe learning disability is highly unlikely to develop such skills, even with ongoing education & training or mentoring.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
**Over 65**

People over 65 may experience the following problems:

If the parents are the carers, they may find this increasingly burdensome, but may be reluctant to arrange alternative care for the person. If the parents die, bereavement may be especially difficult because of communication problems.

Dementia affects people with learning disability at a younger age than the general population. A progressive decline in intellectual and social functioning may be the first manifestation of dementia. As the life expectancy of people with learning disability is increasing, dementia in later life is becoming more common. There is a particular association between Downs syndrome and Alzheimer’s disease.

**Further sources of evidence**

**Claim pack**

Self-assessment is the prime source of evidence, but the claim pack should be checked to see who has completed it. If the form has been filled in by the customer, due to the nature of their condition, it might not necessarily be an accurate or reliable description of their problems.

If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.

The DM should bear in mind that the completion of the corroborative statement by a Health Care Professional does not necessarily mean that they endorse what has been said in the claim pack.

However, because of the complex nature of learning disability and the wide variation in resulting disablement, it is important to try to obtain medical evidence to support information provided by the customer whenever possible.

**Multi-disciplinary community team**

People with learning disability who require active involvement or review will be under the supervision of a community team. Although the majority will have severe or moderate learning disability, those with mild learning disability who are considered at risk will also be under their supervision. A hospital factual report should be requested for completion by any member of the clinical team that may include a consultant psychiatrist, specialist nurse [learning disability] or occupational therapist. A copy of a Community Care Act assessment form can also be requested at the same time.

The following, if available, should also be requested:
• A copy of a completed standardised assessment, for example the Adaptive Behaviour Scale, as this is likely to provide good evidence about functional ability of the person.
• A copy of a Statement of Special Educational Needs as this is likely to provide good evidence of associated needs.

**General Practitioner (GP)**

People with learning disability who are not considered high risk and do not require involvement of the community team will be under the care of the primary care team and in this circumstance it is worth trying to obtain a factual report from the GP. A proportion of GPs keep a register of people with learning disability in their practice.

**Health Care Professional (HCP) Examination Report**

However, it is possible that the GP has no recent information relating to the person and in this event an HCP examination report would be required.

**Social Services and Local Authority**

Copies of previous assessments including educational assessments may be obtained from the Social Services department, Local Authority or carer in the absence of any current health care involvement.

**Accommodation manager**

When the claimant is living in supported accommodation then the type and level of support provided could be helpful in determining their need for help.

A phone call to the accommodation manager could provide useful evidence.

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What you need to know about Acute Lymphoblastic Leukaemia (ALL)

What is ALL?
Leukaemia is cancer of the white blood cells. Symptoms of leukaemia include pale skin, tiredness, breathlessness & having.... Read more on NHS Choices - acute lymphoblastic leukaemia.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even.... Read more about evidence sources.

Activities of Daily Living and Mobility needs
Treatment and recovery for those who successfully undergo combination chemotherapy or bone marrow transplant is likely to.... Read more about ADL & mobility needs.

How long will the needs last?
People with ALL are likely to be very ill on diagnosis; about 80% will go into remission with their first course of chemotherapy. Despite.... Read more about award duration.

Over 65s
Survival rates are lower in older people and treatment related side effects are likely to be worse.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- General Practitioner - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- Community or District Nurse - will have information on any home care or outreach package in place as this is coordinated through the practice.
- Social worker - customer may have a ‘Care plan’ from social services
Hospital
Specialist doctors -:
- Oncologist
- Physician
- Haematologist

Specialist nurses have many different job titles -:
- Clinical Nurse Specialist
- Stoma care nurse
- Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
- Physiotherapist
- Occupational Therapist
- Social worker
- Counsellor
- Psychologist

Also refer to the ‘Symptomatic treatments' page.

Hospice
Hospice Specialists -:
- Palliative Care Physician
- Macmillan Nurse
- Clinical Nurse Specialist
- Social worker
- Physiotherapist
- Occupational Therapist
- Counsellor

Activities of Daily Living and Mobility needs
Treatment and recovery for those who successfully undergo combination chemotherapy or bone marrow transplant is likely to take 1 year to 2 years. Needs are likely, related to both treatment and the disease. During this period they are likely to have periods of being immunosuppressed and be unable to go out in public. Episodes of severe fatigue may endure for many months related to chemotherapy treatment and anaemia.

Mobility
Severe fatigue and reduced exercise tolerance related to any of the following may reduce the ability to walk:
- Chemotherapy treatment
- Anaemia
- Side effects of drugs used – effects on lungs (pulmonary oedema), spinal cord, brain (cerebellum) and nerves

People who are immunosuppressed may be advised to avoid public places.

**Activities of Daily Living**
Severe fatigue may make activities of daily living difficult. Help with activities of daily living from someone else may be required because of pain, fatigue or dizziness.

**How long will the needs last?**
People with ALL are likely to be very ill on diagnosis; about 80% will go into remission with their first course of chemotherapy. Despite aggressive consolidation therapy the majority of them (60%) will relapse again quite quickly. Further treatment may be able to control the disease for a little longer but will not cure it. Without bone marrow transplant treatment first relapse leads to death on average within a year.

Long term survival after treatment depends on subtype of leukaemia and age. 2 year survival with ALL is 35-40% for people under 55 years of age; for older people long term survival rates are lower.

Most deaths from leukaemia occur within the first few years after diagnosis. Those who do become long term survivors are likely to have undergone arduous treatment in addition to being very ill with their leukaemia in the first place. It is recommended that if needs are identified that awards are made for two years. Those who are going to recover from their ALL are likely to have substantially done so at 2 years. Those still undergoing treatment or who have needs at 2 years are likely to have ongoing needs; indefinite awards at 2 year review are recommended for these people.

<table>
<thead>
<tr>
<th>Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Lymphoblastic Leukaemia (ALL)</td>
</tr>
<tr>
<td>Leukaemia – Other / type not known</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Acute Myeloid Leukaemia (AML)

Back to A - Z

What is AML?
Leukaemia is cancer of the white blood cells. Symptoms of leukaemia include pale skin, tiredness, breathlessness & having….Read more on NHS Choices - acute myeloid leukaemia

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even….Read more about evidence sources.

Activities of Daily Living and Mobility needs
Treatment and recovery for those who successfully undergo combination chemotherapy or bone marrow transplant is….Read more about ADL & mobility needs.

How long will the needs last?
People with AML are likely to be very ill on diagnosis, and need to undergo immediate treatment. Many of them will relapse and…. Read more about award duration.

Over 65s
5 year survival rate for people over 60 is about 20%.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- General Practitioner - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- Community or District Nurse - will have information on any home care or outreach package in place as this is coordinated through the practice.
- Social worker - customer may have a ‘Care plan’ from social services

Hospital
Specialist doctors -:
Specialist nurses have many different job titles -:
- Clinical Nurse Specialist
- Stoma care nurse
- Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
- Physiotherapist
- Occupational Therapist
- Social worker
- Counsellor
- Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
- Palliative Care Physician
- Macmillan Nurse
- Clinical Nurse Specialist
- Social worker
- Physiotherapist
- Occupational Therapist
- Counsellor

Activities of Daily Living and Mobility needs

Treatment and recovery for those who successfully undergo combination chemotherapy or bone marrow transplant is likely to take 1 year to 2 years. Needs are likely, related to both treatment and the disease. During this period they are likely to have periods of being immunosuppressed and be unable to go out in public. Episodes of severe fatigue may endure for many months related to chemotherapy treatment and anaemia.

Mobility
Severe fatigue and reduced exercise tolerance related to any of the following may reduce the ability to walk:
- Chemotherapy treatment
- Anaemia
• Side effects of drugs used – effects on lungs (pulmonary oedema), spinal cord, brain (cerebellum) and nerves

People who are immunosuppressed may be advised to avoid public places.

Care
Severe fatigue may make activities of daily living difficult. Help with activities of daily living from someone else may be required because of pain, fatigue or dizziness.

How long will the needs last?

People with AML are likely to be very ill on diagnosis, and need to undergo immediate treatment. Many of them will relapse and require more treatment quite quickly, if first relapse occurs within 3 years of initial treatment, median survival is around 6 months. If first relapse occurs 3 years or more after initial treatment median survival is 18 months. Long term survival after treatment depends on subtype of leukaemia and age. 40% of people of all ages will survive for 3 years after treatment and many of these will be long term survivors – they may be ‘cured’. Long term survival is improved for people under 60, the younger they are the better chance they have of long term survival. 5 year survival rates for people under 60 are about 55%.

Most deaths from leukaemia occur within the first few years after diagnosis. Those who do become long term survivors are likely to have undergone arduous treatment in addition to being very ill with their leukaemia in the first place. It is recommended that if needs are identified that awards are made for two years. Those who are going to recover from their AML are likely to have substantially done so at 2 years. Those still undergoing treatment or who have needs at 2 years are likely to have ongoing needs; indefinite awards at 2 year review are recommended for these people.

Impairment
Acute Myeloid Leukaemia (AML)
Leukaemia – Other / type not known

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Chronic Lymphocytic Leukaemia (CLL)

What is CLL?
Leukaemia is cancer of the white blood cells. Symptoms of leukaemia include pale skin, tiredness, breathlessness & having…. Read more on NHS Choices - chronic lymphocytic leukaemia.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Most people with CLL will be elderly with slowly progressive disease, many will not require treatment or their disease will be controlled…. Read more about ADL & mobility needs.

How long will the needs last?
Time limited awards coinciding with expected recovery from treatment are recommended for those undergoing chemotherapy…. Read more about award duration.

Over 65s
No special features.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
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Hospital
Specialist doctors -:
- Oncologist
- Physician
- Haematologist

Specialist nurses have many different job titles -:
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- Stoma care nurse
- Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

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Hospice Specialists -:
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- Social worker
- Physiotherapist
- Occupational Therapist
- Counsellor

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Activities of Daily Living and Mobility needs
Most people with CLL will be elderly with slowly progressive disease, many will not require treatment or their disease will be controlled with a course of oral Chlorambucil (an anticancer drug). Typically no disabling effects of disease or treatment are present. Anyone who has recurrent disease or has combination chemotherapy or bone marrow or stem cell transplant most likely will have disabling effects related to treatment - particularly fatigue. If needs are identified awards should be time limited to coincide with recovery from treatment. Survival will depend on the stage of the disease at diagnosis and number of recurrences. People with stage A CLL generally live on average for at least 10 years. People with advanced
disease (stage C) generally live on average 2-3 years. People having aggressive treatment or who have advanced disease are more likely to have needs and less likely to return to health after treatment. Longer term or indefinite awards should be considered if disease is described as advanced in the medical evidence or disease has recurred more than once.

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**How long will the needs last?**

Time limited awards coinciding with expected recovery from treatment are recommended for those undergoing chemotherapy treatments for newly diagnosed or first relapse of CLL, this includes those having bone marrow transplant treatment. At review if treatment is ongoing, needs are present or medical evidence describes the patient as having advanced (stage C) disease, indefinite awards are recommended.

<table>
<thead>
<tr>
<th>Impairment</th>
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</thead>
<tbody>
<tr>
<td>Chronic Lymphocytic Leukaemia (CLL)</td>
</tr>
<tr>
<td>Leukaemia – Other / type not known</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Back to top of section**
What you need to know about Chronic Myeloid Leukaemia (CML)

What is CML?
Leukaemia is cancer of the white blood cells. Symptoms of leukaemia include pale skin, tiredness, breathlessness & repeated…. Read more on NHS Choices - chronic myeloid leukaemia.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Treatments for chronic and accelerated phase CML are the same. People with accelerated phase CML are more likely to have…. Read more about ADL & mobility needs.
How long will the needs last?
Routine review of any awards made is recommended. Blast phase - those with blast phase will have needs and are likely to be very…. Read more about award duration.

Over 65s
There are no special features.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- General Practitioner - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
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They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
- Physiotherapist
- Occupational Therapist
- Social worker
- Counsellor
- Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
- Palliative Care Physician
- Macmillan Nurse
- Clinical Nurse Specialist
- Social worker
- Physiotherapist
- Occupational Therapist
- Counsellor

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Activities of Daily Living and Mobility needs
Treatments for chronic and accelerated phase CML are the same. People with accelerated phase CML are more likely to have symptoms but these are likely to resolve with treatment when a person goes into remission. Needs are unlikely to be identified because of either the disease or its treatment. The exception to this is when treatment includes a bone marrow or stem cell transplant. You should follow guidance on care and mobility considerations for bone marrow and stem cell transplant if this treatment is being given. The treatment of chronic CML has improved a lot over the last few years and long term survival with treatment is common. About half of people who have bone marrow or stem cell transplant for chronic CML are cured of their disease and many others achieve long term survival on Imatinib. Progressive disease and needs are most likely in those whose disease has not responded to Imatinib and who are unable to have a bone or stem cell transplant for some reason.
How long will the needs last?
Routine review of any awards made is recommended.

Blast phase
Those with blast phase will have needs and are likely to be very ill with many of the symptoms of acute leukaemia. Indeed, many of them will be terminally ill. Reduced mobility is expected because of anaemia and breathlessness; help may be required with all aspects of daily living. Only about 30% will respond to treatment and median survival for the non-responders is 2-4 months. Those who undergo successful bone marrow or stem cell transplant are likely to become the long term survivors it is recommended awards are given with review at 2 years to those undergoing bone marrow or stem cell transplant. Indefinite awards are recommended for all those who are unable to have this treatment.

<table>
<thead>
<tr>
<th>Impairment</th>
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</thead>
<tbody>
<tr>
<td>Chronic Myeloid Leukaemia (CML)</td>
</tr>
<tr>
<td>Leukaemia – Other / type not known</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Lipomas

Back to A - Z

What is a Lipoma?
Most lumps and swellings under the skin are harmless and can be left alone, but should be checked by a GP so the cause is known…. Read more on NHS Choices - lipomas.

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and Mobility needs
There are unlikely to be any functional or mobility problems associated with this condition even if treatment such as surgical removal is necessary.

How long will the needs last?
There are unlikely to be any functional restrictions associated with this condition.

Over 65s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages -:
Ageing
Falls
Frailty
What you need to know about Liver failure

Back to A - Z

What is Liver failure?
Read more on NHS Choices - alcoholic liver disease
Read more on NHS Choices - liver cirrhosis
Read more on NHS Choices - liver transplant

For information about other liver complaints discuss with Medical Services.

What evidence is available?
People with liver failure will be under hospital care in the majority of cases. Medical reports may be obtained from hospital doctors…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Mild functional restriction - non-specific symptoms of malaise and fatigue resolve, and it is unlikely that they would be severe…. Read more about ADL & mobility needs.

How long will the needs last?
Chronic hepato-cellular failure - the changes of hepatic encephalopathy may be reversible in some cases. However deterioration of…. Read more about award duration.

Over 65s
The size and function of the liver deteriorates with ageing. In general liver diseases in the elderly carry a worse prognosis than…. Read more about effects in the over 65 age group.

What evidence is available?
People with liver failure will be under hospital care in the majority of cases. Medical reports may be obtained from hospital doctors and specialist nurses working in liver units. If someone has recovered completely from acute liver failure they may have no further need to attend a hospital clinic. A general practitioner report will provide details on their current state of health.

Activities of Daily Living and Mobility needs
### Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>Non-specific symptoms of malaise and fatigue resolve, and it is unlikely that they would be severe enough to limit normal daily activities.</td>
</tr>
<tr>
<td>Mobility</td>
<td>People with mild liver failure are unlikely to have any persistent functional restrictions affecting physical mobility. There is unlikely to be a need for guidance or supervision outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>People with mild liver failure are unlikely to have any persistent functional restrictions affecting care.</td>
</tr>
</tbody>
</table>

### Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>The degree of functional limitation experienced by someone with chronic liver disease is caused mainly by liver failure. The individual features of each impairment need to be considered. There is likely to be persistent jaundice, muscle weakness, low body weight, poor nutritional status, susceptibility to infection, increasing ascites and portal hypertension are all indicators of an increasing level of functional limitation.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Mobility may be limited due to severe fatigue and muscle weakness. There is unlikely to be a need for guidance or supervision outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>Typically there may be increasing need for help with washing, dressing, stairs, rising from a chair etc. over time.</td>
</tr>
</tbody>
</table>
Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>Many people with end stage liver failure may be receiving palliative care only and their life expectancy may be expected to be less than six months.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Walking is likely to be significantly restricted. This will include people awaiting a liver transplant. People with hepatic encephalopathy may have a requirement for guidance or supervision out of doors resulting from long-term cognitive impairment.</td>
</tr>
<tr>
<td>ADL</td>
<td>People with advanced liver failure, including all the complications described under the moderate category, are likely to require help with self-care. They may need help with moving around the house, rising from a chair, supervision of medication, and may be prone to falls. People with hepatic encephalopathy may need supervision as a result of confusion, disorientation, drowsiness, abnormal behaviour and inability to think in a rational manner.</td>
</tr>
</tbody>
</table>

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**How long will the needs last?**

**Acute hepato-cellular failure**
Complete recovery may take place in some cases e.g. acute viral hepatitis.

**Fulminant hepatic failure**
The outcome is more variable. Severe and prolonged encephalopathy tends to have a poor outcome, as does the development of other complications.

**Chronic hepato-cellular failure**
The changes of hepatic encephalopathy may be reversible in some cases. However deterioration of liver function is likely to continue over months or years. Increasing jaundice is an adverse indicator in some types of cirrhosis. Ascites in association with cirrhosis reduces survival to 50% in the first year after its development, and to 20% at five years.
<table>
<thead>
<tr>
<th>Impairment and complications</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liver failure with -:</td>
<td></td>
</tr>
<tr>
<td>Ascites</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Hepatic encephalopathy</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Successful liver transplantation</td>
<td>N/A</td>
</tr>
<tr>
<td>Liver transplant with rejection of liver</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Other features of liver failure / features not known</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Liver Failure in people over 65**

The size and function of the liver deteriorates with ageing. In general liver diseases in the elderly carry a worse prognosis than in the younger age. However the clinical features and treatment of the liver impairments are similar in both age groups.

[Back to top of section](#)
What you need to know about Lung cancer

What is Lung cancer?
Lung cancer is one of the most common and serious types of cancer. Symptoms of lung cancer include coughing, unexplained weight loss.... Read more on NHS Choices - lung cancer

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks.... Read more about evidence sources.

Activities of Daily Living and mobility needs
Early lung cancer (20-30%) - the majority of lung cancer cases will be terminally ill. This section applies to the smaller group who have.... Read more about ADL & mobility needs.

How long will the needs last?
In almost all cases, it is appropriate to make an indefinite award as life is likely to be short and disabling effects identified are likely to persist.... Read more about award duration.

Over 65’s
There are no special features in the elderly.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- General Practitioner - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
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• Haematologist

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• Occupational Therapist
• Social worker
• Counsellor
• Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
• Palliative Care Physician
• Macmillan Nurse
• Clinical Nurse Specialist
• Social worker
• Physiotherapist
• Occupational Therapist
• Counsellor

Activities of Daily Living and Mobility needs

Early lung cancer (20-30%)
The majority of lung cancer cases will be terminally ill. This section applies to the smaller group who have had early lung cancer treated by surgery and long term survivors after chemo and radiotherapy. These are the minority of people with lung cancer (20-30%).

For lung cancer treated by surgery and chemotherapy or radiotherapy and chemotherapy; once the initial treatment is complete any residual disabling effects are permanent. Commonly they will have reduced exercise tolerance due to breathlessness following -:
• Surgical removal of lung tissue
• Scarring of lung tissue from radiotherapy
• Associated COPD (chronic obstructive pulmonary disease) Rarely
• Any of the general long term side effects from radio and chemotherapy

Most usually there will be non-disabling breathlessness on exertion and no long term effects from adjuvant treatment. There may be significant anxiety about recurrent disease compared to people with other cancers with better long term outcomes. Of patients with non-small cell cancer who have surgery 60-80% Stage 1 and 25-50% Stage 2 will survive 5 years.

**Metastatic disease (70-80%)**

The majority of people will have metastatic disease from the day of diagnosis. With either type of lung cancer survival is poor. It is common in both types to be significantly disabled by -:

• Cough
• Breathlessness – this may be due to a 'pleural effusion' – this is a collection of fluid around the lung
• Chest pain
• Pain from metastases
• Tiredness
• Anorexia
• Depression

Exercise tolerance may be significantly reduced due to the local effects of the tumour or by general weakness and tiredness associated with cancer related weight loss. Help may be required with all activities of daily living within a short time of diagnosis. When this is due to breathlessness or general debility then mobility is also likely to be severely impaired. Pain can be well controlled with symptomatic treatment but may cause significant drowsiness. There may also be significant disability from metastases in other organs including -:

• Liver – these may cause fatigue and in the later stages, mental confusion, abdominal swelling or pain and jaundice
• Brain – these may cause fits, personality change, confusion, difficulties with balance, walking and self care
• Bone – severe pain and pathological fractures. Hypercalcaemia (raised calcium levels in the blood) may cause confusion, coma and death.

**How long will the needs last?**

In almost all cases, it is appropriate to make an indefinite award as life is likely to be short and disabling effects identified are likely to persist.
Where treatment is very disabling but long term prognosis is good, a limited award for the duration of treatment and a reasonable recovery period is appropriate.

If disease recurs after successful treatment an indefinite award is appropriate.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
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</thead>
<tbody>
<tr>
<td>Bronchus / Lung cancer -:</td>
<td></td>
</tr>
<tr>
<td>Treatment being given</td>
<td>Length of treatment period plus a reasonable recovery period</td>
</tr>
<tr>
<td>Advanced / Recurrent /</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Metastatic</td>
<td></td>
</tr>
<tr>
<td>Mesothelioma</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Other lung cancer -:</td>
<td>Length of treatment period plus a reasonable recovery period</td>
</tr>
<tr>
<td>Treatment being given</td>
<td></td>
</tr>
<tr>
<td>Advanced / Recurrent /</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Metastatic</td>
<td></td>
</tr>
</tbody>
</table>

**Other respiratory tract cancer / type not known -:**

| Treatment being given                           | Length of treatment period plus a reasonable recovery period |
| Advanced / Recurrent /                          | Indefinite award                                  |
| Metastatic                                      |                                                   |

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

*Back to top of section*
What you need to know about Mastoiditis

Back to A - Z

What is Mastoiditis?
Mastoiditis is an uncommon bacterial infection of the mastoid bone behind the ear. It is usually ….. Read more on NHS Choices - Mastoiditis.

What evidence is available?
In adults there should be no persistent loss of function without any ongoing need for help with personal bodily functions or difficulties with walking …..Read more about evidence sources

Activities of Daily Living and mobility needs
Mastoiditis is an acute illness and in most cases it resolves completely within ten days…..Read more about ADL and mobility needs

How long will the needs last?
Most cases of acute mastoiditis resolve completely following effective treatment… …Read more about award duration

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.
Linked pages:
Ageing
Falls
Frailty

What evidence is available?
In adults there should be no persistent loss of function without any ongoing need for help with personal bodily functions or difficulties with walking. Application of ear drops and cleansing of the ear aperture may be needed in some instances but unless there is another disabling condition to prevent the individual carrying out this activity there should be no need for help. Therefore, further evidence would not usually be required.

In cases where complications have occurred there may be some ongoing disability. Intracranial infection may produce longer term neurological effects and in such cases medical evidence should be available to confirm any ongoing disability and this should be assessed on its own merit.
Disruption of the inner ear caused by infection spreading from the middle ear may lead to hearing loss or disturbances of balance. Such additional problems should also be evident from available information and should also be assessed as separate entities.

**Activities of Daily Living and Mobility Considerations**

Mastoiditis is an acute illness and in most cases it resolves completely within ten days. During this period the patient, usually a child is unwell and may need to be hospitalised. When the acute attack has resolved there should be no residual functional loss in most cases.

Some cases present a more chronic low grade inflammation usually associated with chronic suppurative otitis media. There may be recurring attacks of pain and persistent discharge from the ear. In adults there should be no persistent loss of function without any ongoing need for help with personal bodily functions or difficulties with walking. Application of ear drops and cleansing of the ear aperture may be needed in some instances but unless there is another disabling condition to prevent the individual carrying out this activity there should be no need for help.

Children form by far the largest group of cases but other than simple management and possible need for application of ear drops between acute attacks they should not need any care beyond that required for a child of the same age. Regular follow-up visits to hospital may be necessary.

In cases where complications have occurred there may be some ongoing disability. Intracranial infection may produce longer term neurological effects and in such cases medical evidence should be available to confirm any ongoing disability and this should be assessed on its own merit.

Disruption of the inner ear caused by infection spreading from the middle ear may lead to hearing loss or disturbances of balance. Such additional problems should also be evident from available information and should also be assessed as separate entities.

**Variability**

Apart from short term problems generated by the acute illness there should be no significant variation in the condition or level of care needed.

**How long will the needs last?**

Most cases of acute mastoiditis resolve completely following effective treatment. Chronic mastoiditis may persist for several months. Recurrent episodes may occur and some may persist for more prolonged periods. Evidence of such persistence or the ongoing effects of complications may be needed to fully ascertain the prognosis.
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Meningitis

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What is Meningitis?
Meningitis is an infection of the meninges (the protective membranes that surround the brain and spinal cord). Read more on NHS Choices - Meningitis

What evidence is available?
As detailed in Activities of Daily Living and mobility needs, each case is unique and would have to be assessed on its merits.

Activities of Daily Living and mobility needs
The pia and arachnoid outer coverings of the brain are inflamed in all forms of meningitis. Read more about ADLand mobility needs

How long will the needs last?
Usually there are no long-term complications or residual disability with viral meningitis. Read more about award duration

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages:
Ageing
Falls
Frailty

Activities of Daily Living and Mobility needs

Disabling Effects Of Meningitis
The pia and arachnoid outer coverings of the brain are inflamed in all forms of meningitis, and acute symptoms are consequent to viraemia, (virus in the blood) pyaemia (bacteria in the blood) septicaemia, and the effects of inflammation in the brain.

Patients are usually well prior to infection, although immuno-compromised patients (such as those with AIDS or those taking immune supplement drugs) may be at increased risk of infection.
How long will the needs last?

Long – Term Effects

Usually there are no long-term complications or residual disability with viral meningitis.

85% of meningococcal meningitis sufferers make a full recovery within a few weeks (10-15% suffer from persistent neurological defects including hearing loss, speech disorders, loss of limbs, or parts of limbs, learning difficulties and paralysis).

Pyogenic and tuberculoculous meningitis, when recognised at an early stage in the disease and treated with appropriate antibiotic therapy usually results in complete recovery, with no long-term complications or disability.

Untreated Tuberculoculous Meningitis is fatal in a few weeks but complete recovery is the rule with modern treatment if it is started before the appearance of focal neurological signs or stupor. When treatment is started at a later stage the recovery rate is 60% or less, and the survivors may be left with severe mental deficiency, epilepsy, deafness, blindness, or some other permanent neurological deficit. As with meningococcal disease, late diagnosis and consequent delay in treatment may result in permanent neurological damage, and long-term disability. Each case is unique, and would have to be assessed on its merits.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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What you need to know about Metatarsalgia

What is Metatarsalgia?
Metatarsalgia is a type of pain that occurs in the ball of the foot, also called the metatarsal region. Read more on NHS Choices - Metatarsalgia

What evidence is available?
Limitation of mobility only occurs as a result of pain. With corrective action this will be minimal. Therefore, further evidence would not usually be required.

Activities of Daily Living and mobility needs
Limitation of mobility only occurs as a result of pain. With corrective action this will be minimal.

How long will the needs last?
This condition does not usually result in significant functional restrictions and can normally be managed using simple methods by health care professionals

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages:
Ageing
Falls
Frailty

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Migraine

What is a Migraine?
Migraine is a severe headache usually felt as a throbbing pain at the front or on one side of the head. Read more on NHS Choices - Migraine

What evidence is available?
Even during an attack, no specific impairment of function would be expected with no disabling loss of function of the limbs and no cardiovascular impairment. Read more about evidence sources

Activities of Daily Living and mobility needs
The acute attack of migraine can be troublesome and distressing. Read more about ADL and mobility needs

How long will the needs last?
Migraine is usually an intermittent illness with complete recovery between attacks. Read more about award duration

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages:
Ageing
Falls
Frailty

What evidence is available?
Even during an attack, no specific impairment of function would be expected with no disabling loss of function of the limbs and no cardiovascular impairment. Between attacks the person would be expected to function normally apart from sensible adjustments to lifestyle to avoid known trigger factors. Therefore further evidence would not usually be required.

There is a small increased risk of stroke in migraine sufferers. The rare cases that experience severe effects such as unconsciousness or paralysis are likely to be under the care of a neurologist particularly as other more sinister causes of the symptoms need to be excluded.
Activities of Daily Living and Mobility needs
The acute attack of migraine can be troublesome and distressing. The severe head pain, nausea and vomiting can lead to the patient withdrawing to rest in a darkened room.

Frequent attacks can disrupt the normal routine of life. However, even during the attack no specific impairment of function would be expected with no disabling loss of function of the limbs and no cardiovascular impairment.

Even for those who suffer severe attacks, the intermittent nature of the condition means that the person is asymptomatic for most of the time. The condition can demoralise the person but during the attack there should not be any change in awareness or intellect.

There is a small increased risk of stroke in migraine sufferers. The rare cases that experience severe effects such as unconsciousness or paralysis are likely to be under the care of a neurologist particularly as other more sinister causes of the symptoms need to be excluded.

Between attacks the person would be expected to function normally apart from sensible adjustments to lifestyle to avoid known trigger factors.

How long will the needs last?
Migraine is usually an intermittent illness with complete recovery between attacks. It is not life threatening but if attacks occur frequently it can make life miserable. In most cases the attacks occur irregularly and infrequently. Sometimes they can occur at predictable periods of stress and in a small number of cases the attacks become chronic, occurring several times a week if not daily. Cases of this severity would be expected to be under specialist management.

Beyond age 50 years the condition tends to lessen and the condition may resolve.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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What you need to know about Motor neurone disease

What is Motor neurone disease?
Motor neurone disease is a rare condition that progressively damages the nervous system, causing the muscles to waste away... Read more on NHS Choices - Motor neurone disease

What evidence is available?
Neurologists, specialist nurses and general practitioners are able to provide reports confirming the diagnosis of motor neurone disease....Read more about evidence sources

Activities of Daily Living and mobility needs
Muscular weakness affecting the hands and forearms leads to initial difficulties in fine manipulations, gripping, lifting and carrying....Read more about ADL and mobility needs

How long will the needs last?
In the commonest types of motor neurone disease (amyotrophic lateral sclerosis or progressive bulbar palsy) the disease advances relentlessly and the outlook is very poor......Read more about award duration

Over 65’s
Motor Neurone disease affects people in later life. There are no specific features in the elderly.

What evidence is available?
Neurologists, specialist nurses and general practitioners are able to provide reports confirming the diagnosis of motor neurone disease. Additional information regarding the extent of the disabling effects and treatments being used may be obtained from other multidisciplinary team members i.e. specialist nurses, physiotherapists, speech therapists, occupational therapists, community nurses and social workers. The work of the health care professionals may be coordinated by one member of the team, who is designated the key worker or care coordinator.

Many people experiencing rapidly progressive motor neurone disease will be receiving palliative care. Evidence that death may be reasonably expected within six months can provided by general practitioners, hospice
doctors, neurologists and palliative care nurses. Advice should be obtained from Medical Services to establish the stage of the disease, if it is not clear from medical reports. It is important to distinguish cases with rapidly progressive functional restrictions and a short life expectancy, from those cases of the less common types of motor neurone disease who have a longer survival time.

A HCP Examination report is likely to be useful only in the minority of cases with longer life expectancy, where the disabling effects of the condition are localised and less severe earlier in the disease.

Activities of Daily Living and Mobility needs

Muscular weakness affecting the hands and forearms leads to initial difficulties in fine manipulations, gripping, lifting and carrying. Help will be needed with dressing, preparing food and personal hygiene. As the condition progresses to affect all the muscle groups of arms and shoulders, help will be required with all aspects of self-care including feeding and drinking.

Weakness of the feet and lower legs causes unsteadiness in walking, a tendency to trip and a reduction in the distance that can be covered without undue fatigue. The ability to stand for prolonged periods, rise from a chair, to bend down and walk diminishes as the disease progresses. Help will be needed with cooking, with stairs, with the toilet and with moving around. It becomes difficult for the individual to turn in bed at night. As the condition affects both lower limbs walking become severely restricted, and people are likely to use a wheelchair outside and in the home. They will be unable to stand without support and be at risk of falls.

A person with bulbar symptoms is likely to have devices and aids to facilitate nutrition, speech and respiration. Initially they may be able use these themselves if upper and lower limb function is not severely restricted. However symptoms are often rapidly progressive and the ability to use the devices will be compromised by fatigue, shortness of breath, weight loss and general debility, even if limb function remains reasonable. Elderly people with predominantly bulbar symptoms may be unable to learn how to use these devices/aids and need help from the outset. As limb function in people with bulbar palsy deteriorates they need help with all aspects of self-care, and walking starts to be restricted.

Some people with bulbar symptoms may be able to walk until late in the course of the illness. However walking ability will be compromised to a degree in most people in this group by shortness of breath, fatigue, weight loss, recurrent chest infections and the general debilitating nature of the condition. Overall people presenting with bulbar symptoms are likely to have a shorter life span than others.
About 10% of people develop mild symptoms of dementia. However it is likely that their need for help with all aspects of care and mobility will be much greater than any requirement for supervision.

People in the terminal phases of the illness will be receiving a high degree of assistance from others on a 24-hour basis.

Some people with amyotrophic lateral sclerosis which has been diagnosed early, and in whom the initial progression is slow, may have few functional restrictions at first, especially if only one hand or foot is affected. They may be able to care for themselves and walk a reasonable distance for between 1 to 3 years before functional restrictions become generalised. People with the less common variants of motor neurone disease that are known to have a long prognosis may have few functional restrictions for many years.

**How long will the needs last?**

In the commonest types of motor neurone disease (amyotrophic lateral sclerosis or progressive bulbar palsy) the disease advances relentlessly and the outlook is very poor. Severe functional restrictions develop quickly over a relatively short period of time. The prognosis is worse for people who present with progressive bulbar symptoms, usually less than 2 years. People with amyotrophic lateral sclerosis survive 2 – 5 years from onset of symptoms. However since diagnosis may be delayed average survival from the time of diagnosis is only 14 months.

People developing the condition at a younger age i.e. less than 50 years, tend to survive longer, as do people with progressive muscle atrophy.

**All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.**

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What you need to know about Myeloma

What is Myeloma?
Myeloma, also known as multiple myeloma, is a type of bone marrow cancer. Read more on NHS Choices - Myeloma.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. Read more about evidence sources.

Activities of Daily Living and mobility needs
This group are likely to undergo high dose chemotherapy treatment and Peripheral Blood Stem Cell Transplant (PBSCT) or…… Read more about ADL and mobility needs.

How long will the needs last?
The group who have the PBSCT or bone marrow transplant have the best long term outcome.…… Read more about award duration.

Over 65’s
People over 65 have a much worse outlook than people of working age because they are often not fit enough to have intensive treatment.…… Read more about effects in the over 65 age group.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a ‘Care plan’ from social services
Hospital
  Specialist doctors -:
  • Oncologist
  • Physician
  • Haematologist

Specialist nurses have many different job titles -:
  • Clinical Nurse Specialist
  • Stoma care nurse
  • Macmillan Nurse

  They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
  • Physiotherapist
  • Occupational Therapist
  • Social worker
  • Counsellor
  • Psychologist

  Also refer to the ‘Symptomatic treatments’ page.

Hospice
  Hospice Specialists -:

  • Palliative Care Physician
  • Macmillan Nurse
  • Clinical Nurse Specialist
  • Social worker
  • Physiotherapist
  • Occupational Therapist
  • Counsellor
  
  Back to top of section

Activities of Daily Living and Mobility needs

First line treatment
  People of working age and older ‘fit’ people
  This group are likely to undergo high dose chemotherapy treatment and Peripheral Blood Stem Cell Transplant (PBSCT) or bone marrow transplant. Treatment and recovery for those who successfully undergo this treatment is likely to take 18 months to 2 years. During this period they are likely to have periods of being immunosuppressed and be unable to go out in public. Episodes of severe fatigue may endure for many months related to chemotherapy treatment and anaemia.
Some will be unwell and have care or mobility needs for about 3 months only - during the transplant and transplant recovery period. Others will develop needs related to chemotherapy side effects during their first course of chemotherapy, if this happens needs are likely to last through the first course and into the transplant period. Recovery from the transplant is likely to be more prolonged in this group and may take a year from completion of treatment. The main cause of needs is likely to be severe chemotherapy related fatigue.

About a third of people in this group will not respond to treatment well enough to progress to a PBSCT or bone marrow transplant – this group is also likely to develop needs both related to treatment side effects and the disease itself. Some may be terminally ill and have any of the symptoms in the relapsed group above. These cases are likely to apply under special rules.

**People over 65 and people of working age who are ‘unfit’**

This group may have any of the symptoms of myeloma, bone pain is especially common. Pain in the back or legs may affect mobility and or ability to bend. Fatigue is likely to be most severe in those with severe anaemia, immunosuppression, heart failure or renal failure. During the first 6 months of chemotherapy treatment about half will feel much better and go into remission. There are likely to be mild side effects of chemotherapy. Remission is likely to last for 18-24 months, beyond which point symptoms will recur and further treatment will be required. Those that do not respond to initial treatment are likely to have other treatments which may or may not be effective. Of this group as a whole about 55% will still be alive after one year.

**Relapsed or recurrent myeloma**

**Mobility**

These people are often quite disabled by bone pain, renal failure and drug side effects. Severe fatigue and reduced exercise tolerance related to any of the following may reduce the ability to walk:

- Chemotherapy treatment
- Anaemia
- Renal failure
- Skeletal pain
- Fractures
- Peripheral neuropathy affecting the feet (drug side effect)

People who are immunosuppressed may be advised to avoid public places and public transport.

People with myeloma are likely to have bone pain which may be severe. If the site of pain is the back or the legs mobility may be restricted to a few yards or they may be unable to walk at all. If high doses of pain killers are
required to control pain, dizziness and drowsiness associated with these may reduce mobility even if pain is well controlled. Those with spinal cord compression may be unable to walk at all.

Care
Severe fatigue may make activities of daily living difficult. Back pain may limit the ability to bend. Heavy lifting should be avoided because of the possible risk of fracture. Painful myeloma deposits in the upper limbs may reduce the ability to prepare food and self care. Activities such as climbing into the bath or shower and washing may require assistance from someone else because of pain, fatigue or dizziness.

Monoclonal Gammopathy of Undetermined Significance (MGUS)
There are no disabling effects associated with this condition.

Isolated Plasmacytoma of Bone
Radiotherapy treatment almost always successfully puts this disease into remission; however pain may persist after treatment even when disease is in remission. Typically treatment takes 4-6 weeks; recovery from treatment is expected within about 3 months. Myeloma commonly develops about 2-5 years after successful treatment. 1 in 10 will require further local treatment for recurrent disease at the site of their original tumour, no residual disability is expected.

Solitary extramedullary plasmacytoma
Radiotherapy almost always relieves the pain associated with this condition, no residual disability is expected. Typically treatment takes 4-6 weeks, complete recovery from symptoms and treatment is expected within about 3 months. Cure rates are good with 10 year survival of 70%. In the 10 years after treatment about 1 in 5 will develop multiple myeloma. A small group of people who had a large tumour at diagnosis and who required surgery or chemotherapy in addition to radiotherapy treatment may develop needs during treatment related to treatment side effects. They are unlikely to have ongoing needs after recovery.

How long will needs last?

First line treatment
People of working age and older ‘fit’ people
The group who have the PBSCT or bone marrow transplant have the best long term outcome. A return to health is expected in the typical case, time limited awards are recommended, recovery should be substantially complete 1 year after PBSCT or bone marrow transplant. However recurrence of disease is common, if disease has recurred renewal with indefinite award is recommended. Indefinite awards are recommended for those unable to have this treatment.

People over 65 and people of working age who are ‘unfit’
Of this group 55% will still be alive after one year. Those who respond to chemotherapy and go into remission are likely to be in the survivor group. Those who do not respond to treatment are more likely to be terminally ill. This group are likely to have some symptoms and may have identifiable needs, time limited awards are recommended with review at 12-18 months. Those who will recover are likely to be well at this stage. For those in this group who relapse after a period of remission refer to the relapsed or recurrent myeloma section.

**Relapsed or recurrent myeloma**

Needs are likely to be identified in this group, disability is most likely to relate to bone pain, renal failure and drug side effects such as fatigue and neuropathy. Many will be terminally ill; this is particularly likely if relapse has happened within 6 months of first line treatment. If needs are identified life awards are recommended.

**Monoclonal Gamopathy of Undetermined Significance (MGUS)**

There are no disabling effects associated with this condition.

**Isolated Plasmacytoma of Bone**

In the rare case where needs are identified during treatment awards should be time limited to coincide with completion of treatment and recovery – 6-9 months if chemotherapy is being used. If myeloma develops after successful treatment of this condition needs are likely to arise related to myeloma symptoms and treatment.

**Solitary extramedullary plasmacytoma**

Treatment and recovery are complete within three months, enduring needs are not expected. If myeloma develops after successful treatment refer to the myeloma information.

**All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.**

**Over 65**

People over 65 have a much worse outlook than people of working age because they are often not fit enough to have intensive treatment. Before chemotherapy treatment median survival from diagnosis was about 7 months. Median survival with chemotherapy treatment varies from 29-62 months, depending on stage. The overall outlook of everyone with myeloma including the young people who do better is a 1 year survival rate of 55% and a 10 year survival rate of 3%-12%.

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What is Multiple sclerosis (MS)?
Multiple sclerosis (MS) is a disease affecting nerves in the brain and spinal cord, causing problems with muscle movement, balance and vision. Read more on NHS Choices Multiple sclerosis (MS)

What evidence is available?
Generally those patients with significant problems arising from their MS will be under the regular care of a hospital; either a neurologist or rehabilitation specialist. Read more about evidence sources

Activities of Daily Living and mobility needs
The amount of care and mobility requirements of someone with MS will vary from person to person. Variability in symptoms must be taken into account. Read more about ADL and mobility needs

How long will the needs last?
The course of multiple sclerosis is highly varied and unpredictable. Read more about award duration

Over 65’s
In addition to the disabling effects of MS over time disability in the elderly will be compounded by the effects of ageing.

Conditions such as arthritis, heart and lung disease and cognitive decline due to dementia will create additional problems with the ability of elderly people to care for themselves.

Linked pages:
Ageing
Falls
Frailty

What evidence is available?
Note: If considering entitlement to H/R Mobility component under the Severely Visually Impaired (SVI) provisions, the following evidence source must be used:

The Consultant Ophthalmologist will be able to provide information about symptoms, signs, investigations including assessment of vision, treatment/management, and is likely to have information about resulting disability or needs.
Other evidence sources
Generally those patients with significant problems arising from their MS will be under the regular care of a hospital; either a neurologist or rehabilitation specialist. In addition they may be provided with specialist services such as physiotherapy, occupational therapy and sometimes speech therapy. Appointments are commonly every six months or once a year.
Because of the range of severity and frequency of symptoms, it is not possible to infer from just the diagnosis the care and mobility needs of any individual without specific information. Health care professionals involved with the care patients who have significant problems may be better placed than GPs to provide helpful information particularly where the mobility and care needs are not clear.

These health care professionals include :-:

- Consultant Neurologist
- Specialist Nurse
- Occupational therapist & Physiotherapist
- Day centre leader
- General Practitioner

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Activities of Daily Living and Mobility needs
The amount of care and mobility requirements of someone with MS will vary from person to person. Variability in symptoms must be taken into account.

Some people with only a short history but rapidly progressive form of the disease may require much more support than someone with a very slowly progressive form that they have had for over twenty years. Patients particularly with ‘Benign’ MS may well live an active, ‘normal’ life, including a full working life.

The most common symptoms of multiple sclerosis are weakness in one or more limbs, spasticity (muscle rigidity or pronounced stiffness) and spasms, especially in the legs, numbness and loss of sensation, pain, unsteadiness of gait, poor vision, fatigue and difficulties with speech and swallowing.

In the upper limbs, tremor, sufficient to interfere with everyday activities may develop.

As the condition progresses movements may become shaky, irregular and ineffective. Muscle weakness and spasticity may interfere with walking,
sometimes eventually making it impossible while unsteadiness may lead to falls.

Difficulty with bladder control is very common and urinary symptoms are experienced by most people at some point. Bladder problems can affect the person's family, social life and work responsibilities. They include an urgent need to empty the bladder, having to use the toilet frequently, urinary tract infections and incontinence. Occasionally people are unable to empty their bladder without using a catheter.

Bowel problems include constipation, bowel urgency sometimes due to lack of sensation and faecal incontinence.

Impaired vision and weakness or tremor in the upper limbs may make the use of walking aids difficult or impossible and muscle fatigue, particularly when walking, may require the person to stop and rest at frequent intervals. Speech may become slow, slurred and hesitant and in the late stages of the disorder, dementia and mania (excessive elation) may also develop.

Therefore advanced stages of the disease lead to pronounced sensory and motor impairment and can be accompanied by significant cognitive and emotional problems. Short term memory often becomes impaired with poor attention and concentration and there may be depression or exaggerated emotional responses.

**H/R Mobility Severely Visually Impaired (SVI) deeming provision**

**How long will the needs last?**

The course of multiple sclerosis is highly varied and unpredictable. In most patients, most commonly when multiple sclerosis begins with optic neuritis, remissions can last from a few months to over 10 years.

Multiple sclerosis is not a fatal disease although in severe cases may pose a risk because of life-threatening complications. It also shortens the average life span by about six years and in nearly all cases, the negative emotional impact of this disease and its symptoms is considerable. Women tend to have a better outlook than men although the severity of the disease varies widely from patient to patient:

- About 10% to 35% of patients have a very mild form of the disease, with little if any disability, no need for medication and a normal life expectancy. People who have only optic neuritis and symptoms that affect the senses have a better outlook than if symptoms are more widespread.
- About 70% of patients will experience some degree of progression. MS, however, can sometimes remain asymptomatic or become only mildly symptomatic ('Benign' MS).
Generally where relapses become more frequent, people become increasingly disabled, sometimes permanently. Nonetheless, about 75% of people who have multiple sclerosis never need a wheelchair and for about 40% normal activities are not disrupted.

Life expectancy is shortened only slightly with MS and the average survival of patients from the time of diagnosis is over 30 years. The survival rate is linked to disability and secondary complications such as kidney or chest problems or psychiatric disorders.

Remissions of varying length are common, particularly in the early years of the disease; they can last for months or years and in some instances appear to be life long. However, the primary progressive form of the disease can take a rapid downhill course.

The most common pattern is recurring relapses leading to chronic disability with associated complications and eventually some degree of dependency and impaired mobility. Customers with relapsing and remitting type are likely to have periods of greater disability. When considering duration of awards for them all facts must be taken into consideration including the duration of any previous relapses when advising on duration of award.

Customers diagnosed with primary or secondary progressive multiple sclerosis are likely to have ongoing needs once needs are established and indefinite awards are recommended.

Seek advice from the medical services if in any doubt.

**You may need to consider whether H/R Mob SVI deeming provisions are satisfied - [H/R Mobility SVI](#).**

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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What is Myasthenia Gravis?
Myasthenia gravis is an uncommon condition that causes certain muscles to become weak. With treatment, most people can lead a normal life... Read more on NHS Choices - Myasthenia gravis

What evidence is available?
People whose condition is stable and whose symptoms are controlled by regular medication are likely to be under the care of general practitioners.... Read more about evidence sources

Activities of Daily Living and mobility needs
The majority of people with myasthenia gravis are able to pursue a normal life once the diagnosis is made and drug treatment has been stabilised..... Read more about ADL and mobility needs

How long will the needs last?
Prior to the development of successful treatments for myasthenia gravis 25% to 30 % died within 3 years of onset..... Read more about award duration

Over 65’s
Elderly people are more likely to have difficulty in dressing, washing, standing for prolonged periods, bending down, rising from a chair, using the toilet, climbing stairs and in moving around.... Read more about effects in the over 65 age group

What evidence is available?
The diagnosis of myasthenia gravis is invariably confirmed in the hospital setting, because of the nature of the specialist neurological investigations required. Recently diagnosed people will remain under hospital care for some months or longer, while drug treatment is initiated and monitored. Medical reports may be obtained from neurologists and specialist neurological nurses.

Elderly people with myasthenia gravis may be under the care of geriatricians. Additional information may be available from occupational therapists, community nurses or social services that provide assessments and care in the home.
General practitioners can provide information about people with myasthenia gravis who are stable on medication and who visit the hospital clinic infrequently. In some cases an HCP Examination report may be helpful, if there is no up to date information regarding the disabling effects of the condition and its response to treatment.

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Activities of Daily Living and Mobility needs
The majority of people with myasthenia gravis are able to pursue a normal life once the diagnosis is made and drug treatment has been stabilised. Thymectomy is a major operation, but people having this surgery can be expected to have made a good postoperative recovery within 2 to 3 months.

Mild functional restriction
People in the following categories are likely to have no functional restrictions or mild restrictions only:

- those in remission,
- with ocular symptoms only,
- with symptoms well controlled on medication (anticholinesterases drugs +/- stable regime of immunosuppressant drugs)
- under care of GP only or visit the hospital clinic infrequently.

They are unlikely to have a requirement for help with self-care or to be restricted in their ability to walk. Ocular problems are unlikely to cause significant visual impairment necessitating help in finding the way out of doors.

Moderate functional restriction
People in the following categories may have moderate functional restrictions:

- recently diagnosed whose treatment regime is still being stabilised
- recovering from recent thymectomy
- attending hospital clinic on a regular basis for monitoring and modification of drug regimes, or having plasmapharesis ((plasma exchange) or immunoglobulin injection

They may need some help with self-care and preparation of food. It is important to take into account the variability of symptoms during day, and the effects of fatigability. Although people with moderate functional restrictions are able to carry out a task initially, they may have difficulty in repeating or sustaining the activity. Self-care activities may take longer to complete than normal, especially as the day progresses.

Severe functional restriction
People in the following categories may have severe functional restrictions:
• rapidly progressive disease not responding to standard drug treatments,
• recent hospital admission for deteriorating symptoms,
• need for artificial ventilation,
• long standing generalised disease,
• presence of muscle wasting.

People may have difficulty in dressing, washing, standing for prolonged periods, bending down, rising from a chair, using the toilet, climbing stairs and in moving around the house. They may need help in taking frequent doses of medication if manual dexterity is impaired. Walking may be restricted due to weakness of the lower limbs exacerbated, in some cases, by shortness of breath. People may use wheelchairs out of doors and in the home. Some people with severe lower limb weakness may be prone to falls.

It is unlikely that people with severe myasthenia gravis would require constant watching over to prevent a cholinergic or myasthenic crisis, since the onset is usually gradual over some hours.

How long will the needs last?
Prior to the development of successful treatments for myasthenia gravis 25% to 30 % died within 3 years of onset. Now the majority of people (up to 90%) are likely to be able to lead a normal life without undue restrictions. Life expectancy is considered to be close to normal. Complete remission is rare, but up to 20% of cases go into remission, and the disease does not reappear for some years.

However for people whose disease does not remit, the need for drug treatment is life long. Standard drug treatments provide good relief of symptoms, and people are able to carry out many normal daily tasks in the absence of disabling muscle weakness,

Thymectomy improves the prognosis and its benefits in improving symptoms may continue for months or up to several years after the operation.

A poor prognosis is more likely when onset of myasthenia occurs after the age of forty years, when disease progression is rapid and if a thymoma is present. Early mortality occurs in the first three years; after that the disease tends to stabilise.

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<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
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<tbody>
<tr>
<td>Myasthenia gravis</td>
<td>Less than 3 years</td>
<td>3 year award</td>
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<tr>
<td></td>
<td>More than 3 years</td>
<td>Indefinite award</td>
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All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Over 65**

Elderly people are more likely to have difficulty in dressing, washing, standing for prolonged periods, bending down, rising from a chair, using the toilet, climbing stairs and in moving around. Help may be required with self-care and preparation of food including providing puréed foods for those with swallowing difficulties. Some elderly people may have restricted walking ability and use a wheelchair. Elderly people may need assistance with medication, especially if the dose and frequency of administration of tablets requires adjustment to obtain optimal effect and reduce troublesome side effects. Some people with more severe muscle weakness of the legs may be at risk of falling.

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What you need to know about Non-Hodgkin’s lymphoma

What is Non-Hodgkin’s lymphoma?
Non-Hodgkin's lymphoma is a cancer of the lymphatic system. .... Read more on NHS Choices Non-Hodgkin’s lymphoma.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even.... Read more about evidence sources.

Activities of Daily Living and Mobility needs
Low grade Non-Hodgkin Lymphoma - the commonest type of low grade lymphoma is Follicular lymphoma and the.... Read more about ADL & mobility needs.

How long will the needs last?
Treatments effectively control disease in 60-80% of people although it does relapse eventually. The median time to recurrence is.... Read more about award duration.

Over 65s
There are no special features. Over all survival is substantially lower in older people.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- General Practitioner - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- Community or District Nurse - will have information on any home care or outreach package in place as this is coordinated through the practice.
- Social worker - customer may have a ‘Care plan’ from social services

Hospital
Specialist doctors -:
- Oncologist
- Physician
- Haematologist
Specialist nurses have many different job titles:
- Clinical Nurse Specialist
- Stoma care nurse
- Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine:
- Physiotherapist
- Occupational Therapist
- Social worker
- Counsellor
- Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
- Hospice Specialists:
  - Palliative Care Physician
  - Macmillan Nurse
  - Clinical Nurse Specialist
  - Social worker
  - Physiotherapist
  - Occupational Therapist
  - Counsellor

Activities of Daily Living and Mobility needs

Low grade Non-Hodgkin Lymphoma
The commonest type of low grade lymphoma is Follicular lymphoma and the care and mobility needs refer to this type of lymphoma. Other low grade lymphomas have varying outcomes. These different types and their features are listed and should be referred to when reviewing care and mobility needs.

First line treatments early disease
There are unlikely to be disabling effects of disease. Treatment usually consists of a short course of radiotherapy over 4 weeks. A return to health for a prolonged period is expected in the typical case. Long term survival of 10 years without relapsed disease is good at 80%. Those with relapsed disease will go on to have further treatment.
First line treatment for advanced disease (stage II, III, IV) or Relapsed disease (second line, third line treatment etc.)

The commonest treatment likely to be given is combination chemotherapy. This is an arduous treatment and needs related to side effects may be identified. Time limited awards of one year are recommended.

Mobility

Severe fatigue and reduced exercise tolerance related to any of the following may reduce the ability to walk:-

- Chemotherapy treatment e.g. peripheral neuropathy affecting the feet
- Anaemia
- Disease effects e.g. lung involvement causing breathlessness

People who are immunosuppressed may be advised to avoid crowded public places.

Care

Severe fatigue may make activities of daily living difficult. Help with activities of daily living from someone else may be required because of pain, fatigue or dizziness.

High grade Non-Hodgkin Lymphoma

The commonest type of high grade lymphoma is Diffuse large cell lymphoma and the care and mobility needs refer to this type of lymphoma. Other high grade lymphomas have varying outcomes. These different types and their features are listed and should be referred to when reviewing the Care and Mobility needs.

High grade Non-Hodgkin Lymphoma First line treatment for advanced disease (stage II, III, IV) or Relapsed disease (second line, third line treatment etc)

First line treatment and recovery for those who successfully undergo combination chemotherapy is likely to take 6 months to a year.

People with relapsed disease will have salvage chemotherapy. If they respond to this they will go on to have high dose chemotherapy and Peripheral Blood Stem Cell Transplant (PBSCT) or bone marrow transplant. Non responders will usually live less than 6 months. For those who undergo bone marrow or stem cell transplant the treatment and recovery period is likely to take 12 months occasionally upto18 months.

During recovery from transplant they are likely to have periods of being immunosuppressed and be advised to avoid crowded or enclosed public places e.g. public transport at busy times and people who are unwell. Episodes of severe fatigue may endure for many months related to chemotherapy treatment and anaemia.
Some will be unwell and have care or mobility needs for about 3 months - during the transplant and transplant recovery period. Some will be unwell for much longer.

The main cause of ongoing needs in both groups is likely to be severe chemotherapy related fatigue.

If high dose chemotherapy and transplant has already been used then other types of chemotherapy may be given to control disease and symptoms, in this case ongoing needs may relate to symptoms of disease as well as treatment.

**Mobility**

Severe fatigue and reduced exercise tolerance related to any of the following may reduce the ability to walk:-

- Chemotherapy treatment e.g. peripheral neuropathy affecting the feet
- Anaemia
- Disease effects e.g. lung involvement causing breathlessness

People who are immunosuppressed may be advised to avoid crowded public places.

**Care**

Severe fatigue may make activities of daily living difficult. Help with activities of daily living from someone else may be required because of pain, fatigue or breathlessness.

**How long will the needs last?**

Treatments effectively control disease in 60-80% of people although it does relapse eventually. The median time to recurrence is 3-4 years. Refer to table of types of lymphoma for information on outcome for less common types of lymphoma.

Treatments are arduous especially bone marrow or stem cell transplant, treatment and recovery may take 12-18 months. Combination chemotherapy treatments may also be arduous therefore time limited awards of 1 year are recommended if needs are identified.

In people under the age of 60 five year recurrence-free survival is approximately 60% and in people over the age of 60 recurrence-free survival rates drop to 50%. A return to health is expected in the typical case. People whose disease relapses a second or third time do less well and are generally incurable; this group may collect enduring disabling problems related to the disease or its treatment. In this group long term or life awards are more appropriate – some may be terminally ill. Refer to the lymphoma tables for information on less common types of lymphoma.
High grade Non-Hodgkin Lymphoma First line treatment for early disease

A return to health is expected in the typical case. 5 year survival is as high as 70%. There are unlikely to be any long term care and mobility needs after treatment. The exception to this are the enduring but rare side effects of chemotherapy or radiotherapy. In the rare situation where an award is appropriate during treatment with chemotherapy, the award should last for the duration of treatment and then be reviewed.

Any needs arising from these are likely to be long term and life awards are recommended.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

[Back to top of section]
What you need to know about Obesity

What is Obesity?
Obesity is when a person is carrying too much body fat for their height and sex. Read more on NHS Choices - Obesity

What evidence is available?
The claimant should be able to provide sufficient evidence with regard to his/her disabling effects from the claim pack. Read more about evidence sources

Activities of Daily Living and mobility needs
Obsessions and compulsions are distressing, time consuming and have a negative impact on the person's interpersonal relationships and career.
Read more about ADL and mobility needs

How long will the needs last?
There are many complex factors that influence weight loss in the individual including genetic, environmental and behavioural influences.
Read more about award duration

Over 65's
There is a natural tendency for people to put weight on as they get older, part of the reason being that they are less active.
Read more about effects in the over 65 age group

What evidence is available?
The claimant should be able to provide sufficient evidence with regard to his/her disabling effects from the claim pack.

• However, independent and accurate evidence may be needed especially if co-morbidities are claimed. More detailed information would be provided by a GPFR. An accurate Body Mass Index (BMI) value would be needed as well as a record of what co-morbidities are present.
• If the person is morbidly obese and has multidisciplinary care, including obesity clinic attendance, specialist surveillance with a view to further treatment such as bariatric surgery may be required. If the person has had bariatric surgery a hospital factual report may be required.
• In some situations, interpretation of information, results or reports may be needed and Medical Services would be able to help in this regard.
Activities of Daily Living and Mobility needs

The risk of suffering disabling effects of obesity depends on many factors. Obesity is likely to worsen the disabling effects of impairments such as osteoarthritis and ischaemic heart disease.

A BMI of 55 to 60 is usually the cut-off point where it will be expected that a person with that BMI is likely to suffer disabling effects.

The disabling effects of obesity itself (without co-morbidities) are considered below.

### Mild Functional Restriction (BMI = 35 to 45)

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>In a typical person with a BMI of 35 to 45 there are normally no functional restrictions, which are significant enough to lead to care or mobility needs.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with a mild functional restriction would normally be able to walk several hundred metres at a normal or slightly slower pace without assistance. He/she would normally be able to get around in an unfamiliar place without assistance.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with a mild functional restriction would normally be able to cope with all activities of self-care such as getting in or out of a bed or chair unaided, getting on &amp; off the toilet, washing bathing and dressing him/herself and preparing and cooking a meal. He/she should be able to bend to get food in or out of an oven and self-medicate. He/she would still normally be able to climb stairs unaided, though he/she may be somewhat breathless having reached the top. There would be no supervisory needs.</td>
</tr>
</tbody>
</table>

### Moderate Functional Restriction (BMI > 45 to < than 55)

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>In a typical person with a BMI of more than 45 to less than 55, though they would be likely to have some limitations, there are usually no functional restrictions,</td>
</tr>
</tbody>
</table>
which are significant enough to lead to care or mobility needs.
A person with a moderate functional restriction would normally be able to walk at least 200 to 300 metres at a slightly slower pace without assistance. He/she would normally be able to get around in an unfamiliar place without assistance.

ADL
A person with a moderate functional restriction would normally be able to cope with all activities of self-care such as getting in or out of a bed or chair unaided, getting on & off the toilet, washing bathing and dressing him/ herself, and preparing and cooking a meal, but may have some difficulty.
He/she should normally still be able to bend to get food in or out of an oven, and self-medicate.
He/she would still normally be able to climb stairs unaided, though he/she may have to stop on the way up and may be breathless having reached the top. There would normally be no supervisory needs.

Severe Functional Restriction (BMI = 55 and over)

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>A person with a severe functional restriction would have a BMI of 55 or over and may have one or more of the following as a result of their obesity -: Breathlessness on minimal exertion. Heart failure, leading to greatly reduced exercise tolerance. Hypoventilation leading to accumulation of toxic levels of CO2 in the blood and the requirement for supplementary oxygen. Severe sleep apnoea with daytime sleepiness and loss of mental clarity. Reduced mobility. Reduced manual dexterity (due to obese hands).</td>
</tr>
</tbody>
</table>
**Mobility**

Because of breathlessness and heart failure, a person with a severe functional restriction would normally not be likely to be able to walk more than 30 metres at a slow pace. If a person is very severely obese, he/she may be able to walk only a few steps or not at all.

**ADL**

A person with a severe functional restriction may need assistance with most aspects of self-care such as getting in and out of bed or out of a chair, getting on and off the toilet, cleaning him/herself after the toilet and other aspects of personal hygiene and bathing or showering. He/she may not be able to get about unaided in or out of doors.

Preparation of a meal may not be possible because of reduced manual dexterity and he/she may not be able to safely manage hot pans and would be unlikely to be able to bend to an oven.

He/she would normally be able to take medication safely but if mental clarity is affected (in very rare cases) the person may need assistance.

He/she may not be able to manage stairs without assistance. At night, he/she may suffer from sleep apnoea and may need help with CPAP or oxygen, changing position in bed and to get comfortable.

He/she may need help in getting out of bed in the night and on and off the toilet.

He/she would not normally require supervision for any aspect of daily living or for finding his/her way about in an unfamiliar place.

---

**How long will the needs last?**

There are many complex factors that influence weight loss in the individual including genetic, environmental and behavioural influences. Each person would respond slightly differently to a weight loss programme because of his/her unique physiological makeup.

There are three main elements, which may be used in a weight loss programme -:

- Diet.
- Exercise.
- Medication.
In reality, surgical options are not used so frequently on the NHS.

It is a fundamental fact that any changes to lifestyle (with the aim of losing weight), especially in diet and exercise must be lifelong to make a lasting difference. If the changes are short-term, the weight will almost certainly go back on again. The changes must be manageable such as moderate exercise and a diet which is varied and enjoyable, otherwise the person will not persist in the changes.

Many experts believe that yo-yo dieting, as it is called, encourages the deposition of abdominal fat with the associated complications and prognosis may be worse in these individuals than if they had not lost weight at all.

The longer a person remains overweight, the less likelihood there is of the person losing weight, unless there are very strong motivating factors. Other factors may not make it completely possible, such as the taking of permanent steroid medication. Generally speaking, if a person has been obese for 5 years it is likely that they will remain so.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Duration of needs</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obesity – BMI 55+</td>
<td>Less than 5 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 5 years</td>
<td>Indefinite award</td>
</tr>
<tr>
<td></td>
<td>Awaiting or recently undergone surgery</td>
<td>2 year award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Obesity in people over 65**

- There is a natural tendency for people to put weight on as they get older, part of the reason being that they are less active. Around 1 in 4 people over the age of 50 are considered obese.

- Body mass index is not a useful means of measuring obesity in the elderly. Waist circumference instead should be measured. In elderly individuals with excessive intra-abdominal fat (visceral obesity) and sarcopenia (where there is loss of muscle mass), there is the greatest risk of excess morbidity and mortality.
The risk of Vascular and Alzheimer’s dementia is increased in obese elderly people because of the related complications of hypertension and Type 2 Diabetes compounding increased susceptibility.

Persisting ageist attitudes to the elderly include the acceptance that they are more likely to have a poor diet and that they are not expected to exercise. Consequently, they may not be encouraged to change these important aspects of their lifestyle.

The findings of a study (Korea, 2002) were that elderly obese patients were worse off (health-wise) than obese younger patients and non-obese older patients.

Reference: (Principles and Practice of Geriatric Medicine…. Pathy, Sinclair, Morley)
What you need to know about Obsessive Compulsive Disorder (OCD)

What is Obsessive Compulsive Disorder (OCD)?
Obsessive compulsive disorder (OCD) is a chronic (long-term) mental health condition that is usually associated with obsessive thoughts and compulsive behaviour. Read more on NHS Choices - Obsessive Compulsive Disorder (OCD)

What evidence is available?
Self-assessment is the prime source of evidence, but the claim pack should be checked to see who has completed it. If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.

Activities of Daily Living and mobility needs
Obsessions and compulsions are distressing, time consuming and have a negative impact on the person’s interpersonal relationships and career. Read more about ADL and mobility needs

How long will the needs last?
Obsessive Compulsive Disorder (OCD) may follow an acute, episodic, chronic unremitting, deteriorating or relapsing course. Read more about award duration

Over 65’s
Obsessive Compulsive Disorder (OCD) may occasionally occur for the first time in old age. Read more about effects in the over 65 age group
The DM should bear in mind that the completion of the corroborative statement by a mental health professional does not necessarily mean that they endorse what has been said in the claim pack.

**Note:** In cases of moderate and severe OCD it is highly probable that a consultant psychiatrist will have been involved in the management and treatment of the individual. Indeed the absence of any documented history of a psychiatric consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required.

A **HCP Examination Report** may be helpful if the person has physical problems.

Other sources of information include the following:

**Care co-ordinator**
When the customer is being supported by a community mental health team the care co-ordinator on that team will be the preferred source of further evidence.

They have lead responsibility for the delivery of the care plan and so they can give details of the support that the customer has been assessed as needing. They will also know whether the customer is being helped by an Assertive Outreach or Crisis Resolution team.

**Community Mental Health Team**
The community mental health team provides a multidisciplinary team approach. The team will include psychiatrists, community psychiatric nurses, occupational therapists and social workers working in close collaboration with social service departments. One member of the team may co-ordinate the care and is known as the Care Co-ordinator.

**Community Psychiatric Nurse (CPN)**
A customer may be in regular contact with a CPN who will have assessed their care requirements. Advice is given about the amount of psychiatric nursing required and the administration of drugs.

The CPN will be in contact with other mental health professionals. They are well placed to provide detailed evidence about the customer’s needs.

**NHS Care Programme Approach (CPA) care plan**
When the customer is in contact with mental health services there will be a care plan under the NHS Care Programme Approach. The care plan will include information on health and social care as well as domestic support and is reviewed regularly.

The customer is given their own copy, which could be requested, as it will contain useful evidence of needs.
Social Services care plan

Social Services departments may be approached for help by someone with mental health problems. A community care assessment by a social worker/care manager will be arranged and a care plan produced.

The care plan will include details of the customer’s day-to-day living and the support provided. A copy can be obtained from the customer.

Mental Health Social Worker

Where a mental health social worker has been appointed to support a customer they will have information about the customer’s ability to cope with everyday living.

Subject to consent to approach them being given, the mental health social worker will be able to provide some useful evidence about the customer’s needs.

Day Centre and Psychiatric Day Hospital

Attendance at a day centre (not on hospital site) or psychiatric day hospital (on hospital site) is likely to indicate severe disability.

These are therapeutic environments for evaluation, diagnosis and treatment of patients with mental health problems. They are staffed by psychiatric nurses, and there is input from all other members of the community mental health team. Attendance presents an alternative for patients whose condition requires intensive treatment, but do not need to be hospitalised.

Accommodation manager

When the customer is living in supported accommodation then the type and level of support provided could be helpful in determining their need for help.

A phone call to the accommodation manager could provide useful evidence.

Crisis Resolution Team

The customer may have been supported during a crisis by the Crisis Resolution Team. The teams are mainly comprised of CPNs, who would make urgent visits, day or night to anyone who is thought to be in need of hospitalisation.

The idea is to provide intensive treatment at home instead. The Crisis Resolution Team would be well placed to provide details of the customer’s condition.
General practitioner factual report
If there is no specialist mental health professional involvement or evidence cannot be obtained from them, then it may be necessary to request a factual report from the customer’s own doctor.

The G.P may have only limited knowledge of customer’s mental health problems, even when there is no one else involved.

Activities of Daily Living and Mobility needs
Obsessions and compulsions are distressing, time consuming and have a negative impact on the person’s interpersonal relationships and career.

Social isolation may occur in people with more severe OCD, partly because they spend most of their day performing rituals and partly because others regard their behaviour as peculiar.

Obsessional thoughts interfere with concentration on study and work. Two thirds of people report lowered career aspiration. 47% experienced work interference and 40% were unable to work for an average of 2 years.

Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Disabling effects</td>
<td>People with a mild functional restriction are likely to:</td>
</tr>
<tr>
<td></td>
<td>• Be managed by the primary health care team</td>
</tr>
<tr>
<td></td>
<td>• Have never received treatment or received treatment with low intensity Cognitive Behavioural Therapy (CBT) (including Exposure and Response Prevention ERP) or Selective Serotonin Reuptake Inhibitors (SSRI).</td>
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<tr>
<td></td>
<td>• Alone if unable to engage in low intensity CBT.</td>
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<tr>
<td></td>
<td>• Live independently</td>
</tr>
<tr>
<td></td>
<td>• Enjoy contact with friends and family</td>
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<tr>
<td></td>
<td>• Have no loss of interests or hobbies</td>
</tr>
<tr>
<td></td>
<td>• Be able to leave the house unaccompanied</td>
</tr>
<tr>
<td>Mobility</td>
<td>They would normally have no physical difficulty in getting around.</td>
</tr>
<tr>
<td></td>
<td>They should not have difficulty finding their way around unfamiliar places and should not require guidance or supervision.</td>
</tr>
<tr>
<td>Care</td>
<td>They should not normally exhibit significant self-neglect.</td>
</tr>
<tr>
<td></td>
<td>They should not normally have any significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities.</td>
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</table>
## Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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</thead>
</table>
| Disabling effects | People with a moderate functional restriction are likely to:  
• Be managed by either primary or secondary health care teams  
• Have received more intensive CBT (including ERP) or SSRI alone  
• Live independently  
• Have reduced social interaction with friends and family  
• Have a reduction in interests and hobbies  
• Be unable to complete an unfamiliar journey without a companion |

### Mobility
They would normally have no physical difficulty in getting around.  
They may have such severe obsessions and compulsions (for example, of contamination or fear of harm to self) that they are unable to leave the house or complete an unfamiliar journey without a companion for reassurance.  
Should the companion not be present the person may not be able to reach their destination.

### Care
They may spend so much time performing rituals or have compulsive slowness to a degree that this may result in a loss of their ability to carry out normal day-to-day activities and may lead to self neglect.

## Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
</table>
| Disabling effects | People with a severe functional restriction are likely to:  
• Have received previous treatment with drugs and CBT to little or no effect and are most likely to have been referred to more intensive specialist treatment services. |
Mobility

They would normally have no physical difficulty in getting around. Some patients particularly with obsessions concerning perfectionism, have the urge to perform every action “correctly” and can be extremely slow in speech and in movement and can thus appear to have severe learning difficulties and mobility problems.

They may have such severe obsessions and compulsions (for example of contamination or fear of harm to self) that they are unable to leave the house or complete an unfamiliar journey without a companion for reassurance. They may be so occupied by obsessional thoughts that their awareness is affected and may not be aware of common dangers, such as traffic.

Care

They may spend so much time performing rituals or have compulsive slowness to a degree that this is likely to result in a loss of their ability to carry out normal day-to-day activities and may lead to self neglect. Some individuals restrict fluid intake and may seriously harm their kidney function and physical health. Urinary or faecal incontinence can occur in patients who become “stuck” in their compulsive rituals and unable to attend to this aspect of self-care. Alternatively, they may be so occupied by obsessional thoughts that their awareness is affected, and may not be aware of common dangers, for example, leaving gas taps on. People with this level of disability will normally be considered for more intensive treatments, hospital admission or supported accommodation.

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How long will the needs last?

Obsessive Compulsive Disorder (OCD) may follow an acute, episodic, chronic unremitting, deteriorating or relapsing course. For some people the symptom type will remain unchanged, but for others the symptoms change over time. Intermittent, episodic disorder is more common in the early stages of the disorder whereas chronic illness is more common in the later stages.

The response to treatment is usually good. For example, Exposure and Response Prevention (ERP) has response rates of up to 85% in people who complete the treatment, but this may take several months. The response to drug treatment increases gradually over weeks and months and the benefits continue to accrue for at least six months and have been shown for up to 2 years. Resistant cases that require different types of treatment may take a year or more to achieve functional improvement.

A recent study of people with severe OCD showed that 6 to 8 years after treatment, approximately:
• 27% no longer met the criteria for the diagnosis of OCD (i.e. were effectively “cured”)
• 17% had mild symptoms
• 34% had moderate symptoms
• 24% had severe symptoms

Worse outcome was associated with longer duration of illness before treatment.
Therefore for people who are undergoing treatment, a short term award of 2 years is recommended, in order to give time to assess the response to treatment.

For people who have received treatment but have responded poorly, a longer term award of 10 years is recommended, as it is possible that further treatments may be instituted in the future.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Duration of needs</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obsessive Compulsive Disorder (OCD)</td>
<td>Currently undergoing treatment</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>Poor response to previous treatment</td>
<td>10 year award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Over 65**

Obsessive Compulsive Disorder (OCD) may occasionally occur for the first time in old age. In addition, OCD frequently persists into old age. Clinical features and severity are similar to younger people with OCD. However, older people are more likely to have obsessions relating to having sinned and compulsions to hand washing relative to younger people. Because depression and OCD commonly coexist, depression is more likely to be recognised in the elderly and treatment of OCD may be inadequate.

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What you need to know about Oesophageal cancer
Back to A - Z

What is Oesophageal cancer?
Cancer of the oesophagus, also known as oesophageal cancer, is an uncommon but serious type of cancer that affects the oesophagus (gullet)… Read more on NHS Choices - Oesophageal cancer.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even… Read more about evidence sources.

Activities of Daily Living and mobility needs
Advanced oesophageal cancer and recurrent oesophageal cancer - This group which includes 60-70% of those with oesophageal…. Read more about ADL and mobility needs.

How long will the needs last?
Those who have had treatment for ‘Barrett’s oesophagus’ are expected to make a complete recovery and are unlikely to experience recurrent…. Read more about award duration.

Over 65’s
This disease is more common in the over 65s but there are no special features.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a ‘Care plan’ from social services
Hospital
Specialist doctors -:
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• Physician
• Haematologist

Specialist nurses have many different job titles -:
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Professions Allied to Medicine -:
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• Occupational Therapist
• Social worker
• Counsellor
• Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
• Palliative Care Physician
• Macmillan Nurse
• Clinical Nurse Specialist
• Social worker
• Physiotherapist
• Occupational Therapist
• Counsellor

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Activities of Daily Living and Mobility needs

Advanced oesophageal cancer and recurrent oesophageal cancer
This group which includes 60-70% of those with oesophageal cancer have an average survival despite chemotherapy treatment of less than one year. Symptoms of disease may include many of the following:

• difficulty swallowing – ‘dysphagia’
• regurgitation of food or vomiting of food
• acid indigestion
• pain in the back or chest or on swallowing – ‘odynophagia’
• hoarseness or coughing
• weight loss

Over time they are likely to lose a huge amount of weight becoming very frail, they may be unable to walk more than a few steps or cope with shopping and cleaning. In the terminal phase they are likely to require help with all aspects of personal care. Between 30% and 60% will respond to chemotherapy in that their symptoms will be less troublesome for some weeks or months. Many will go on to have further treatments such as stenting to maintain swallowing. Weight loss and fatigue are likely to be significant problems even when swallowing can be maintained. Any of the symptoms of metastatic disease may also be present e.g. bone pain from bony metastases and liver metastases causing jaundice and increased fatigue.

How long will the needs last?

Localised (early stage) oesophageal cancer

Those who have had treatment for Barrett’s oesophagus are expected to make a complete recovery and are unlikely to experience recurrent disease. Ongoing problems for them may include difficulty eating large meals and symptoms of dumping syndrome such as nausea, bloating, pain and diarrhoea.

Those who have had treatment of Oesophageal cancer with major surgery are likely to be self caring and mobile three months into recovery although full recovery is likely to take at least 1 year. If needs are identified during treatment these are likely to be much reduced at 3 months and in the typical case no needs would be anticipated at 1 year. The exception to this might be those who have developed enduring side effects of surgery. Ongoing problems for this group may include difficulty eating large meals and symptoms of dumping syndrome. Many patients remain underweight for a long time after surgery and will feel tired for a large part of the day.

Those who have had chemoradiation treatment for localised Oesophageal cancer may have identifiable needs during treatment which lasts for 3-4 months. It may take several months to recover from this treatment but needs are unlikely to persist unless the rare but enduring side effects of radiotherapy have developed.

Some people who have had either type of treatment for Oesophageal cancer may have a prolonged recovery period after treatment. This condition is particularly difficult and slow to recover from because of the profound weight loss and malnutrition that having difficulty swallowing causes. In addition many will develop recurrent disease within 5 years of successful treatment. 5 year survival rates after surgery are at best 30% and for chemoradiation therapy also around 30%. If disease recurs, needs are likely to occur and information relating to the advanced/recurrent disease stage is appropriate.
In cases where needs are identified during treatment of the primary tumour, awards should be time limited to cover the period of treatment and recovery. People affected are unlikely to regain their normal weight but a return to near normal function is expected in the typical case. If disease has recurred after successful treatment of any stage of oesophageal cancer, information relating to the advanced/recurrent disease stage is appropriate.

Life awards are recommended even if palliative treatment has appeared to significantly help with symptoms.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Oral cancer

What is Oral cancer?
Mouth cancer (also known as oral cancer) is an uncommon type of cancer that usually develops on the surface of…. Read more on [NHS Choices - oral cancer](http://www.nhschoices.org)

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Outpatient treatments for this condition are unlikely to take more than 3 months to complete. The main disabling effects of…. Read more about ADL & mobility needs.

How long will the needs last?
Where needs are identified as a result of weakness and malnutrition related to mouth cancer and its treatment and if…. Read more about award duration.

Over 65s
Although this disease is more common in the over 65s, there are no special features.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A [hospital factual report](http://www.nhsfactualreport.org) will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a ‘Care plan’ from social services
Hospital
Specialist doctors -:
- Oncologist
- Physician
- Haematologist

Specialist nurses have many different job titles -:
- Clinical Nurse Specialist
- Stoma care nurse
- Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
- Physiotherapist
- Occupational Therapist
- Social worker
- Counsellor
- Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
- Palliative Care Physician
- Macmillan Nurse
- Clinical Nurse Specialist
- Social worker
- Physiotherapist
- Occupational Therapist
- Counsellor

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Activities of Daily Living and Mobility needs
Treatment of primary disease that is not advanced
Eating and Swallowing
Speech
Advanced or recurrent lip, mouth and oropharyngeal cancer
ADL
Mobility
Psychological Problems

Outpatient treatments for this condition are unlikely to take more than 3 months to complete. The main disabling effects of this condition are likely
to arise from the enduring effects of treatment on function of the mouth, particularly surgery.

Treatment of primary disease that is not advanced

Minimal enduring disabling effects would be expected. However when a person has had major surgery to the mouth or lip there may be residual disabling effects. In these cases evidence of ongoing problems and needs should be available from the Head and Neck clinical nurse specialist or speech therapist. Such problems may include:

- Difficulties with speech
- Dribbling/difficulty eating
- Difficulty swallowing
- Disfigurement
- Mental health problems

Eating and Swallowing

If a large area around the mouth has been reconstructed especially using free flaps from the arm or leg for example the new reconstructed area will be numb or ‘insensate’. Numbness around the mouth has a major impact on function. Activities such as eating and drinking will be very difficult. If the area around the mouth is numb people are unable to recognise the presence of food in the mouth, and to manipulate it for an effective and safe swallow. If the tongue (all or part) has been removed and reconstructed, it will be difficult to prepare food into a bolus or ball for normal swallowing and also difficult to propel the bolus of food to the back of the throat. A delay in triggering the swallow reflex may also occur, and in some people there may a risk of aspirating or inhaling food into the airway. This is very common immediately after the operation but can be an enduring problem.

Some people may be able to learn safer swallow techniques; for example, altering of their head posture during swallowing, to protect the airway. Others may need supervision when eating because of ongoing aspiration. Other problems with eating and drinking include diminished lip seal following surgical intervention. This results in the drooling of food and fluid from the mouth (made worse by the fact that the lower lip is likely to be numb). Pocketing of food in the cheek areas may also occur, and reduced range of movement of the tongue can make it extremely difficult to retrieve food and fluid from around the mouth using the tongue. If part of the hard palate has been removed, food and fluid may be ejected into the nasal cavity.

Speech

Communication may also be a major problem, depending on the extent of the surgery, the reconstruction, and the structures involved. Communication difficulties may arise as a result of the range and speed of tongue movement, degree of lip closure and soft palate function. Patients who have had a dental clearance may have an even further reduced
reertoire of sounds. This loss of ability to communicate can be devastating to head and neck cancer patients; resulting in frustration, social isolation and depression.

**Advanced or recurrent lip, mouth and oropharyngeal cancer**

This group are likely to have disabling effects from both the disease and its treatment, symptoms of disease may include:

- Ulceration in the mouth
- pain in the mouth that does not go away
- lump in the lip, mouth or throat
- pain on chewing or swallowing
- difficulty chewing or swallowing
- bleeding in the mouth
- numbness in the mouth
- loose teeth
- difficulty opening the mouth
- speech difficulty
- bad breath (halitosis)

The following may be symptoms of advanced disease:

- a lump in the neck
- loss of weight
- a large tumour may cause difficulty breathing

They may in addition have any of the side effects of previous treatment, the most disabling of these include:

- Pain
- Dental caries – widespread and severe resulting in loss of teeth
- Osteonecrosis – literally means bone death, this may affect the upper or lower jaw, and the symptoms are pain, loose teeth or numbness.
- Trismus – inability to open the jaw, usually because of pain. This can also be caused by scarring and fibrosis of the muscles of mastication (chewing), causing restricted mobility of the lower jaw. This may be due to radiotherapy, surgery, or tumour invasion. Some people may require use of mechanical devices to stretch the jaws, and this should be used frequently throughout the day (approximately seven 15 minute sessions per day). Some patients can only open their mouth a minimal amount (i.e. a few millimetres) and may be reliant on gastrostomy feeding or liquid diet. Oral hygiene may also be a problem, and trismus can also impact on communication.

**Activities of Daily Living**

There may be ongoing problems with activities of daily living related to previous surgical treatment of disease, recent surgical treatment or advanced disease. These may include:
- Disfigurement
- Difficulty eating, including dribbling
- Difficulty swallowing
- Difficulty with speech
- They may need help cleaning and inserting and removing any prosthesis worn or mouth care. Dentures and obturators (a prosthesis that occludes the opening in the roof of the mouth) become coated in plaque and food debris, and can harbour infection. They must be cleaned frequently and meticulously using a soft brush and water. This must be done after every meal and when oral care is performed. Rinsing and soaking alone are not sufficient to remove plaque and debris effectively. Someone else will have to do this if there are any disabilities affecting hand movement or dexterity.
- Food preparation may be more onerous if a special diet is required.
- Supervision to help with choking/aspirating food at meal times.
- General weakness because of weight loss.
- Shoulder dysfunction – loss of shoulder function because of damage to the accessory nerve is likely to have a significant impact on activities of daily living if both shoulders are affected. These will include washing and brushing the hair and dressing because of restricted movement of both upper limbs. Any activity involving raising the arms above shoulder level will be restricted. Typical activities affected would include hanging a coat up on a coat hook, reaching up to kitchen wall cupboards or high shelves.

Changes in the ability to eat and drink in a socially acceptable fashion are a difficult issue. People who feel they are unable to eat in company because of such difficulties, may become socially isolated and stop going out at all. Head and neck cancer is very visible and the consequences of this can be devastating. Treatments for head and neck cancers can result in permanent, visible mutilation which is difficult to disguise. People with such disabilities are likely to fear isolation and rejection, be concerned about the reactions of others and may become socially isolated, depressed and anxious.

**Mobility**

Mobility is not likely to be affected by this condition except where there is severe weight loss - general debility and fatigue may reduce mobility. Free flaps taken from the hip or lower leg do not have a long term effect on mobility although the donor site may be sore for a few months.

**Psychological Problems**

Mental health conditions such as depression can occur as a result of treatment of any type of cancer. Cancer of the mouth is especially challenging as it may involve disfigurement, difficulty eating and difficulty communicating. Social isolation is a common problem. Mental health conditions may cause additional needs and problems with activities of daily living.

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How long will the needs last?
Where needs are identified as a result of weakness and malnutrition related to mouth cancer and its treatment and if the treatment is expected to be successful, time limited awards of 1 year are recommended. A return to normal function is expected in these cases.

Life awards are recommended if needs are identified in people with advanced or recurrent disease. If needs are identified because of functional difficulties with the lips, mouth or throat following surgical treatment given more than 12 months previously life awards are also recommended.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Organic brain disorders

What are Organic brain disorders?
- Read more on NHS Choices - Alzheimer's disease
- Read more on NHS Choices - Creutzfeldt-Jakob disease (CJD)
- Read more on NHS Choices - Dementia
- Read more on NHS Choices - Huntington's disease
- Read more on NHS Choices - Head injury - minor
- Read more on NHS Choices - Head injury - severe

For information about other organic brain disorders Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
The claimant and / or carer should be able to provide the information required to accurately assess mobility and care needs …… Read more about evidence sources.

Activities of Daily Living and mobility needs
People with a mild restriction are likely to have mild cognitive deficit …. Read more about ADL and mobility needs.
Linked page: CAPE test & scoring system

How long will the needs last?
The prognosis is determined by the underlying condition …. Read more about award duration.

Over 65’s
The clinical features and treatment of Organic Brain Disorders in the elderly are similar to those in people under the age of 65.

What evidence is available?
The claimant and / or carer should be able to provide the information required to accurately assess mobility and care needs. However, if further details are needed, the Specialist Nurse, Occupational therapist or Consultant is an appropriate source of information.

Activities of Daily Living and Mobility needs
### Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a mild restriction are likely to have mild cognitive deficit.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Physical walking ability is unlikely to be impeded in the absence of neuromuscular problems affecting the lower limbs. Impairment of cognitive function is not likely to be sufficient to cause difficulties satisfactorily using unfamiliar routes independently.</td>
</tr>
<tr>
<td>ADL</td>
<td>The resulting disability is unlikely to affect their ability to independently carry out activities of daily living. They may be more at risk than a normal person of causing damage or injury in performing everyday activities due to forgetfulness. However this is usually not markedly above a person without early dementia.</td>
</tr>
</tbody>
</table>

### Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a moderate restriction are likely to have moderate cognitive deficit.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Physical walking ability is unlikely to be impeded in the absence of neuromuscular problems affecting the lower limbs. Impairment of cognitive function is likely to be sufficient to cause difficulties satisfactorily using unfamiliar routes independently.</td>
</tr>
<tr>
<td>ADL</td>
<td>The resulting disability may lead them to require assistance with undertaking complex activities. They may require prompting or supervision to prepare food, take medication, deal with correspondence and financial matters and undertake appropriate activities.</td>
</tr>
</tbody>
</table>
They are not likely to require assistance with most aspects of bodily function and they are not likely to require continual supervision to prevent potentially dangerous behaviours or activities.

Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a severe restriction are likely to have severe cognitive deficit.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Physical walking ability may be significantly restricted as a result of neuromuscular problems affecting the lower limbs. Impairment of cognitive function is likely to cause difficulties satisfactorily using unfamiliar routes independently.</td>
</tr>
<tr>
<td>ADL</td>
<td>The resulting disability is likely to lead them to require assistance with all activities of daily living. They are likely to require assistance with most aspects of bodily function and they are likely to require supervision to prevent potentially dangerous behaviours or activities.</td>
</tr>
</tbody>
</table>

Click on the link for details of -:
CAPE test & scoring system
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How long will the needs last?
The prognosis is determined by the underlying condition.

Most organic brain disorders are usually irreversible. Once care needs are established they are unlikely to improve and a life award should be considered.

However, if there is progressive pathology, for example in dementia, further deterioration in cognitive function is likely, with consequential increase in care and mobility needs.
<table>
<thead>
<tr>
<th>Impairment</th>
<th>Prognosis</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delirium</td>
<td>Delirium usually clears within a week but can last up to a month. It is associated with a high mortality. The prognosis depends upon successful treatment of the causative illness and the underlying state of the brain. 15% of the elderly do not survive. 40% are in institutional care at 6 months.</td>
<td>N/A</td>
</tr>
<tr>
<td>Dementia</td>
<td>With some exceptions, dementia is an irreversibly declining condition. The time from onset to death varies according to the type of dementia.</td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>On average, people spend several years in the mild or minimal stages (although it can be as long as 5 to 10 years), between 4 and 5 years in the moderate stages, and up to a year in the final stage.</td>
<td></td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>Characteristically there is stepwise progression. The course varies but can be as severe and rapid as Alzheimer’s disease despite treatment of the underlying cause.</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Dementia with Lewy Bodies (DLB)</td>
<td>Similar to Alzheimer’s disease. In the later stages an akinetic-rigid syndrome can cause severe disability in mobility and swallowing and increase the number of falls.</td>
<td></td>
</tr>
<tr>
<td>Fronto-temporal dementia (Pick’s disease)</td>
<td>The disease is progressive and the average time from onset to death is between 5 and 10 years.</td>
<td></td>
</tr>
<tr>
<td>Prion diseases</td>
<td>Both Variant Creutzfeldt-Jacob disease (vCJD) and Creutzfeldt-Jacob disease (CJD) have poor prognoses. The average time from onset to death is 14 months for vCJD and 4 months for CJD.</td>
<td></td>
</tr>
<tr>
<td>Huntington’s disease</td>
<td>Death is usually within 15 years of onset of Huntington’s disease.</td>
<td></td>
</tr>
<tr>
<td>Impairment</td>
<td>Prognosis</td>
<td>Date of Onset</td>
</tr>
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<td>---------------</td>
</tr>
<tr>
<td>Head Injury -:</td>
<td>For people with a minor head injury at 3-month follow-up, 79% still have headache, 59% have symptomatic memory disturbance and 34% have not returned to work. For people with a moderate head injury 63% remain disabled at 1 year. For people with a severe head injury, 85% remain disabled at 1 year. The majority of physical recovery occurs in the first 12 months (mostly in the first 6 months) but psychological recovery can take up to 2 years and further small changes can take place over five years or more from the date of injury. Life expectancy of severely disabled survivors appears to be reduced by about 5 years. However, those who are very dependent may be at increased risk of respiratory complications, resulting in a decrease in life expectancy of 10 years. For people in vegetative state the mean survival rate is 3 - 4 years. For people with severe head injury follow up studies (2 to 10 years post injury) have demonstrated that the long term effects and rehabilitation needs are often extensive as detailed below.</td>
<td>Less than 2 years</td>
</tr>
<tr>
<td>Causing cognitive impairment</td>
<td></td>
<td>More than 2 years</td>
</tr>
<tr>
<td>Causing sensori-motor impairment</td>
<td></td>
<td>Less than 2 years</td>
</tr>
<tr>
<td></td>
<td></td>
<td>More than 2 years</td>
</tr>
<tr>
<td><strong>Causing cognitive &amp; sensorimotor impairment</strong></td>
<td><strong>Independence</strong></td>
<td><strong>Less than 2 years</strong></td>
</tr>
<tr>
<td>------------------------------------------------</td>
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<td>----------------------</td>
</tr>
<tr>
<td>Approximately one half is ultimately able to live independently, one quarter live independently with support services and/or are in sheltered accommodation, one quarter are fully dependent upon the family or an institution.</td>
<td>More than 2 years</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

**Occupation** - Approximately two thirds are unemployed.

**Leisure and social life** - Half report limited contact with friends. Sixty percent have no boyfriend or girlfriend. Many therefore remain dependent upon others, including family members for their leisure and social life.

**Marital relationships** - One study of people with very severe head injury demonstrated that very few relationships remained intact at 10-15 year follow-up.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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**CAPE (Clifton Assessment Procedures for the Elderly) test and scoring system**

CAPE assesses the severity of impairment in mental and behavioural functioning. It was originally devised for use in elderly, long-term psychiatric patients. The CAPE consists of two components, the Cognitive Assessment Scale (CAS) and the Behaviour Rating Scale (BRS).

The CAPE is generally administered by nurses treating a patient and includes a 12-item information and orientation subtest (taking the form of questions such as “what is your date of birth?”), a brief mental abilities test (e.g. “Will you count up from 1 to 20 for me – as quickly as you can?”) and a psychomotor performance test that involves tracing a line through a maze. The time taken for the psychomotor maze test and the number of errors on the other tests are converted into a CAS score out of 12. A cut-
off point of 8 is recommended with scores of 7 or less generally indicating dementia or acute organic brain syndrome.

The BRS contains 18 items and is completed by relatives or staff familiar with the patient’s behaviour. It covers physical disability including performance of activities of daily living (ADLs), apathy, communication difficulties and social disturbance. BRS scores range from 0 to 36 with higher scores within this range indicating greater disability.

Scores on the two components are transferred onto a report form that summarises ‘raw’ scores in a five-category grading of the patient’s level of dependency and hence, the support the patient is likely to require.

<table>
<thead>
<tr>
<th>CAPE grade</th>
<th>CAPE grading description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade A</td>
<td>No mental impairment and no significant behavioural disability.</td>
</tr>
<tr>
<td>Grade B</td>
<td>Mild impairment in both areas requiring some support for people living in the community.</td>
</tr>
<tr>
<td>Grade C</td>
<td>Medium levels of impairment requiring considerable support for community living.</td>
</tr>
<tr>
<td>Grade D</td>
<td>Marked impairment and dependency. People in this category are usually institutionalised.</td>
</tr>
<tr>
<td>Grade E</td>
<td>Maximal impairment typical of psycho-geriatric patients requiring a great deal of nursing attention and care.</td>
</tr>
</tbody>
</table>

The CAPE has been tested in several studies using large samples of patients. The results show good reliability and high sensitivity and specificity when used with psychiatric inpatients. It has been mainly tested on hospital populations but its performance on ‘community’ samples remains unknown.

The issue has been raised of how to score the CAPE when a patient cannot complete the maze test as a result of blindness or impairment of the hands e.g. by arthritis. The original approach of awarding ‘zero’ may lead to falsely classifying physical difficulties as a cognitive problem; pro-rating the score based on scores in other parts of the CAPE does not work well.

Overall, the CAPE provides reliable estimates of cognitive and behavioural impairment for the institutionalised elderly population. As a screening test for ‘community’ use, the CAPE is considered probably to be less adequate than other available instruments such as the Mini Mental State Examination (MMSE).

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What you need to know about Osteoarthritis (OA)

What is Osteoarthritis (OA)?
Osteoarthritis is a condition that affects the joints. It is the most common type of arthritis in the UK. Around 1 million people….Read more on NHS Choices - osteoarthritis.

What evidence is available?
The claimant and / or carer should be able to provide the information required to accurately assess mobility and care…. Read more about evidence sources.

Activities of Daily Living and Mobility needs
The overall level of functional restriction will depend upon the number of joints affected and the combination of upper and…. Read more about ADL & mobility needs.
Linked pages -:
OA spine (no neurological signs) - Mechanical back pain - ADL and Mobility needs
OA spine (with neurological signs) - Specific back pain - ADL and Mobility needs
How long will the needs last?
Any person with mobility restricted to a degree that they are virtually unable to walk (VUTW) will have seen their GP and…. Read more about award duration.

Over 65s
The prevalence of Osteoarthritis increases with age. Clinical features are similar to those in a younger age group…. Read more about effects in the over 65 age group.

What evidence is available?
The claimant and / or carer should be able to provide the information required to accurately assess mobility and care needs. However, in cases of ‘working age’ customers, if further details are needed (e.g. Safeguarding), the Consultant is the most appropriate source of information. If a HFR cannot be obtained, the case should be discussed with Medical Services to decide the next best evidence source i.e. either a GPFR or a HCP Examination report.

In AA cases, where there is any doubt about care needs, the most appropriate source for any third party evidence needed should be discussed with Medical Services.
Activities of Daily Living and Mobility needs
The overall level of functional restriction will depend upon the number of joints affected and the combination of upper and lower limb involvement. Please click on the appropriate link below to access the relevant care and mobility needs.
Lower limb - Mild Functional Restriction
Lower limb – Moderate Functional Restriction
Lower limb – Severe Functional Restriction
Upper limb – Mild Functional Restriction
Upper limb – Moderate Functional Restriction
Upper limb – Severe Functional Restriction

For ADL and Mobility details for OA Spine (without neurological signs) click on the link below -:
Activities of Daily Living and Mobility considerations – Mechanical back pain

For ADL and Mobility details for OA Spine (with neurological signs) click on the link below -:
Activities of Daily Living and Mobility considerations - Specific back pain

Activities of Daily Living and Mobility considerations
Lower limb - Mild Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with this level of functional restriction would not normally have any noticeable disabilities on an everyday basis. There may be some pain and joint discomfort particularly after resting for any length of time, but this will quickly wear off. There may be some flare ups of the condition but these are likely to be infrequent and of short duration.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with mild restriction would normally have no physical difficulty in getting around nor would they require guidance or supervision outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with mild restriction would normally be able to safely manage all aspects of their personal care, including the ability to dress independently and put on socks and shoes, using simple technical aids if required. The ability to rise from sitting, attend to own toilet needs and prepare a main meal would not be impaired to any significant degree. Such a person would normally be expected to care for themselves by maintaining personal hygiene and preparing meals etc. They would have little or no functional limitation on a day-to-day basis arising from any symptoms. No supervision or watching over needs would be present.</td>
</tr>
</tbody>
</table>

Bear in mind that where there is also upper limb involvement, the combined effect of the functional restrictions may lead to greater mobility and care needs.

**Lower limb – Moderate Functional Restriction**
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with this level of functional restriction would normally experience persistent pain in one or more of their major joints or their feet. They are likely to have swelling of the joints (with the exception of the hip), and in some cases there will be deformity of these joints. There may be some pain on weight bearing and knee instability (if the knee is affected) may also be present. Stiffness would normally be worse after resting for any length of time.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with moderate restriction would normally have no physical difficulty getting around. Nor would they require guidance or supervision outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with moderate restriction may have difficulty getting out of bed, rising from the toilet and with dressing and washing. This is likely to be more apparent immediately after getting up in the morning, however these difficulties may be reduced by the use of prescribed assistive equipment, such as a raised toilet seat or grab rails. Knee instability could cause difficulty using stairs and may increase risk of falls; however the use of prescribed assistive equipment such as a stick or other mobility aids may help to reduce this. They would not need supervision or watching over.</td>
</tr>
</tbody>
</table>

Bear in mind that where there is also upper limb involvement, the combined effect of the functional restrictions may lead to greater mobility and care needs.

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**Lower limb – Severe Functional Restriction**
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>- People with this level of functional restriction would normally have lower limb joint deformity in at least one joint and restriction of movement in that joint. They would also have pain on weight bearing and joint swelling (except for the hip). Joint pain may wake the person at night even with the use of painkillers. Where the knee is affected it is likely to be unstable and give way leading to falls. They may be on the waiting list for hip or knee replacement surgery.</td>
</tr>
<tr>
<td>Mobility</td>
<td>- A person with severe restriction would normally need physical assistance from another person in getting around. The use of a walking aid may help prevent falls but it would not improve physical walking ability. The person would not require guidance or supervision outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>- A person with severe restriction would normally have joint deformity with pain and restriction of movement. Knee instability is likely to be present and hence an increased risk of falls. However, the use of a stick may help reduce the risk of falls and may also assist in rising after a fall. Such a person would normally need assistance from another person with dressing, bathing and attending to toilet needs. Help is likely to be needed with rising from sitting, getting out of bed, the bath and in using stairs. No supervision or watching over needs would be present.</td>
</tr>
</tbody>
</table>

Bear in mind that where there is also upper limb involvement, the combined effect of the functional restrictions may lead to greater mobility and care needs.

**Upper limb – Mild Functional Restriction**
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with this level of functional restriction are unlikely to have any noticeable disabilities on an everyday basis. Pain, discomfort, joint swelling and/or stiffness will often be low grade or minimal, and normally wears off quite quickly. Although there may be exacerbations, these would be infrequent and not occur on a regular basis. They probably would not have any significant long-term care or mobility needs.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with mild restriction would normally have no physical difficulty in getting around nor would they need guidance or supervision outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with mild restriction would normally be able to dress independently, including managing buttons, and put on socks and shoes, using simple technical aids if required. The ability to rise from sitting, attend to own toilet needs and prepare a main meal would not be impaired to any significant degree. Such a person would normally be expected to care for themselves by maintaining personal hygiene, preparing meals etc. have little or no functional limitation on a day to day basis arising from any symptoms. They would not need supervision or watching over.</td>
</tr>
</tbody>
</table>

Bear in mind that where there is also lower limb involvement, the combined effect of the functional restrictions may lead to greater mobility and care needs.

**Upper limb – Moderate Functional Restriction**
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with this level of functional restriction may have swelling and deformity of their upper limb and hand joints. There may be some deformity of some of their joints together with some significant restriction of joint movement. There would normally be some restriction of manual dexterity when the hands are involved. Stiffness would normally be worse after resting for any length of time. Where the neck is involved neck movements would normally be painful and restricted but without neurological signs, muscle wasting and weakness in the arms.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with moderate restriction would normally have no physical difficulty in getting around nor would they need guidance or supervision outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with moderate restriction could have difficulty coping with some activities of daily life. They would normally have no difficulty rising out of bed or chair (particularly if raised) but may have some difficulty getting out of a bath. Reduced manual dexterity could lead to problems with dressing, feeding, washing, shaving, toileting and aspects of main meal preparations such as lifting pans and peeling vegetables.</td>
</tr>
</tbody>
</table>

Bear in mind that where there is also lower limb involvement, the combined effect of the functional restrictions may lead to greater mobility and care needs.

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Upper limb – Severe Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with this level of functional restriction would normally have gross joint deformity of at least one joint and swelling (with the exception of the shoulder), together with pain and significant limitation of joint movement. The joints would be likely to be stiff after resting for any length of time, and morning stiffness may be present. In many cases the finger joints would be deformed with swelling and pain leading to significant problems with manual dexterity. The joint pain may wake the person at night (even with the use of analgesics/painkillers). Where the neck is involved neck movements would normally be painful and restricted. Pins and needles, muscle wasting and weakness in the arms and very rarely in the legs may also occur. If the elbow is affected, a fixed flexion deformity may be present so that the person will be unable to straighten the arm fully. Rotational movements at the elbow (supination/pronation) will also be reduced.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with severe restriction may need physical assistance from another person in getting around due to difficulty in gripping and/or holding prescribed mobility aids. They would not need guidance or supervision outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with severe restriction would normally have difficulty coping with many activities of daily life. They may have difficulties getting out of bed and getting out of a bath. Manual dexterity may be severely restricted if the finger joints are involved, leading to problems with dressing, feeding, washing, shaving, toileting and aspects of main meal preparations such as lifting pans and peeling vegetables. Due to the severity of this condition simple aids are unlikely to be helpful and assistance may be needed in rising from a chair.</td>
</tr>
</tbody>
</table>

Bear in mind that where there is also lower limb involvement, the combined effect of the functional restrictions may lead to greater mobility and care needs.
## How long will the needs last?

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>OA Hip/s</td>
<td>*Possible/potential Joint surgery</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>+No joint surgery taken place / planned (due to refusal of surgery or another condition prevents surgery)</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>OA Knee/s</td>
<td>* Possible/potential Joint surgery</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>+No joint surgery taken place / planned (due to refusal of surgery or another condition prevents surgery)</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>OA of other single joint e.g. Carpo-metacarpal (big toe) joint</td>
<td>* Possible/potential Joint surgery</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>+No joint surgery taken place / planned (due to refusal of surgery or another condition prevents surgery)</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Gen OA of 2 or more joints / Arthritis (except hips or knees)</td>
<td>* Possible/potential Joint surgery</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>+No joint surgery taken place / planned (due to refusal of surgery or another condition prevents surgery)</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

Any person with mobility restricted to a degree that they are VUTW will have seen their GP and will have been offered referral to a consultant well before they get to this stage of immobility. A consultant would offer hip or knee replacement surgery well in advance of this level of restricted mobility unless there is a contraindication or the person refuses surgery. If there is no consultant involvement and claimed needs are consistent with entitlement, the DM should investigate the reasons for non referral to a
consultant and whether there is a prospect of joint replacement surgery. If such reasons cannot be found, it must cast doubt on the situation and possibly Departmental Medical Services advice should be sought.

+In cases where there is another medical condition preventing surgery, the duration should be based on that condition or the reasons for refusal for treatment. If there is absolutely no prospect of joint replacement surgery then as OA is a degenerative progressive disease and surgery is the only way of improving function, an indefinite duration is appropriate.

*Possible/potential joint surgery means joint surgery that has been discussed by the consultant with the customer and, which the customer has been advised will or is strongly expected to take place in the foreseeable short-term future (e.g. 6-12 months). It does not mean surgery that the consultant has loosely alluded to the customer needing or may need at some, as yet undetermined point in the future. This distinction must be established by the Decision Maker.

It should be noted that generally, the outcome of joint replacement surgery in the lower limbs is very successful. Following surgery, rehabilitation and return to a reasonable level of activity can be expected within 2 months in the absence of complications. The elderly and frail and those with other significant medical problems may take longer to regain function but most should make a good recovery within 3 months even if the hip or knee replacement is bilateral.

Toe surgery is usually fusion of the joint, ‘fixing’ it in the optimal position for function, which should make the joint pain free. Again, rehabilitation and return to a reasonable level of activity can be expected within 2 months in the absence of complications.

Surgery for joint replacement in the upper limbs for OA is rare and the success more limited than for hips/knees but in the absence of complications better function should be obtained in 3 months.

If surgery is planned but the exact date is not known a maximum award period of 2 years is suggested to take account of the national variation in waiting times and the anticipated rehabilitation period. If a date of surgery is known, or the customer has been on the waiting list for some months, a shorter award period should be considered based on the individual circumstances of the case.

*In AA cases, bear in mind that no ‘Prospective Test’ needs to be considered and also the length of the award period in relation to the following renewal claim.

*Careful consideration should therefore be given as to whether the ‘Prospective Test’ is likely to be satisfied.
All information must be taken into account when considering the duration of award and the duration of award must be based on the particular circumstances of the individual claimant.

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**Generalised Osteo-arthritis in people over 65**

The prevalence of Osteoarthritis increases with age.

Clinical features are similar to those in a younger age group.

Treatment is similar to that in a younger age group with some minor differences. For example, use of non-steroidal anti-inflammatory drugs should be avoided if possible in view of the increased susceptibility to gastrointestinal side effects and the benefits of surgery must be weighed against the potential risks.
What you need to know about Osteoporosis

What is Osteoporosis?
Osteoporosis is a condition that affects the bones, causing them to become weak and fragile and more likely to break (fracture).

Read more on NHS Choices - Osteoporosis

What evidence is available?
Hospital Factual Report for diagnosis, clinical findings and treatment

Read more about evidence sources

Activities of Daily Living and mobility needs
From middle age onwards, bones gradually become less dense and are more liable to fracture.

Read more about ADL and mobility needs

How long will the needs last?
Osteoporosis is a progressive disease, which does not necessarily cause care or mobility needs.

Read more about award duration

Over 65’s
Osteoporosis makes the person more susceptible to fractures. Healing is likely to be slower but in general fractures should heal within 6 months. It may help to consult separate guidance on ageing, falls and frailty.

Linked pages:
Ageing
Falls
Frailty

What evidence is available?
The following may give sources of useful further evidence:

- Hospital Factual Report for diagnosis, clinical findings and treatment
- General Practitioner for diagnosis, clinical findings and treatment
- Physiotherapist for functional assessment

Activities of Daily Living and Mobility needs
From middle age onwards, bones gradually become less dense and are more liable to fracture. This is a normal part of the ageing process.
Osteoporosis is a condition where this process of bone thinning is greatly accelerated. Osteoporotic bones are brittle and are much more likely to fracture. The healing of osteoporotic fractures is not impaired, so any resultant disability may not last more than a few weeks or months. This is often the case in the younger person. However in the elderly, who have sustained repeated fractures and progressive collapse of the spine, no significant improvement in disability is likely.

Osteoporosis alone does not typically cause functional restrictions or problems with self-care or difficulty getting around. However, resulting fractures or vertebral collapse may have a significant impact to self-care or getting around.

Activities of Daily Living and Mobility needs - Fractures

The immediate effects of a fractured bone may cause significant functional restrictions. In many cases, such restrictions are unlikely to persist beyond three months. This period allows for the majority of fractures to heal (unite) and for general physical recovery to take place.

- In a minority of cases, the fractured bones do not knit together (non-union) and recovery of function may be delayed. Surgery may be required to assist the healing process.
- Some fractures are complicated by infection. Established bony infection (Osteomyelitis) may be very difficult to treat and result in longstanding disability. Such individuals may also be generally unwell.
- Delayed healing may also occur where the fractured bone has a single blood supply, such as the lower third of the tibia, and the neck of femur. In some cases a fracture may occur through a joint, damaging the joint structure. If possible, such fractures should be treated by operation.
- Secondary osteo-arthritis often complicates a fracture through a joint, and full recovery of function may not occur. In such cases, care and/or mobility needs may occur.

How long will the needs last?

Osteoporosis is a progressive disease, which does not necessarily cause care or mobility needs. Functional restrictions are likely to be due to fractures and the prognosis will depend on the healing of the fracture. If awarding on the basis of Osteoporosis, an indefinite award is appropriate.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Osteoporosis</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>
How long will the needs last? - Fractures

The repair of a fracture is a continuous and gradual process. The amount of time taken for a fracture to unite depends upon the type of fracture and which bones are affected. However, as a general rule, fractures need to be immobilised for between two to eight weeks. Following this, gentle exercises and movements are important, to build up bone and muscle strength. Physiotherapy may be required to assist this process. As a general rule, a return to about full function within 3 months usually occurs.

The healing of osteoporotic fractures is not impaired, so any resultant disability may not last more than a few weeks or months. This is often the case in the younger person. However in the elderly, who have sustained repeated fractures and progressive collapse of the spine, no significant improvement in disability is likely.

If a fracture has occurred, and this is the reason for the functional restrictions, the fracture should heal within 6 months.

<table>
<thead>
<tr>
<th>Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pelvis – Fracture of</td>
</tr>
<tr>
<td>Spine – Fracture of</td>
</tr>
<tr>
<td>Thorax - Fracture of</td>
</tr>
<tr>
<td>Lower limb - Fracture of</td>
</tr>
<tr>
<td>Upper limb - Fracture of</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Ovarian cancer

What is Ovarian cancer?
The ovaries are a pair of small organs in the female reproductive system that contain and release an egg once a month. Read more on NHS Choices - Ovarian cancer.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even. Read more about evidence sources.

Activities of Daily Living and mobility needs
Stage 1 and 2 disease - Long term side effects of treatment are infertility and early menopause. Read more about ADL and mobility needs.

How long will the needs last?
In stage 1 and 2 of the disease, recovery from disabling effects of treatment and long term survival is expected. Read more about award duration.

Over 65's
Ovarian cancer is common in this age group; survival rates are much lower than in younger women.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a ‘Care plan’ from social services

Hospital
Specialist doctors -:
• Oncologist
• Physician
• Haematologist

Specialist nurses have many different job titles -:
• Clinical Nurse Specialist
• Stoma care nurse
• Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person's treatment and disabilities.

Professions Allied to Medicine -:
• Physiotherapist
• Occupational Therapist
• Social worker
• Counsellor
• Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice

Hospice Specialists -:
• Palliative Care Physician
• Macmillan Nurse
• Clinical Nurse Specialist
• Social worker
• Physiotherapist
• Occupational Therapist
• Counsellor

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Activities of Daily Living and Mobility needs

Stage 1 and 2 disease

Long term side effects of treatment are infertility and early menopause. There are unlikely to be any long term care and mobility needs after treatment. The exception to this is the enduring but rare side effects of chemotherapy. Needs are likely to arise when disease recurs.
Stage 3 disease
Long term side effects of treatment are infertility and early menopause. There are no long term disabling effects other than the rare enduring side effects of chemotherapy. Recurrent disease is common and may occur only a few months after treatment of initial disease – up to date medical evidence from the treating hospital will be important.

Stage 4 disease
Survival for two years after diagnosis with this stage of disease is a good outcome. Most of these people are terminally ill. Those that are fit enough to have surgery are likely to go on to have chemotherapy. A proportion may have many of the problems of the recurrent disease group described above.

Problems specific to ovarian cancer include -:

- Pelvic pain syndromes
- Problems with the bowel or bladder, these may affect continence of either and occasionally the formation of a stoma such as a colostomy or ileostomy if the lower bowel or rectum is affected by the cancer may be necessary

Metastatic and recurrent disease
The aim of treatment is to remove the cancer and try to get that person into remission usually with chemotherapy. Remission may last for a variable length of time. During remission a woman would be expected to be well with no disabling effects. Once disease has returned and remission has ended it is a case of controlling the disease for as long as possible. Further chemotherapy and/or surgery or radiotherapy may induce a second shorter remission but it will not cure it. For some women 4 – 6 lines of treatment may be given in this way over a number of years.

There may be disabling effects from metastatic disease anywhere in the body including -:

- Liver metastases – these may cause pain, fatigue and in the later stages, mental confusion, abdominal swelling or pain and jaundice
- Abdominal bloating /distension due to fluid accumulation (ascites)
- Nausea /vomiting/ sub acute bowel obstruction due to peritoneal metastases – this may result in recurrent hospital admission in advanced disease
- Lung metastases or malignant pleural effusion – may cause very disabling breathlessness reducing mobility to a few yards.
- Brain metastases – these may cause fits, personality change, confusion, difficulties with balance, walking and self care
- Bone metastases – pain and pathological fractures (rare)
How long will the needs last?

In stage 1 and 2 of the disease, recovery from disabling effects of treatment and long term survival is expected. If needs are identified due to effects of treatment, a time limited award is likely to be appropriate. The same applies to stage 3 of the disease for needs arising due to treatment. However treatment is more intensive so it is expected that enduring effects of treatment and associated needs will be more common in this group. Recurrent disease is also common and needs are likely to arise for the first time or re-occur when cancer returns. Indefinite awards may be appropriate for some in this group.

In stage 4 or recurrent disease or where treatment including chemotherapy and surgery is not possible, the woman is likely to be terminally ill. Indefinite awards will usually be appropriate.

Stage 1 and 2 disease

Five year survival from stage 1a or 1b disease is 80-90%.
Five year survival from stage 2 disease is 60-70%.

In the rare situation where an award is appropriate during treatment of stage 1 or 2 ovarian cancer, the award should last for the duration of treatment and then be reviewed.

Stage 3 disease

Five year survival from stage 3 disease is 15-35%.

Stage 4 disease

Five year survival for stage 4 disease is 5-14%.

Metastatic and recurrent disease

This person is likely to be terminally ill although the expected survival may be longer than six months.

After treatment of ovarian cancer the disease may recur often as a growth in either the pelvis or abdominal cavity. The majority of women with ovarian cancer have late stage disease when they are diagnosed. For this reason the majority of women with ovarian cancer will have recurrent disease at some point and most women diagnosed with ovarian cancer will die of the disease eventually.
Stages 1, 2 or 3  Period of treatment plus reasonable recovery period
Stage 4, Metastatic and Recurrent disease  Indefinite award

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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What you need to know about Pancreatic cancer

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What is Pancreatic cancer?
Cancer of the pancreas (also known as pancreatic cancer) is not as common as some other forms, such as lung, breast, bowel or prostate.... Read more on NHS Choices - Pancreatic cancer.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even.... Read more about evidence sources.

Activities of Daily Living and mobility needs
Advanced - This group which includes 80% of those with pancreatic cancer are terminally ill; their median survival even with.... Read more about ADL and mobility needs

How long will the needs last?
Localised (early stage) pancreatic cancer - This group includes only 20% of those with pancreatic cancer.... Read more about award duration

Over 65’s
There are no special features.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- General Practitioner - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- Community or District Nurse - will have information on any home care or outreach package in place as this is coordinated through the practice.
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• Counsellor

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Activities of Daily Living and mobility needs

Advanced Pancreatic Cancer
This group which includes 80% of those with pancreatic cancer are terminally ill; their median survival even with the best treatment is only 6 months. From diagnosis onwards they are likely to have some disabling symptoms including:
• Recurrent jaundice which may require repeat ERCPs (Endoscopic retrograde cholangiopancreatography)
• Upper abdominal pain which may be severe and gnawing in character
• Severe weight loss
• Bowel obstruction or persistent nausea and vomiting
• Any of the symptoms of metastatic disease

Over the next few months they are likely to lose weight and become frailer. They may be unable to walk far or cope with shopping and cleaning. In the terminal phase they are likely to require help with all aspects of personal care. Some will respond very well to palliative treatment, maintain weight and be able to function well for several months before entering the terminal phase.

How long will the needs last?

Localised (early stage) pancreatic cancer
This group includes only 20% of those with pancreatic cancer, they are likely to have presented with painless jaundice and gone on to have major surgery as treatment of their pancreatic cancer. Unless major complications such as pancreatic fistula develop as a result of surgery they are likely to be recovered from surgery and any adjuvant therapy within 6-9 months of starting treatment.

Those with pancreatic fistula will require a year to recover and get back to normal activities. These people are likely to attend hospital very frequently and may have a surgical drain and/or wound dressings to manage for many months. They are likely to be on a supervised diet and take multiple prescribed drugs. They are likely to require help with washing and dressing wounds, possibly with getting dressed and be unable to manage a complex diet and supplements without help or support. Fatigue is likely to limit both mobility and self care.

Once recovery is made from surgery and adjuvant treatment there may be a period of health where normal activities are possible. For some there will be an ongoing need to treat diabetes and take pancreatic enzyme supplements to maintain weight and health. For many this will be a short period, median survival after surgical treatment of early stage pancreatic cancer is only around 2 years. Where treatment is very disabling but long term prognosis is good, an award for the duration of treatment with review is appropriate. Around 15% will still be alive after five years.

Advanced / Recurrent disease
In this group needs are unlikely to be identified unless there are ongoing complications from surgery. Because of the poor outcome for this group
any awards made during treatment should be for an indefinite period. The majority of this group will develop recurrent disease within two years of treatment; they are likely to have any of the symptoms of the advanced cancer group and at this stage once recurrent disease has developed, projected survival is less than six months.

In all cases where needs are identified, it is appropriate to make indefinite awards as life is likely to be short. If disease recurs, survival and disabling effects are as for advanced pancreatic cancer.

Life awards are recommended even if palliative treatment has appeared to restore health.

Hormone producing or ‘islet’ cell tumours.
Needs are unlikely to be identified during treatment except where there are severe complications after surgery – recovery may take up to a year. It is recommended time limited awards are made to coincide with the anticipated end of the recovery period. In the typical case a full return to health is expected. In the rare case where islet tumours are not amenable to surgery or there is metastatic disease treat as an advanced pancreatic cancer case.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Pancreatitis

What is Pancreatitis?
Acute pancreatitis is a serious condition where the pancreas becomes inflamed over a short period of time. ... Read more on NHS Choices - Acute pancreatitis

Chronic pancreatitis is a condition where the pancreas becomes inflamed and the inflammation lasts for many years. ... Read more on NHS Choices - Chronic pancreatitis

What evidence is available?
People whose condition is stable and whose symptoms are controlled by regular medication are likely to be under the care of general practitioners. ... Read more about evidence sources

Activities of Daily Living and mobility needs
People may experience symptoms of fatigue and general debility for some weeks or even a few months after acute pancreatitis. ... Read more about ADL and mobility needs

How long will the needs last?
People with episodes of mild / moderate acute pancreatitis usually recover fully after some weeks with no long term ill effects. ... Read more about award duration

Over 65's
Elderly people may take longer to recover from acute pancreatitis. ... Read more about effects in the over 65 age group

What evidence is available?

Acute Pancreatitis
Reports pertaining to episodes of acute pancreatitis may be obtained from Consultants or general practitioners. Once recovery is complete people are likely to be discharged from hospital outpatient care, and the general practitioner may be the most useful source of current clinical information.
Chronic pancreatitis

People whose condition is stable and whose symptoms are controlled by regular medication are likely to be under the care of general practitioners from whom reports may be obtained. Newly diagnosed cases or those with progressive disease are likely to attend hospital out-patients, usually surgical or gastroenterology clinics.

People with severe pain, including problems with opiate dependency, are likely to attend pain management clinics, from which reports can be requested. Specialist nurses and other health care professionals such as occupational therapists, psychologist’s etc. working in these clinics may be able to provide information.

Additional information may be obtained from community alcohol misuse services, or mental health services, in cases where alcohol misuse is the major coexisting health problem.

An HCP examination report may be the most useful source of up to date information, if the condition is stable with infrequent clinic or GP attendance, or where there are additional disabling effects due to the psychological, physical and cognitive complications of alcohol misuse. Advice from Medical Services should be obtained when the management of chronic pancreatitis is complicated by the co existing problems of alcohol misuse and /or opiate dependency.

Activities of Daily Living and Mobility needs

Acute Pancreatitis

People may experience symptoms of fatigue and general debility for some weeks or even a few months after acute pancreatitis. However these are unlikely to restrict function to such a degree that mobility is limited or help with personal care is needed. Full recovery can be anticipated within a few weeks or months.

Chronic pancreatitis

There is much variation in the amount of abdominal pain experienced by people with chronic pancreatitis, and the resultant degree of functional restriction.

In people with mild levels of functional restriction exacerbations of pain are intermittent, respond to treatment and resolve over the course of several days. It is unlikely that they will need help with self care, preparation of food or be restricted in their walking on a long term basis.
Moderate levels of functional restrictions will be seen in people who require regular prescription of a more complex analgesic regime comprising several drugs, and who may take pancreatic supplements to prevent malabsorption. They may need additional analgesics and other treatments for exacerbations of pain, including hospital admission. Limitations in their ability to bend and stand for prolonged periods may affect their ability to prepare a meal or attend to all aspects of self care independently. Ability to walk long distances may be affected by abdominal pain and decreased muscle bulk, but most should be able to cover reasonable distances.

People with severe long-term pain (i.e. those on complex analgesic regimes including opiates and likely to be attending pain management clinics) may be restricted in their ability to stand, walk, bend, kneel, rise from a chair/toilet. Marked weight loss and poor muscle bulk will cause additional debility. They may need help with self care or cooking a meal; some may have significant problems in walking. Although opiate drugs have sedative effects, these effects are less pronounced in long term users and are unlikely to lead to a need for continuous supervision in the home or out of doors.

Needs may be more complex when there is associated alcohol misuse (see Alcohol misuse guidance). If cognitive impairment is present, there may be additional requirements to supervise medicines, to ensure adequate nutrition to prevent weight loss, to attend to bodily functions etc.

How long will the needs last?

**Acute Pancreatitis**

People with episodes of mild / moderate acute pancreatitis usually recover fully after some weeks with no long term ill effects. Those who have had more severe episodes requiring some time in hospital, or whose recovery has been complicated by development of pseudo-cysts etc. may take several months to make a full recovery. When cholecystectomy is advised in the convalescence phase recovery takes a few weeks longer.

Some people are prone to relapsing episodes of acute pancreatitis, especially if they continue to drink excessive amounts of alcohol.

**Chronic pancreatitis**

There is no curative treatment for chronic pancreatitis once the condition is established. When the cause is alcohol ingestion abstinence is necessary to prevent deterioration. In milder cases, use of analgesics may be intermittent and in some cases attacks of pain will diminish and abate. As the condition worsens long-term use of pain relieving drugs is the norm.
Good relief from the symptoms of malabsorption is possible in many people with pancreatic enzyme supplements, and attention to diet to maintain a reasonable body weight. Once malabsorption is established the need for these formulations is life long.

Following diagnosis only half of the people with the condition survive more than seven years. The worse prognosis is seen in those who continue to drink alcohol. Chronic pancreatitis predisposes to the development of cancer of the pancreas, which typically has a very limited prognosis (6-18 months). Up to one fifth of deaths are due to pancreatic cancer.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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Over 65

Acute Pancreatitis
Elderly people may take longer to recover from acute pancreatitis, in particular if they have had complications or subsequent gallstone surgery. They may have a limited need for help with self care, especially if they have pre existing disabling medical conditions.

Chronic Pancreatitis
Elderly people with chronic pancreatitis are likely to require more assistance with self-care, attention to diet, supervision of medication and help with toilet needs if diarrhoea is a long-term problem. They may also be prone to falls if they are underweight, frail or taking strong analgesics. The development of diabetes mellitus, and in particular the administration of insulin, may increase the requirements for assistance and supervision.

Back to top of section
## What you need to know about Parkinson’s disease

### What is Parkinson’s disease?
Parkinson’s disease is a condition in which part of the brain becomes progressively more damaged over many years (a progressive neurological condition). Read more on [NHS Choices - Parkinson's disease](https://www.nhs.uk/conditions/parkinsons-disease/).

### What evidence is available?
NICE (National Institute of Clinical Excellence) guidance currently recommends that people with suspected PD should be referred by the GP to a specialist in order to confirm the diagnosis and initiate treatment. However, a significant proportion of people with PD will be under the care of the GP alone. Therefore, if further medical evidence is required, and the person is under the care of a specialist, a hospital factual report should be sent. If the person is under the care of the GP alone, a GP factual report should be sent.

### Activities of Daily Living and Mobility needs
People with a mild restriction are likely to have early disease. Read more about ADL and mobility needs.

### How long will the needs last?
PD usually starts with mild unilateral involvement but in the majority of people progresses to bilateral disease with increasing difficulty in activities of daily living and self-care. Read more about award duration.

### Over 65’s
The clinical features and treatment of Parkinson’s disease in the elderly are similar to those in people under the age of 65.

## What evidence is available?
NICE (National Institute of Clinical Excellence) guidance currently recommends that people with suspected PD should be referred by the GP to a specialist in order to confirm the diagnosis and initiate treatment. However, a significant proportion of people with PD will be under the care of the GP alone. Therefore, if further medical evidence is required, and the person is under the care of a specialist, a hospital factual report should be sent. If the person is under the care of the GP alone, a GP factual report should be sent.

### Activities of Daily Living and Mobility needs

#### Mild Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a mild restriction are likely to have early disease. They are likely to have unilateral tremor, normal balance, normal cognition and a UPD rating scale score of 1-10.</td>
</tr>
<tr>
<td>Mobility</td>
<td>The ability to walk is unlikely to be impeded and they would normally be able to find their way around in unfamiliar places.</td>
</tr>
<tr>
<td>Care</td>
<td>The resulting disability is unlikely to affect their ability to independently carry out activities of daily living.</td>
</tr>
</tbody>
</table>

**Moderate Functional Restriction**
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a moderate restriction are likely to have bilateral symptoms of tremor, rigidity and bradykinesia but normal or mildly disturbed balance and rare falls, mild impairment of cognition and a UPD rating scale score of 11-20.</td>
</tr>
<tr>
<td>Mobility</td>
<td>The ability to walk may be impeded and may fluctuate with some falls but they would normally be able to find their way around in unfamiliar places.</td>
</tr>
<tr>
<td>Care</td>
<td>The resulting disability may lead them to require assistance with undertaking complex activities and may require prompting to prepare food, take medication, deal with correspondence and financial matters and undertake appropriate activities. They may require assistance with some aspects of bodily function that includes toileting, washing, dressing, eating and drinking. They are not likely to require supervision to prevent potentially dangerous behaviours or activities.</td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
</tr>
<tr>
<td>----------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Disabling Effects</td>
<td>People with a severe restriction are likely to have bilateral symptoms of tremor, rigidity and bradykinesia and impairment of balance: Dementia, psychosis or confusion; and a UPD rating scale score of 21-30.</td>
</tr>
<tr>
<td>Mobility</td>
<td>The ability to walk is highly likely to be impeded and they would not normally be able to find their way around safely in unfamiliar places.</td>
</tr>
<tr>
<td>Care</td>
<td>The resulting disability is likely to lead them to require assistance with most or even all activities of daily living.</td>
</tr>
<tr>
<td></td>
<td>They are likely to require assistance with most aspects of bodily function that includes toileting, washing, dressing, eating and drinking.</td>
</tr>
<tr>
<td></td>
<td>They are likely to require supervision to prevent potentially dangerous behaviours or activities.</td>
</tr>
</tbody>
</table>

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**How long will the needs last?**

PD usually starts with mild unilateral involvement but in the majority of people progresses to bilateral disease with increasing difficulty in activities of daily living and self-care.

Symptoms confined to one side are often seen early in the disease course (Hemi-parkinsonism). Eventually in those most severely affected, the person becomes bed or chair bound and unable to move. Many people however remain reasonably active but with increasing restrictions until they die from other causes.

The rate of progression is very variable. Prior to the introduction of levodopa the average life expectancy was 9 years. With current treatment life expectancy has improved but is still slightly less than the normal population.
**Staging is as follows:**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>Unilateral involvement only.</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Bilateral involvement without impairment of balance.</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Impairment of balance and functional restriction.</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Fully developed disease retaining ability to walk and stand unassisted but otherwise markedly incapacitated.</td>
</tr>
<tr>
<td>Stage 5</td>
<td>Bed bound or wheelchair bound unless aided.</td>
</tr>
</tbody>
</table>

PD is a progressive condition and there is likely to be no improvement in mobility and care needs.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parkinson’s disease</td>
<td>Indefinite award</td>
<td>G26</td>
</tr>
<tr>
<td>Parkinson’s syndrome / Parkinsonism</td>
<td>Indefinite award</td>
<td>G27</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Peripheral Vascular Disease (PVD)/Peripheral arterial disease (PAD)

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What is Peripheral Vascular Disease (PVD)/ Peripheral arterial disease (PAD)?
Peripheral arterial disease (PAD) is a common but often overlooked condition in which a build-up of fatty deposits (atheroma) in the arteries restricts the blood supply to leg muscles. It is also known as peripheral vascular disease.

Read more on NHS Choices - Peripheral arterial disease (PAD)

What evidence is available?
Self-assessment is the prime source of evidence and in most cases the needs will be clear from the claim pack. … Read more about evidence sources

Activities of Daily Living and mobility needs
With mild functional restriction there are normally no disabling effects which are significant enough to lead to care or mobility needs … Read more about ADL and mobility needs

How long will the needs last?
A person with PVD has a six to seven times greater risk of coronary artery disease, heart attack, stroke … Read more about award duration

Over 65’s
PVD is very common in the elderly, 10% of those over 70 will have symptoms.
… Read more about effects in the over 65 age group

What evidence is available?
Self-assessment is the prime source of evidence and in most cases the needs will be clear from the claim pack, but the claim pack should be checked to see who has completed it and that it is an accurate and reliable description of their problems.
If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.

**Hospital Factual Report**

In cases of moderate and severe peripheral vascular disease, a [Consultant Vascular Surgeon](#) would normally have been involved in the diagnosis, management and treatment of the individual. Indeed the absence of any documented history of a specialist consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required.

**General Practitioner Factual report**

The [General Practitioner](#) would normally have made the initial referral of the claimant to the Consultant, and would normally be aware of the results of tests, and current medication. If there is no specialist health professional involvement, or evidence cannot be obtained from them, then a factual report from the claimant’s own doctor would be more appropriate.

**HCP Examination Report**

An [HCP examination report](#) would be likely to be necessary when the person claims significant disability (equivalent to a moderate or severe condition), but there is no supporting evidence from the GP or Hospital Specialist; if no corroborative evidence has been able to be obtained; or if it is the only means whereby the claimant’s needs can be clarified.

**Medical Services**

The [Medical Services doctor](#) may be asked to request relevant information such as test results from the GP or Hospital Consultant, and to interpret test results and other information.

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**Activities of Daily Living and Mobility needs**

**Mild Functional Restriction**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling effects</td>
<td>With mild functional restriction there are normally no disabling effects which are significant enough to lead to care or mobility needs.</td>
</tr>
</tbody>
</table>
Mobility

A person with mild functional restriction would normally be able to manage to walk more than two hundred metres at a normal or slightly slower pace.

He/she would normally be able to get around in an unfamiliar place without assistance. The person should be encouraged to walk to build up a collateral circulation. Their mobility depends on their lifestyle.

ADL

A person with mild functional restriction would normally be able to cope with all activities of self-care such as getting in or out of a bed or chair unaided, getting on & off the toilet, washing, bathing, dressing him/herself and preparing and cooking a meal. He/she should be able to get about indoors satisfactorily, bend to get food in or out of an oven and self-medicate.

He/she would still normally be able to climb stairs unaided, though he/she may have some calf pain on reaching the top. There would be no supervisory needs.

Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling effects</td>
<td>With moderate functional restriction there are normally no disabling effects, which are significant enough to lead to care needs. There will however be a significant restriction of walking ability as the ‘claudication’ distance will be quite short. These persons may be on a waiting list for surgery, which if successful, normally greatly improves mobility.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with moderate functional restriction would normally only be able to walk a distance of more than 50 metres and less than 100 metres at a slightly slower pace than usual. After a rest he/she can resume walking and manage the same distance as before (this will be constant; it is the ‘claudication’ distance). The recovery time can be quite variable. He/she would normally be able to get around in an unfamiliar place without assistance.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with moderate functional restriction would normally be able to cope with all activities of self-care such as getting in or out of a bed or chair unaided, getting on &amp; off the toilet, washing, bathing, dressing him/herself and preparing and cooking a meal. He/she should normally still be able to bend to get food in or out of an oven and self-medicate. He/she would still normally be able to get about indoors and climb stairs unaided, though he/she may have to stop on the way up and at the top of the stairs. There would be no supervisory needs.</td>
</tr>
</tbody>
</table>
## Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling effects</td>
<td>A person with severe functional restriction may have severe diffuse disease which is not amenable to surgery, or be on the waiting list for surgery, because of the extent of the narrowing of the artery/arteries. They are likely to suffer from rest pain and may have ulceration of the skin of the foot or leg. They may be about to lose a limb or may have lost a limb and would normally have considerable mobility needs and significant care needs.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with severe functional restriction may have one or both limbs amputated and may be wheelchair or bed bound or alternatively may have a prosthetic limb. They may be on the waiting list for surgery and would range from having intermittent rest pain to severe and constant rest pain. He/she would normally, if mobile be only able to walk a few steps at a slow pace, (certainly less than 25 metres), or may not be capable of walking at all. Even a distance of 25 metres can be severely disabling, because of recovery time. However, there are not likely to be any supervisory needs outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with severe functional restriction would normally need assistance with most aspects of self-care, such as getting in and out of bed or out of a chair, getting on and off the toilet, bathing or showering. He/she may not be able to get about unaided in or out of doors. Preparation of a meal may not be possible because he/she may not be able to safely manage hot pans and would be unlikely to be able to bend to an oven satisfactorily. He/she would normally be able to take medication safely. He/she would not be able to manage stairs. At night, he/she may need assistance to change position in bed and to get comfortable. He/she would need help normally in getting out of bed in the night and to get on and off the toilet. However, a bottle could be used instead. The person may be bed bound or chair bound because of greatly reduced mobility. He/she may already have an amputation to one or both legs. The person normally does not require supervision for any aspect of daily living but would normally need to be very careful not to injure their lower limbs because any injuries would be likely to take a very long time to heal or lead to ulceration.</td>
</tr>
</tbody>
</table>
How long will the needs last?

A five year review of patients with claudication has shown that :

- About 75% remain stable or have an improvement in symptoms. These people need to be reviewed, as they may not have disabling effects
- 20% develop worsening claudication
- 5% develop critical ischaemia
- 1% undergo limb amputation

A person with PVD has a six to seven times greater risk of coronary artery disease, heart attack, stroke, or transient ischaemic attack (mini-stroke) than the rest of the population. If a person has heart disease, he/she has a 1 in 3 chance of having blocked arteries in the legs. (Reference: NHLBI US Department of Health & Human Services)

It also depends on what has caused the PVD in the first place:

- Treatment of a single cause (such as an embolus) normally gives good results.
- A supervised exercise regime in persons with chronic lower limb ischaemia, due to generalised arteriosclerosis definitely improves claudication distance.
- Worsening, severe ischaemia in the lower limbs treated with angioplasty or bypass grafting (CABG) produces good results.
- The annual mortality rate of persons with intermittent claudication is greater than 5% (which is 2 to 3 times higher than the “normal” population.
- The annual mortality rate of those with severe disease (severe critical ischaemia) is 25% (mostly from other cardiovascular events such as heart attack or stroke).

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peripheral Vascular disease (PVD) / Claudication</td>
<td>-</td>
</tr>
<tr>
<td>If awaiting surgery</td>
<td>1 year award</td>
</tr>
<tr>
<td>If no surgery is planned</td>
<td>indefinite award</td>
</tr>
<tr>
<td>Buerger’s disease</td>
<td>-</td>
</tr>
<tr>
<td>If awaiting surgery</td>
<td>1 year award</td>
</tr>
<tr>
<td>If no surgery is planned</td>
<td>indefinite award</td>
</tr>
</tbody>
</table>

| Other peripheral arterial disease (excluding coronary) / type not known |- |
| If awaiting surgery                           | 1 year award     |
| If no surgery is planned                      |
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Over 65**

PVD is very common in the elderly, 10% of those over 70 will have symptoms.

They may omit to, or forget to mention symptoms of intermittent claudication or critical ischaemia to their doctor. The symptoms may be masked, if they decrease their exercise levels.

Lifestyle changes, exercise rehabilitation programmes and medical treatment should be offered to and given to elderly patients. Surgical treatment and procedures should be implemented; as long as the patient’s general condition is good enough.
What you need to know about the Personality disorders

What are Personality disorders?
Personality disorders are mental health conditions that affect how people manage their feelings and how they relate to other people. ... Read more on NHS Choices - Personality disorders

What evidence is available?
Self-assessment is the prime source of evidence .... Read more about evidence sources

Activities of Daily Life and mobility needs
The difficulties experienced by a person with a personality disorder (PD) depend upon the type of disorder and the degree to which it is exhibited ... Read more about ADL and mobility needs

How long will the needs last?
Personality disorders (PD) are lifelong conditions so no major change is likely .... Read more about award duration

Over 65's
Some disorders, especially emotional disorders can improve with age and maturation.... Read more about effects in the over 65 age group

What evidence is available?
Self-assessment is the prime source of evidence, but the claim pack should be checked to see who has completed it. If the form has been filled in by the customer, due to the nature of their condition, it might not necessarily be an accurate or reliable description of their problems.

If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.

The DM should bear in mind that the completion of the corroborative statement by a mental health professional does not necessarily mean that they endorse what has been said in the claim pack.
In the vast majority of cases of moderate and severe personality disorders a consultant psychiatrist will have been involved in the management and treatment of the individual. Indeed the absence of any documented history of a psychiatric consultation should raise doubts about the nature and/or severity of the given diagnosis. However in some areas, people with moderate or severe personality disorders may not be referred to psychiatric services. Hospital factual reports should therefore be obtained if they are required and they are available.

An HCP examination report may be helpful if the person has physical problems

Other sources of information include the following:

**Care co-ordinator**
When the customer is being supported by a community mental health team the care co-ordinator on that team will be the preferred source of further evidence.

They have lead responsibility for the delivery of the care plan and so they can give details of the support that the customer has been assessed as needing. They will also know whether the customer is being helped by an Assertive Outreach or Crisis Resolution team.

**Community Mental Health Team**
The community mental health team provides a multidisciplinary team approach. The team will include psychiatrists, community psychiatric nurses, occupational therapists and social workers working in close collaboration with social service departments. One member of the team may co-ordinate the care and is known as the Care Co-ordinator.

**Community Psychiatric Nurse (CPN)**
A customer may be in regular contact with a CPN who will have assessed their care requirements. Advice is given about the amount of psychiatric nursing required and the administration of drugs.

The CPN will be in contact with other mental health professionals. They are well placed to provide detailed evidence about the customer’s needs.

**NHS Care Programme Approach (CPA) care plan**
When the customer is in contact with mental health services there will be a care plan under the NHS Care Programme Approach. The care plan will include information on health and social care as well as domestic support and is reviewed regularly.
The customer is given their own copy, which could be requested, as it will contain useful evidence of needs.

**Social Services care plan**
Social Services departments may be approached for help by someone with mental health problems. A community care assessment by a social worker/care manager will be arranged and a care plan produced.

The care plan will include details of the customer’s day-to-day living and the support provided. A copy can be obtained from the customer.

**Mental Health Social Worker**
Where a mental health social worker has been appointed to support a customer they will have information about the customer’s ability to cope with everyday living.
Subject to consent to approach them being given, the mental health social worker will be able to provide some useful evidence about the customer’s needs.

**Day Centre and Psychiatric Day Hospital**
Attendance at a day centre (not on hospital site) or psychiatric day hospital (on hospital site) is likely to indicate severe disability.

These are therapeutic environments for evaluation, diagnosis and treatment of patients with mental health problems. They are staffed by psychiatric nurses, and there is input from all other members of the community mental health team. Attendance presents an alternative for patients whose condition requires intensive treatment, but do not need to be hospitalised.

**Accommodation manager**
When the customer is living in supported accommodation then the type and level of support provided could be helpful in determining their need for help.
A phone call to the accommodation manager could provide useful evidence.

**Crisis Resolution Team**
The customer may have been supported during a crisis by the Crisis Resolution Team. The teams are mainly comprised of CPNs, who would make urgent visits, day or night to anyone who is thought to be in need of hospitalisation.
The idea is to provide intensive treatment at home instead. The Crisis Resolution Team would be well placed to provide details of the customer’s condition.

**General practitioner factual report**

If there is no specialist mental health professional involvement or evidence cannot be obtained from them, then it may be necessary to request a [GP factual report](#) from the customer’s own doctor.

The GP may have only limited knowledge of customer’s mental health problems, even when there is no one else involved.

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**Activities of Daily Life and Mobility needs**

The difficulties experienced by a person with a personality disorder (PD) depend upon the type of disorder and the degree to which it is exhibited.

There is a continuum of behaviour from the exhibition of a particular personality trait to the actual diagnosis of a personality disorder. Some of these traits may be desirable attributes in particular occupations e.g. obsessional traits in research or in the legal profession and histrionic characteristics in the performing arts.

The different features of the individual personality disorders can affect a person’s functional capacity in specific ways.

Coping with tasks involving contact with others may be affected by people with most of the diagnostic categories, but particularly avoidant, dependent and borderline PD. For example, anxiety and agitation may be so severe as to cause accidents, avoidance behaviour may cause inability to open letters or pay bills, and disturbed self-image may make productive working relationships impossible. People with obsessive compulsive PD may have difficulty in completing tasks within a reasonable period.

Daily living may be affected in schizoid, borderline, narcissistic, avoidant and dependent disorders; self-neglect can be extreme at times, and activities such as shopping or using public transport can cause considerable anxiety. There may be extreme emotional lability in borderline disorders or an abnormal fixation with appearance in narcissistic and histrionic disorders.

Social interaction is affected by all disorders to a greater or lesser extent. The conditions exerting the greatest effect are schizoid (where a person has no interest in relating to others) and avoidant (where he or she fears interaction with others). These people may lead solitary existences without any normal family or social contact. Those with paranoid, schizotypal, narcissistic, obsessive compulsive or histrionic PD may exhibit
interactions with others characterised by bizarre behaviour or beliefs. Antisocial PD may or may not be manifest in day-to-day social interactions.

### Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a mild functional restriction are likely to have some of the following:-</td>
</tr>
<tr>
<td></td>
<td>• Not be receiving psychiatric care or supervision and have no care plan.</td>
</tr>
<tr>
<td></td>
<td>• Be able to enjoy interests and hobbies for most of the time.</td>
</tr>
<tr>
<td></td>
<td>• Be able to do their own shopping, cooking and cleaning.</td>
</tr>
<tr>
<td></td>
<td>• Manage their own finances.</td>
</tr>
<tr>
<td>Mobility</td>
<td>They should not have difficulty finding their way around unfamiliar places and should not require guidance or supervision.</td>
</tr>
<tr>
<td>ADL</td>
<td>They would not normally exhibit significant self-neglect and would not normally put themselves or others at risk of danger. They should not normally have any significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities.</td>
</tr>
</tbody>
</table>

### Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a moderate functional restriction are likely to have some of the following:-</td>
</tr>
<tr>
<td></td>
<td>• Have co morbidity with drug or alcohol abuse or other psychiatric illnesses.</td>
</tr>
<tr>
<td></td>
<td>• Be receiving drug treatment or psychosocial interventions.</td>
</tr>
<tr>
<td></td>
<td>• Be attending psychiatric outpatients or psychiatric day hospital.</td>
</tr>
<tr>
<td></td>
<td>• Be under the care of the community mental health team.</td>
</tr>
<tr>
<td></td>
<td>• Be on a standard care plan.</td>
</tr>
<tr>
<td></td>
<td>• Have had more than one episode of self harm.</td>
</tr>
<tr>
<td></td>
<td>• Left previous employment due to excessive anxiety and inability to cope.</td>
</tr>
<tr>
<td></td>
<td>• Be living with little social contact.</td>
</tr>
</tbody>
</table>
### Mobility

They are unlikely to have any physical difficulty with walking. They are unlikely to have difficulty finding their way around unfamiliar places and are unlikely to require guidance or supervision. They may be reluctant to go out but are unlikely to benefit from having a companion to encourage them to go out.

### ADL

They may have intermittent episodes of self neglect but these are unlikely to last for more than a few weeks at a time. Because of their reluctance to go out, together with their inability to carry out day to day activities in a timely fashion, they may require help with activities such as shopping, preparing meals and management of housing and financial affairs. It should be noted that they may be unwilling to accept help in engaging in social activities. They may engage in risk taking behaviour, for example, unprotected sex or drug taking but presence of a companion is not likely to be able to prevent this.

### Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
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</tr>
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<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a severe functional restriction are likely to have some of the following:-</td>
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<tr>
<td></td>
<td>- Have had a compulsory psychiatric admission in the past.</td>
</tr>
<tr>
<td></td>
<td>- Have had frequent episodes of self harm in the past.</td>
</tr>
<tr>
<td></td>
<td>- Have co morbidity with drug or alcohol abuse or another psychiatric illness.</td>
</tr>
<tr>
<td></td>
<td>- Be living in supported accommodation or homeless.</td>
</tr>
<tr>
<td></td>
<td>- Be on an enhanced care plan.</td>
</tr>
<tr>
<td></td>
<td>- Have bizarre or frightening behaviour towards other people.</td>
</tr>
<tr>
<td></td>
<td>- Have a chaotic unstructured lifestyle.</td>
</tr>
<tr>
<td></td>
<td>- Be living in social isolation.</td>
</tr>
</tbody>
</table>
Mobility

They are unlikely to have any physical difficulty with walking. They may have difficulty finding their way around unfamiliar places and may require guidance or supervision either because they may be considered a danger to themselves or others or because of overwhelming anxiety and lack of self confidence.

ADL

They may have persistent self neglect. Because of their unstable mental state they may require prompting for all activities of daily living such as maintaining hygiene, shopping, preparing meals and management of housing and financial affairs. They may be distressed at night and on occasion this may require someone to watch over them in order to provide reassurance and prevent injury or danger to themselves or others.

How long will the needs last?

Personality disorders (PD) are lifelong conditions so no major change is likely. Some disorders, especially of emotional control, can improve with age and maturation. This is less so for obsessive compulsive, schizoid and paranoid types. Normal individuals tend to become less emotional and impulsive and more cautious and careful with age; a person with a personality disorder less so. People with antisocial personality disorder are usually most destructive in their early life. They are diagnosed most frequently between the ages of 30 and 35 and can “burn out” later in life, becoming less antisocial. Domestic disturbances, child abuse and alcohol abuse may persist.

There is also a higher incidence of death by violence and suicide. Between 30 and 60% of completed suicides retrospectively show evidence of a personality disorder.

People with obsessional personality disorders are at a high risk of progression to Obsessive Compulsive Disorder (OCD) or to depressive illness. People with OCD can be severely functionally restricted and people with obsessive compulsive PD, although they are less anxious than those with OCD, may be equally functionally restricted.

People with paranoid and schizotypal PD may progress to schizophrenia, but those with schizoid PD do not.

Borderline PD carries a relatively favourable prognosis with clinical recovery in over 50% at 10 to 25 year follow up.
The prognosis for personality disorders is improved if the person establishes a stable relationship with another person.

Specialised treatment results in substantial improvement in 1/3 to 2/3 of patients. Specialised treatment may take up to 4 years to achieve full effect. People who do not receive specialised treatment are unlikely to improve in the long term.

Therefore the following awards should be considered:-

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personality disorder</td>
<td>First award - 5 year award</td>
</tr>
<tr>
<td>Receiving specialised treatment</td>
<td>Subsequently - Indefinite award</td>
</tr>
<tr>
<td>Not receiving specialised treatment</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

However, in some cases there is potential for improvement in the condition in the longer term especially if further specialised treatment is received.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Over 65**

Some disorders, especially emotional disorders can improve with age and maturation. This is less so for obsessive compulsive, schizoid and paranoid disorders. Normal individuals tend to become less emotional and impulsive and more cautious and careful with age; a person with a personality disorder much less so. People with antisocial personality disorder are usually most destructive in their early life. They are diagnosed most frequently between the ages of 20 and 35 and can “burn out” later in life, becoming less antisocial. Family difficulties, child abuse and alcohol abuse may persist.

[Back to top of section](#)
What you need to know about Pelvic inflammatory disease (PID)

What is Pelvic inflammatory disease (PID)?
Pelvic inflammatory disease (PID) is a bacterial infection of the female upper genital tract, including the womb, fallopian tubes and ovaries. …….. Read more on NHS Choices - Pelvic inflammatory disease (PID)

What evidence is available?
As there is usually no significant associated long-term disability, or functional impairment, further evidence would not normally be required.

Activities of Daily Living and mobility needs
Although this can be a distressing and painful condition, there is usually no significant associated long-term disability, or functional impairment …..Read more about ADL and mobility needs

How long will the needs last?
Although this can be a distressing and painful condition, there is usually no significant associated long-term disability, or functional impairment …..Read more about award duration

Over 65’s
This is a disease, which affects women of childbearing age.

Activities of Daily Living and Mobility needs
Although this can be a distressing and painful condition, there is usually no significant associated long-term disability, or functional impairment. Women may be temporarily disabled and require some help with certain activities of daily living for short periods of time with e.g., acute infective episodes, and following diagnostic and therapeutic surgical procedures, but there should be no prolonged and/or chronic functional impairment.

Many women live with this condition, and successfully have children and full-time occupations, with only intermittent short periods of disability, during acute exacerbations of their disease.

How long will needs last?
Although this can be a distressing and painful condition, there is usually no significant associated long-term disability, or functional impairment. Women may be temporarily disabled and require some help with certain activities of daily living for short periods of time with e.g., acute infective episodes, and following diagnostic and therapeutic surgical procedures, but there should be no prolonged and/or chronic functional impairment.

Many women live with this condition, and successfully have children and full-time occupations, with only intermittent short periods of disability, during acute exacerbations of their disease.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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What you need to know about a Phlebitis

What is Phlebitis?
Phlebitis is the general term for an inflammation of the wall of a vein which can be caused by several factors. When the vein wall becomes inflamed it can result in the development of thrombosis (blood clot) within the lumen which blocks the flow of blood. It is rare for phlebitis to occur without thrombosis. Phlebothrombosis is the general term for blood-clotting within a vein. If the superficial veins are affected the condition is known as ‘superficial thrombophlebitis’ and as 'deep vein thrombosis' (DVT) when deep veins are involved.

What evidence is available?
In cases with complications or where there is residual severe venous insufficiency.

Activities of Daily Living and Mobility needs
Superficial thrombophlebitis should not present any problems with general bodily function.

How long will the needs last?
Unless there is an associated condition which increases the likelihood of recurrence the prognosis is good with return to normal activity expected in most cases.

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages:
Ageing
Falls
Frailty
What evidence is available?

In cases with complications or where there is residual severe venous insufficiency there may be functional deficit affecting walking and standing. The severity of disability and outlook for these individuals should be evident from information available from a hospital or the General Practitioner.

Activities of Daily Living and Mobility Considerations

Superficial thrombophlebitis

This should not present any problems with general bodily function. An attack is likely to be short-lived and although it can be recurrent the overall effect on function should be negligible. It may occur in association with an underlying condition such as heart, chest or malignant disease which may functional disability in their own right but the overall needs of the individual would need to be assessed in light of the available evidence relating to the other conditions. Other than in the acute phase walking need not be avoided and indeed reasonable exercise is considered to be beneficial for improving venous circulation.

Deep Vein Thrombosis

This is generally a benign treatable condition but can have disastrous effects if it results in thromboembolism. Sudden death can occur in unrecognised disease. However most recover with treatment with no residual limitation of activity. As with superficial vein disease exercise is generally beneficial for improving venous circulation and prevention of further episodes of thrombosis.

How long will the needs last?

Unless there is an associated condition which increases the likelihood of recurrence the prognosis is good with return to normal activity expected in most cases.

In the small number of cases with advanced complications further evidence is needed to evaluate the severity of any residual disability.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about the Plantar Fasciitis

What is Plantar Fasciitis?
The plantar fascia is a tough and flexible band of tissue that runs under the sole of the foot. …… Read more on NHS Choices - Heel pain

What evidence is available?
With successful treatment, and sensible footwear regime there should be no effect on walking ability and full function should be restored.

Activities of Daily Living and mobility needs
With successful treatment, and sensible footwear regime there should be no effect on walking ability and full function should be restored.

How long will the needs last?
With successful treatment, and sensible footwear regime there should be no affect on walking ability and full function should be restored.

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.
Linked pages: Ageing Falls Frailty

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Poliomyelitis

What is Poliomyelitis?
Polio is essentially a disease of the past. However, an increasing number of people who have had polio are developing a condition called post-polio syndrome (PPS). … Read more on NHS Choices - Post-polio syndrome

Poliomyelitis – Decision Makers are advised to discuss with the Departments Medical Services provider

What evidence is available?
Neurologists, specialist nurses in neurological clinics, rheumatologists, orthopaedic surgeons, physiotherapists, occupational therapists, speech therapists and rehabilitation experts may be approached for reports….Read more about evidence sources

Activities of Daily Living and mobility needs
The severity and extent of the functional restrictions after recovery depends on ….Read more about ADL and mobility needs

How long will the needs last?
50% of people with paralytic polio recover completely; the remainder have a variety of residual disabilities ….Read more about award duration

Over 65’s
Elderly people with previous polio may need additional help at an earlier stage due to the additional disabling effects of other medical conditions. Weakness of the lower limbs, deformed joints, poor balance and osteoporosis may also render them more prone to falls and fractures.

What evidence is available?

Acute Poliomyelitis

People recovering from acute paralytic poliomyelitis are likely to have received hospital care from neurologists, physiotherapists, occupational therapists, orthopaedic surgeons and specialists in rehabilitation medicine. General practitioners are also able to provide medical reports. It may be helpful to obtain an HCP Examination Report, if a person’s condition is
stable and they are no longer attending hospital clinics for treatment or follow up. HCP Examination Report is also the most useful option when the infection was contracted and treated abroad, and there are no readily available medical records.

Late Effects of Polio and the Post Polio Syndrome

Neurologists, specialist nurses in neurological clinics, rheumatologists, orthopaedic surgeons, physiotherapists, occupational therapists, speech therapists and rehabilitation experts may be approached for reports. General practitioners may also be unable to provide medical reports. An HCP Examination report is useful in cases where there is no up to date information on the existing level of disability from other sources, or deterioration has occurred since the last assessment.

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Activities of Daily Living and Mobility needs

Acute Poliomyelitis

Following an acute paralytic attack recovery takes place over 12 months and in many cases there are ultimately minimal or mild functional restrictions only. People are able to care for themselves and are not restricted in their ability to walk.

The severity and extent of the functional restrictions after recovery depends on whether both upper and lower limbs are affected, which limb(s) are weak or paralysed, and whether respiratory problems causing shortness of breath persist.

The person who is left with a shortened wasted leg may be restricted in their ability to stand for prolonged periods, to walk far and to bend down. Use of aids such as callipers, orthoptic splints, walking sticks etc. can improve the ability to stand and walk. Some people with severe weakness of both legs may need to use a wheelchair. They may also be prone to falls and unable to walk without support.

Paralysis and weakness of one or both upper limbs may cause difficulties in reaching, lifting, carrying, gripping and carrying out fine movements. The person may need help with washing, dressing, personal hygiene and preparing food. People who have functional restrictions affecting both upper and lower limbs will have a greater need for help from others.

People who require assisted ventilation on a long-term basis may need help from others to use the equipment at home. This is more likely to be the case if they have upper limb weakness or paralysis. Assisted ventilation may only be required overnight. People with residual respiratory difficulties may be short of breath and fatigued when they walk.
Late Effects of Polio and the Post Polio Syndrome

The severity of the functional restrictions in a person with late polio will depend to a large extent on the nature and extent degree of the original disabling effects (see acute poliomyelitis guidance). It is necessary to consider which limbs are affected, whether there is spinal and/or chest deformity and whether there are bulbar symptoms affecting breathing. It is unlikely that existing care needs will lessen significantly in most cases, although replacement of arthritic joints may improve individual limb function.

Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effects</td>
<td>In people with weakness or wasting in one limb only, or with lesser degrees of weakness in two limbs, functional restrictions may be mild.</td>
</tr>
<tr>
<td>Mobility</td>
<td>They are able to walk reasonable distances without undue difficulty. Function may be improved by provision of new aids, joint replacement and rehabilitation as described above.</td>
</tr>
<tr>
<td>ADL</td>
<td>They are able to care for themselves. Function may be improved by provision of new aids, joint replacement and rehabilitation as described above.</td>
</tr>
</tbody>
</table>

Moderate Functional Restriction
## Effects

The degree of functional restriction is likely to be greater if the function of more than one limb is affected by the original illness, or by the presence of arthritis or deformity of the non-affected limb. Increased muscle weakness and wasting in affected limbs will further restrict function. Moderate functional restriction will also be present if pain from spinal deformities and spinal arthritis affects arm and/or leg use. Fatigue and shortness of breath may also restrict activities.

## Mobility

If the lower limbs are affected there may be restricted walking, that is exacerbated by pain, fatigue and shortness of breath.

## ADL

People with moderate functional restrictions may take longer to carry out tasks than previously. Many are likely to need some help with certain aspects of self-care and/or food preparation.

### Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Effects</strong></td>
<td>Severe functional restriction is most likely when both upper and lower limbs are weak, wasted and paralysed. Associated spinal conditions, deformity of the spine and/or chest may be present.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>People are likely to be using wheelchairs and other aids or walking may be significantly reduced by pain, fatigue and shortness of breath.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>They may already have home adaptations to aid function and enable independent living. The use of mechanical ventilation at home is likely to an indication of more severe levels of functional restriction. The time taken to carry out tasks may be significantly reduced by pain, fatigue and shortness of breath. People with severe functional restrictions are likely to need help with all aspects of dressing, personal hygiene and food preparation. They may need help to feed and to drink, and with using aids e.g. to assist respiration. Help may be needed to move around the house, to manage stairs, to rise from a chair, to use the toilet and to get in and out of wheelchair.</td>
</tr>
</tbody>
</table>

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How long will the needs last?

Acute Poliomyelitis

50% of people with paralytic polio recover completely; the remainder have a variety of residual disabilities. Paralysed muscles continue to recover over several months; however paralysis still present at 12 months tends to be permanent.

Since the acute disease is often contracted in childhood or adolescence before growth is complete, the disabling effects may be complicated by the normal development of the rest of the body. For example, while one leg may be wasted and paralysed by the disease, the other leg will however grow normally. This results in the affected leg becoming shorter than the normal leg. Similarly abnormal development of one upper or lower limb may lead to curvature of the spine causing deformity of the trunk. The chest may become deformed due to unequal muscle development predisposing to recurrent infections and breathing problems.

Although recovery of the respiration usually occurs, some people may need long-term assistance with breathing. They may continue to require mechanical ventilation at night, because weakened respiratory muscles function less effectively when the person lies down. During the day they are able to breathe spontaneously. Some people who have had bulbar polio have long-term difficulties with swallowing and speech.

In cases of polio contracted in childhood or adolescence the pattern and extent of the residual disabling effects stabilise by the early twenties.

Late Effects of Polio and the Post Polio Syndrome

Functional improvement for the individual is the aim of the multidisciplinary management described above, and many people can be helped in this way. Recognition of late functional deterioration and the post polio syndrome does not necessarily imply that the condition is progressive in that person, or that significant deterioration in function should be anticipated in the future. The condition often stabilises.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poliomyelitis / Post Poliomyelitis syndrome</td>
<td>First award period - 5 year award</td>
</tr>
<tr>
<td></td>
<td>Subsequently - Indefinite award</td>
</tr>
</tbody>
</table>
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Polycythaemia

What is Polycythaemia?
Polycythaemia means having a high concentration of red blood cells in your blood. Read more on NHS Choices - Polycythaemia

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and Mobility needs
Symptoms are many and varied but are usually not severe. Read more about ADL and Mobility needs

How long will the needs last?
Symptoms are many and varied but are usually not severe. Read more about award duration

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.
Linked pages:
Ageing
Falls
Frailty

Activities of Daily Living and Mobility needs
Symptoms are many and varied but are usually not severe, and do not normally cause any significant impairment of mobility, or the ability to carry out all the various activities of daily living.

Treatment usually brings about relief of many symptoms. People may suffer functional impairment and disability as the result of primary medical conditions causing polycythaemia, and also following certain complications of polycythaemia e.g. stroke.

None of the types of polycythaemia are infectious. The condition cannot be passed on to family or friends.
How long will the needs last?

Symptoms are many and varied but are usually not severe, and do not normally cause any significant impairment of mobility, or the ability to carry out all the various activities of daily living.

Prognosis in Polycythaemia Vera is approximately 14 years with treatment, 30% will develop Myelofibrosis, and 5% Acute Leukaemia.

<table>
<thead>
<tr>
<th>Impairment and complications</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Polycythaemia vera causing a stroke</td>
<td>Less than 2 years</td>
<td>2 year award</td>
</tr>
<tr>
<td>Polycythaemia vera causing IHD -:</td>
<td>More than 2 years</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Awaiting surgery (PTCA or CABG)</td>
<td>N/A</td>
<td>1 year award</td>
</tr>
<tr>
<td>Not awaiting surgery</td>
<td>N/A</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Prognosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secondary polycythaemia</td>
<td>The condition should be successfully treated and resolved within 6 months of diagnosis and no persisting functional restrictions would be present.</td>
</tr>
<tr>
<td>Polycythaemia vera - without complications</td>
<td></td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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What you need to know about Polymyalgia Rheumatica

What is Polymyalgia Rheumatica?
Polymyalgia rheumatica is a condition that causes pain and stiffness in the muscles around the shoulders, neck, buttocks and hips because of inflammation. Read more on NHS Choices - Polymyalgia rheumatica

What evidence is available?
Self-assessment is the prime source of evidence. Read more about evidence sources

Activities of Daily Living and mobility needs
A person’s care and mobility needs should be assessed in relation to their symptoms and response to treatment. Read more about ADL and mobility needs

How long will the needs last?
Polymyalgia Rheumatica normally improves dramatically with treatment. Read more about award duration

Over 65’s
It is a disease which is not diagnosed under the age of 55. Read more about effects in the over 65 age group

What evidence is available?

Claim pack
Self-assessment is the prime source of evidence.
If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it would provide good evidence.

GP
A GP factual report should provide information about the patient’s condition, as often they are treated by the GP, without being referred to the Hospital Consultant.
Hospital factual Report

In the absence of a GP factual Report, a report from a Hospital Consultant would provide information about investigations, treatment, response to the treatment, condition of the patient, and visits to the clinic.

HCP Examination Report

An HCP visit providing history and examination may be necessary in the absence of any other available corroborative evidence, if there is contradictory information or if it is the only means by which the claimant’s needs can be clarified.

Medical Services

Medical Services are available to interpret information including investigation results, and also to request relevant information from the GP or hospital Consultant.

Activities of Daily Living and Mobility needs

A person's care and mobility needs should be assessed in relation to their symptoms and response to treatment. Depending on the severity of the symptoms, a person may have difficulties with the following activities:

Self-care

Getting in and out of bed, washing, bathing including getting in and out of the bath, going to the toilet, dressing and undressing, preparing a meal, walking in the house, and climbing stairs.

Mobility

Walking on the flat may be impaired by muscle pain and stiffness.

However, response to treatment is usually quite rapid; the person feels better in a matter of days rather than weeks. These needs may be present for a short time only and that is usually a few weeks at the most.

In summary, treatment should alleviate the symptoms and the person should have few or no care needs arising from Polymyalgia Rheumatica (PMR).

How long will the needs last?
Polymyalgia Rheumatica normally improves dramatically with treatment, so care and mobility needs may only be present for a few weeks at the most, though steroid treatment is likely to need to continue for at least 2 years.

The only disabling effects would be from vascular complications such as complete or partial loss of vision or stroke.

Click the link for details of:-
Visual Impairment
Stroke

Also, bearing in mind the side effects of long-term steroid use, there may be associated problems (such as osteoporosis, weight gain, diabetes and high blood pressure) and the maintenance dose should be kept as low as possible. Also osteoporosis prevention medication should be used (usually calcium and vitamin D and a biphosphonate).

Sudden blindness may be permanent, and if a stroke (rarely) occurs, there will not be likely to be improvement after 2 years.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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Over 65

It is a disease which is not diagnosed under the age of 55.

The most problematic factor is the dependence on long-term steroids and the side-effects caused by this treatment. Side-effects are less if the maintenance dose is kept below 7.5mg per day. Azathioprine may be used to reduce the dose of steroid.

Medication to prevent osteoporosis (calcium and Vitamin D and a biphosphonate such as disodium etidronate) should be routinely used but particularly in the older person.
What you need to know about Post Traumatic Stress Disorder

What is Post Traumatic Stress Disorder?
Post-traumatic stress disorder (PTSD) is an anxiety disorder caused by very stressful, frightening or distressing events. Read more on NHS Choices - Post-traumatic stress disorder

What evidence is available?
It is vital to have corroborating evidence of the severity and nature of the precipitating trauma. Read more about evidence sources

Activities of Daily Living and mobility needs
Having functional impairment is part of the diagnosis of PTSD. Read more about ADL and mobility needs

How long will the needs last?
Long term outcome depends upon initial symptom severity, duration of illness, social support and past history. Read more about award duration

Over 65’s
PTSD in elderly people usually results from exactly the same reasons as any other age group. Read more about effects in the over 65 age group

What evidence is available?
It is vital to have corroborating evidence of the severity and nature of the precipitating trauma and the initial reaction and help seeking behaviour of the person to the trauma. Examples of suitable evidence might include asking the person for a copy of a Criminal Injuries Compensation Board (CICB) report if available or requesting a factual report from an appropriate Health Care Professional.

Activities of Daily Living and Mobility needs
Having functional impairment is part of the diagnosis of PTSD. If there is no functional impairment another diagnosis should be considered.
## Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a mild functional restriction are likely:-:</td>
</tr>
<tr>
<td></td>
<td>• Not to have been referred for trauma focussed psychological treatment</td>
</tr>
<tr>
<td></td>
<td>• Be under GP care only</td>
</tr>
<tr>
<td></td>
<td>• Not be attending day centre or day hospital</td>
</tr>
<tr>
<td></td>
<td>• Have no associated psychiatric disorder</td>
</tr>
<tr>
<td>Mobility</td>
<td>They will have no physical difficulty in getting around.</td>
</tr>
<tr>
<td></td>
<td>They should not have difficulty finding their way around unfamiliar places</td>
</tr>
<tr>
<td></td>
<td>and should not require guidance or supervision.</td>
</tr>
<tr>
<td>ADL</td>
<td>They should not normally exhibit significant self-neglect.</td>
</tr>
<tr>
<td></td>
<td>They should not normally have any significant functional loss that will</td>
</tr>
<tr>
<td></td>
<td>result in a reduction of their ability to carry out normal day-to-day</td>
</tr>
<tr>
<td></td>
<td>activities.</td>
</tr>
</tbody>
</table>

## Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a moderate functional restriction are likely to:</td>
</tr>
<tr>
<td></td>
<td>• Have current involvement of or awaiting assessment by counsellor, CPN,</td>
</tr>
<tr>
<td></td>
<td>psychologist, occupational therapist</td>
</tr>
<tr>
<td></td>
<td>• Not be attending day centre or day hospital</td>
</tr>
<tr>
<td></td>
<td>• Have mild associated psychiatric disorder(s)</td>
</tr>
</tbody>
</table>
### Mobility

They will have no physical difficulty in getting around. They should not have difficulty finding their way around unfamiliar places and should not require guidance or supervision.

### ADL

They should not normally exhibit significant self-neglect. They should not normally have any significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities.

### Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
</table>
| Disabling Effects | People with a severe functional restriction are likely to:  
  - Be unable to resume their occupation because of avoidance behaviour  
  - Have been treated with trauma focussed psychological treatment and drug treatment (drug treatment at maximum tolerated limit or use of olanzapine)  
  - Have current involvement of or awaiting assessment by psychiatrist within the community mental health team  
  - Attend day centre or day hospital or be discharged due to failure to respond to treatment or failed to attend due to severity of symptoms  
  - Have severe associated psychiatric disorder(s)                                                                                                                                                                                                                                                                                                                                                                                                                                   |
### Mobility

They will have no physical difficulty in getting around. Their psychological avoidance may make it difficult for them to carry out certain activities, depending upon the nature of the traumatic event. For example they may have difficulty getting into a car, getting onto a bus or the tube etc. Alternatively they may only be able to carry out these activities with a companion for reassurance. However, they are unlikely to be unable to find their way around in unfamiliar surroundings.

### ADL

The majority of people will have no care requirements. However, in a minority, if there is a severe associated psychiatric disorder, the following care requirements may be necessary:

- Need encouragement to get out of bed in the morning
- Need encouragement to wash, dress and maintain hygiene
- Assistance in preparing meals
- Encouragement to go out and engage in social activities
- Help with domestic crises
- Assistance with taking medication and obtaining prescriptions
- Attendance at doctors appointments, hospital appointments and day hospital
- Help with correspondence, financial matters and paying bills

---

**How long will the needs last?**

Long term outcome depends upon initial symptom severity, duration of illness, social support and past history. In general people with PTSD who have no previous history and normal stable backgrounds tend to have a good prognosis.
People who fail to recover tend to have coexisting or previous psychiatric history or a complicating factor such as depression or substance abuse. The prognosis for people with severe initial symptoms is worse than for people with less severe initial symptoms. The prognosis is worse the longer the duration of the illness. About half of people with PTSD will recover within 12 months. About two thirds of people with PTSD will recover within 6 years. One third of people with PTSD have a chronic illness lasting more than 6 years. Therefore the following awards should be considered:

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post Traumatic Stress Disorder (PTSD)</td>
<td>First award period – 1 year award</td>
</tr>
<tr>
<td></td>
<td>Second award period – 5 year award</td>
</tr>
<tr>
<td></td>
<td>Subsequently - Indefinite award</td>
</tr>
</tbody>
</table>

However, in some cases there is potential for improvement in the condition in the longer term.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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Over 65

PTSD in elderly people usually results from exactly the same reasons as any other age group, for example as a result of being a victim of crime or violence. Very occasionally it can result from problems earlier in life. Symptoms may be persistent or intermittent, and the disorder may be time-limited or chronic. Increasing severity of trauma and pre-morbid psychiatric illness predispose to the development of PTSD, and certain personality traits and good psychosocial support protect against it. Elderly people do not appear more predisposed than young persons to develop PTSD, and symptoms of the disorder are similar to those in younger people. Treatment is identical to that of younger people although no research has been carried out on the treatment of PTSD in the elderly.
What you need to know about Primary biliary cirrhosis

What is Primary biliary cirrhosis?
Primary biliary cirrhosis (PBC) is a type of chronic (long-term) liver disease. Read more on NHS Choices - Primary biliary cirrhosis.

What evidence is available?
Most cases of primary biliary cirrhosis will have been diagnosed and assessed in a hospital clinic. Read more about evidence sources.

Activities of Daily Living and mobility needs
People with minimal symptoms are likely to have few functional restrictions. Read more about ADL and mobility needs.

How long will the needs last?
People with few or no symptoms at diagnosis develop some symptoms within five to seven years. Read more about award duration.

Over 65's
Over 25% of cases present over the age of 65 years. Increasing age tends to be associated with a worse prognosis. Disabling complications such as malnutrition, muscle weakness and osteoporosis are likely to be prominent and care needs will be greater.

What evidence is available?
Most cases of primary biliary cirrhosis will have been diagnosed and assessed in a hospital clinic. They will be followed up in gastroenterology or specialist liver clinics to monitor treatment response and to determine when referral for liver transplantation should be considered. Hospital reports may be obtained from hospital doctors and specialist nurses working in these clinics.

People with early disease or whose condition progresses slowly, may visit the hospital infrequently. General Practitioner factual reports will confirm the diagnosis, provide details of drug treatment and information about other medical conditions that may contribute to care and mobility needs.

It may be appropriate to consider a claim under Special Rules for people with this condition who develop hepato-cellular carcinoma.
Activities of Daily Living and Mobility needs

People with minimal symptoms are likely to have few functional restrictions. This situation may pertain for a number of years and they will have no care and mobility needs. As the disease progresses severe fatigue may limit daily activities. The severity of the fatigue may not correlate closely with other symptoms and signs of the disease. When severe it may lead to a need for help with personal care and limit ability to walk. Other factors such as low body weight, muscle weakness, bone pain, increasing jaundice etc. may limit function. People will have difficulties rising from a chair, using the toilet, preparing food, walking around the house, climbing stairs.

People with the late complications including advanced liver failure, ascites and portal hypertension are likely to need care and have reduced mobility. This will include those waiting for a transplant for end stage failure, most of who may be considered to be in the terminal phase.

If evidence shows that the customer has liver failure, which may have resulted from primary biliary cirrhosis then go to Liver Failure guidance.

For further information about cirrhosis please see Cirrhosis guidance.

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How long will the needs last?

People with few or no symptoms at diagnosis develop some symptoms within five to seven years. Progression is however very variable and some people remain relatively well for many years, surviving at least twenty years. Overall the disease reduces life expectancy.

Factors associated with a poor outlook are weight loss, hepatomegaly (enlarged liver), splenomegaly (enlarged spleen), increasing age, increasing jaundice and evidence of impaired liver function. People presenting with jaundice survive on average less than five years.

One year survival after transplantation is 85-90% with a good outlook thereafter.

In about 10% of people undergoing transplantation the disease recurs in the new liver a few years later.

For further information about cirrhosis go to Cirrhosis guidance.
If evidence shows that the customer has liver failure, which may have resulted from primary biliary cirrhosis then go to [Liver Failure](#) guidance.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary biliary cirrhosis (PBC) – No transplant surgery planned</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Successful liver transplantation</td>
<td>N/A</td>
</tr>
<tr>
<td>Liver transplant with rejection of liver</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant. [Back to top of section](#)
What you need to know about Prostate cancer

Back to A - Z

What is Prostate cancer?
The prostate is a small gland in the pelvis that is found only in men. Read more on NHS Choices - Prostate cancer.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Activities of Daily Living and mobility needs
Treatments such as radical radiotherapy or prostatectomy have significant long term side effects for some men. Read more about ADL and mobility needs.

How long will the needs last?
Treatment and recovery is likely to take up to a year. Read more about award duration.

Over 65's
Many prostate cancers behave benignly; they do not spread beyond the prostate or cause any disabling effects. Read more about effects in the over 65 age group.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a 'Care plan' from social services
Hospital
Specialist doctors -:
- Oncologist
- Physician
- Haematologist

Specialist nurses have many different job titles -:
- Clinical Nurse Specialist
- Stoma care nurse
- Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
- Physiotherapist
- Occupational Therapist
- Social worker
- Counsellor
- Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
- Palliative Care Physician
- Macmillan Nurse
- Clinical Nurse Specialist
- Social worker
- Physiotherapist
- Occupational Therapist
- Counsellor

Activities of Daily Living and Mobility needs

Localised prostate cancer that has never required treatment
Typically, there are no disabling effects.
Localised prostate cancer treated by radical radiotherapy or surgery

Treatments such as radical radiotherapy or prostatectomy have significant long-term side effects for some men. These include urinary incontinence and impotence after treatment and diarrhoea after radical radiotherapy. A return to normal activities is expected in the majority of cases. 5-10% of men are likely to be very affected by ongoing side effects 12 months after treatment. If needs are present at this stage they are likely to persist.

Locally advanced, metastatic or recurrent disease

Treatment such as radiotherapy may cause significant fatigue and diarrhoea. There may be any of the effects of metastatic disease but bone metastasis are particularly common and are painful. Metastases in the spine are common and back pain may significantly affect the ability to walk. Medication for pain may increase fatigue. Spinal cord compression may cause lower limb problems from numbness and unsteady gait to paralysis of the legs with bladder and bowel control problems. These may or may not resolve with appropriate treatment, it is a sign of advanced disease.

Hormone therapy causes significant and sometimes distressing changes in body image, hot flushes and fatigue. Once hormone therapy treatment has stopped working, any disabling effects of disease are likely to be permanent or get worse. Survival after treatment has stopped working is likely to be in the range of 4-18 months. Needs are likely develop in this group and increase over time.

How long will the needs last?

Localised prostate cancer treated by radical radiotherapy or surgery

Treatment and recovery is likely to take up to a year. Needs identified as a result of treatment of side effects would be expected to resolve on return to health. Small numbers of men will experience ongoing side effects at one year and these men are likely to have ongoing needs. Long term side effects of treatment may arise years later and give rise to needs, which are also likely to be ongoing.

Locally advanced, metastatic or recurrent disease

Once needs are identified these are likely to continue and may increase as disease progresses. Life awards are recommended.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate cancer</td>
<td></td>
</tr>
</tbody>
</table>
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Over 65

Many prostate cancers behave benignly; they do not spread beyond the prostate or cause any disabling effects. Such a person is likely to be on no treatment for their prostate cancer although they may have had some surgery to improve their urine flow. They will be kept under ‘active surveillance’ to make sure treatment starts as soon as it is needed. This type of prostate cancer is rare in men under 50 and common in men over 70.

Back to top of section
What you need to know about Rheumatoid arthritis

Back to A - Z

What is Rheumatoid arthritis?
Rheumatoid arthritis is a condition that causes pain and swelling in the joints. Hands, feet and wrists are commonly affected, but it can also damage other parts of the body. ….. Read more on NHS Choices - Rheumatoid arthritis

What evidence is available?
The claimant and/or carer is unlikely to be able to provide the information required to accurately assess mobility and care needs. Further details should be obtained from the General Practitioner or Consultant.

Activities of Daily Living and Mobility needs
The overall level of functional restriction will depend upon the number of joints affected and the combination of upper and lower limb involvement.

How long will the needs last?
Duration of functional limitations will depend on the length of time the person has had Rheumatoid Arthritis. Read more about award duration

Over 65’s
Although the most frequent age of onset is 35 to 55 years, RA not infrequently occurs for the first time in older people, up to age 70 and older. Read more about effects in the over 65 age group

What evidence is available?

The claimant and/or carer is unlikely to be able to provide the information required to accurately assess mobility and care needs. Further details should be obtained from the General Practitioner or Consultant.

Activities of Daily Living and Mobility needs
The overall level of functional restriction will depend upon the number of joints affected and the combination of upper and lower limb involvement.
## Activities of Daily Living and Mobility needs

### Lower limb – Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with this level of functional restriction would not have any noticeable disabilities on an everyday basis. Pain, discomfort, joint swelling and/or stiffness will often be low grade or minimal, and normally wears off quite quickly as the person “limbers up” in the morning. Although there may be exacerbations, these would be infrequent and not occur on a regular basis.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>A person with mild restriction would normally have no physical difficulty in getting around. Nor would they require guidance or supervision outdoors.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>A person with mild restriction would normally be able to dress independently and put on socks and shoes, using simple technical aids if required. The ability to rise from sitting, attend to own toilet needs and prepare a main meal would not be impaired to any significant degree. Such a person would normally be capable of maintaining personal hygiene. They would have little or no functional limitation on a day-to-day basis arising from any symptoms and would not need supervision or watching over.</td>
</tr>
</tbody>
</table>
**Disabling Effects**

People with this level of functional restriction may experience persistent swelling (effusions) of their hips, knees, ankles and/or feet. Deformity of some or all of these joints may be present. There may be instability of one or both knees. Pain and joint stiffness would be present on rising in the morning, or following prolonged inactivity, for up to one hour. However, there may be periods of “flare-ups” when increased help is needed with self-care. A “flare-up” typically lasts between 10 to 14 days.

**Mobility**

A person with moderate restriction may have significant difficulty getting around in terms of distance due to an abnormal gait, walking stiffly and with a limp. They will be unable to walk at normal speed and distance is likely to be in the range of 40-100 metres. Such a person may need physical assistance from another person in getting around and may require guidance or supervision outdoors on account of an increased risk of falling.

**ADL**

A person with moderate restriction may have difficulties with getting out of a normal height chair, out of bed, rising from a toilet and getting out of a bath. These problems would normally be most severe after resting. The use of prescribed assistive equipment such as a raised chair, a raised toilet seat or grab rails may help to reduce these difficulties. Such a person may have knee instability, which could indicate risk of falls, though use of prescribed assistive equipment such as a stick may help to reduce this. No supervision or watching over needs are likely to be present.

### Activities of Daily Living and Mobility needs

#### Lower limb – Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
</table>


| **Disabling Effects** | People with this level of functional restriction would have gross lower limb joint deformity and restriction of joint movement. They may be on the waiting list for hip, knee or ankle replacement surgery, or for surgery to correct foot and/or toe deformities. Pain and/or stiffness would be present for up to two hours after rising, and may affect the person during the night.

A person with severe restriction would have joint destruction with marked deformities and weakness of ligaments, tendons and muscles. This would lead to an increased risk of falls and reduced mobility. |
|---|
| **Mobility** | Mobility may be impaired, with active inflammation (flare-ups) of lower limb joints. When the feet are affected, there may be severe pain on walking. If the knees and hips are involved, standing and sitting can be difficult and painful, and mobility will be restricted even further. Joint instability may also occur. Instability affecting the knee joint will lead to an increased risk of falls with restriction of mobility.

A person with severe restriction would need physical assistance from another person in getting around and may require guidance or supervision outdoors on account of an increased risk of falling. |
| **ADL** | Such a person would need assistance from another person with dressing and washing, getting out of bed and attending to toilet needs, and to prevent falls. Help may be needed with care needs during the day for much of the time. |
### Activities of Daily Living and Mobility needs

**Upper Limb Condition – Mild Functional Restriction**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with this level of restriction are unlikely to have any noticeable disabilities on an everyday basis. Pain, discomfort, joint swelling and/or stiffness will often be low grade or minimal, and normally wears off quite quickly as the person “limbers up” in the morning. Although there may be exacerbations, these would be infrequent and not occur on a regular basis. They are probably would not have any significant long-term care or mobility needs.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>A person with mild restriction would normally have no physical difficulty in getting around. Nor would they require guidance or supervision.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>A person with mild restriction would normally be able to dress independently, including managing buttons, and put on socks and shoes, using simple technical aids if required. The ability to rise from sitting, attend to own toilet needs and prepare a main meal would not be impaired to any significant degree. Such a person would normally be expected to be capable of maintaining personal hygiene. They would have little or no functional limitation on a day-to-day basis arising from any symptoms and would not need supervision or watching over.</td>
</tr>
</tbody>
</table>
## Activities of Daily Living and Mobility needs

### Upper Limb – Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with this level of restriction may experience persistent swelling (effusions) of their fingers, shoulder, elbow and/or wrist. Deformity of some or all of these joints may be present, together with reduced range of movement. Pain and joint stiffness would be present on rising in the morning, or following prolonged inactivity, for up to one hour. Painful and/or restricted neck movements may occur, but without any neurological signs (pins and needles) in the arms. However, there may be periods of “flare-ups” when increased help is needed with self-care. A “flare-up” typically lasts between 10 to 14 days.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>A person with moderate restriction would normally have no physical difficulty in getting around. Nor would they require guidance or supervision.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>A person with moderate restriction may need help with getting out of bed, and with dressing and washing. Reliance on simple kitchen aids and prescribed assistive equipment such as dressing aids or the occasional use of splints is probable. The ability to care for themselves during the majority of the day however, including preparing a main meal for one, would not be significantly restricted. They</td>
</tr>
</tbody>
</table>


would not need supervision or watching over.

Activities of Daily Living and Mobility needs

Upper Limb – Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with this level of functional restriction would experience gross joint deformity and/or restriction of joint movements. They may be on the waiting list for shoulder, elbow or wrist replacement surgery, or for surgery to realign or replace a finger or thumb. Pain and/or joint stiffness would be present for up to two hours after rising, and may affect the person during the night. Painful and/or restricted neck movements may occur accompanied by neurological signs (pins and needles) in the arms.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with severe restriction may need physical assistance from another person in getting around due to difficulty in gripping and/or holding prescribed mobility aids. They would not require guidance or supervision.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with severe restriction would need help with getting out of bed, dressing and washing, attending to toilet needs and preparing a main meal. Due to deformity, weakness of muscles, ligaments and tendons, grip would be significantly impaired. Some people may experience further impairment of grip and upper limb function due to loss of sensation and ‘pins and needles’ in the arms. These problems may lead to an inability to adequately grip crutches or other mobility aids, making any mobility restriction worse.</td>
</tr>
</tbody>
</table>
Such a person may need assistance with getting out of bed, help with dressing and washing and help with attending to toilet needs. They may need someone to assist in rising from a chair and with cutting up certain foods and with main meal preparation. They would not need supervision or watching over.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rheumatoid arthritis</td>
<td>Less than 4 years</td>
<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 4 years</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Rheumatoid Arthritis in people over 65**

Although the most frequent age of onset is 35 to 55 years, RA not infrequently occurs for the first time in older people, up to age 70 and older.

Clinical features are similar to those in a younger age group. Usually the onset is insidious with development of joint stiffness and swelling over several months. In about a quarter of people, the onset takes place more rapidly, over a period of days or weeks, and is associated with more generalised symptoms that may include night sweats and fever.

Some people with RA have a decline in disease activity and are left with residual disability due to joint damage.

In others, the disease remains active and they continue to develop new nodules and associated sequelae of RA, such as vasculitis.
The principles of treatment are similar to those in younger people. There are some noticeable differences however, and these include:

Treatment goals should take into account other disabilities. For example, major joint surgery may not be considered appropriate in elderly people with major deformities of the feet or other problems that preclude eventual walking or independence.

Treatment goals may need to be scaled down in people with significant cognitive impairment.

Many people may be depressed, and this may require treatment in its own right.

Undernutrition is a common problem and requires careful assessment and treatment.

Social support and the provision of assistive equipment and environmental modifications should take high priority.

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What you need to know about Rodent ulcer/Basal cell carcinoma

What is a Rodent ulcer?
Skin cancer is one of the most common cancers in the world. Non-melanoma skin cancer refers to a group of cancers that slowly develop in the upper layers of the skin. …… Read more on NHS Choices - cancer of the skin

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and mobility needs
With early and successful treatment this condition is unlikely to cause any functional or mobility problems ……. Read more about ADL and mobility needs

How long will the needs last?
With early and successful treatment this condition is unlikely to cause any functional or mobility problems…. Read more about award duration

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages:
Ageing
Falls
Frailty

Activities of Daily Living and Mobility needs
With early and successful treatment this condition is unlikely to cause any functional or mobility problems.

If untreated, the tumour would grow larger and would ulcerate and bleed. If near the eye or mouth, the tumour could grow into these structures and lead to blindness or perforation. In some people who refuse treatment or do not seek help, the tumour can become very large and disfiguring. With ulceration, infection can get into the skin and the tumour can become weepy and smelly. The tumour is unlikely to cause death unless a vital structure such as a main artery is affected. As these tumours are normally very curable, treatment should be given as soon as possible.
How long will the needs last?

With early and successful treatment this condition is unlikely to cause any functional or mobility problems.

If untreated, the tumour would grow larger and would ulcerate and bleed. If near the eye or mouth, the tumour could grow into these structures and lead to blindness or perforation. In some people who refuse treatment or do not seek help, the tumour can become very large and disfiguring. With ulceration, infection can get into the skin and the tumour can become weepy and smelly. The tumour is unlikely to cause death unless a vital structure such as a main artery is affected. As these tumours are normally very curable, treatment should be given as soon as possible.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about a ruptured tendon

What is a ruptured tendon?
For information about the site of a ruptured tendon discuss with Medical Services. Read more on NHS Choices - Tendonitis

What evidence is available?
There would normally be no significant restriction of ADL s or in the ability to get around in cases of a ruptured tendon and therefore further evidence would not usually be required.

Activities of Daily Living and Mobility needs
Provided treatment of the ruptured tendon is successful, full function should be restored within 4-6 months. Older people may find that healing is not rapid but with rehabilitation there should be minimal functional effects.

How long will the needs last?
Provided treatment of a ruptured tendon is successful, full function should be restored within 4-6 months. Older people may find that healing is not rapid but with rehabilitation there should be minimal functional effects.

Over 65’s
There are no significant special features of a ruptured tendon in the elderly. You may wish to consult the following pages:
Ageing
Falls
Frailty

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Schizophrenia

Back to A - Z

What is Schizophrenia?
Schizophrenia is a long-term mental health condition that causes a range of different psychological symptoms. ...... Read more on NHS Choices Schizophrenia

What evidence is available?
The claimant may not be a reliable source of information therefore the carer should be able to provide the information required to accurately assess mobility and care needs. ......Read more about evidence sources

Activities of Daily Living and mobility needs
People whose behaviour is very disturbed may put themselves or others at risk. Supervision by day and night might be required in some cases. .. Read more about ADL and mobility needs

How long will the needs last?
A good recovery from an acute episode of schizophrenia may occur with treatment. ....Read more about award duration

Over 65’s
The term “late paraphrenia” is often used to describe the most common psychotic illness in people over 60 years of age. .... Read more about effects in the over 65 age group

What evidence is available?
The claimant may not be a reliable source of information therefore the carer should be able to provide the information required to accurately assess mobility and care needs.

However, if further details are needed, the Specialist Nurse or Consultant Psychiatrist is an appropriate source of information.

The claimant may be supported by the Care Programme Approach (CPA) and hold written information outlining the level of external support required, which is a useful first source of further medical evidence.
Activities of Daily Living and Mobility needs

General Information

In some parts of the country resources may be limited, and people are unable to obtain help with their medical condition and personal care that would be deemed to be necessary. A simple arithmetical approach to how much attention/supervision is given to a person on a daily basis may underestimate considerably the amount of care and/or supervision the person actually needs, especially if that care is not readily available to the individual.

Schizophrenia may develop in a middle-aged person (30 to 50 years) when the main symptom is one of delusions of persecution. They believe that other people, including family and friends, are trying to harm them. This can lead to hostility and an aggressive attitude towards others. These delusions may be of a circumscribed nature only, i.e. that others are trying to harm them, and respond to medication. The person is less likely to be affected by the negative symptoms of the condition and carries on with the majority of the usual tasks of daily life. He or she is unlikely to have any long-term requirement for care or supervision.

People whose behaviour is very disturbed may put themselves or others at risk. Supervision by day and night might be required in some cases. The most severely disturbed are likely to be admitted to hospital. People, who are stable on medication once the acute episode is treated, are unlikely to require supervision at night. A history of suicide attempts would increase the need for supervision. A suicide attempt is more likely in someone who has been acutely disturbed and whose treatment is not fully controlling the symptoms. The risk might be greatest after a recent hospital discharge, and especially in those with newly diagnosed schizophrenia.

People with schizophrenia should not have a physical difficulty in walking. Side effects of drugs causing stiffness of muscles and involuntary movements may affect the lower limbs, but not to such an extent that walking is severely limited.

People with schizophrenia may need supervision or guidance out of doors as a result of poor concentration, impaired thought processes, odd behaviour and social withdrawal. Problems may occur if people are very disturbed or deluded, although this situation should be short lived when medication is used to control such symptoms. Some people may engage in inappropriate conversations with total strangers, or be so socially withdrawn they would be unable to ask someone else for directions or help. Many people however with moderate schizophrenia well controlled on medication who live in the community are able to find their way around with little difficulty.

The following tables present pen pictures of customers’ likely mobility and care needs at varying levels of functional severity.
### Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>Many people with this level of functional restriction would not have any noticeable disabilities on an everyday basis. Their mood would be normal; they would be alert and orientated with no evidence of confusion, memory loss, poor concentration, disordered thinking or impaired judgement. Symptoms of anxiety or panic arising from the schizophrenia would be unlikely to be prominent or cause any functional limitation. Limb function would be normal.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>People with this level of restriction would, for example normally have no difficulty finding their way around outdoors because they do not usually experience any confusion, inattention, memory loss or impaired judgement. Physical walking ability is unaffected.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>People with this level of restriction would, for example normally be expected to care for themselves by maintaining personal hygiene and preparing meals etc. They would have little or no functional limitation on a day-to-day basis arising from any symptoms nor would they need supervision or watching over to prevent abnormal or untoward behaviour.</td>
</tr>
</tbody>
</table>

### Moderate Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with this level of functional restriction may experience hallucinations, delusions and disordered thinking such that they are unable to initiate and complete the usual tasks of daily living. Insight into their medical condition may be limited and the need for treatment denied. Self-neglect, social isolation and/or social withdrawal may occur. Confusion, incoherent speech, decreased memory and impaired judgement may be present. Symptoms of anxiety and panic disorder may occur as part of the schizophrenic illness. Limb function would be normal.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>People with this level of restriction would, for example display inattention, confusion, incoherent speech, memory loss, impaired judgement and anxiety and panic disorder which would indicate that they may need guidance or supervision outdoors. Physical walking ability is unaffected.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>People with this level of restriction would, for example need to be encouraged to initiate and complete activities of daily living e.g. they may need to be told and encouraged to get up, wash, dress and prepare meals to maintain a reasonable standard of hygiene and nutrition. They may have support mechanisms in place to maintain a stable routine for the person to prevent relapse and exacerbations of symptoms or need to be reminded and encouraged to attend a day center, hospital or psychiatric clinic appointments. They may need to be encouraged to participate in social and leisure activities to reduce social withdrawal and isolation, need help with communication, correspondence and financial matters or need someone to supervise their medication. Some supervision indoors due to inattention, confusion, incoherent speech, memory loss and impaired judgement may be required.</td>
</tr>
</tbody>
</table>

**Severe Functional Restriction**
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>Hallucinations, delusions and thought disorder may impair ability to carry out normal tasks of daily living. The person may be disorientated, confused, have poor concentration and loss of memory. Speech may be unintelligible. At times, behaviour may be bizarre, anti social and, very occasionally, hostile or aggressive. Some people may be very withdrawn and apathetic with minimal social interaction such that self-neglect is severe. Insight into the illness may be very limited.</td>
</tr>
<tr>
<td>Mobility</td>
<td>People with this level of functional restriction would, for example display inattention, confusion, incoherent speech, memory loss and impaired judgement, which is likely to indicate that they would need guidance or supervision outdoors. They would perhaps exhibit antisocial, bizarre or occasionally hostile or aggressive behaviour, which is likely to indicate that they would need guidance or supervision outdoors. Physical walking ability is unaffected.</td>
</tr>
</tbody>
</table>
People with this level of restriction would need, for example help to initiate and complete activities of daily living e.g. they may need to be told and encouraged to get up, wash, dress and prepare meals in order to maintain reasonable standard of hygiene and nutrition. Need regular contact to prevent self-neglect and a decline into apathetic behaviour. If not encouraged, the customer may lie in bed all day and do nothing, or engage in aimless, repetitive activities. They would need be reminded and encouraged to attend day hospital, day center, hospital and psychiatric clinic appointments. Help in communicating with others including correspondence and financial matters. Need to be encouraged to interact with other people, to participate in social and leisure activities to reduce social withdrawal and isolation. They would have support mechanisms in place to maintain a stable routine and environment to prevent relapse or exacerbation of symptoms and need supervision from a carer to reduce risks of self-harm to themselves, and occasionally others. They would need encouragement to eat or drink and require supervised medication.

How long will the needs last?

A good recovery from an acute episode of schizophrenia may occur with treatment. The person may not have had any long term disabling effects. A similar situation may occur for those who have infrequent relapses, perhaps once every few years, which respond well to treatment. A limited award would be appropriate in cases where the Decision Maker considers
that the person qualifies for benefit. It is suggested that each case is discussed with medical services.

Development of paranoid schizophrenia in a middle-aged person may not necessarily be associated with any long-term requirement for care or supervision. It is a circumscribed condition that can usually be controlled by medication.

The following features are likely to indicate long-term disability:

- Insidious onset at a young age with social withdrawal, loss of motivation, thought disorder and suspicious paranoid state.
- Long term prescription of medication, in particular depot preparations.
- Presence of extra-pyramidal side effects.
- History of relapses.
- History of multiple hospital admissions.
- In sheltered or supervised accommodation.
- On going care from a mental health team and enhanced Care Plan Approach (CPA) status.
- Previous sections of the Mental Health Act.

Some people with Schizophrenia will show no or minimal improvement in their care and mobility needs while others will make a significant recovery. Recovery, if it is going to occur, will take place within 5 years of the onset of the illness.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia</td>
<td>Less than 5 years</td>
<td>Limited award of up to 5 years – suggest discuss each case with Medical Services</td>
</tr>
<tr>
<td></td>
<td>More than 5 years</td>
<td>Indefinite award</td>
</tr>
<tr>
<td>Schizoaffective disorder</td>
<td>Less than 5 years</td>
<td>Limited award of up to 5 years – suggest discuss each case with Medical Services</td>
</tr>
<tr>
<td></td>
<td>More than 5 years</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Schizophrenia in people over 65

The term “late paraphrenia” is often used to describe the most common psychotic illness in people over 60 years of age.

Although relatively uncommon, the true incidence is not known.

In late paraphrenia, delusions are usually persecutory, but differ from schizophrenia in younger people in that they are more mundane. For example, the person is more likely to complain that the neighbours are trying to kill him or her, rather than alleging a plot by aliens. Hallucinations are also common. They are usually auditory, but tactile and olfactory hallucinations can occur. Visual hallucinations are rare.

Personality deterioration can occur, but less frequently than in schizophrenia in younger people.

Although late paraphrenia is the most common presentation of psychotic illness in people over 60, other presentations may include:

- Paranoid schizophrenia with symptoms identical to those in younger people.
- A mixed depressive and schizophrenic illness.
- Paranoid states proceeding rapidly to dementia.

In late paraphrenia, between 50 and 75 percent of people have a full or partial response to antipsychotic medication. Although it is unusual for delusions to completely resolve, they are often reduced to a level where the person can function normally. People with late paraphrenia are often reluctant to commence treatment, and many require admission to hospital to start medication.

Schizoaffective disorder (an equal mixture of schizophrenia and mood disorder or schizophrenic illness followed by a mood disorder or vice versa) occurs in people over 65. The outcome is less favourable than for depressive illness. The treatment is the same as that for younger people.
What you need to know about Scleroderma

What is Scleroderma?
Scleroderma is an uncommon disease that results in hard, thickened areas of skin and sometimes problems with internal organs and blood vessels. …… Read more on NHS Choices - Scleroderma

What evidence is available?
The claimant and / or carer should be able to provide the information required to accurately assess mobility and care needs. ……Read more about evidence sources

Activities of Daily Living and mobility needs
The disabling effects of scleroderma vary widely depending on the type of disease and its manifestations. ……Read more about ADL and mobility needs

How long will the needs last?
Scleroderma is a chronic condition, for which there is no cure and no change likely. …Read more about award duration

Over 65’s
Many elderly people may have severe or late disease and a factor for poor prognosis in this condition is advanced age.

What evidence is available?
The claimant and / or carer should be able to provide the information required to accurately assess mobility and care needs. However, if further details are needed the General Practitioner, Consultant or Specialist Scleroderma / Rheumatology nurse is an appropriate source of information.

All treatment is based on presenting symptoms. Typically the diagnosis will be made and the care will be managed by a Rheumatologist and team, but other specialists may well be involved, depending on what specific areas of the body are affected. A Dermatologist, Cardiologist, Renal Physician, Respiratory Physician and/or Gastroenterologist may be involved.
The Specialist Nurse

Specialist nurses are hospital based in scleroderma / rheumatology units to offer a holistic approach to care. These nurses work to meet the medical and psychological needs of the patients. Their roles comprise mainly:

- Clinical Work (monitoring clinical condition and medication)
- Education of patients & health professionals
- Patient advocacy & support
- Liaison & Coordination of care (referral to appropriate specialist for follow up care: occupational therapist, gastroenterologist, pulmonary physician, renal physicians, mental health professionals etc)
- Research & audit

Since scleroderma is so variable, they provide personalised care plans and reassessment especially during times of rapid deterioration. They provide vital support in coping with this chronic illness and are extremely important for the well being of scleroderma patients.

Activities of Daily Living and Mobility needs

Disabling Effects of Scleroderma

The disabling effects of scleroderma vary widely depending on the type of disease and its manifestations. The main disabling effects are due to limb involvement, particularly contractures and ulceration of digits. Later in the course of systemic disease, significant effort tolerance limitation may occur due to pulmonary hypertension.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Manifestations</th>
<th>Disabling effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Localised Scleroderma</td>
<td>• One to several patches of scleroderma (thickened skin)</td>
<td>• Effects are cosmetic (psychological) – there are no care or mobility needs.</td>
</tr>
<tr>
<td>a.) Localised Morphea</td>
<td>• Affects only the skin and subcutaneous fat</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Can occur all over the body, but usually affects trunk</td>
<td></td>
</tr>
<tr>
<td>Localised Scleroderma</td>
<td>• Less common</td>
<td></td>
</tr>
<tr>
<td>b.) Generalised Morphea</td>
<td>• More severe</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Large patches thick tight skin affecting trunk, arms and legs.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Rarely, if the morphea is extensive, respiration may be affected (therefore</td>
<td></td>
</tr>
</tbody>
</table>
exercise tolerance and mobility
• If there is joint involvement, there may be contractures which would reduce mobility (lower limbs) and use of upper limb(s)
• Carpal tunnel syndrome may occur if wrist area affected
• Occurrence in children often leads to severely affected limb growth.
• Disabling effects would depend on the extent and type of lesion
• Peripheral nerve involvement may occur
• Mobility may be restricted

Localised Scleroderma
• Usually presents in childhood (<14 years)
• Highly visible bands of thick tight skin
• Follows distribution of skin dermatomes and can damage structures down to bones and joints.
• “En coup de sabre” deformity, patients may have seizures, headaches, trigeminal neuralgia, muscle weakness, hemiparesis and visual changes.
• Both sides often affected

Systemic Scleroderma
• Long history of Raynaud’s Phenomenon (see below)
• Skin changes involve hands, face, feet and forearms
• Also known as CREST
• High incidence of pulmonary arterial hypertension arising around 10 years following diagnosis

a.) Limited Cutaneous Systemic Sclerosis (Crest Syndrome) Accounts for at least 60% of cases
• Raynaud’s phenomenon can affect manual dexterity. Further complications such as ulceration of extremities, loss of tips of fingers, contractures and sclerodactyly also impair manual dexterity, and therefore may affect many aspects of self-care and meal preparation. Additionally, coping with bowel
incontinence if present, may prove difficult with dexterity problems.

- Fatigue is a major symptom that can limit quality of life.
- Pulmonary arterial hypertension may affect exercise tolerance and therefore reduce mobility.

There may be difficulties with eating because of small, tight mouth, lack of saliva, loose teeth and swallowing problems.

Systemic Scleroderma

b.) Diffuse Cutaneous Systemic Sclerosis (33% of cases)

- Rapid onset
- Diffuse swelling and stiffness of fingers leads to sclerosis followed by involvement of the trunk. Raynaud’s disease may develop later
- Systemic features (kidneys, lungs, heart, and gastrointestinal system)
- Skin disease rapidly progresses
- Joint, muscle and bone involvement

As in the limited cutaneous form, manual dexterity can be affected (see above for effects)

- Joint involvement may lead to contractures which would reduce mobility (lower limbs) and use of the upper limbs
- Fatigue, kidney failure, pulmonary hypertension, cardiac involvement may all lead to reduced exercise tolerance, and subsequent care and mobility needs.

Systemic scleroderma

3) Scleroderma sine scleroderma (Less than 2%)

- No skin changes
- May have Raynaud’s Phenomenon
- Complications of lungs, heart, kidneys or gastrointestinal system.

As above
How long will the needs last?

- Scleroderma is a chronic condition, for which there is no cure and no change likely. Once the care and mobility needs are established any award would be likely to be indefinite.

- There is an increased mortality risk which persists for around 15 years.

- The localised type of disease (that is, the Morphea or Linear forms) does not change into the systemic form and the disease is generally not so severe.

- In Limited Cutaneous Systemic Sclerosis the condition has less severe internal organ involvement and the 10 year survival rate is 70%. However, death can occur later in the disease from pulmonary arterial hypertension (15% develop this).

- In Diffuse Cutaneous Systemic Sclerosis there is often severe internal organ involvement and many patients die from kidney, heart or lung complications. The 10 year survival is 55%. The prognosis is worst for those who exhibit early symptoms and signs of kidney, heart or lung damage, however, some patients may do well.

Reference: Clinical Medicine Kumar and Clark 5th Edition

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about Sickle cell anaemia

What is Sickle cell anaemia?
Sickle cell anaemia is a genetic (inherited) blood disorder in which red blood cells, which carry oxygen around the body, develop abnormally. Read more on NHS Choices - Sickle cell anaemia

What evidence is available?
Many people with sickle cell anaemia attend hospitals that specialise in the condition. Read more about evidence sources

Activities of Daily Living and mobility needs
People with mild functional restrictions are unlikely to require any long-term help with self-care. Read more about ADL and mobility needs

How long will the needs last?
Early diagnosis and treatment, especially of infection, improves prognosis. Read more about award duration

Over 65’s
There is no specific guidance for over 65’s.

What evidence is available?
Many people with sickle cell anaemia attend hospitals that specialise in the condition, where a multi-disciplinary team provide advice on all physical, psychological, social and genetic aspects of the disorder. Others who do not live near a specialist centre attend the haematology clinic of the local hospital. Some people are routinely advised to attend the hospital clinic for treatment in the event of a painful crisis. Doctors and specialist nurses working in hospital clinics are able to provide medical reports for people who attend hospital for the majority of their treatments and regular monitoring.

People with milder disease including those who have infrequent crises or few health problems may be solely under the care of general practitioners from whom medical reports may be obtained.

It may be helpful to obtain a HCP medical examination report for people with stable or uncomplicated disease, who have little no regular contact.
with their medical attendants, or for whom there are no recent medical reports.

Medical Services can provide advice about people who have less common types of sickle cell disorders and thalassaemias, in which the clinical presentations and disabling effects differ from those found in classical sickle cell anaemia.

**Activities of Daily Living and Mobility needs**

Mild functional restriction  
Moderate functional restriction  
Severe functional restriction

**Mild functional restriction**

People in the followings categories are likely to have minimal or mild functional restrictions only:

- Occasional or infrequent crises only
- Able to manage crises at home themselves, or with some input from the general practitioner or community nurse
- Full recovery after crises and return to normal activities
- Haemoglobin levels within normal range, or mild anaemia only, for majority of time
- Not under regular hospital care
- Sickle cell anaemia without complications

During a crisis a person is likely to be confined to bed for up to a week, and would be expected to return to normal activities within seven to ten days.

People with mild functional restrictions are unlikely to require any long-term help with self-care, nor are they restricted in their ability to walk. Constant watching over does not prevent sickle cell crises occurring, and people would usually be able to seek assistance if needed, when a crisis was developing.

**Moderate functional restriction**

People in the followings categories are likely to have moderate functional restrictions, in particular as long term complications of sickle cell anaemia develop:
• Frequent painful crises (2 or more per month) - full recovery between crises less likely and more potent analgesics taken most of the time.

• Persistent moderate to severe anaemia (haemoglobin level - 50% of normal or less 6-8g/dl ) between crises

• Arthritis of the joints of the upper and/or lower limbs and persistent bone pain requiring regular medication

• Avascular necrosis of the hip and/or shoulder joint.

• Regular admission to hospital for treatment or need for frequent regular clinic attendance to maintain stable condition

• People with persistent leg ulcers requiring regular treatment

• Recovering from a stroke

People with moderate functional restrictions may need some help with self-care and preparations of meals. The activities of people with moderate to severe anaemia will be limited by fatigue and shortness of breath, and tasks may take longer to complete. The ability to walk may be restricted due to arthritis of the hip joint and/or other joints in the lower limbs. Painful leg ulcers may impede walking, and anaemia causing fatigue and shortness of breath may also limit the distance covered.

**Severe functional restriction**

Severe functional restrictions are likely to be present when people are limited by the combined effects of a number of the complications described above under moderate functional restriction. In addition the following conditions restrict capacity -:

- Severe arthritis affecting both upper and lower limbs
- Bilateral hip and shoulder deformity due to avascular necrosis, especially if not amenable to joint replacement surgery
- Persistent neurological deficits following stroke or cerebral haemorrhage
- Seizures and epilepsy
- Long term lung damage, including chronic pulmonary hypertension, causing more severe shortness of breath
- Enlarged heart (cardiomyopathy) and heart failure
- Renal failure

People with severe functional restrictions are likely to need help with all aspects of self-care including washing, dressing, bathing, rising from a chair, moving around the house, with the toilet, on stairs, administering medication, maintaining nutrition and fluid intake. Severe lower limb arthritis or long term neurological deficits after stroke are likely to cause
considerable restriction in walking, and people with these problems may be prone to falls.

The majority of adults with mild to moderate sickle cell disease have normal cognitive function and are unlikely to require supervision in the home or out of doors. 20% of adults have some level of cognitive impairment related to infarcts; the most likely impairment is learning difficulty. Constant watching over does not prevent sickle cell crises occurring and people would usually be able to seek medical assistance when a crisis was developing.

**How long will the needs last?**

Early diagnosis and treatment, especially of infection, improves prognosis. In developing countries with inadequate medical services babies with sickle cell anaemia frequently die within the first two years of life.

In the UK diagnosis of sick cell anaemia and initiation of treatment is usual in the first year of life. The aim of treatment is for the child to lead a normal life, attend school and enter adulthood with few or no complications of the disease. However, up to 8% of children have had strokes by the age of 14 years. A higher number of children are at risk of stroke and will be treated with regular blood transfusions to prevent it.

In adults the condition may be relatively static over the years. However some people experience progressive deterioration with frequent crises, the development of disabling complications and poor general health.

The prognosis has improved in recent years and people with sickle cell anaemia can expect to live into their fifties and beyond.
What you need to know about Somatoform disorders

Back to A - Z

What are Somatoform disorders?
Somatoform disorders are disorders where the person has physical symptoms that have no obvious physical explanation …..Read more about Somatoform disorders

Decision Makers are advised to discuss with the Departments Medical Services provider

What evidence is available?
In cases of moderate and severe somatoform disorders it is highly probable that a consultant psychiatrist will have been involved in the management and treatment of the individual….Read more about evidence sources

Activities of Daily Living and Mobility needs
The extent of functional restriction is dependent upon the nature and severity of the physical symptoms. …..Read more about ADL and Mobility needs

How long will the needs last?
Most people with a conversion disorder of recent onset recover quickly…..Read more about award duration

Over 65’s
Somatoform disorders are less common in the elderly. The principles of treatment are the same as for younger people although it may be more difficult for them to obtain appropriate treatment.

What are Somatoform disorders?
Somatoform disorders are disorders where the person has physical symptoms that have no obvious physical explanation and in which emotional or psychological factors are important contributors.

Somatoform disorders include conversion disorder, somatisation disorder, hypochondriasis, body dysmorphic disorder and pain disorder.

Somatoform disorders are relatively common but the exact prevalence is difficult to determine.
What evidence is available?

In cases of moderate and severe somatoform disorders it is highly probable that a consultant psychiatrist will have been involved in the management and treatment of the individual. Indeed the absence of any documented history of a psychiatric consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required.

Activities of Daily Living and Mobility needs

The extent of functional restriction is dependent upon the nature and severity of the physical symptoms.

Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with a mild functional restriction are likely to:</td>
</tr>
<tr>
<td></td>
<td>• Have minor physical symptoms that do not affect day to day functioning</td>
</tr>
<tr>
<td></td>
<td>• Be under GP care only</td>
</tr>
<tr>
<td></td>
<td>• Live independently in the community</td>
</tr>
<tr>
<td></td>
<td>• Never have attended pain clinic (if they suffer from a painful condition)</td>
</tr>
<tr>
<td></td>
<td>• Not use aids or adaptations</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>They would normally have no physical difficulty in getting around.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>They should not have difficulty finding their way around unfamiliar places and should not require guidance.</td>
</tr>
<tr>
<td></td>
<td>They should not normally have any significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities.</td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
</tr>
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<td>---------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with a moderate functional restriction are likely to:</td>
</tr>
<tr>
<td></td>
<td>• Have moderate physical symptoms that have some effect on day to day functioning</td>
</tr>
<tr>
<td></td>
<td>• Be (or have been) under the care of the community mental health team or be (or have been) under the care of another specialist e.g. neuropsychiatrist or neurologist or be (or have been) under the care of a hospital or community based disability team</td>
</tr>
<tr>
<td></td>
<td>• Live at home and have been assessed as requiring twice daily supervision</td>
</tr>
<tr>
<td></td>
<td>• Have attended pain clinic (if they suffer from a painful condition)</td>
</tr>
<tr>
<td></td>
<td>• Use aids or adaptations</td>
</tr>
<tr>
<td></td>
<td>They may have physical difficulty in getting around.</td>
</tr>
<tr>
<td></td>
<td>They are unlikely to have difficulty finding their way around unfamiliar places and should not require guidance.</td>
</tr>
<tr>
<td></td>
<td>They may have a significant functional loss that may result in a reduction of their ability to carry out normal day-to-day activities, the extent of which will be determined by the severity of their physical symptoms.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td></td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td></td>
</tr>
</tbody>
</table>

Severe Functional Restriction
Disabling Effects

People with a severe functional restriction are likely to:

- Have severe physical symptoms that have a major effect on day to day functioning
- Attend psychiatric day hospital or be under the care of the community mental health team or be under the care of another specialist e.g. neuropsychiatrist or neurologist or be under the care of a hospital or community based disability team
- Live in residential care or long term hospital care or if living at home been assessed as requiring 12 to 24 hour supervision
- Have attended pain clinic (if they suffer from a painful condition)
- Use aids or adaptations

Mobility

They are likely to have physical difficulty in getting around.
They are unlikely to have difficulty finding their way around unfamiliar places and are unlikely to require guidance.

ADL

They are likely to have significant functional loss that results in a reduction of their ability to carry out normal day-to-day activities, the extent of which will be determined by the severity of their physical symptoms.

How long will the needs last?

Conversion disorder

Most people with a conversion disorder of recent onset recover quickly. However, if the condition persists for more than a year it is likely to last for many years. Initially therefore, a short term award of 2 years should be considered. Thereafter, an indefinite award should be considered.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Impairment  Award period

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conversion disorder</td>
<td>First award period - 2 year award</td>
</tr>
<tr>
<td></td>
<td>Further award period - indefinite</td>
</tr>
</tbody>
</table>

Somatisation disorder

People with somatisation disorder are usually chronically ill for the majority of their lives. They rarely make a full recovery but can make a partial
recovery. The degree of disability varies from person to person, insofar as some are able to work but others are chair or bed bound and completely dependent. Initially therefore, a short term award of 2 years should be considered. Thereafter, an indefinite award should be considered.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somatisation disorder</td>
<td>First award period - 2 year</td>
</tr>
<tr>
<td></td>
<td>award</td>
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<tr>
<td></td>
<td>Further award period -</td>
</tr>
<tr>
<td></td>
<td>indefinite</td>
</tr>
</tbody>
</table>

**Hypochondriasis**

Primary hypochondriasis follows a chronic fluctuating course. Treatment may help reduce symptoms but it is rarely curative. Initially therefore, a short term award of 2 years should be considered. Thereafter, an indefinite award should be considered. Hypochondriasis may be secondary to another disorder such as depression, in which case it may be relieved by treatment of the depression. The prognosis is determined by the primary disorder. For such cases please refer to the guidance on prognosis for the primary disorder.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypochondriasis</td>
<td>First award period - 2 year</td>
</tr>
<tr>
<td></td>
<td>award</td>
</tr>
<tr>
<td></td>
<td>Further award period -</td>
</tr>
<tr>
<td></td>
<td>indefinite</td>
</tr>
</tbody>
</table>

**Body Dysmorphic Disorder (BDD)**

BDD usually begins in adolescence and follows a fluctuating chronic course. A majority of people improve over time but cure is unusual. Initially therefore, a short term award of 2 years should be considered. Thereafter an indefinite award should be considered.
Pain disorder

The prognosis of pain disorder is uncertain. Many people with pain disorder are unwilling to accept treatment or are considered unsuitable. However, treatment can result in a sustained improvement. Initially therefore, a short term award of 2 years should be considered. Thereafter an indefinite award should be considered.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain disorder</td>
<td>First award period - 2 year award</td>
</tr>
<tr>
<td></td>
<td>Further award period - indefinite</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

[Back to top of section]
What you need to know about Sprains

Back to A - Z

What is a sprain?
A sprain occurs when one or more of your ligaments have been stretched, twisted, or torn.

What evidence is available?
There would normally be no significant restriction of self-care activities.

Activities of Daily Living and mobility needs
There are 3 grades describing the degree of the sprain.

How long will the needs last?
The amount of rehabilitation and the time needed for full recovery after a sprain depends on the severity of the injury and the rate of healing.

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages:
Ageing, Falls, Frailty

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

However, in the minority of cases where disability may have occurred it may be necessary to request a factual report from the customer’s own General Practitioner.

Activities of Daily Living and Mobility needs
There are 3 grades describing the degree of the sprain.

- A mild sprain - there may be minimal pain, slight swelling and little or no loss of functional ability. Bruising is absent or slight and the weight-bearing on the affected joint bearable. A mild sprain may take up to 3-6 weeks to recover fully.
- A moderate sprain - there is bruising, moderate pain and swelling. There is usually more difficulty weight-bearing and there could be some loss of function. A moderate sprain taking 2-3 months.
- A severe sprain - the pain, swelling and bruising are usually severe and should the sprain affect the lower limb, then weight bearing would be very difficult. A severe sprain can take up to 8-12 months to regain full function.

How long will the needs last?

The amount of rehabilitation and the time needed for full recovery after a sprain depends on the severity of the injury and the rate of healing.

- A mild sprain may take up to 3-6 weeks to recover fully.
- A moderate sprain taking 2-3 months.
- A severe sprain can take up to 8-12 months to regain full function.

It is unusual, however, for a person not to return to full activities after treatment and rehabilitation.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Back to top of section
What you need to know about Stomach cancer

What is Stomach cancer?
Stomach cancer is when an abnormal groups of cells, known as a tumour, develops inside the stomach. It’s also known as gastric cancer. [Read more on NHS Choices - Stomach cancer.]

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even... [Read more about evidence sources.]

Activities of Daily Living and mobility needs
Over time they are likely to lose weight becoming frailer... [Read more about ADL and mobility needs.]

How long will the needs last?
In cases where needs are identified during treatment of the primary tumour... [Read more about award duration.]

Over 65’s
This disease is more common in older people but there are no special features.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- **General Practitioner** - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- **Community or District Nurse** - will have information on any home care or outreach package in place as this is coordinated through the practice.
- **Social worker** - customer may have a ‘Care plan’ from social services
Hospital
Specialist doctors -:
• Oncologist
• Physician
• Haematologist

Specialist nurses have many different job titles -:
• Clinical Nurse Specialist
• Stoma care nurse
• Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
• Physiotherapist
• Occupational Therapist
• Social worker
• Counsellor
• Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
• Palliative Care Physician
• Macmillan Nurse
• Clinical Nurse Specialist
• Social worker
• Physiotherapist
• Occupational Therapist
• Counsellor

Activities of Daily Living and Mobility needs

Advanced stomach cancer and Recurrent stomach cancer
This group which includes 80% of those with stomach cancer have a median survival with chemotherapy treatment of 6-9 months. Symptoms of disease may include many of the following:
- Indigestion, acid indigestion
- Belching
- Difficulty swallowing - ‘dysphagia’
- Nausea or vomiting – may be bloody – ‘haematemesis’
- Feeling full after smaller amounts of food than normal, the medical term for this is ‘early satiety’
- Abdominal pain
- Bleeding from tumours in the lining of the stomach
- Low blood count – ‘anaemia’ from gastrointestinal bleeding
- Loss of appetite – ‘anorexia’
- Weight loss

Over time they are likely to lose weight becoming frailer, they may be unable to walk far or cope with shopping and cleaning. In the terminal phase they are likely to require help with all aspects of personal care. Some will respond very well to palliative treatment, maintain weight and be able to function well for some time before entering the terminal phase.

**How long will the needs last?**

**Localised (early stage) stomach cancer**

This group includes only 20% of those with stomach cancer; they are likely to have had major surgery and possibly a course of chemotherapy. They are likely to be recovered from surgery and any chemotherapy given afterwards within 9-12 months of starting treatment. They may have needs during chemotherapy treatment if side effects of therapy are severe, these should resolve when treatment is complete.

In this group ongoing needs are unlikely to be identified unless there are ongoing rare complications from surgery or chemotherapy treatment. Needs are likely to arise only when disease recurs. The chances of this depend on the stage of the disease at diagnosis. Five year survival for stage 1 stomach cancer is 70%, stage 2 40% and stage 3 20%. Of the group who have curative treatment less than half (30% to 50%) will survive for 5 years as a whole. When disease recurs refer to guidance for advanced/recurrent disease.

In cases where needs are identified during treatment of the primary tumour, awards should be time limited to cover the period of treatment and recovery. A return to health is expected in the typical case. If disease has recurred after successful treatment of any stage of stomach cancer, information relating to the advanced/recurrent disease stage is appropriate.

Life awards are recommended even if palliative treatment has appeared to restore health.
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Strokes

What is a stroke?
A stroke is a serious medical condition that occurs when the blood supply to part of the brain is cut off. .... Read more on NHS Choices - Strokes

What evidence is available?
The claimant and/or carer should be able to provide the information required to accurately assess mobility and care needs .... Read more about evidence sources

Activities of Daily Living and mobility needs
The overall level of functional restriction will depend upon the number of joints affected .... Read more about ADL and mobility needs

How long will the needs last?
Rehabilitation following a stroke may take time. .... Read more about award duration
Linked page: H/R Mobility SVI deeming provisions

Over 65’s
Stroke risk increases as a person gets older, and 2/3 of stroke victims are over 60 years of age.... Read more about effects in the over 65 age group

What evidence is available?

Note: If considering entitlement to H/R Mobility component under the Severely Visually Impaired (SVI) provisions, the following evidence source must be used:

The Consultant Ophthalmologist will be able to provide information about symptoms, signs, investigations including assessment of vision, treatment/management, and is likely to have information about resulting disability or needs.
Other evidence sources

The claimant and/or carer should be able to provide the information required to accurately assess mobility and care needs. However, if further details are needed, the Specialist Nurse, Physiotherapist, Occupational Therapist or Consultant is an appropriate source of information. If details of peripheral visual defect are needed, the Ophthalmologist or Optometrist is an appropriate source of information.

Activities of Daily Living and Mobility needs

The overall level of functional restriction will depend upon the number of joints affected and the combination of upper and lower limb involvement. Please click on the appropriate link below to access the relevant care and mobility needs.

Activities of Daily Living and Mobility considerations (Lower limb)

It is important to bear in mind that damage to specific parts or functions of the brain (which may be physically small) may cause disproportionate, and devastating disability. Some examples of this are dysphasia (difficulty with expressing and understanding language), hemianopia, and the inability to recognize faces. It is especially true of language loss, which may occur in isolation. A person with aphasia would not be able to speak, read, manage mathematical calculations etc. Spinal cord strokes may well affect bowel and bladder control.

There may be other effects such as:

- Speech disorders, such as:
  - Dysarthria (poorly articulated speech, caused by problems in muscle control)
  - Aphasia (disorder of the language content of speech, a defect or loss of the ability to comprehend or express words)
  - Anomia (inability to produce the correct word)
  - Dysphonia (hoarse or whispered speech)
- Hemianopia (loss of half of the visual field)
- Cognitive function – effect on thinking, awareness of surroundings, attention, learning, judgement and memory
- Hemianaesthesia (loss of sensation of the affected part)
- Perceptual problems (lack of awareness of the affected part of the body)
- Mood disturbances or depression
- Ataxia (problems with co-ordination, unsteadiness)
- Vertigo (balance disturbance)
- Problems controlling movements of the eyes
- Problems with swallowing
- Problems with bowel and bladder control
**Vision guidance** is available in addition where appropriate.

### Lower Limb condition – Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with this level of functional restriction have normal or minimal loss of muscle power, and minimal or no spasticity of the affected lower limb. They are able to stand unaided or with the use of walking stick.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>People with such a restriction would normally be able to walk at over two hundred metres at a normal or near normal speed. They would normally have some restriction of lower limb function, causing a mild impairment of gait, such as a mild limp, but they would be unlikely to suffer from falls.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>People with this level of restriction would normally be able to safely manage all aspects of their personal care, as they would normally have reasonable lower limb muscle power. Such a person would normally be able to independently maintain personal hygiene and prepare and cook a meal. They would have little or no functional limitation on a day-to-day basis arising from any symptoms.</td>
</tr>
</tbody>
</table>

### Lower Limb condition – Moderate Functional Restriction
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with this level of functional restriction would normally be unable to stand unassisted, would have moderate loss of muscle power, and some difficulty in straightening the affected limb.</td>
</tr>
<tr>
<td>Mobility</td>
<td>People with this level of restriction would normally be unable to walk at normal speed. They would normally have an abnormal gait, may have problems with balance and would walk with a noticeable limp. They may need physical support, in order to walk. Such people may be able to walk 50 to 100 metres at a slow or very slow speed and they may suffer from falls.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with this level of restriction may have difficulty coping with many activities of daily life. There may be spasticity of muscles (a state in which the normal tone of the muscle is increased leading to difficulty in movement). In other cases weakness of the muscles may be present. Spasticity and weakness of muscles may also co-exist. Any of these problems may cause difficulty with dressing, getting out of a normal chair, out of bed, rising from a toilet and getting out of a bath. There may be difficulty in climbing stairs, safely dealing with hot pans, and bending to the oven. People with such a condition may suffer from falls, and may have difficulty rising independently from a fall.</td>
</tr>
</tbody>
</table>

**Lower limb condition – Severe Functional Restriction**
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with this level of functional restriction would normally be unable to stand unsupported, would have severe loss of muscle power, and significant spasticity of the affected lower limb.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Walking would normally be significantly restricted in terms of speed, distance (unable to manage more than 50 metres) and gait. The person would normally be unable to walk without physical support, or the person may be unable to walk at all, or even stand unsupported. There is a significant risk of falls.</td>
</tr>
<tr>
<td>ADL</td>
<td>People with this level of restriction would normally have significant difficulty coping with most activities of daily life. They may be unable to, or have significant difficulty in rising, leading to difficulty or inability to get out of a normal chair, out of bed, rise from the toilet or out of the bath. They would normally have significant difficulty or be unable to climb stairs safely. A risk of falls is likely, and due to muscle weakness or spasticity they would normally be unable to get up following a fall.</td>
</tr>
</tbody>
</table>

Where there is upper limb and lower limb and cognitive involvement while each is considered separately when assessing functional restriction it must be borne in mind that the combined effects on a persons ability to self care and get around may be greater than the individual components.

**Activities of Daily Living and Mobility considerations (Upper limb)**

It is important to bear in mind that damage to specific parts or functions of the brain (which may be physically small) may cause disproportionate, and devastating disability. Some examples of this are dysphasia (difficulty with expressing and understanding language), hemianopia, and the inability to recognize faces. It is especially true of language loss, which may occur in
isolation. A person with aphasia would not be able to speak, read, manage mathematical calculations etc. Spinal cord strokes may well affect bowel and bladder control.

There may be other effects such as:

- **Speech disorders, such as:**
  - Dysarthria (poorly articulated speech, caused by problems in muscle control)
  - Aphasia (disorder of the language content of speech, a defect or loss of the ability to comprehend or express words)
  - Anomia (inability to produce the correct word)
  - Dysphonia (hoarse or whispered speech)

- **Hemianopia** (loss of half of the visual field)
- **Cognitive function** – effect on thinking, awareness of surroundings, attention, learning, judgement and memory)
- **Hemianaesthesia** (loss of sensation of the affected part)
- **Perceptual problems** (lack of awareness of the affected part of the body)
- **Mood disturbances or depression**
- **Ataxia** (problems with co-ordination, unsteadiness)
- **Vertigo** (balance disturbance)
- **Problems controlling movements of the eyes**
- **Problems with swallowing**
- **Problems with bowel and bladder control**

  **Vision guidance** is available in addition where appropriate.

**Upper Limb condition – Mild Functional Restriction**
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with this level of restriction would normally have reasonable grip, manual dexterity, and muscle power in the affected arm, and would not be likely to experience spasticity.</td>
</tr>
<tr>
<td>Mobility</td>
<td>A person with mild upper limb stroke would normally have no physical difficulty in getting around and would not require guidance or supervision.</td>
</tr>
<tr>
<td>ADL</td>
<td>People with mild upper limb stroke would normally be able to safely manage all aspects of their personal care. People with this condition would normally be able to safely manage all aspects of their personal care, as they would normally have reasonable grip, manual dexterity, and muscle power in the hands/arms. They would normally be able to prepare and cook a main meal and would have little functional restriction on a day-to-day basis.</td>
</tr>
</tbody>
</table>

**Upper Limb condition – Moderate Functional Restriction**
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with this level of restriction may have some restriction of hand function and manual dexterity, as well as weakness of the muscles, and spasticity of the affected upper limb.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>Walking aids may help with mobility, but upper limb difficulties may preclude their use.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>A person with this level of restriction would normally have difficulties coping with many activities of daily life. Reduced manual dexterity may lead to difficulty with dressing, including small buttons and fastenings, feeding, washing, shaving, toileting, administering medication, medical treatment, and peeling vegetables, which requires good bimanual dexterity. Due to reduced muscle power, though the person would normally be able to turn a sink tap, or control knobs on a cooker, he/she would normally have difficulty handling hot pans. The person would not normally need supervision or watching over.</td>
</tr>
</tbody>
</table>

**Upper Limb Condition – Severe Functional Restriction**
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>In a person with this level of restriction manual dexterity and muscle power would normally be severely affected, as well as there being the presence of significant spasticity, of the affected upper limb.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Walking aids are unlikely to be of any use as this person would be likely to have great difficulty in gripping, holding and using any prescribed mobility aids.</td>
</tr>
<tr>
<td>ADL</td>
<td>A person with this level of restriction would normally have great difficulty in coping with most activities of daily life. They may have difficulty getting out of bed. They would normally have significant difficulty with or inability to: feed, wash, shave, get in or out of a bath, dress, manage buttons and fastenings, attend to toilet needs, and administer medicines or medical treatment. They would normally have difficulty with or inability to cut up food. Because of severe restriction of manual dexterity, and severe loss of muscle power, the preparation of a main meal would not normally be possible. Due to muscle weakness or spasticity, the people may not be able to help themselves up after a fall.</td>
</tr>
</tbody>
</table>

Where there is upper limb and lower limb and cognitive involvement while each is considered separately when assessing functional restriction it must be borne in mind that the combined effects on a persons ability to self care and get around may be greater than the individual components.

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Activities of Daily Living and Mobility considerations (cognitive)
It is important to bear in mind that damage to specific parts or functions of the brain (which may be physically small) may cause disproportionate, and
devastating disability. Some examples of this are dysphasia (difficulty with expressing and understanding language), hemianopia, and the inability to recognize faces. It is especially true of language loss, which may occur in isolation. A person with aphasia would not be able to speak, read, manage mathematical calculations etc.

Spinal cord strokes may well affect bowel and bladder control.

There may be other effects such as:

- Speech disorders, such as:
  - **Dysarthria** (poorly articulated speech, caused by problems in muscle control)
  - **Aphasia** (disorder of the language content of speech, a defect or loss of the ability to comprehend or express words)
  - **Anomia** (inability to produce the correct word)
  - **Dysphonia** (hoarse or whispered speech)
  - **Hemianopia** (loss of half of the visual field)
  - **Cognitive function** – effect on thinking, awareness of surroundings, attention, learning, judgement and memory)
  - **Hemianaesthesia** (loss of sensation of the affected part)
  - **Perceptual problems** (lack of awareness of the affected part of the body)
  - **Mood disturbances or depression**
  - **Ataxia** (problems with co-ordination, unsteadiness)
  - **Vertigo** (balance disturbance)
  - Problems controlling movements of the eyes
  - Problems with swallowing
  - Problems with bowel and bladder control

**Vision guidance** is available in addition where appropriate. A customer with visual problems related to a stroke may also satisfy the H/R Mobility criteria under the Severely Visually Impaired (SVI) deeming provisions. Click on the link [H/R Mobility SVI](#).

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**Cognitive Function – Mild Functional Restriction**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabling Effects</strong></td>
<td>People with a mild restriction are likely to have mild cognitive deficit.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>People with a mild cognitive impairment would normally be able to find their way around outdoors.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>People with a mild cognitive impairment would not need supervision or watching over.</td>
</tr>
</tbody>
</table>
## Cognitive Function – Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a moderate restriction are likely to have moderate cognitive deficit.</td>
</tr>
<tr>
<td>Mobility</td>
<td>People with a moderate cognitive impairment would normally be able to find their way around outdoors.</td>
</tr>
<tr>
<td>ADL</td>
<td>The resulting disability may lead them to require assistance with undertaking complex activities. They may require prompting to prepare food, take medication, deal with correspondence and financial matters and undertake appropriate activities. They are not likely to require supervision to prevent potentially dangerous behaviours or activities.</td>
</tr>
</tbody>
</table>

## Cognitive Function – Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a severe restriction are likely to have severe cognitive deficit.</td>
</tr>
<tr>
<td>Mobility</td>
<td>People with a severe cognitive impairment would not normally be able to find their way around in unfamiliar surroundings.</td>
</tr>
<tr>
<td>ADL</td>
<td>The resulting disability is likely to require supervision to prevent potentially dangerous behaviours or activities.</td>
</tr>
</tbody>
</table>

Where there is upper limb and lower limb and cognitive involvement while each is considered separately when assessing functional restriction it must be borne in mind that the combined effects on a person’s ability to self care and get around may be greater than the individual components.
How long will the needs last?

Rehabilitation following a stroke may take time. Most of a person’s recovery will occur within the first 6 months following a stroke, with the majority of this occurring in the first 12 weeks. Improvement may continue for up to one year especially in younger people. After one year from the stroke further recovery is likely to be limited.

All cognitive disorders following a stroke are considerable obstacles to successful rehabilitation and independent living. Apraxias are especially disabling.

Of those who do not die within a few days following a stroke:
1/3 make a full recovery
1/3 are disabled to some extent
1/3 are severely disabled and dependent

In view of the potential for improvement in the first 12 months it would be reasonable to award for a limited period.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Date of Onset (date of stroke)</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke / Cerebro vascular accident (CVA)</td>
<td>Less than 2 years</td>
<td>2 year award (from date of claim)</td>
</tr>
<tr>
<td></td>
<td>More than 2 years</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

You may need to consider whether H/R Mob SVI deeming provisions are satisfied. Click on the link [H/R Mobility SVI](#).

Transient ischaemic attacks (TIA)

The average duration of a TIA is a few minutes with the majority fully resolving within an hour, therefore care and mobility needs are not appropriate.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

[Back to top of section](#)
Strokes in people over 65

Effects of Ageing

- Older people who have strokes usually have atheroma and atherosclerosis in other parts of the body, and are likely to have co-existing peripheral vascular disease, and ischaemic heart disease.
- Because older people often have a variety of health problems, older people with stroke are more likely to have COPD (chronic obstructive pulmonary disease), eyesight difficulties, osteo-arthritis and other conditions, which increases their general frailty and vulnerability.

General points

Stroke risk increases as a person gets older, and 2/3 of stroke victims are over 60 years of age. The same risk factors operate as for those of younger people, however the risk of atrial fibrillation (which causes one sort of stroke – embolic stroke) doubles with each additional decade of age.

An older person with stroke is more likely to have suffered previous stroke or transient ischaemic attack (TIA). Older people, as long as they are fit, benefit from procedures such as carotid endarterectomy, which is a preventative measure in people who have suffered TIA’s or strokes, and reduces the risk of further TIA/ stroke by around 75%.

In general, the presentation of a stroke will be the same in older people as for the younger population, but in some elderly people, the severity of the stroke may be hard to assess because of existing cognitive deficit, communication difficulties, or musculo-skeletal disorders. Diffuse, small vessel disease is very common in older people, particularly over the age of 70. Because a series of small strokes occurs, there is a gradual and insidious deterioration, rather than a dramatic change, which occurs with other strokes, and it causes problems with gait, speech, or vascular dementia (multi-infarct).

Another preventative measure - warfarin (to prevent embolic stroke from atrial fibrillation), may not be possible in the elderly, if the person has a history of falls, or takes other medication which could interact. Older people may therefore be at a disadvantage in these circumstances.

Though age should not prevent recovery from a stroke, full recovery and rehabilitation may not be possible, and the person’s needs may not be fully met, if the person is frail, has other disabling physical and mental conditions, social isolation, and transport difficulties.

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What you need to know about SubSTANCE abuse

What is Substance abuse?
The effects of drugs ..... Read more on NHS Choices - substance abuse
Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
In cases of moderate and severe substance abuse it is highly probable that the community drug team will have been involved in the management and treatment of the individual ..... Read more about evidence sources

Activities of Daily Living and Mobility needs
Many people abuse drugs and experience only minor mental, physical or social disability. ..... Read more about ADL and Mobility needs

How long will the needs last?
For people with drug dependence problems, there is no quick solution and no 'cure' for drug abuse..... Read more about award duration

Over 65's
Substance abuse occurs in older people, but less frequently than in younger people......... Read more about over 65's

What evidence is available?
In cases of moderate and severe substance abuse it is highly probable that the community drug team will have been involved in the management and treatment of the individual. Indeed the absence of any documented history of their involvement should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required from the community drug team.

Activities of Daily Living and Mobility needs
Many people abuse drugs and experience only minor mental, physical or social disability.

Substance dependence in the absence of chronic physical or mental complications should not be expected to give rise to significant care and mobility needs.

Episodes of acute intoxication on their own cannot be prevented by reasonable supervision, although intermittent intervention by another person at specific times may reduce the risk at those times.

Withdrawal symptoms usually last for several days only and should not require long term help from another person.

Self neglect in people with substance dependency in the absence of chronic physical or mental complications may require short-term help from another person. However, such help should not be long term once substance use has been discontinued.

During periods of rehabilitation the person may require support from others but this should not amount to a need for attention or supervision.

The onset of chronic physical or mental complications is likely to imply moderate or severe disability.

**Mild Functional Restriction**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a mild functional restriction are likely to be those who have some of the following -:</td>
</tr>
<tr>
<td></td>
<td>• Use drugs recreationally only</td>
</tr>
<tr>
<td></td>
<td>• Have no symptoms of dependence</td>
</tr>
<tr>
<td></td>
<td>• Have no associated psychiatric symptoms</td>
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<tr>
<td></td>
<td>• Have no associated physical problems</td>
</tr>
<tr>
<td></td>
<td>• Have no associated social problems</td>
</tr>
<tr>
<td></td>
<td>• Have had no hospital admissions for drug dependency</td>
</tr>
<tr>
<td></td>
<td>• Live at home</td>
</tr>
</tbody>
</table>
- Not be on care plan
- Be under GP care only

**Mobility**

They should not have any physical problem with walking. They should not have difficulty finding their way around unfamiliar places and should not require guidance or supervision.

**ADL**

They would not normally exhibit significant self-neglect and would not normally put themselves or others at risk of danger.

They should not normally have any significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities.

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**Moderate Functional Restriction**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>People with a moderate functional restriction are likely to be those who have some of the following -:</td>
</tr>
<tr>
<td></td>
<td>• Have been drug dependent for &lt;10 years</td>
</tr>
<tr>
<td></td>
<td>• Have non psychotic psychiatric symptoms</td>
</tr>
<tr>
<td></td>
<td>• Have mild or moderate physical problems, for example local complications or non-disabling systemic complications.</td>
</tr>
<tr>
<td></td>
<td>• Have mild or moderate social problems, for example relationship problems, work related problems, unemployment and engagement in criminal activity.</td>
</tr>
<tr>
<td></td>
<td>• Have had no hospital admissions in the last 12 months</td>
</tr>
<tr>
<td></td>
<td>• Live at home or in be in short term residential accommodation</td>
</tr>
<tr>
<td></td>
<td>• Be under the care of the community drug team or GP with special interest in substance</td>
</tr>
</tbody>
</table>
misuse with or without social services involvement.

| Mobility                      | They should not have any physical problem with walking.  
|                              | They are unlikely to have difficulty finding their way around unfamiliar places and are unlikely to require guidance or supervision. |
| ADL                           | They would not normally exhibit significant self-neglect and would not normally put themselves or others at risk of danger.  
|                              | They may have difficulty in carrying out normal day-to-day activities in a timely fashion, due to, for example, impaired concentration and motivation. For example they may require encouragement to prepare meals, take medication (but this is likely to be limited to once or twice a day) and get out and about, but this is unlikely to be a long term need. |

<table>
<thead>
<tr>
<th>Severe Functional Restriction</th>
<th>People with a severe functional restriction are likely to be those who have some of the following -:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category</td>
<td>Description</td>
</tr>
</tbody>
</table>
| Disabling Effects            | Have been drug dependent for >10 years  
|                              | Use multiple drugs  
|                              | Have persistent severe psychiatric symptoms.  
|                              | Have severe physical problems, for example chronic liver failure secondary to hepatitis or moderate or severe disability secondary to HIV/AIDs  
|                              | Have had hospital admissions in the last 12 months |
- Be socially isolated and have a chaotic and disorganised lifestyle
- Have persistent self neglect
- Have bizarre behaviour towards other people
- Live in long term residential accommodation or homeless
- Be under the care of specialist substance misuse services (the community drug team) with or without involvement from social services

<table>
<thead>
<tr>
<th>Mobility</th>
<th>They may have difficulty walking if they have a severe drug related physical problem such as leg ulceration or other vascular complications from injecting drug misuse, e.g. chronic deep vein thrombosis, amputations etc.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>They may have difficulty finding their way around unfamiliar places and may require guidance or supervision.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ADL</th>
<th>They may exhibit significant self-neglect and may put themselves or others at risk of danger.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>They may have a significant functional loss that will result in a reduction of their ability to carry out normal day-to-day activities.</td>
</tr>
</tbody>
</table>

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**How long will the needs last?**

For people with drug dependence problems, there is no quick solution and no 'cure' for drug abuse. The eventual outcome of drug abuse is, like its initiation, dependent on the unique interaction between drug, individual and society in addition to the treatment intervention. Once dependence has developed, it is generally a chronic condition of relapse and remission lasting for years rather than months and one that is difficult but not impossible to overcome.

Studies have shown that it is the less chronic addicts who are likely to become abstinent in the short term, and that short-term or early improvement is more likely to lead to long-term improvement.
Most of the studies looking at deaths of people with addiction problems report that 2-3% of addicts are dead within one year of making contact with a clinic or helping agency.

Several factors determine the prognosis for any individual. These include:

- The substance of abuse. Substances that have high rates of dependence and severe or prolonged withdrawal symptoms are associated with a worse prognosis.
- The reasons for the substance abuse. Teenage experimentation or drug abuse during reversible life crises is associated with a good prognosis.
- Personal vulnerability. Poor family background, poor school record and truancy, thrill seeking, impulsivity and personality disorders are associated with a worse prognosis.
- Associated psychiatric disorders. People with associated psychiatric disorders, for example people with depression, schizophrenia and personality disorders tend to have a worse prognosis.
- Multiple substance or alcohol abuse is associated with a worse prognosis.
- Poor social environment, for example homelessness and unemployment is associated with a poor prognosis.
- The duration of the substance abuse. A worse prognosis is associated with longer duration of substance abuse.
- Motivation of the person to change. Lack of motivation is associated with a worse prognosis.
- Support available to the person. Lack of availability of support services are associated with a worse prognosis.

The prognosis for certain specific individual substances is briefly described below.

<table>
<thead>
<tr>
<th>Amphetamines</th>
<th>Cannabis</th>
<th>Heroin and other opioids</th>
<th>Nitrites (Poppers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anabolic steroids</td>
<td>Cocaine</td>
<td>Ketamine</td>
<td>Phencyclidine (angel dust)</td>
</tr>
<tr>
<td>Barbiturates</td>
<td>Ecstasy</td>
<td>Khat</td>
<td>Psilocybe mushrooms</td>
</tr>
<tr>
<td>Benzodiazepines</td>
<td>Gamma hydroxybutyric acid (GHB)</td>
<td>Lysergic acid diethylamide (LSD)</td>
<td>Solvents (volatile substances)</td>
</tr>
</tbody>
</table>

**Amphetamines**

Amphetamine use is more likely to be recreational than opioid use. It is thought that the vast majority of young adults give them up in due course. A very small proportion of amphetamine injector’s progress to high dose...
daily usage. Complications and contact with psychiatric services is more likely in dependent users and in episodes of psychosis. The prognosis is good provided the person abstains from drug use after any related psychiatric disorder occurs. The prognosis is worse in people with associated personal or social difficulties or psychiatric disorder including personality disorder.

**Anabolic steroids**

The prognosis is not known because no long-term follow up or large treatment trials are available.

**Barbiturates**

The prognosis is not known because no trials or long term follow up studies are available.

**Benzodiazepines**

Success rates for supervised withdrawal are high. Of those people who participate in supervised withdrawal programmes, about half complete a programme and of these, half to two thirds remain benzodiazepine free after 1 to 3 years. A few people continue to experience withdrawal like symptoms for months or even years after cessation of benzodiazepines (prolonged withdrawal syndrome). A considerable proportion of people may temporarily take benzodiazepines again and some may need other psychotropic medication.

**Cannabis**

The vast majority of users do not abuse the drug or become dependent on it. The 12 month prevalence rate of cannabis abuse in general population is 0.7% and 6% of those who used cannabis in the past year are dependent. Only a minority of people seek treatment from a health professional. Post treatment abstinence rates are low.

**Cocaine**

Cocaine use is more likely to be recreational than opioid use. It is thought that the vast majority of young adults give them up in due course. Heavy use of cocaine is difficult to sustain and its use tends to be periodic in nature. Success rates for treatment of cocaine abuse are high with up to 75% abstinence at 5 years post treatment. The prognosis is worse in people with associated personal or social difficulties or psychiatric disorder including personality disorder. Good prognosis is associated with longer treatment programmes and in women.

Due to the recent increased availability of crack cocaine, there are increasing numbers of cases of very severe dependence with a corresponding very distressing abstinence syndrome. Crack cocaine use
seems to be associated with a high mortality rate and criminal involvement and treatment does not appear to be effective in reducing drug use.

Ecstasy
The prognosis is good provided the person abstains from drug use. The prognosis is worse in people with associated personality disorders.

Gamma hydroxybutyric acid (GHB)

There is insufficient evidence available to comment on the prognosis following treatment.

Heroin and other opioids
There is a significant mortality (10 to 15%) over 10 years in opioid abusers. Common causes of death include accidental overdose, suicide, HIV and hepatitis.

Abstinence rates following treatment vary but between 10 to 40% are abstinent 6 months following treatment and the majority of people who relapse do so 3 to 4 months after discharge.

Good prognosis is associated with a greater range of treatment services (health care, family therapy, cognitive behavioural therapy etc) and substantial periods of employment and marriage. Worse prognosis is associated with more severe pre-treatment psychopathology and dependence. Abstinence is often related to change in life circumstance, for example in opiate addicted returning Vietnam veterans.

Approximately 50% abstinence has been reported at 10 year follow up. It has been demonstrated that eventual cessation of opiate use is a very slow process and becomes increasingly unlikely the longer the person has taken the drug.

Ketamine
The vast majority of people stop using ketamine without treatment as the psychedelic effects diminish as tolerance develops.

Khat
There is insufficient evidence available to comment on the prognosis following treatment.

Lysergic acid diathylemide (LSD)
The long term prognosis for LSD abuse is good provided that the person discontinues use of the drug. Hallucinogen persisting perception disorder
may resolve over a period of months or years after last drug use but persists in about 50%. Prolonged psychotic episodes have a relatively poor prognosis and there is a high risk of suicide.

Nitrites (Poppers)
The prognosis is not known because there are no available treatment trials or long-term follow up studies.

Phencyclidine (angel dust)
The majority of people stop taking phencyclidine once they pass young adulthood. The prognosis for chronic phencyclidine psychosis is poor.

Psilocybe mushrooms
Users do not usually regard themselves as having a problem and almost never present to drug services for help with cutting down or stopping.

Solvents
For many users, experimentation is a temporary phase which does not result in persistent abuse or dependence. However, treatment is difficult for the dependent subgroup with associated personality disorder and chaotic social circumstances.

All substances

Therefore the following awards should be considered:-:

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substance (drug) abuse</td>
<td>First award - 2 year award</td>
</tr>
<tr>
<td></td>
<td>Second award - 5 year award</td>
</tr>
<tr>
<td></td>
<td>Subsequent award - Indefinite award</td>
</tr>
</tbody>
</table>

However, in some cases there is potential for improvement in the condition in the longer term.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
Substance abuse occurs in older people, but less frequently than in younger people.

Benzodiazepines are the most common drugs of dependence in the elderly. Dependence is usually the result of long-term prescription, rather than illicit use. Major adverse effects include daytime sedation, unsteadiness, mood disturbance and cognitive impairment. Cognitive impairment may present as memory difficulties and continual use may result in a dementia like syndrome. Benzodiazepine use increases the risk of falls and hip fracture. Driving skills may be impaired. Memory and other cognitive functions improve after discontinuation of long term benzodiazepine treatment. Elderly people are less likely to withdraw from benzodiazepines and are more likely to relapse after withdrawal than younger people.

Abuse of prescribed opiates by elderly people is uncommon unless the person was an opioid abuser when younger. Elderly people who become dependent on prescribed opioids tend to have significant psychiatric problems.

Although use of illicit drugs is uncommon in elderly people, use of over the counter preparations is common and can result in medical and psychological problems. For example, chronic aspirin ingestion can result in a dementia like syndrome with tinnitus and irritability.

There is clearly a rise in the number of drug mis-users maintained over a long period of time on substitute medications e.g. Methadone. It is not unusual for clinicians these days to be caring for an older drug using population including patients in their 60’s or older.

Older drug mis-users may also have special health needs. Overdose death incidence can be represented as a U-shaped curve, most common in the young and older age groups. There are many reasons why increasing age may affect the individual vulnerability to the effects of drugs (prescribed or non-prescribed) and alcohol.

Health problems resulting from prolonged drug use (including tobacco and cannabis) and alcohol can exacerbate the decline in health that older adults already experience. Loneliness, loss of loved ones, or a declining sense of purpose can also lead older adults to return to drugs they used casually as younger people or to alcohol.

Advanced age, frailty and an increased need for prescription medications are all factors that contribute to the patient’s risks of developing a drug related problem.

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What you need to know about Systemic Lupus Erythematosus (SLE)

What is Systemic Lupus Erythematosus (SLE)?
Systemic lupus erythematosus (SLE) is a type of lupus that can affect most of the body’s tissues and organs. SLE is what most people mean when they use the term "lupus". … Read more on NHS Choices - SLE

What evidence is available?
Management of lupus is ideally multidisciplinary … Read more about evidence sources

Activities of Daily Living and mobility needs
In mild disease there will be few or no disabling effects … Read more about ADL and mobility needs

How long will the needs last?
Modern treatment, better clinical awareness and improved serological testing techniques have dramatically improved survival … Read more about award duration

Over 65’s
5% of SLE develops after the age of 65…. Read more about effects in the over 65 age group

What evidence is available?

Management of lupus is ideally multidisciplinary, involving the Consultant Rheumatologist, Specialist Nurse, Physiotherapist and Occupational Therapist.
In many areas of the country there are now Lupus Nurse Specialists, whose role is to provide advice, counselling, education and information. This is important at initial diagnosis and at times of acute flare.

Advice lines provide contact with Specialist units. The patient and family are able to have consultations with the Specialist Nurse and discuss the condition, and management options in detail.
The disease varies from person to person and their needs may include rehabilitative treatment. Graded exercise programmes help improve cardiovascular fitness and in some cases reduce fatigue. This is through Physiotherapy assessment. The Occupational Therapist, after assessment, helps the person manage their fatigue and the impact on their activities of daily living.

**Activities of Daily Living and Mobility needs**

**Note:** The disabling effects are only considered here for the condition of SLE itself and not with regard to the complications.

Disabling effects would be due to -:

- **Fatigue, fever, malaise & weight loss**
- **Joint pain**
- **Organ complications**
- **Skin complications**

If serious organ failure occurs, such as in the heart, lungs or kidneys, those effects must be considered separately.

In mild disease there will be few or no disabling effects, as the consequences of the disease would not affect the person’s ability to look after him/herself or get about. However, fatigue and malaise may limit physical activities.

In active disease, fatigue and morning stiffness can affect self-care and mobility but with treatment, it is unusual for significant care / mobility needs to arise. Flare ups can vary from person to person and the intensity and length of the flare ups depends on the individual’s response to the disease and the treatment.

The course of SLE varies and is unpredictable, the systems involved vary from person to person and the involvement can be as follows:

**Fatigue, fever, malaise and weight loss**

Are all universal symptoms of lupus. Fatigue may be mild in chronic SLE and not affect the person’s ability to self-care and get about, to any extent. However, severe fatigue, which accompanies a flare-up of the disease, may affect the person’s ability to self-care and get about, a great deal. The needs which a person may have, depends on how long the flare-ups last, how controlled the condition is and what the complications of the disease are.
Joint pain :-

- Moderate joint symptoms can mimic early rheumatoid arthritis, but tends not to be erosive, unlike rheumatoid arthritis. However, tendons and ligaments can be affected, and that can impact on daily activities. This may affect peeling and chopping vegetables, managing buttons and small fastenings, handling medications, injections etc.
- Joint pain may be severe, and mobility may be affected to a variable degree. Occasionally, some people may have destructive disease such as avascular necrosis of the hip, (which is the term for the ischaemia and death of the bone which may occur after injury. The neck of the femur is one of the bones of the body particularly susceptible to this occurrence). This complication would cause significant pain and affect mobility.
- Jaccoud’s Arthropathy may occur in a small percentage of people (It is a deformity of the fingers and thumb which is a consequence of tendon inflammation and damage). In these cases the effects (dressing, hygiene, vegetable preparation, and the ability to manage boiling water) are due to this complication.

Details for :-

Rheumatoid Arthritis

Organ Complications :-

- **Central Nervous System** - the person may develop milder symptoms such as migraine, depression, damage to a single nerve in the arm or leg, or more severe symptoms such as psychosis, fits, stroke, and other neurological complications. Disabling effects would be likely to be a consequence of complication, and may be very significant
- **Kidney** - Kidney disease is often rapidly progressive and difficult to control, leading to kidney failure. Again, any disabling effects will be as a result of kidney failure, or the need for dialysis, or transplant
- **Heart and Lungs** - Pericarditis, damage to the heart muscle itself or the coronary arteries, pleurisy and restrictive lung disease (pulmonary fibrosis) may all be a consequence of the disease. There is a major risk of accelerated atherosclerosis, ischaemic heart disease and thromboembolic disease. Individuals are advised to stop smoking. Ability to self-care and get about may be seriously affected by these complications

Skin complications

Skin rashes, hair loss, and mouth ulcers are a nuisance, but do not in themselves cause lasting disabling effects. The person may have to avoid sunlight and other sources of ultraviolet light. Hair loss may be reversed or may remain permanent because of scarring. This can cause emotional distress. Mouth ulcers and ulcers that occur in other sites (such as the nose) can occur in crops and can be quite distressing.
Raynaud’s Disease can be secondary to lupus; persistent Raynaud’s Disease may lead to problems with self-care, because of the effects on manual dexterity.

Basically, SLE is normally a treatable, manageable condition for the majority of people and treatment aims to control disease activity and enable independence. Also, it is important to note that the severity of the disease cannot be judged on the basis of the type or dosage of the drugs used to control the disease.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**How long will the needs last?**

**General**
- Modern treatment, better clinical awareness and improved serological testing techniques have dramatically improved survival.
- However, 10% of lupus patients die within 5 years of diagnosis. Even moderate disease should be under the care of a Specialist centre. The disease should never be “taken for granted”, as there is a risk of major organ effects and death.
- Also, inevitably, there are people who suffer serious side effects from the treatment, which can complicate symptoms, and in rare cases, lead to death. An example is the use of steroids which can lead to hypertension, diabetes, hypercholesterolaemia, or osteoporosis (18% have the metabolic syndrome). A person who is on long-term immunosuppressive treatment may succumb to an overwhelming infection. However, the treatment is always aimed at controlling the underlying inflammation and minimising risks from the treatment.
- The disease is relapsing and remitting, in both mild and severe cases.
- Prognosis has improved greatly in the last few years; and 5 – year survival is now around 90%.
- Good control of early inflammatory symptoms leads to a better long-term prognosis.
- Long – term prognosis also depends on early detection and treatment of complications, such as kidney disease.
- The main cause of death is accelerated atherosclerosis and kidney disease. The prophylactic prevention and management of cardiovascular risk is very important in improving the person’s prognosis.

If any of the following complications are present, the prognosis & duration details for that impairment should be referred to and followed.
Specific

Musculo-skeletal complications -:

- Jaccoud’s Arthropathy is not likely to improve.

A person who has avascular necrosis of the hip may have a total hip replacement, in which case this particular condition is likely to improve.

Details for:-

Rheumatoid Arthritis
Osteoarthritis

Skin complications -:

- Scarring of the scalp and hair loss can be permanent.
- Persistent Raynaud’s Disease can be a permanent problem, but it may improve if amenable to treatment, such as Nifedipine. More severe and unresponsive cases may require more specialist intervention.

Mental Health and Central Nervous System Complications

Symptoms may fluctuate, and the symptoms may range from

- Mild to severe effects such as mild depression to severe psychosis and
- Either a mental health effect (ranging from depression to psychosis), or a central nervous effect, such as epilepsy, ataxia, neuropathy or hemiplegia for example.

Kidney Complications

Clinical kidney involvement occurs in around 30% of cases and affects prognosis. Kidney disease is one of the two main causes of death in lupus.

The person may be in renal failure, requiring dialysis or a transplant and prognosis will depend on the treatment and response to that treatment.

Details for:-

Kidney disorders
Hypertension

Cardiovascular complications

Accelerated atherosclerosis is the other main cause of death in SLE. Good preventative measures must be implemented in order to improve prognosis.

Arrhythmias (irregular heartbeat) may arise as a result of a mild myocarditis.
Thromboembolic disease is another complication, especially in the antiphospholipid syndrome. Prognosis would relate to the presence of these conditions, the efficacy of treatment and the individuals stopping smoking.

Details for:-

Ischaemic heart Disease
Cardiac Arrythmias
Stroke
Peripheral Vascular Disease

Lung Complications
Repeated episodes of pleurisy and pleural effusions can be treated and the prognosis will relate to the response to treatment and the length of time it takes. Restrictive lung disease and lung fibrosis will gradually worsen and the effects are permanent.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Over 65

- 5% of SLE develops after the age of 65.
- It tends to take a milder course and certain symptoms such as joint pain and sicca (dry) symptoms, such as dry eyes, mouth, problems with swallowing etc occur more commonly.
- Because older people are more likely to be on medication, drug-induced SLE presents more often and takes a relatively mild course.
What you need to know about Giant Cell (Temporal) Arteritis

What is Giant cell (Temporal) arteritis?
Giant cell arteritis causes inflammation of the lining of the body’s medium and large arteries (vasculitis). The scalp’s arteries can be particularly affected.…… Read more on NHS Choices - Giant cell arteritis

What evidence is available?
Self-assessment is the prime source of evidence …. Read more about evidence sources

Activities of Daily Living and mobility needs
A person’s care and mobility needs should be assessed in relation to their symptoms and response to treatment …. Read more about ADL and mobility needs
Linked page: H/R Mob SVI deeming provision

How long will the needs last?
Temporal Arteritis normally improves dramatically with treatment…. Read more about award duration
Linked pages: H/R Mob SVI deeming provision

Over 65’s
Temporal Arteritis tends to occur in the older person…. Read more about effects in the over 65 age group

What evidence is available?
Note: If considering entitlement to H/R Mobility component under the Severely Visually Impaired (SVI) provisions, the following evidence source must be used:

The Consultant Ophthalmologist will be able to provide information about symptoms, signs, investigations including assessment of vision, treatment/management, and is likely to have information about resulting disability or needs.
Other evidence sources

Claim pack
Self-assessment is the prime source of evidence. If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it would provide good evidence.

GP
A GP factual report should provide information about the patient’s condition, as often they are treated by the GP, without being referred to the Hospital Consultant.

Hospital factual Report
In the absence of a GP factual Report, a report from a Hospital Consultant would provide information about investigations, treatment, response to the treatment, condition of the patient, and visits to the clinic. If details of peripheral visual defect are needed, the Ophthalmologist or Optometrist is an appropriate source of information.

HCP Examination Report
An HCP visit providing history and examination may be necessary, in the absence of any other available corroborative evidence, if there is contradictory information, and if it is the only means by which the claimant’s needs can be made clear.

Medical Services
Medical Services are available to interpret information including investigation results, and also to request relevant information from the GP or hospital Consultant.

Activities of Daily Living and Mobility needs
A person’s care and mobility needs should be assessed in relation to their symptoms and response to treatment. Depending on the severity of the symptoms, a person may have difficulties with the following activities -:
**Self-care**

Getting in and out of bed, washing & bathing, including getting in and out of the bath, going to the toilet, dressing and undressing, preparing a meal, walking in the house, and climbing stairs.

**Mobility**

Walking on the flat may be impaired by muscle pain and stiffness.

However, response to treatment is usually quite rapid; the person feels better in a matter of days rather than weeks. These needs may be present for a short time only and that is a few weeks at the most.

A customer with visual problems related to temporal arteritis may satisfy the H/R Mobility criteria under the [Severely Visually Impaired (SVI) deeming provisions](#).

In summary, treatment should alleviate the symptoms and the person should have few or no care needs arising from Temporal Arteritis.

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**How long will the needs last?**

Temporal Arteritis normally improves dramatically with treatment, so care and mobility needs may only be present for a few weeks at the most, though steroid treatment is likely to need to continue for at least 2 years.

The only disabling effects would be from vascular complications, such as complete or partial loss of vision or stroke.

**Click the link for details of:-**

- Visual Impairment
- H/R Mob SVI deeming provision
- Stroke

Also, bearing in mind the side-effects of long-term steroid use, there may be associated problems (such as osteoporosis, weight gain, diabetes and high blood pressure) so the maintenance dose should be kept as low as possible. Also osteoporosis prevention medication should be used, usually calcium and vitamin D and a biphosphonate.

Sudden blindness may be permanent and if a stroke (rarely) occurs, there will not be likely to be improvement after 2 years.
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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**Over 65**

Temporal Arteritis tends to occur in the older person, the most problematic factor is the dependence on long-term steroids, and the side-effects caused by this treatment. Side effects are less if the maintenance dose is kept below 7.5mg per day. Azathioprine may be used to reduce the dose of steroid.

Medication to prevent Osteoporosis (calcium and Vitamin D and a biphosphonate such as disodium etidronate) should be routinely used, but particularly in the older person.
What you need to know about Tennis/Golfer’s elbow

What is Tennis/Golfer’s elbow?
Tennis elbow is a condition that results in pain around the outside of the elbow. It often occurs after strenuous overuse of the muscles and tendons of the forearm, near the elbow joint. Read more on NHS Choices - Tennis elbow

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and mobility needs
In most mild tennis/golfer’s elbow there is sufficient elbow function to carry out all daily activities. Read more about ADL and mobility needs

How long will the needs last?
In more chronic conditions there may be more pain and occasionally the presence of swelling and limitation of movement. This does not usually hinder arm use to any great degree. Read more about award duration

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages:-
Ageing
Falls
Frailty

Activities of Daily Living and Mobility needs
In most mild tennis/golfer’s elbow there is sufficient elbow function to carry out all daily activities.
In more chronic conditions there may be more pain and occasionally the presence of swelling and limitation of movement. This does not usually hinder arm use to any great degree.
Prolonged lack of normal use may result in muscle weakness causing people to drop things. This may be a problem in, for example, carrying
heavy pots and pans in the kitchen, or occasionally with other activities of
daily living such as washing and dressing. This is highly unusual.
However, with treatment, rest and support or at the last resort surgery it is
possible to recover full function. This, however, may take several months.

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<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Golfer’s elbow (Medial epicondylitis)</td>
<td>1 year award (If entitlement appropriate)</td>
</tr>
<tr>
<td>Tennis elbow (Lateral epicondylitis)</td>
<td>1 year award (If entitlement appropriate)</td>
</tr>
</tbody>
</table>

*All information must be taken into account when considering the
duration of disabling effects and the duration of disabling effects must
be based on the particular circumstances of the individual claimant.*

[Back to top of section]
What you need to know about Testicular cancer

What is Testicular cancer?
Cancer of the testicles, also known as testicular cancer, is an uncommon type of cancer that primarily affects younger men. Read more on NHS Choices - Testicular cancer.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even... Read more about evidence sources.

Activities of Daily Living and mobility needs
Disability related to surgery for testicular cancer is likely to be short lived. On the rare occasion when needs are identified..., Read more about ADL and mobility needs.

How long will the needs last?
Most men will experience some side effects during treatment of testicular cancer. Any needs identified are likely to be related to..., Read more about award duration.

Over 65's
Testicular cancer mainly affects young men; it is rare in older men. There are no special features.

What evidence is available?
Information about cancer patients needs to be up to date as prognosis and treatment may change dramatically even over a few weeks. A hospital factual report will contain this information.

Community
- General Practitioner - the family doctor will have information from the hospital on diagnosis and treatment, this may not be up to date. For people who are living at home with disabilities, the GP is likely to have up to date information on how they are.
- Community or District Nurse - will have information on any home care or outreach package in place as this is coordinated through the practice.
- Social worker - customer may have a ‘Care plan’ from social services
Hospital
Specialist doctors -:
• Oncologist
• Physician
• Haematologist

Specialist nurses have many different job titles -:
• Clinical Nurse Specialist
• Stoma care nurse
• Macmillan Nurse

They are likely to be very knowledgeable about the disease in which they specialise and have up to date knowledge on a person’s treatment and disabilities.

Professions Allied to Medicine -:
• Physiotherapist
• Occupational Therapist
• Social worker
• Counsellor
• Psychologist

Also refer to the ‘Symptomatic treatments’ page.

Hospice
Hospice Specialists -:
• Palliative Care Physician
• Macmillan Nurse
• Clinical Nurse Specialist
• Social worker
• Physiotherapist
• Occupational Therapist
• Counsellor

Activities of Daily Living and Mobility needs

Care and Mobility needs during treatment
Disability related to surgery for testicular cancer is likely to be short lived. On the rare occasion when needs are identified because of Radiotherapy and Chemotherapy treatments, they can be expected to resolve when treatment is complete.
Disabling effects of treatments

Chemotherapy

The majority of men will have early stage disease (stage 1) and are likely to require only one cycle of chemotherapy after surgery, recovery will be complete, typically within two to three months. For those with metastatic disease treatment is likely to be more prolonged e.g. 4 cycles of chemotherapy and extra treatments such as further surgery, chemo or radiotherapy. The minimum time for treatment and recovery for these men is six months but treatment related disability may extend over a period of years.

If there is time men are offered the opportunity to bank sperm before chemotherapy starts because of potential chemotherapy-related infertility. Those who have high dose chemotherapy and bone marrow transplant are at high risk of developing infection and experience quite severe side effects during treatment. In the long term they may never fully recover physical strength and may have any of the enduring effects of chemotherapy especially fatigue.

Radiotherapy

Treatment for seminoma is given over 10 to 14 days. Specific side effects include diarrhoea and nausea.

Further surgery

Some men may need further surgery either before or after chemotherapy and radiotherapy treatment. This will usually be to remove 'lumps' or 'masses' of secondary cancer identified on Computerised Tomography (CT) scanning.

These operations and their side effects are:-

- **‘Lymphadenectomy’** - Removal of lymph nodes from the back wall of the abdomen. This may be carried out as an open or laparoscopic operation; the recovery time is 2-6 weeks.
- **Lung surgery** is major surgery and requires 3-12 weeks for recovery. If a significant amount of lung tissue is removed this may result in reduced exercised tolerance – getting out of breath easily and not being able to exercise as hard as before.

Long term disabling effects of treatment

These are important in testicular cancer because it affects young men, often in their twenties; by the time they are in their forties a significant number may already have developed long term side effects of treatment. Risks include an increased chance of developing leukaemia, melanoma,
sarcoma, cancers of stomach, bladder, colon, pancreas, lung, prostate, kidney and thyroid. They are at increased risk of developing coronary heart disease. They may experience any of the enduring side effects of chemotherapy.

Having cancer at a young age is hard to cope with psychologically. They will be coping with potential loss of life, side effects of treatment, loss of a testicle and hair loss. They may have to stop work or change their type of work as a result of their diagnosis. Their worries may include significant financial problems, fears of the future related to their disease and problems with body image, any of which may cause depression.

How long will the needs last?

Most men will experience some side effects during treatment of testicular cancer. Any needs identified are likely to be related to treatment and recovery is expected when treatment is complete, typically within 2-3 months. Five year survival for testicular cancer in the UK is 96% - most men have early stage disease and make a full recovery. Those with more advanced disease at diagnosis are also expected to make a full recovery, time taken for treatment and recovery is likely to be longer and at least six months. Some men will have enduring side effects of treatment which persist when it is complete and they are in remission. New long term side effects may develop years later particularly after radiotherapy treatment.

Stage 1 disease
 Five year survival is 95%. The majority of men are expected to make a full recovery. There are no long term disabling effects other than the rare enduring side effects of chemotherapy and infertility in some men. The men who have had radiotherapy treatment may develop late side effects of this treatment some years later.

Stage 2 disease
 Five year survival is 80-90%, with non-seminoma being at the lower end. The majority of men are expected to make a full recovery. There are no long term disabling effects other than the rare enduring side effects of chemotherapy and infertility in some men.

Stage 3 disease
 Five year survival is 70% for both types of testicular cancer. The majority of men are expected to make a full recovery. Treatment and recovery are likely to take at least six months. There are no long term disabling effects other than the rare enduring side effects of chemotherapy and infertility in some men. Recurrent disease is fairly common and may cause any of the symptoms in the recurrent/metastatic disease group.
Stage 4 disease

This is advanced testicular cancer at diagnosis; they may have any of the disabling effects of metastatic disease. Five year survival for these men is 48% for men with non-seminoma testicular cancer and 72% for seminoma type cancer. Treatment and recovery are likely to take at least six months.

Metastatic and Recurrent disease

Those who have recurrent disease, which is not responding to treatment or who have had more than two recurrences are more likely to have indefinite needs and may be terminally ill.

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<thead>
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</tr>
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<td>Testicular cancer - Stages 1, 2, 3</td>
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<tr>
<td>and 4</td>
<td></td>
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<tr>
<td>Metastatic &amp; Recurrent disease</td>
<td>Indefinite award</td>
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All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Thalassaemia

What is Thalassaemia?
Thalassaemia is the name given to a group of inherited blood disorders that affect the body’s ability to create red blood cells. Read more on NHS Choices - Thalassaemia

What evidence is available?
Children and adults with major forms of Thalassaemia will be attending specialist hospital centres on a long-term basis for regular monitoring and treatment. Read more about evidence sources

Activities of Daily Living and Mobility needs
The most severe functional restrictions are likely to be found in individuals who have not been treated adequately in childhood. Read more about ADL and Mobility needs

How long will the needs last?
Without regular transfusions children with beta-Thalassaemia major die before the age of five from heart failure or infection. Read more about award duration

Over 65’s
There is no specific guidance for over 65’s.

What evidence is available?
Children and adults with major forms of Thalassaemia will be attending specialist hospital centres on a long-term basis for regular monitoring and treatment. Reports may be obtained from doctors, specialist nurses and other health care professionals working in these centres.

People with less severe types of Thalassaemia attend haematology clinics or are under the care of general practitioners. Medical reports may be obtained confirming that the anaemia is mild and asymptomatic.

Activities of Daily Living and Mobility needs
Mild functional restrictions

People in the following categories are likely to have few or no functional restrictions:

- Adults with mild asymptomatic anaemia due to Thalassaemia minor variants, have no functional restrictions. They are able to lead normal lives, care for themselves and walk without problem.

- People with Thalassaemia intermedia who have mild to moderate anaemia (haemoglobin in range 8 -11 g/dl). The body adapts to this degree of anaemia and the person is not usually fatigued, debilitated or short of breath. They are unlikely to have any functional restrictions and have no ADL or mobility needs.

- Some adults with successfully treated beta-Thalassaemia major and no substantial complications may have few or minor functional restrictions only. Although they may require regular blood transfusions on a 3 – 4 weekly basis their haemoglobin is maintained within the range 9.5 – 11 g/dl. They are able to function normally for the majority of the time, even in the week prior to transfusion, and are able to care for themselves fully and walk without problem. Someone with an additional problem such as mild asthma will cope less well with the drop in haemoglobin and is more likely to be in the moderate functional restrictions group.

Moderate functional restrictions

Moderate to severe anaemia (Hb 8 g/dl or less) in a person with Thalassaemia intermedia may cause functional restriction on a day-to-day basis. They may be persistently fatigued and short of breath on exertion, and require some help with dressing, bathing and preparation of food. Walking may be limited due to both fatigue and shortness of breath.

The following complications of long-term anaemia and iron overload in adults may cause moderate functional restrictions in people classified in the intermediate and major groupings. The ability to self-care and to walk may be affected by these medical conditions, either singly or in combination, and will be exacerbated by fatigue and shortness of breath.

- heart failure and dysrhythmias (dysrhythmia is often a cause of death)
- limb deformities, arthritic joints, osteoporosis
- abnormal liver function, liver failure, cirrhosis
- long term leg ulceration
- pulmonary hypertension
- diabetic complications
- hepatitis C
Severe functional restrictions

The most severe functional restrictions are likely to be found in individuals who have not been treated adequately in childhood. Such individuals will have failed to grow and develop normally, will be short with longer limbs in proportion to the spine and abnormally shaped heads (typically described as a chipmunk facies). The latter may lead to deafness. They are likely to have heart disease, of those patients who are in inadequately treated 55% will have died by age 35.

Adults with severe iron overload may also have severe functional restrictions due to heart failure, liver failure and diabetic complications – see relevant guidance. The most severe problem is heart failure which will require 24 hour infusion treatment, often using a portacath. Heart failure is commonly so severe that they are unable to walk up stairs and dysrhythmias further limit exercise tolerance when they occur. Ejection fraction is commonly monitored regularly in these cases, information on this test is available in the heart failure guidance.

Neuropathy and ulceration of the lower limbs is common and is likely to limit mobility in those patients with Thalassaemia intermedia.

People with these problems are likely to need help with all aspects of self-care and are likely to be restricted in their walking.

How long will the needs last?

Thalassaemia major

Without regular transfusions children with beta-Thalassaemia major die before the age of five from heart failure or infection. Successful survival into adulthood depends on close monitoring of the affected person in a specialist Thalassaemia centre where all the physical, psychological, genetic and social effects of the condition can be addressed.

From a therapeutic stand point successful treatment includes avoidance of iron overload through chelation therapy. Without treatment of iron overload death from heart disease occurs in the early twenties. Life expectancy in adults is reduced due to liver and/or heart disease secondary to iron overload.

Bone marrow transplantation is more likely to be successful if undertaken before the age of sixteen, and when the marrow is donated by a close
relative, usually a sibling, who has a good genetic match to the recipient. The prognosis is less favourable for the recipient with beta-Thalassaemia complications such as liver damage and iron overload.

Cord blood transfusion is a relatively new procedure and there is little data at present on long-term outcomes.

**Thalassaemia intermedia**

Children and adults with Thalassaemia intermedia have a better prognosis. Individuals with more severe levels of anaemia are likely to have reduced life expectancy and poor overall health due to complications of the condition.

**Thalassaemia minor/carrier**

People are asymptomatic, lead normal lives and have a normal life expectancy.

[Back to top of section]
What you need to know about Thyroid Gland disorders

What are disorders of the Thyroid Gland?

- Read more on [NHS Choices - Goitre](https://nhschoices.nhs.uk/health/articles/goitre)
- Read more on [NHS Choices - Underactive thyroid](https://nhschoices.nhs.uk/health/articles/hypothyroidism) - also known as Hypothyroidism or Myxoedema
- Read more on [NHS Choices - Overactive thyroid](https://nhschoices.nhs.uk/health/articles/hyperthyroidism) - also known as Hyperthyroidism or Thyrotoxicosis
- For information about other thyroid gland disorders Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and mobility needs
If untreated euthyroid goitre usually progresses slowly but adverse effects are limited to the increasing cosmetic defect of the swelling and the possibility of secondary pressure effects.....[Read more about ADL and mobility needs](https://nhschoices.nhs.uk/health/articles/mobility)

How long will the needs last?
If untreated euthyroid goitre usually progresses slowly but adverse effects are limited to the increasing cosmetic defect of the swelling and the possibility of secondary pressure effects.....[Read more about award duration](https://nhschoices.nhs.uk/health/articles/mobility)

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.

Linked pages:-
- [Ageing](https://nhschoices.nhs.uk/health/articles/ageing)
- [Falls](https://nhschoices.nhs.uk/health/articles/falls)
- [Frailty](https://nhschoices.nhs.uk/health/articles/frailty)

Activities of Daily Living and Mobility needs
If untreated euthyroid goitre usually progresses slowly but adverse effects are limited to the increasing cosmetic defect of the swelling and the possibility of secondary pressure effects. Once treated the size of the gland should gradually regress over a period of several months. No residual disability and no variability in the condition would be expected.

Myxoedema can produce a significant degree of illness and untreated can lead to coma and possible death. Once recognised it can be treated effectively and recovery occurs quickly, usually within three months. However difficulties with establishing control and an effective replacement dose of thyroxine may delay full recovery by up to six months. Hypothyroidism in infants and children can lead to serious failure to thrive, small stature and failure of intellectual development (the syndrome of cretinism) which if unrecognised or untreated can result in permanent impairment of intellectual development and leads to severe dependency. Once treated the effects of myxoedema would not be expected to cause significant disability with no continuing effect on function of the limbs, the spine, the cardiovascular system or mental state.

The effects of thyrotoxicosis depend on the duration of the condition, the age of the patient and response to treatment. It can result in a severe thyrotoxic crisis with fever, delirium or coma, seizures, vomiting, diarrhoea and jaundice, death being caused by arrhythmias, heart failure or hyperthermia. However, the condition is usually recognised well before such dramatic presentation occurs and once the cause has been established it can be treated effectively. Delay in establishing effective dosage of medication or recovery from surgery may impede progress but full recovery to normal existence is expected in all but a few cases.

In some cases signs of thyrotoxicosis can occur without increase in activity of the thyroid gland. This occurs in some forms of thyroiditis and in cases where excess doses of thyroid hormone have been taken as treatment of hypothyroidism. Malignant disease of the thyroid gland, rarer forms of thyroid disease or the particular effects of ionising radiation on thyroid function can cause complex long-term illness and require separate consideration.

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**How long will the needs last?**

**Goitre**

If untreated euthyroid goitre usually progresses slowly but adverse effects are limited to the increasing cosmetic defect of the swelling and the possibility of secondary pressure effects. Once treated the size of the gland should gradually regress over a period of several months. No residual disability and no variability in the condition would be expected.
**Myxoedema**

Onset of symptoms of myxoedema is usually insidious and the condition may not be recognised in early stages. Once the condition has been diagnosed and treated recovery should be complete with no residual disability after a few month’s treatment. Relapse can occur as a result of poor compliance with treatment but day-to-day variability in the condition would not be expected.

**Thyrotoxicosis**

Thyrotoxicosis tends to develop insidiously at first but progresses fairly rapidly to overt symptoms. Treatment should achieve control of the condition in the great majority of cases with many achieving an effective cure. Long-term follow-up to monitor progress may be needed. Symptomatic improvement should occur within three months of treatment and unless there is medical evidence of complications that are not amenable to treatment, no continuing loss of function would be expected. Function of limbs or spine, the cardiovascular system and mental state would be expected to be normal. Once recognised and treated there should be little or no variability other than from adverse effects of antithyroid drugs or poor compliance with treatment. Such changes should be recognisable by the patient and effectively managed by routine medical follow-up. Apart from when caused by malignant disease or where secondary to another coincidental condition, thyrotoxicosis can be treated effectively. Life-long medication may be needed in some cases but patients should be able to follow a normal life-style with no continuing disability. There would need to be medical evidence of chronic secondary complications or difficulty with control of the condition, to support claims of chronic functional disability from this and other thyroid disorders.

<table>
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<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
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</tr>
<tr>
<td>Myxoedema / Hypothyroidism</td>
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</tr>
<tr>
<td>Thyroid disease – Other / type not known</td>
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</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

[Back to top of section]
What you need to know about a Torn knee cartilage (meniscus tear)

What are the menisci?
Sitting between the upper and lower leg bones at the knee joint are rubbery pads of tissue called menisci. Read more on NHS Choices - Knee pain - Damage to the menisci

What evidence is available?
There would normally be no lasting significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and Mobility needs
Recovery from removal of a meniscal tear requires the use of crutches for longer walks only until the patient can walk without limping (typically 5-7 days). With a proper rehabilitation programme one can usually expect to be back in sports within 4-6 weeks after the meniscectomy.

How long will the needs last?
Recovery from removal of a meniscal tear requires the use of crutches for longer walks only until the patient can walk without limping (typically 5-7 days). With a proper rehabilitation programme one can usually expect to be back in sports within 4-6 weeks after the meniscectomy.

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.
Linked pages:-
Ageing
Falls
Frailty

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What is Ulcerative colitis?
Ulcerative colitis is a long-term (chronic) condition affecting the colon.

What evidence is available?
People with well-controlled disease on medication and those in remission are likely to be under the care of general practitioners.

Activities of Daily Living and Mobility needs
People with mild symptoms and those in remission have no significant functional restrictions and are able to follow an independent lifestyle.

How long will the needs last?
In many cases good control of the symptoms and exacerbations can be achieved with appropriate medication.

Over 65’s
Elderly people with moderate to severe ulcerative colitis, and some debilitated older people recovering from surgery, may be functionally restricted.

What evidence is available?
People with well-controlled disease on medication and those in remission are likely to be under the care of general practitioners.

People with moderate to severe disease attend gastroenterology clinics for treatment of relapses and monitoring of drug therapy. Some will also attend surgical outpatients. Information can be obtained from doctors and specialist gastroenterology nurses who work in these clinics. Specialist stoma nurses provide care and advice for people with ileostomy. They work in both hospital clinics and in the community.
Activities of Daily Living and Mobility needs

People with mild symptoms and those in remission have no significant functional restrictions and are able to follow an independent lifestyle. They do not need care from others, nor are they restricted in their ability to walk.

People with moderate symptoms of abdominal pain and diarrhoea may experience some restriction in normal activities during flare-ups. It is likely however those symptoms will remit after a few weeks with treatment. There is unlikely to be any need for long-term assistance with self-care.

Adults who have undergone surgery for ulcerative colitis, whether emergency or elective surgery would be expected to make a good recovery with a few weeks or months. They should also be able to learn to manage an ileostomy independently within this time scale.

People with moderate and severe disease are unlikely to be restricted in ability to walk, since lower limb function is not affected by the condition. Urgency of defaecation or the need to find a toilet when out, is not considered to lead to a need for guidance or supervision.

Similarly, in the majority of cases, the care needs of those with a severe functional restriction will be insufficient to satisfy entitlement conditions.

How long will the needs last?

In many cases good control of the symptoms and exacerbations can be achieved with appropriate medication. At any one time 50% of people are asymptomatic, 30% have mild symptoms and 20% have moderate to severe disease. People learn to control the symptoms themselves by use of medication and attention to nutrition. Many people have long periods of complete remission. Overall life expectancy is the same as that of the general population.

In comparison with older people younger people tend to have more extensive disease. Older people however may have more adverse outcomes, if they have a severe attack with complications.

After thirty years a third of people with ulcerative colitis affecting the whole colon develop colonic cancer.

Surgical removal of the entire colon is associated with a good prognosis removing the need for long-term medication to prevent remission, and eliminates the risk of developing colonic cancer.
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

**Over 65**

Elderly people with moderate to severe ulcerative colitis, and some debilitated older people recovering from surgery, may be functionally restricted. They may need help to move around house, get upstairs, get on and off the toilet and help with personal hygiene, dressing and bathing. They may also need help with using pads and waterproof pants to control faecal incontinence if diarrhoea is persistent, or limited mobility slows down access to the toilet. Elderly people may take longer, up to several months, to learn to manage an ileostomy. Problems with manual dexterity, visual impairment or dementia might lead a long-term need for help with ileostomy care. Frail elderly, especially if underweight or subject to poor nutrition, may have a much longer requirement for self-care, assistance with medication, encouragement to maintain adequate nutrition and fluid intake, and may also be prone to falls.
What you need to know about Urticaria

What is Urticara?
Urticaria (also known as hives, welts or nettle rash) is a raised, itchy rash that appears on the skin. The rash can be limited to one part of the body or spread across large areas of the body…… Read more on NHS Choices - Urticaria

What evidence is available?
There would normally be no significant restriction of self-care activities or the ability to get around and therefore further evidence would not usually be required.

Activities of Daily Living and Mobility needs
The rash causes discomfort and the irritation may disturb sleep. However urticaria does not usually impair function of the limbs or the individual ability to care for personal needs…. Read more about activities of daily living and mobility needs

How long will the needs last?
Urticaria does not usually cause significant functional restrictions…. Read more about award duration

Over 65’s
There are no significant special features in the elderly. You may wish to consult the ageing, falls and frailty guidance.
Linked pages:-
Ageing
Falls
Frailty

Activities of Daily Living and Mobility needs
The rash causes discomfort and the irritation may disturb sleep. However urticaria does not usually impair function of the limbs or the individual ability to care for personal needs.

Pressure urticaria affecting the soles of the feet may cause discomfort on standing and walking but the effect is generally short-lived.
Chronic urticaria can be disabling particularly where there is an associated systemic reaction with joint pain and fever but such circumstances should not persist for more than a few weeks other than in rare cases.

Patients who have persistent disabling chronic urticaria would be expected to be under the care of a specialist and medical evidence of the severity of the condition should be available to confirm the ongoing disability.

**How long will the needs last?**

Urticaria does not usually cause significant functional restrictions. Once it has developed, allergic sensitisation tends to persist for life and the urticarial reaction can recur with any exposure to the relevant allergen. In many cases, a degree of tolerance can develop and the condition may resolve spontaneously. Where sensitivity is due to a known agent that can be avoided, such as a particular drug, the condition may never recur.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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What you need to know about Valvular heart disease

What is Valvular heart disease?

- Read more about NHS Choices - Mitral valve problems
- Read more about NHS Choices - Aortic valve replacement
- Read more about NHS Choices - Congenital heart disease

For information about other valvular heart conditions Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?

Self-assessment is the prime source of evidence but the claim pack should be checked to see who has completed it and that it is an accurate and reliable description of their problems ….. Read more about evidence sources

Activities of Daily Living and Mobility needs

The main disabling effects of valvular heart disease are due to the consequences of the diseased valve and include heart failure and stroke… …..Read more about ADL and Mobility needs

How long will the needs last?

Any ADL s and mobility needs are likely to be the result of secondary effects of the valvular heart disease such as stroke or heart failure …. Read more about award duration

Over 65’s

Valvular heart disease is a disease of ageing and most people over the age of 70 show symptomatic evidence of valve dysfunction…….. Read more about over 65’s

What evidence is available?

Self-assessment is the prime source of evidence but the claim pack should be checked to see who has completed it and that it is an accurate and reliable description of their problems.

If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.
Hospital Factual Report

In all cases of moderate and severe cardiac disease a Consultant Cardiologist and a Specialist Cardiac Nurse would normally have been involved in the diagnosis, management and treatment of the individual. Indeed the absence of any documented history of a Cardiology consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required.

If a person has undergone a successful valve replacement operation, the claimant will be followed up in the hospital Outpatient Department, and this will be the best source of information for his/her residual needs.

The Cardiac Rehabilitation Nurse

The Cardiac Rehabilitation Nurse is a Specialist nurse, who works in close contact with the Cardiologist, and is part of the Cardiac Rehabilitation Team.

She/he is closely involved with the patient, from the start of the hospital stay, and, as well as attending to the physical needs of the patient, is crucial in advising and supporting the patient.

Heart failure patients suffer from an enormous impact on their confidence in their ability to do things and a large proportion of them suffer from depression and the Specialist Nurse is there to support them. She/he also can act as an intermediary between the Consultant (and the rest of the team) and the patient, giving advice on medication, dose adjustments, lifestyle, social issues and so on. He/she is also in a position to tell the patient about their illness and discuss things like prognosis, which may be worrying the patient, as well as being an important issue.

This contact is kept up after the patient is discharged, for both medical and psychological reasons; and phone contact, for reassurance of the patient, may take place several times a week, in cases of severe heart failure. At late-stage or end-stage disease, the patient may contact the nurse many times because of the need for psychological, financial or social support and for advice on managing often quite complex treatment regimes. Obviously, the amount of contact varies with the severity of the condition and the readiness of the patient to seek help.

The Specialist Nurse can also act as a go-between for the patient, GP and Consultant co-ordinating and adjusting the treatment options.

Therefore, this role is recognized as being extremely important for the well-being of the patients and more and more hospitals use their services on a permanent basis.

General Practitioner Factual report

The General Practitioner would normally have made the initial referral of the claimant to the Cardiologist and would normally be aware of the results
of tests, and current medication. The general practitioner may not have such detailed knowledge of the claimant’s needs, if he/ she is more frequently managed by the Consultant Cardiologist, and the Specialist Cardiac Nurse, (who are more likely to have detailed knowledge of exercise tolerance, and the disabling effects of the condition).

If there is no specialist health professional involvement or evidence cannot be obtained from them, then a factual report from the claimant’s own doctor would be more appropriate.

**HCP examination Report**

An [HCP examination report](#) would be likely to be necessary when the person claims significant disability (equivalent to a moderate or severe condition), but there is no supporting evidence from the GP or hospital Specialist; if no corroborative evidence has been able to be obtained; or if it is the only means whereby the claimant's needs can be clarified.

**Medical Services**

The [Medical Services](#) doctor may be asked to request relevant information such as test results from the GP or Hospital Consultant, and to interpret test results and other information.

**Activities of Daily Life and Mobility needs**

**Disabling Effects**

The main disabling effects of valvular heart disease are due to the consequences of the diseased valve and include heart failure and stroke. If evidence suggests that the customer has heart failure or has had a stroke, which may have resulted from valvular heart disease then go to [Heart Failure guidance](#) or [Strokes guidance](#).

In the case of aortic stenosis, angina may occur because of a sudden drop in blood pressure resulting in an inadequate supply of oxygen to the heart muscle even where the coronary arteries are healthy.

**How long will the needs last?**

Any mobility and care needs are likely to be the result of secondary effects of the valvular heart disease such as stroke or heart failure. If evidence suggests that the customer has heart failure or has had a stroke, which may have resulted from valvular heart disease then go to to [Heart Failure guidance](#) or [Strokes guidance](#).
Valvular Heart disease -:

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<th>Condition</th>
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<tbody>
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<td>Stroke / Cerebro vascular accident (CVA)</td>
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<td>2 year award</td>
</tr>
<tr>
<td></td>
<td>More than 2 years</td>
<td>Indefinite award</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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Valvular Heart disease in people over 65

Both the incidence (number of new cases reported in a population over a certain period of time) and prevalence (percentage of the population affected with a particular condition at a given time) of valvular heart disease increases with increasing age.

As with other conditions in older people, the existence of other pathology can confuse the issue, (as far as diagnosis is concerned) and the older person may present with heart failure, palpitations, dizziness, falls, breathlessness, angina, fainting or collapse.

Valvular heart disease is a disease of ageing and most people over the age of 70 show symptomatic evidence of valve dysfunction and around 10% show evidence of significant disease; the process is likely to have begun earlier than that (from the age of 60).

Senile degeneration can be a cause of both valve stenosis and valve regurgitation (incompetence). However, in older people who suffered from rheumatic fever (without the benefit of antibiotics), mitral valve regurgitation, mitral valve stenosis, aortic valve regurgitation, aortic valve stenosis and tricuspid valve stenosis may result (with often more than one valve being affected).
Tricuspid valve regurgitation is often associated with a severe, longstanding lung disorder and is therefore more likely to occur in older people.

Aortic Valve Stenosis

In the Western world, aortic valve stenosis is mainly a disease of older people as the pathological process involves scarring and calcification in the cusps of the valve. It normally presents in a person’s 70’s or 80’s. Aortic valve stenosis is a common cause of fainting, angina and heart failure in older people and there is a real risk of sudden death on exertion.

Coronary Artery disease and Valvular Heart disease

20% of people with aortic regurgitation have coronary artery disease. A common cause of mitral regurgitation is a myocardial infarction, where the papillary (supporting) muscles of the mitral valve are damaged.

Surgery in Valvular Heart disease

Surgery can take place even in the very elderly with a great deal of benefit but because of the likelihood of reduced health, strength and resilience and the possible presence of other disease conditions, the mortality risk may be higher.

If valve replacement surgery is undertaken, a biological valve may be preferable to use in an older person for two reasons:

- It is likely to last the patient’s lifespan,
- There is no need for the use of anticoagulants (the use of which requires careful monitoring and which have potentially serious side effects).

The person may be too frail to be a candidate for surgical valve replacement and drug therapy may alleviate symptoms to some extent.
What you need to know about Venous disorders

What is a Venous disorder?

- Read more on NHS Choices - Deep Vein Thrombosis
- Read more on NHS Choices - Pulmonary embolism
- Read more on NHS Choices - Varicose eczema
- Read more on NHS Choices - Varicose veins
- Read more on NHS Choices - Venous leg ulcers
- Read more on Chronic Venous Insufficiency
- Read more on Superficial Thrombophlebitis

For information about other Venous disorders Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?

Self-assessment is the prime source of evidence and in most cases the needs will be clear from the claim pack. …Read more about evidence sources

Activities of Daily Living and Mobility needs

There may well be quite intense pain and swelling in the acute phase. ….Read more about ADL and mobility needs

How long will the needs last?

There may well be quite intense pain and swelling in the acute phase ….Read more about award duration

Over 65’s

DVT is common in the elderly because many of the precipitating factors are common (immobility, fractures, etc.). Anti-coagulant therapy involves a greater risk of bleeding in older patients.

Chronic Venous Insufficiency

What is it?
Chronic venous insufficiency is a condition in which the blood, which normally would flow back to the heart from the veins in the legs, does not do so efficiently, because the valves in the veins are damaged or absent.

As a result, blood pools in the legs, and causes complications without treatment. Conditions which may result are pain and swelling of the legs, skin infections or skin ulcers.

Causes
- Congenital absence, weakness or damage to the valves of the leg veins, (both of the superficial veins and the perforating veins)
- The condition may also be caused by a deep vein thrombosis (DVT). This may be referred to as the “post-thrombotic syndrome” or “post-phlebitic syndrome”.
- Increased venous pressure in the legs
- Rarely, varicose veins.

Risk factors
- Increased age
- Other family members with the condition
- Lifestyle – that includes obesity, sedentary lifestyle or jobs (involving sitting or standing for long periods of time), smoking, wearing tight or restrictive clothing which impair the venous circulation.

Symptoms
- Pain in the legs, worse on standing and improved by elevating the legs
- Swelling of the legs
- Dull, aching, itching, cramping feeling, due to venous hypertension

Signs can include:
- Swelling (oedema) of the leg/s
- Varicose veins
- Non-healing ulcers on the leg/s, especially on the insides of the ankles (this is where the pressure in the veins is greatest)
- Characteristic skin changes which include scaly skin, hard and pigmented skin on the legs. The pigment is a reddish brown due to a leakage of red blood cells into the skin.
- “Champagne Bottle Leg” which describes the calf of the leg becoming permanently enlarged, with a narrow ankle. This is as a result of the leakage of plasma into the subcutaneous (fatty) tissue, which causes fibrosis of this tissue layer. This is known as lipodermatosclerosis.
Superficial Thrombophlebitis

The term “superficial thrombophlebitis” means a clot, with inflammation, occurring in a vein under the skin.

It often occurs in varicose veins, but can also occur as a result of injury to the vein, such as from an intravenous injection, indwelling intravenous cannula, or from intravenous drug abuse (use of street drugs). There is a sudden, localized inflammatory reaction in the vein wall with a secondary thrombus (clot) which is strongly adherent to the vessel wall.

The clinical picture is of pain, redness and swelling along the vein, which can be seen and felt as a hard, cord-like structure.

Normally it is not possible for superficial thrombophlebitis to cause an embolus, but unlike in superficial veins in other parts of the body (such as in the legs and arms) superficial thrombophlebitis in groin veins may spread into a deep vein, where the clot may break off and cause an embolus.

Treatment is with aspirin, elevating the affected limb and the use of topical non-steroidal anti-inflammatory cream, and hirudoid cream.

Sometimes, thrombophlebitis repeatedly occurs in normal veins. When this occurs it is known as Thrombophlebitis Migrans and it may be associated with cancer of an organ such as carcinoma of the body or tail of the pancreas, and ovarian carcinoma. A person who presents with this symptom should be carefully evaluated, as there may be an underlying serious condition.

Disabling Effects

The inflammatory effects of superficial thrombophlebitis are normally short – lived, and respond well to treatment, and there should be no lasting disabling effects, though the vein is likely to feel hard for a considerable time. If Thrombophlebitis Migrans is present, the care and mobility needs will depend on the patient’s general condition and the extent of the underlying severe illness, such as cancer of the pancreas.

What evidence is available?

Self-assessment is the prime source of evidence and in most cases the needs will be clear from the claim pack, but the claim pack should be checked to see who has completed it and that it is an accurate and reliable description of their problems.
If the claim pack has been completed on behalf of the customer, by someone who has a good understanding of his or her needs, then it could provide good evidence.

**Hospital Factual Report**

In cases of moderate and severe peripheral vascular disease, a Consultant Vascular Surgeon would normally have been involved in the diagnosis, management and treatment of the individual. Indeed the absence of any documented history of a specialist consultation should raise doubts about the nature and/or severity of the given diagnosis. Hospital factual reports should therefore be obtained if required.

**General Practitioner Factual report**

The General Practitioner would normally have made the initial referral of the claimant to the Consultant, and would normally be aware of the results of tests, and current medication. If there is no specialist health professional involvement, or evidence cannot be obtained from them, then a factual report from the claimant’s own doctor would be more appropriate.

**HCP Examination Report**

An HCP examination report would be likely to be necessary when the person claims significant disability (equivalent to a moderate or severe condition), but there is no supporting evidence from the GP or Hospital Specialist; if no corroborative evidence has been able to be obtained; or if it is the only means whereby the claimant's needs can be clarified.

**Medical Services**

The Medical Services doctor may be asked to request relevant information such as test results from the GP or Hospital Consultant, and to interpret test results and other information.

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**Activities for Daily Living and Mobility needs**

Deep Vein Thrombosis (DVT)

There may well be quite intense pain and swelling in the acute phase, and mobility will be affected, but this phase should last no longer than a few weeks at the most. Any intercurrent condition, such as fractures or major illness should be taken into consideration as well.
How long will the needs last?

**Deep Venous Thrombosis (uncomplicated)**

There may well be quite intense pain and swelling in the acute phase, and mobility will be affected, but this phase should last no longer than a few weeks at the most.

**Pulmonary Embolus**

A massive pulmonary embolus is normally fatal. Multiple small infarcts may cause lung damage. There would normally be reduction in the person’s ability to exert him / herself affecting both ability to self - care and to get about. If the person is sufficiently breathless to have care/mobility needs the prognosis is as follows :-

- Acute condition – should last no longer than a few weeks.
- Chronic condition (that is, present for more than 9 months) – If an award is made then award for an **Indefinite period**.

**Post – Thrombotic Syndrome and Venous Ulcers**

Incompetence of superficial and perforator veins only (excellent long-term results where up to 90% of venous ulcers heal completely after surgical treatment) -:

- With surgical treatment - no care/mobility needs after recovery from operation which would normally be about 6 weeks.
- Without surgical treatment - If an award is made then award for an **Indefinite period**.

Most symptoms can be controlled by the wearing of elastic stockings. However, if the deep veins are incompetent, there could be a high rate of recurring problems. In this case, any care/mobility needs are likely to be indefinite.

**Varicose Veins**

The condition responds very well to elastic support stockings and surgery, and there should be no disabling effects after successful use of support stockings and after successful surgery.

**Superficial Thrombophlebitis**

The inflammatory effects of superficial thrombophlebitis are normally short-lived, and respond well to treatment, and there should be no lasting disabling effects, though the vein is likely to feel hard for a considerable time.
<table>
<thead>
<tr>
<th>Condition</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deep Vein Thrombosis (DVT)</td>
<td>N/A</td>
</tr>
<tr>
<td>Phlebitis</td>
<td>N/A</td>
</tr>
<tr>
<td>Post-Thrombotic syndrome</td>
<td>N/A</td>
</tr>
<tr>
<td>Eczema – varicose type</td>
<td>N/A</td>
</tr>
<tr>
<td>Pulmonary embolism -:</td>
<td>N/A</td>
</tr>
<tr>
<td>Acute</td>
<td>N/A</td>
</tr>
<tr>
<td>Chronic (i.e. present for more than 9 months)</td>
<td>Indefinite</td>
</tr>
<tr>
<td>Superficial Thrombophlebitis</td>
<td>N/A</td>
</tr>
<tr>
<td>Venous Insufficiency - Chronic</td>
<td>N/A</td>
</tr>
<tr>
<td>Venous ulcer -:</td>
<td></td>
</tr>
<tr>
<td>- Surgery planned or undertaken</td>
<td>N/A</td>
</tr>
<tr>
<td>- No surgery planned or undertaken</td>
<td>Indefinite award (where entitlement appropriate)</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
What you need to know about Viral Hepatitis

What is Viral Hepatitis?
- Read more on NHS Choices - Hepatitis A
- Read more on NHS Choices - Hepatitis B
- Read more on NHS Choices - Hepatitis C

What evidence is available?
Hepatitis A resolves in the majority of cases … Read more about evidence sources

Activities of Daily Living and Mobility needs
Because of the short lived nature of the condition and its spontaneous resolution… Read more about ADL and mobility needs

How long will the needs last?
Hepatitis A resolves in the majority of cases without any specific treatment…… Read more about award duration

Over 65’s
The size and function of the liver deteriorates with ageing. In general liver diseases in the elderly carry a worse prognosis than in the younger age. However the clinical features and treatment of the liver impairments are similar in both age groups.

What evidence is available?

Hepatitis A
Hepatitis A resolves in the majority of cases without any specific treatment.

Hepatitis B
General Practitioner factual reports provide information on diagnosis and management in those who have recovered from an acute attack of hepatitis B. They may also be useful in confirming chronic carriage of hepatitis B, or for people with chronic infection whose condition is stable, and who have few symptoms.
People who have had a severe episode of infection, those who have chronic hepatitis B and those being treated with drugs like interferon will be under hospital care. Similarly individuals with complications such as cirrhosis, and those being assessed for or awaiting liver transplantation, will be under the care of specialist liver centres. Reports should be obtained from hospital doctors or specialist nurses working in these clinics.

**Hepatitis C**

Initial diagnosis will follow blood testing and most people will be referred to hospital for assessment of disease severity. People who are chronic carriers or those who have mild disease and few symptoms may be followed up by General Practitioners. General practitioner reports will confirm the diagnosis and provide information on any functional limitations.

People with progressive disease (chronic hepatitis), those having drug therapy and with late manifestations such as cirrhosis are followed up in hospital clinics including specialist liver units. Hospital doctors and specialist nurses should be approached for reports. Medical Services can advise on the severity of the condition if this is not clear from information provided in medical reports.

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**Activities of Daily Living and Mobility needs**

**Hepatitis A**

Because of the short lived nature of the condition and its spontaneous resolution, there are unlikely to be any functional restrictions leading to care/mobility needs.

**Hepatitis B**

Someone recovering from acute hepatitis B infection may experience fatigue and lethargy for a few months. Recovery is usually complete, and symptoms would not be so severe, that it is likely that help would be necessary with personal care or walking would be restricted to any degree.

Chronic hepatitis B carriers are generally asymptomatic and do not have functional restrictions on a day-to-day basis.

People with established chronic hepatitis B may experience some non-specific symptoms of malaise and fatigue. These are unlikely to limit activities in the early years but may become more prominent with time. Late complications including cirrhosis, ascites, portal hypertension and hepatic encephalopathy are likely to lead to decreased mobility and a need for help with self-care and supervision.
Drug treatment for chronic hepatitis may be associated with increased levels of fatigue and general debility, which may have additive effects in respect of existing functional limitations. Medical Services advice may be helpful in determining if extra help with care is necessary during the duration of treatment.

Hepatitis C

Acute hepatitis C resolves spontaneously over some weeks or a few months. There are no functional limitations that are likely to be severe or persistent.

People with positive blood tests for hepatitis C (chronic carriers) will be asymptomatic for many years and have no functional problems. Even those known to have progressive disease (chronic hepatitis C) may have few symptoms with minimal disabling effects for up to 20 years or more. With the development of cirrhosis and progressive impairment of liver function functional restrictions may be attributable to severe fatigue, weight loss, muscle weakness, jaundice, anorexia, ascites etc. Help may be needed with personal care, moving around, rising from a chair, preparing food etc. and walking may be restricted.

The side effects of the drug treatment for hepatitis C can be debilitating. They may increase the degree of functional restrictions experienced by someone who already has clinical features of liver damage. People with hepatitis C of moderate severity however may have few symptoms or functional restrictions when drug treatment commences. In these cases any resultant care needs or difficulties in walking attributable to drug side effects such as fatigue, flu like symptoms etc. should be carefully evaluated. In many cases they will not be sufficiently severe to affect personal care or to restrict mobility, and will only persist for the limited duration of the treatment.

If evidence shows that the customer has cirrhosis, which may have resulted from Chronic Hepatitis C then go to Cirrhosis guidance.

If evidence shows that the customer has liver failure, which may have resulted from Chronic Hepatitis C then go to the Liver Failure guidance.

How long will the needs last?

Hepatitis A

Hepatitis A resolves in the majority of cases without any specific treatment. Most cases recover within 10 days; in some people recovery may be delayed for up to 3 months. Fatal liver failure can occur in 0.3% of cases, often in very elderly people.
Hepatitis B
Most people who have an acute episode of hepatitis B infection make a complete recovery within 6 to 12 months. Chronic carriers of the hepatitis B virus often remain well without symptoms for many years. They are however a potential source of infection to others via infected blood and other body fluids.

A small percentage of people with persistent virus infection develop chronic hepatitis. Progressive deterioration in their health and liver function occurs over a number of years. Ultimately they may develop liver failure, cirrhosis and hepato-cellular carcinoma, all of which potentially have an adverse prognosis.

Hepatitis C
Following a symptomatic acute infection there is spontaneous recovery within a few weeks or months.

For individuals with chronic infection the following factors are associated with a worse outlook and more rapid progression to severe liver disease:

- Male gender,
- Alcohol consumption,
- Age over 40 years at time of infection,
- Additional infection with HIV and/or hepatitis B,
- Treatment with immunosuppressive drugs.

However many people with chronic infection live out a normal life span.

If evidence shows that the customer has liver failure, which may have resulted from Chronic Hepatitis C then go to the Liver Failure guidance.

If evidence shows that the customer has cirrhosis, which may have resulted from Chronic Hepatitis C then go to Cirrhosis guidance.

<table>
<thead>
<tr>
<th>Impairment – no complications</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis B &amp; D infection</td>
<td>N/A</td>
</tr>
<tr>
<td>Hepatitis C infection</td>
<td>N/A</td>
</tr>
</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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What you need to know about Visual Impairment

Back to A - Z
What is Visual Impairment?

- Read more on NHS Choices - Glaucoma
- Read more on NHS Choices - Cataracts - age related
- Read more on NHS Choices - Macular Degeneration
- Read more on NHS Choices - Diabetic retinopathy
- Read more on NHS Choices - Retinal detachment
- Read more on NHS Choices - Squint
- Read more on NHS Choices - Eye injuries
- Read more on NHS Choices - Astigmatism
- Read more on NHS Choices - Long-sightedness
- Read more on NHS Choices - Short-sightedness
- Read more on NHS Choices - Uveitis
- Read more on NHS Choices - Lazy eye (Amblyopia)
- Read more on NHS Choices - Double vision(Diplopia)

For all other Visual diseases Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
The Consultant Ophthalmologist will be able to provide information about symptoms, signs, investigations including assessment of vision, treatment/management, and is likely to have information about resulting disability or needs…… Read more about evidence sources

Activities of Daily Living and Mobility needs
A person with moderate visual impairment would normally have a visual acuity (for distant vision) of 6/18 (20/60) or worse, but better than 6/36 (10/60). .... Read more about ADL and Mobility needs

Linked pages:
Visual acuity conversion chart
Visual Acuity
Deeming Provisions
Registration of Blindness / Partially Sighted
Visual Conversion Tool – attached to this pdf

How long will the needs last?
The most common visual conditions are covered by this guidance….. Read more about award duration

Over 65’s
Visual problems are more common and eye disease likely to be more advanced in the elderly… Read more about the effects in the over 65 age group
What evidence is available?

Note: If considering entitlement to H/R Mobility component under the Severely Visually Impaired (SVI) provisions, the following evidence source must be used:

The Consultant Ophthalmologist will be able to provide information about symptoms, signs, investigations including assessment of vision, treatment/management, and is likely to have information about resulting disability or needs.

Please note: If the Consultant Ophthalmologist doesn't have up to date information, consider arranging for an eyecare examination.

Other evidence sources

The claimant and / or carer may be able to provide information about near and distant visual acuity or perhaps provide a certificate confirming registration of partial sightedness or blindness (if appropriate). However, if details of central or peripheral visual defect are needed, the Consultant or General Practitioner is an appropriate source of information.

ROVIC (Rehabilitation Officers Visually Impaired Children) will be able to provide information about Symptoms, signs, investigations including assessment of vision, treatment/management, and likely to have information about resulting disability or needs.

The Orthoptist will be able to provide information about assessment of vision (visual acuity and fields).

The Optometrist will be able to provide information about symptoms, signs, investigations including assessment of vision, treatment/management, and likely to have information about resulting disability, needs and provision of low vision aids.

Certificate of Visual Impairment (CVI)

The CVI provides details of near and distant visual acuity. However, it can also provide details of visual field loss and additional information that may be useful to the DM. A copy of the CVI is sent to the customer and GP therefore it is worthwhile asking the customer / carer for a copy if one is available.
Low Vision Assessment Report

For some visually impaired claimants (usually those with a recent sight loss) a low vision assessment report could be helpful. Services across the country may differ, and can also be called different things in different places, however, they come under the umbrella of Social Services. There are national standards for Social Services departments called 'Progress in Sight' but they are not mandatory. In some places the low vision service could be in-house with Social Services, in others it may be contracted to a local voluntary group. However for those people who have had a low vision assessment, the report could be of great use in describing the practical difficulties arising from their vision loss.

In certain circumstances (e.g. deaf / blind cases), it may be appropriate for the Decision Maker to request an Audiological report (a technical assessment) to establish the extent of deafness in a customer.

RNIB Website
Visionary – Linking Local Light Sight Loss Charities

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Activities of Daily Living and Mobility needs

NB. For mild, moderate and severe impairment and for H/R Mobility SVI, this refers to vision corrected with glasses or contact lenses.

Mild Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>A person with mild visual impairment (acuity or visual field loss) would normally have a visual acuity of better than 6/18 (20/60) distant vision and up to and including N24 (near). He/she has a reasonable field of vision.</td>
</tr>
</tbody>
</table>
### Mobility

The person has no physical difficulty in walking, and normally has sufficient vision to read signs, cross roads, and negotiate kerbs and steps safely, though he/she may have to be more vigilant.

### ADL

He/she would normally be capable of all self-care tasks, such as bathing, dressing, and attending to toilet and hygiene needs. He/she may require extra light or glasses to cut out glare or for reading (large print books) and for fine tasks such as preparing a meal, combing hair, etc but, in general, adaptations would not be needed. He/she would normally be able to read large print, write, use a computer and watch TV.

### Moderate Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>A person with moderate visual impairment would normally have a visual acuity (for distant vision) of 6/18 (20/60) or worse, but better than 6/36 (10/60). He/she is not able in general, to see well in the distance, that is, he/she may have difficulty in recognising a friend across a road. (&quot;Recognising a friend&quot; implies the ability to recognise a friend’s facial features, and not from the clothes they are wearing). His/her near visual acuity would normally be worse than N24, up to N36, and he/she would be likely to have difficulty in seeing fine detail close up, and may have difficulty reading even quite large print. He/she may have quite a reduced field of vision.</td>
</tr>
<tr>
<td>Mobility</td>
<td>The person has no physical difficulty in walking. A person with this level of visual impairment would normally have sufficient vision to get about in unfamiliar surroundings, although he/she would normally have problems negotiating irregular ground, or obstacles, without assistance. However, there are a proportion of people whose visual impairment is such that they would not normally be able to read signs, or see a car coming, and so would not be able to get around in unfamiliar surroundings, safely, on their own.</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td></td>
</tr>
<tr>
<td>A person with moderate visual impairment should be able, in general, to look after his/her own personal hygiene, such as washing, bathing, showering, cleaning teeth, dressing, and attending to toilet needs, but there are some people whose vision is impaired to the extent that they may be unable to complete this activity without assistance. Also, for the most part, he/she should be able to prepare and cook a main meal but there may be some people whose visual impairment is such that they may not be able to peel and chop vegetables, and handle hot pans safely. They may have considerable difficulty reading recipes, and checking cooker dials, but in some cases these difficulties may be overcome by using visual aids. They would be normally unable to read labels on medicine bottles, and check medication levels on syringes, and would normally need assistance to take tablets, and administer injections (in the case of diabetics). They are likely to have problems with small fastenings, and, with some people, their ability to see fine detail is affected to the extent that they may need assistance in checking that clothes are clean, match and are appropriate. A person with moderate visual impairment would only be able to work or study in an environment which is adapted to visual impairments. Extra vigilance and indeed assistance may be needed on stairs. They may be registered Partially Sighted.</td>
<td></td>
</tr>
</tbody>
</table>
Severe Functional Restriction

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabling Effects</td>
<td>This is when the visual acuity is greatly reduced even with correction, or there is considerable reduction in visual fields. A person with severe visual impairment would normally have 6/36 (10/60) visual acuity for distant vision, worse than N36 for near vision, or considerably reduced visual fields. He/she may only be able to see shapes or hand movements, or friends at close quarters. He/she may not be able to tell light from dark, or the shape of furniture in a room.</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>The person would have no physical difficulty walking. He/she would normally have difficulty in reading signs, crossing roads safely, and negotiating kerbs, and therefore would not normally be able to find his way around in unfamiliar surroundings without assistance. They may also satisfy the H/R Mobility criteria under the Deaf/blind or the Severely Visually Impaired (SVI) deeming provisions (See below).</td>
</tr>
<tr>
<td><strong>ADL</strong></td>
<td>The person would normally have difficulty in checking that clothes are appropriate, and that they are clean, and match, and would normally need assistance in this activity, but should be able to dress and attend to toilet needs him/herself. He/she would normally need assistance in having a bath or shower, as he/she would not normally be able to do this safely on his own. The person would normally need help with administering medicines, checking needles (in the case of diabetics) reading instructions, and would not normally be able to peel or chop vegetables safely, handle pans of boiling water safely or turn cooker knobs to the correct temperature. Assistance would normally be required for cutting up food. The person would be unable to read, but may use Braille. Writing would not normally be possible. In the home, he/she would be likely to need a clear space for getting around, without obstacles, and some people may need assistance. The person would normally not be able to use stairs safely on his/her own.</td>
</tr>
</tbody>
</table>
H/R Mobility Deaf/blind criteria

A claimant can satisfy the conditions for the higher rate mobility component if:

- they are both deaf and blind and
- as a result of the combined effects

they are unable to walk to their destination out of doors without the assistance of another person.

Legislation advises that the claimant must be 100% disabled due to blindness and 80% disabled due to deafness to be considered under the Deeming Provisions.

H/R Mobility Severely Visually Impaired (SVI) criteria

This applies to people aged between 3 and under 65 on 11 April 2011 who have been certified as severely visually impaired by a consultant Ophthalmologist AND their visual acuity is:

Less than (<) 3/60; or
3/60 or more but less than (<) 6/60 with a complete loss of peripheral visual field and a central visual field of no more than 10 degrees in total?

Click on the links for details of:

- Visual acuity conversion chart
- Visual Acuity
- Deeming Provisions
- Registration of Blindness / Partially Sighted
- Visual Conversion Tool – attached to this pdf

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How long will the needs last?

<table>
<thead>
<tr>
<th>Condition</th>
<th>Progression</th>
<th>Treatment</th>
<th>Prognosis</th>
<th>Award Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cataract</td>
<td>Worsens gradually</td>
<td>Yes, surgery improves condition.</td>
<td>Recovery should occur within 6 months of surgery.</td>
<td>1 year award</td>
</tr>
<tr>
<td>Condition</td>
<td>Worsens</td>
<td>Outcome Description</td>
<td>Indefinite award</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>-------------------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>-------------------</td>
<td></td>
</tr>
<tr>
<td>Glaucoma</td>
<td>Worsens</td>
<td>Yes, surgery may be necessary. Drops for life.</td>
<td>Indefinite award</td>
<td></td>
</tr>
<tr>
<td>Diabetic Retinopathy</td>
<td>Worsens</td>
<td>Condition stabilised but not improved by treatment.</td>
<td>Indefinite award</td>
<td></td>
</tr>
<tr>
<td>Macular Degeneration</td>
<td>Worsens</td>
<td>“Dry” Type – no treatment available. “Wet” Type – treatment is available for this type, which may stabilise the progression of the disease to some extent.</td>
<td>Indefinite award</td>
<td></td>
</tr>
<tr>
<td>Retinitis Pigmentosa</td>
<td>Worsens</td>
<td>No treatment.</td>
<td>Indefinite award</td>
<td></td>
</tr>
<tr>
<td>Retinal Detachment</td>
<td>Worsens</td>
<td>Treatment needed or vision rapidly deteriorates.</td>
<td>Indefinite award</td>
<td></td>
</tr>
</tbody>
</table>

The most common visual conditions are covered by this guidance. Some of the more unusual conditions not covered may have care / mobility needs depending on the degree of visual loss. Medical Services advice should be obtained in these cases.
Other diseases affecting vision / type not known

Details of the progression, treatment and prognosis and duration will need to be discussed with Medical Services depending upon the diagnosis.

The table above gives suggested award duration depending upon the nature of visual impairment present and will be correct in the majority of cases. There will be rare cases where there is blindness of sudden onset in a person of working age resulting in a particular level of entitlement for a certain period, which may reduce following a period of re-adjustment.

However, in general -:

- A need for guidance or supervision is likely to be permanent unless there is an improvement in vision.
- Sudden onset blindness (Infrequent) is likely to result in extensive day care/supervision but with time, the person will adapt and be likely to safely find their way around their own home.
- Unless there is improvement in vision, the person will unlikely to ever be capable of safely preparing a cooked main meal, selecting clothing and checking their appearance.
- Careful consideration should be given to the person’s ability to safely move around indoors and use a bottle or commode.
- Interaction between blindness and other disabling conditions needs to be carefully considered.

### Entitlement to H/R Mobility under the Deaf/blind provisions is appropriate
The Hearing Loss guidance must also be consulted to decide award duration

### Entitlement to H/R Mobility under the SVI provisions is appropriate
Indefinite award

If information/evidence suggests that an indefinite award is not appropriate, discuss with Medical Services.

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

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Visual Impairments in people over 65

Visual problems are more common and eye disease likely to be more advanced in the elderly, with 83% of those registered blind over the age of 65. The common causes of registration are macular degeneration (49%), glaucoma (15%), diabetes (6%), and cardiovascular disease (5%).
With ageing, the lens stiffens, causing presbyopia (difficulty in focusing on near objects), with the result that the person needs glasses for reading. In addition cataracts (opacities of the lens) develop (75% of the over-65's).

The retina becomes less sensitive to light making it more difficult to see in low light, and the pupils react more slowly, making it difficult to react to changes in light levels. This makes night driving difficult for affected persons, also finding their way around safely in the home, (for instance, with using stairs).

Older people are more likely to have co-existing age-related hearing loss (presbyacusis), and the combination of the two can have a very disabling effect.

Deeming Provisions

Combination of blindness and hearing loss (Deaf-blind)

Deaf-blindness is defined by Sense (the National Deaf-blind and Rubella Association) as -:

“A severe degree of combined visual and auditory impairment resulting in special needs in the areas of communication, access to information and mobility.”

100% blind

This is defined as being so blind as to be unable to perform any work for which eyesight is essential, the same criterion for being registered blind (see Registration of blindness/Partially sighted section). This equates to visual acuity of 3/60 or less or inability to count fingers beyond 50cms. Consideration of the visual fields as well as acuity is needed if these are very restricted.

80% Deaf

The level of hearing loss must be 87dB or greater when aids are used and it is usual to assess the degree of hearing loss by audiometry. However, since audiograms are almost invariably performed without aids, it has been accepted that at this level of hearing loss, the use of a hearing aid is unlikely to provide significant improvement. Medical Services advice should be sought in these cases.
**Deaf - Blind Deeming Provision**

Under the Deeming Provisions for DLA, a claimant can satisfy the conditions for the higher rate mobility component if:

- they are both deaf and blind and
- as a result of the combined effects

they are unable to walk to their destination out of doors without the assistance of another person.

Legislation advises that the claimant must be 100% disabled due to blindness and 80% disabled due to deafness to be considered under the Deeming Provisions.

**Higher Rate Mobility component Severely Visually Impaired (SVI) Deeming Provision**

Under the Deeming Provisions for DLA, a claimant can satisfy the conditions for the higher rate mobility component if:

They have been certified as severely visually impaired by a consultant Ophthalmologist AND their visual acuity is:

- Less than (<) 3/60 ; or
- 3/60 or more but less than (<) 6/60 with a complete loss of peripheral visual field and a central visual field of no more than 10 degrees in total?

If this is the case, the Severely Visually Impaired (SVI) deeming provision is satisfied.

For details of the registration of blindness click on the link below:

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**Registration of Blindness / Partially Sighted**

These notes have been taken from the Department of Health’s CVI form Explanatory Notes.

**Certified Blind (Severely sight – impaired)**

A person can be certified blind (or severely sight impaired) if they are “so blind as to be unable to perform any work, for which eyesight is essential”. (This equates to 100% disablement for the deaf / blind deeming provisions.)
The eyesight, only, is taken into account, and that is measured by visual acuity, and also visual fields are taken into consideration.

**Those who should be certified blind are:**

- Those who have a visual acuity below 3/60 or 1/18 (tested with Snellen’s Test type).
- Those who have acuity better than 3/60, but below 6/60 with a very restricted visual field.

**Certified Partially Sighted (sight – impaired)**

Guidelines for this suggest that a person can be certified as partially sighted if “they are substantially and permanently disabled by defective vision caused by congenital defect or illness or injury”.

Those who should be certified partially sighted are:

- Those who have a visual acuity of from 3/60 to 6/60 (Snellen’s) with a full field.
- Those whose acuity is up to 6/24 (Snellen) with moderate contraction of the field, or aphakia (lens removal) or opacities blocking vision in the eye itself.
- Those whose acuity is 6/18 or better, if they have a gross defect of visual fields (of both eyes, such as hemianopia) or marked contraction of the visual field (i.e. in retinitis pigmentosa, or glaucoma).

The old BD8 form used for certification, has been replaced by the “Certificate of Vision Impairment“, and when this is signed by a Consultant Ophthalmologist, this becomes formal notification needed for registration.

There are also two letters, which can be issued to Social Services with regards to a patient, who is not currently registered but who has a “serious loss of vision”.

These are:

- The Hospital Eye Service Referral of Vision Impaired patient for Social Needs Assessment (RV1 form).
- Letter concerning vision impairment needs (LV1 form) – (Optometrist Identification of a person with significant sight problems).

This information can be looked up in more detail, at [http://www.dh.gov.uk/sensoryimpairment](http://www.dh.gov.uk/sensoryimpairment)- “identification and notification of sight loss”.

Users who can access the NHS web, should use the link:

How do I register as disabled?
Visual acuity

The Assessment of Vision

Vision is assessed, by formally testing the acuity of both distant and near vision, visual fields, (that is, how far you can see all around at the side, while looking straight ahead) checking the health of the eye and looking at the retina. Binocular vision is vision using both eyes and monocular vision is vision using one eye. Distant and near vision are tested by using the Snellen’s Test Types. Each eye is tested individually. The Ophthalmologist or Optometrist will always do a test of binocular vision during the test for visual acuity. However, if this result is not available, the better of the two monocular visual acuities should be used.

Most reports will provide monocular acuities i.e. vision in each eye independently and so the VA of the one eye should be used.

It may be helpful to give some examples:

<table>
<thead>
<tr>
<th>Left eye</th>
<th>Right eye</th>
<th>Binocular vision</th>
</tr>
</thead>
<tbody>
<tr>
<td>6/6</td>
<td>6/6</td>
<td>6/6</td>
</tr>
<tr>
<td>6/12</td>
<td>6/6</td>
<td>6/6</td>
</tr>
<tr>
<td>6/12</td>
<td>No vision</td>
<td>6/12</td>
</tr>
</tbody>
</table>

The rule is therefore if this information is available when monocular vision is recorded, take the better of the two eyes to give what is in effect binocular vision. If information is not available then we need to obtain VAO and an optometrist report is likely to be the best source.

For distant vision:

The person sits or stands at 6 metres, and reads down the vision chart from the largest letter at the top, to the smallest letter at the bottom. The chart is a large card or a lighted box, which displays the letters.

If a person can only see the top letter, their vision is described as 6/60; that means that, while at a distance of 6 metres they can only see what a person could normally see at a distance of 60 metres.

However, if they can see the letters on the second bottom line, their vision will be described as 6/6 (they can see with equal clarity at 6 metres what another person with unimpaired vision standing at 6 metres will see), or the smallest letters on the bottom line, their vision will be described as 6/5, which means that they can clearly see at 6 metres, what a person with unimpaired vision, standing at 5 metres can see. 6/5 vision would be better than average.

The vision test card, and light box, should be well illuminated.
The visual acuity is tested firstly without, and then with the use of corrective spectacles, or contact lenses.

If the person cannot see the numbers on the chart, the person is moved to 3 or 4 metres from the chart, and tested. If this is not possible, counting fingers, and hand movements (at 30cm), or light perception are recorded. In these cases the reports and the Certificate of Visual Impairment may describe the visual acuity in the following manner:

- NPL – no perception of light
- PLO – perception of light only
- HM – hand movements
- CF – count fingers

Snellen Visual Acuity Chart
Snellen's chart with equivalent LogMar measurements

LogMar is a scale that expresses visual acuity as a decimal. It is usually used for statistical purposes and is rarely used in clinical practice.

<table>
<thead>
<tr>
<th>Snellen 6 metres</th>
<th>Snellen 3 metres</th>
<th>LogMar</th>
</tr>
</thead>
<tbody>
<tr>
<td>6/60</td>
<td>3/30</td>
<td>1.0</td>
</tr>
<tr>
<td>6/48</td>
<td>3/24</td>
<td>0.9</td>
</tr>
<tr>
<td>6/38</td>
<td>3/19</td>
<td>0.8</td>
</tr>
<tr>
<td>6/30</td>
<td>3/15</td>
<td>0.7</td>
</tr>
<tr>
<td>6/24</td>
<td>3/12</td>
<td>0.6</td>
</tr>
<tr>
<td>6/19</td>
<td>3/9.5</td>
<td>0.5</td>
</tr>
<tr>
<td>6/15</td>
<td>3/7.5</td>
<td>0.4</td>
</tr>
<tr>
<td>6/12</td>
<td>3/6</td>
<td>0.3</td>
</tr>
<tr>
<td>6/9.5</td>
<td>3/4.8</td>
<td>0.2</td>
</tr>
<tr>
<td>6/7.5</td>
<td>3/3.8</td>
<td>0.1</td>
</tr>
<tr>
<td>6/6</td>
<td>3/3</td>
<td>0.0</td>
</tr>
</tbody>
</table>

For Near vision:

Near vision is tested by using a test card and each eye is tested individually. The card has number of printed paragraphs with print of varying sizes. Each paragraph is described in terms of “points” measuring the body of the print – where a “point” is 1/72 of an inch. In a common test, N48 is the largest type, and N5 is the smallest, which an unimpaired eye can see, held at a comfortable reading distance, (usually 14 inches), from the eyes. This type is N12.

Snellen Test Card
He moved forward a few fine chattering gems.

He knew exactly who would now sneeze calmly through an open door. Had there been another year of peace the battalion would have made a floating system of perpetual drainage.

A silent fall of immense snow came near oily remains of the purple-blue supper on the table.

We drove on in our old sunless walnut. Presently classical eggs ticked in the new afternoon shadows.
### Snellen and LogMar measurements

**Visual Acuity**

<table>
<thead>
<tr>
<th>Snellen (x/60)</th>
<th>LogMAR</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.75/60</td>
<td>1.9</td>
</tr>
<tr>
<td>1/60</td>
<td>1.8</td>
</tr>
<tr>
<td>1.5/60</td>
<td>1.6</td>
</tr>
<tr>
<td>2/60</td>
<td>1.5</td>
</tr>
<tr>
<td>3/60</td>
<td>1.3</td>
</tr>
<tr>
<td>4/60</td>
<td>1.2</td>
</tr>
<tr>
<td>5/60</td>
<td>1.1</td>
</tr>
<tr>
<td>6/60</td>
<td>1.0</td>
</tr>
<tr>
<td>7.5/60</td>
<td>0.9</td>
</tr>
<tr>
<td>10/60</td>
<td>0.8</td>
</tr>
<tr>
<td>15/60</td>
<td>0.6</td>
</tr>
<tr>
<td>20/60</td>
<td>0.5</td>
</tr>
<tr>
<td>30/60</td>
<td>0.3</td>
</tr>
<tr>
<td>36/60</td>
<td>0.2</td>
</tr>
<tr>
<td>48/60</td>
<td>0.1</td>
</tr>
<tr>
<td>60/60</td>
<td>0.0</td>
</tr>
<tr>
<td>72/60</td>
<td>-0.1</td>
</tr>
<tr>
<td>96/60</td>
<td>-0.2</td>
</tr>
<tr>
<td>120/60</td>
<td>-0.3</td>
</tr>
</tbody>
</table>

Increasing sight impairment

[Back to top of section]
### List of NHS hospitals with Ophthalmology departments

#### England

<table>
<thead>
<tr>
<th>Hospital Name</th>
<th>Hospital Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Addenbrooke's Hospital</td>
<td>Hills Road, Cambridge, Cambridgeshire, CB2 0QQ</td>
</tr>
<tr>
<td>Airedale General Hospital</td>
<td>Skipton Road, Steeton, Keighley, West Yorkshire, BD20 6TD</td>
</tr>
<tr>
<td>Alder Hey Hospital</td>
<td>Eaton Road, West Derby, Liverpool, Merseyside, L12 2AP</td>
</tr>
<tr>
<td>Alexandra Hospital</td>
<td>Woodrow Drive, Redditch, Worcestershire, B98 7UB</td>
</tr>
<tr>
<td>Altrincham General Hospital</td>
<td>Market Street, Altrincham, Cheshire, WA14 1PE</td>
</tr>
<tr>
<td>Andover War Memorial Hospital</td>
<td>Charlton Road, Andover, Hampshire, SP10 3LB</td>
</tr>
<tr>
<td>Arrowe Park Hospital</td>
<td>Arrowe Park Road, Upton, Wirral, Merseyside, CH49 5PE</td>
</tr>
<tr>
<td>Ashford Hospital</td>
<td>London Road, Ashford, Middlesex, TW15 3AA</td>
</tr>
<tr>
<td>Axminster Hospital</td>
<td>Chard Street, Axminster, Devon, EX13 5DU</td>
</tr>
<tr>
<td>Barnsley Hospital</td>
<td>Gawber Road, Barnsley, S75 2EP</td>
</tr>
<tr>
<td>Basingstoke and North Hampshire Hospital</td>
<td>Aldermaston Road, Basingstoke, Hampshire, RG24 9NA</td>
</tr>
<tr>
<td>Bassetlaw Hospital</td>
<td>Kilton Hill, Worksop, Nottinghamshire, S81 0BD</td>
</tr>
<tr>
<td>Bedford Hospital</td>
<td>South Wing, Kempston Road, Bedford, Bedfordshire, MK42 9DJ</td>
</tr>
<tr>
<td>Berkeley Hospital</td>
<td>Marybrook Street, Berkeley, Gloucestershire, GL13 9BL</td>
</tr>
<tr>
<td>Bexhill Hospital</td>
<td>Holliers Hill, Bexhill-on-Sea, East Sussex, TN40 2DZ</td>
</tr>
<tr>
<td>Bideford Hospital</td>
<td>Abbotsham Road, Bideford, Devon, EX39 3AG</td>
</tr>
<tr>
<td>Birch Hill Hospital</td>
<td>Union Road, Rochdale, Lancashire, OL12 9QB</td>
</tr>
<tr>
<td>Birmingham Midland Eye Centre (Bmec)</td>
<td>Dudley Road, Birmingham, West Midlands, B18 7QH</td>
</tr>
<tr>
<td>Bishop Auckland Hospital</td>
<td>Cockton Hill Road, Bishop Auckland, County Durham, DL14 6AD</td>
</tr>
<tr>
<td>Blackpool Victoria Hospital</td>
<td>Whinney Heys Road, Blackpool, Lancashire, FY3 8NR</td>
</tr>
<tr>
<td>Blandford Community Hospital</td>
<td>Milldown Road, Blandford Forum, Dorset, DT11 7DD</td>
</tr>
<tr>
<td>Bradford Royal Infirmary</td>
<td>Duckworth Lane, Bradford, West Yorkshire, BD9 6RJ</td>
</tr>
<tr>
<td>Bridlington and District Hospital</td>
<td>Bessingby Road, Bridlington, North Humberside, YO16 4QP</td>
</tr>
<tr>
<td>Hospital Name</td>
<td>Address</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Bridport Community Hospital</td>
<td>Hospital Lane, Bridport, Dorset, DT6 5DR</td>
</tr>
<tr>
<td>Bristol Eye Hospital</td>
<td>Lower Maudlin Street, Bristol, Avon, BS1 2LX</td>
</tr>
<tr>
<td>Broomfield Hospital</td>
<td>Court Road, Chelmsford, Essex, CM1 7ET</td>
</tr>
<tr>
<td>Buckland Hospital</td>
<td>Coombe Valley Road, Dover, Kent, CT17 0HD</td>
</tr>
<tr>
<td>Burnley General Hospital</td>
<td>Casterton Avenue, Burnley, Lancashire, BB10 2PQ</td>
</tr>
<tr>
<td>Calderdale Royal Hospital</td>
<td>Salterhebble, Salterhebble, Halifax, West Yorkshire, HX3 0PW</td>
</tr>
<tr>
<td>Cannock Chase Hospital</td>
<td>Brunswick Road, Cannock, Staffordshire, WS11 5XY</td>
</tr>
<tr>
<td>Chase Farm Hospital</td>
<td>The Ridgeway, Enfield, Middlesex, EN2 8JL</td>
</tr>
<tr>
<td>Chelsea and Westminster Hospital</td>
<td>369 Fulham Road, London, Greater London, SW10 9NH</td>
</tr>
<tr>
<td>Cheltenham General Hospital</td>
<td>Sandford Road, Cheltenham, Gloucestershire, GL53 7AN</td>
</tr>
<tr>
<td>Chesterfield Royal Hospital</td>
<td>Calow, Chesterfield, Derbyshire, S44 5BL</td>
</tr>
<tr>
<td>Chippenham Hospital</td>
<td>Rowden Hill, Chippenham, Wiltshire, SN15 2AJ</td>
</tr>
<tr>
<td>Chorley and South Ribble Hospital</td>
<td>Preston Road, Chorley, Lancashire, PR7 1PP</td>
</tr>
<tr>
<td>Christchurch Hospital</td>
<td>Fairmile Road, Christchurch, Dorset, BH23 2JX</td>
</tr>
<tr>
<td>Cirencester Hospital</td>
<td>Tetbury Road, Cirencester, Gloucestershire, GL7 1UY</td>
</tr>
<tr>
<td>Clayton Hospital</td>
<td>Northgate, Wakefield, West Yorkshire, WF1 3JS</td>
</tr>
<tr>
<td>Conquest Hospital</td>
<td>The Ridge, St. Leonards-on-Sea, East Sussex, TN37 7RD</td>
</tr>
<tr>
<td>Countess Of Chester Hospital</td>
<td>The Countess Of Chester Health Park, Chester, Cheshire, CH2 1UL</td>
</tr>
<tr>
<td>County Hospital Louth</td>
<td>High Holme Road, Louth, Lincolnshire, LN11 0EU</td>
</tr>
<tr>
<td>Crawley Hospital</td>
<td>West Green Drive, Crawley, West Sussex, RH11 7DH</td>
</tr>
<tr>
<td>Cromer and District Hospital</td>
<td>Mill Road, Cromer, Norfolk, NR27 0BQ</td>
</tr>
<tr>
<td>Cumberland Infirmary</td>
<td>Newtown Road, Carlisle, Cumbria, CA2 7HY</td>
</tr>
<tr>
<td>Darent Valley Hospital</td>
<td>Darent Wood Road, Darent Wood Road, Dartford, Kent, DA2 8DA</td>
</tr>
<tr>
<td>Darlington Memorial Hospital</td>
<td>Hollyhurst Road, Darlington, County Durham, DL3 6HX</td>
</tr>
<tr>
<td>Delancey Hospital</td>
<td>Charlton Lane, Cheltenham, Gloucestershire, GL53 9DT</td>
</tr>
<tr>
<td>Hospital Name</td>
<td>Address</td>
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<tr>
<td>---------------------------------------------------</td>
<td>----------------------------------------------</td>
</tr>
<tr>
<td>Derriford Hospital</td>
<td>Derriford Road, Crownhill, Plymouth, Devon, PL6 8DH</td>
</tr>
<tr>
<td>Dewsbury and District Hospital</td>
<td>Halifax Road, Dewsbury, West Yorkshire, WF13 4HS</td>
</tr>
<tr>
<td>Diana, Princess Of Wales Hospital</td>
<td>Scartho Road, Grimsby, North East Lincolnshire, DN33 2BA</td>
</tr>
<tr>
<td>Doncaster Royal Infirmary</td>
<td>Armthorpe Road, Doncaster, South Yorkshire, DN2 5LT</td>
</tr>
<tr>
<td>Dorset County Hospital</td>
<td>Williams Avenue, Dorchester, Dorset, DT1 2JY</td>
</tr>
<tr>
<td>Ealing Hospital</td>
<td>Uxbridge Road, Southall, Middlesex, UB1 3HW</td>
</tr>
<tr>
<td>East Surrey Hospital</td>
<td>Canada Avenue, Redhill, Surrey, RH1 5RH</td>
</tr>
<tr>
<td>Eastbourne District General Hospital</td>
<td>Kings Drive, Eastbourne, East Sussex, BN21 2UD</td>
</tr>
<tr>
<td>Edenbridge War Memorial Hospital</td>
<td>Mill Hill, Edenbridge, Kent, TN8 5DA</td>
</tr>
<tr>
<td>Edgware Community Hospital</td>
<td>Burnt Oak Broadway, Edgware, Middlesex, HA8 0AD</td>
</tr>
<tr>
<td>Ellesmere Port Hospital</td>
<td>114 Chester Road, Whitby, Ellesmere Port, Merseyside, CH6 6SG</td>
</tr>
<tr>
<td>Epsom Hospital</td>
<td>Dorking Road, Epsom, Surrey, KT18 7EG</td>
</tr>
<tr>
<td>Essex County Hospital</td>
<td>Lexden Road, Colchester, Essex, CO3 3NB</td>
</tr>
<tr>
<td>Fairfield General Hospital</td>
<td>Rochdale Old Road, Bury, Lancashire, BL9 7TD</td>
</tr>
<tr>
<td>Fairford Hospital</td>
<td>The Croft, Fairford, Gloucestershire, GL7 4BB</td>
</tr>
<tr>
<td>Farnham Hospital</td>
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</tr>
<tr>
<td>Finchley Memorial Hospital</td>
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</tr>
<tr>
<td>Friarage Hospital</td>
<td>Northallerton, North Yorkshire, DL6 1JG</td>
</tr>
<tr>
<td>Frimley Park Hospital</td>
<td>Portsmouth Road, Frimley, Surrey, GU16 7UJ</td>
</tr>
<tr>
<td>Frome Victoria Hospital</td>
<td>Park Road, Frome, Somerset, BA11 1EY</td>
</tr>
<tr>
<td>Furness General Hospital</td>
<td>Dalton Lane, Barrow-In-Furness, Cumbria, LA14 4LF</td>
</tr>
<tr>
<td>George Eliot Hospital</td>
<td>College Street, Nuneaton, Warwickshire, CV10 7DJ</td>
</tr>
<tr>
<td>Gloucestershire Royal Hospital</td>
<td>Great Western Road, Gloucester, Gloucestershire, GL1 3NN</td>
</tr>
<tr>
<td>Good Hope Hospital</td>
<td>Rectory Road, Sutton Coldfield, West Midlands, B75 7RR</td>
</tr>
<tr>
<td>Goole and District Hospital</td>
<td>Woodland Avenue, Goole, North Humberside, DN14 6RX</td>
</tr>
<tr>
<td>Hospital Name</td>
<td>Hospital Address</td>
</tr>
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<td>---------------------------------------------------</td>
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<tr>
<td>Gosport War Memorial Hospital</td>
<td>Bury Road, Gosport, Hampshire, PO12 3PW</td>
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York Hospital
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Scotland

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What you need to know about Work Related Upper Limb Disorder (WRULD)

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What is Work Related Upper Limb Disorder (WRULD)?
Work related upper limb disorder (WRULD) is a general term that covers a number of musculoskeletal conditions which affect the shoulder, elbow, forearm, wrist or hand. Read more about WRULD.

Decision Makers are advised to discuss with the Departments Medical Services provider.

What evidence is available?
Several medical professionals may be involved in the treatment of an individual with WRULD. Read more about evidence sources.

Activities of Daily Living and Mobility needs
Work related upper limb disorder (WRULD) can be a painful and distressing problem and at its very worst it may cause a sufferer to have to give up or change a job and stop a particular activity completely. Read more about ADL and Mobility needs.

How long will the needs last?
Work related upper limb disorder (WRULD) can be a painful and distressing problem but in most cases it will not cause significant functional restrictions. Read more about award duration.

Over 65’s
There is no specific guidance for over 65’s.
Linked pages:-

Ageing
Falls
Frailty

What is Work Related Upper Limb Disorder

Work related upper limb disorder (WRULD) is a general term that covers a number of musculoskeletal conditions which affect the shoulder, elbow, forearm, wrist or hand. It is not a specific disease, but a group of
conditions. Previously the terms repetitive strain or stress injury (RSI) were frequently used.

There are also specific conditions affecting the upper limbs which may be work-related if it can be shown they are due to occupational overuse. These conditions usually occur in adults of working age.

Some conditions are well defined with accepted diagnostic criteria, recognised risk factors and well established medical management. Other conditions, in which there is non-specific forearm or upper limb pain, are less well defined.

**Classification**

**Specific Upper Limb Disorders**

These include:

- Tenosynovitis (including De Quervain’s Syndrome)
- Trigger finger or thumb
- Rotator cuff syndrome
- Thoracic outlet syndrome
- Vibration induced white finger
- Reflex Sympathetic Dystrophy
- Carpal tunnel syndrome (see [Carpal tunnel syndrome](#) guidance)
- Cramp of the hand (Writer’s Cramp) (see [Dystonia](#) guidance)
- Epicondylitis (see [Tennis/Golfer’s Elbow](#) guidance)
- Tendonitis (see [Tennis/Golfer’s Elbow](#) guidance)

**Non-Specific Work Related Upper Limb Disorders (WRULD)**

A significant number of individuals with upper limb pain and dysfunction do not show signs which are easily recognised or fit with a definitive diagnosis. Such individuals may have pain which is not localised to one area and the pain may move from one area to another and be of a very indeterminate nature. Examination may often identify very little in the way of objective abnormality. The diagnosis is made when other specific conditions have been ruled out. Non-specific forearm pain has been defined for research purposes as ‘pain in the forearm in the absence of a specific diagnosis or pathology’ (Harrington et al. 1998). It is one of the commonest work related upper limb complaints but estimates of its prevalence vary widely. Other features which may be present include loss of function, weakness, cramp, muscle tenderness, burning and non-specific paraesthesia, and often a feeling of swelling.

[Back to top of section]
What evidence is available?

Several medical professionals may be involved in the treatment of an individual with WRULD. These may include:

- Physiotherapist
- Occupational Therapist
- Occupational Physician
- Rheumatologist
- Psychologist
- General Practitioner

Should further evidence be required there needs to be verification with the customer about which healthcare professional is seen on a regular basis.

Activities of Daily Living and Mobility needs

Work related upper limb disorder (WRULD) can be a painful and distressing problem and at its very worst it may cause a sufferer to have to give up or change a job and stop a particular activity completely. Most commonly however, it is managed with conservative measures and individuals may achieve a return to the workplace.

The return to work should initially be on a part-time basis with a subsequent incremental increase in hours and activities. Severe cases of WRULD may result in significant functional problems in self care activities (such as dressing and main meal preparation) but this is only in a very small percentage of cases. There are usually no significant restrictions in the ability to be mobile as a consequence of WRULD.

How long will the needs last?

Work related upper limb disorder (WRULD) can be a painful and distressing problem but in most cases it will not cause significant functional restrictions. At its very worse it may cause a sufferer to have to give up or change a job or stop a particular activity.

Most commonly however, it is managed with conservative measures and considerable improvement in function would be reasonably expected in 12 months. Although it is a troublesome condition, it usually does not cause significant functional problems.

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All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.
The effects of ageing

Introduction
Normal ageing
Ageing & disease
Clinical features of normal ageing
Effects of multiple conditions
Side effects of treatment
Case example

Introduction

Ageing is a gradual and continuous process.

Ageing can be defined in various ways, including: -

- “a distinct and progressive decline in function which makes us more vulnerable to disease”,
- “a loss of adaptability and failure to maintain the body’s homeostasis (metabolic equilibrium)”,
- “a process leading to the functional impairment of tissues and organs”,
- “A series of changes that lead to the loss of function of organs and cells, with the eventual outcome of death”.

It is basically the changes that occur with time, to make a person different from how they were when younger. Obvious, visible signs of ageing, such as greying hair and wrinkles, will be accompanied by less obvious, but progressive deterioration of bodily systems, (such as bone thinning, and stiffening of the arteries), and gradual increased susceptibility to disease and death.

The process of ageing is still not fully understood, but it is felt that there are many mechanisms involved. One of the most favourite theories is that the formation of “free radicals”, (a by-product of the body’s use of oxygen), causes damage at cellular level, and the ability of the individual’s maintenance and repair systems to counter this process determines how quickly a person ages.

With ageing, there is an increased risk of death, due to internal and/or external factors. However, individuals vary greatly in the rate at which they age, and how they age, which is genetically determined, and it is important to bear this in mind when considering the older person’s functional ability. An older person’s unique characteristics of genetic makeup and lifestyle may render them much more healthy than a person 20 years younger.
Several other factors, which are not intrinsic, may influence the rate of ageing. Lifestyle features, such as poor diet, lack of exercise, and cigarette smoking can exacerbate osteoporosis, atrophy of muscles, and reduced lung function, for example. Where you live (that is, in a developed world country or a third world country, as well as how advantaged is your local community), is important as well as other environmental factors, such as exposure to toxins and infections, and psychological issues, such as depression (with resultant lack of motivation to live a healthy lifestyle).

Many species have a set lifespan; the maximum possible lifespan for humans is 120 years.

Life expectancy in the developed world is now 80 years for females, and 75 years for males.

The percentage of elderly people in the population is rising, and also the numbers of elderly people, with implications for the amount of chronic and degenerative diseases in the population, as a whole, in the future.

**Normal ageing**

“Normal” ageing is ageing which occurs without disease, that is there are a number of physiological changes, that do not involve a pathological process, and, though there may be bodily changes in the person, the person enjoys good function of mind and body, and is able to live independently, and with a good quality of life.

**The impact of normal ageing**

A situation, which would have a minor effect on a younger person (such as an operation on a lower limb), may have considerable effects on an elderly person because the enforced bed rest may cause pressure sores (the skin is thinner, more fragile, and less well able to heal). Also, the bones and joints may become stiffer because of disuse therefore taking longer to return to their usual state. Following an operation, older people are also more susceptible to chest or wound infections (reduced immunity), confusion or even psychosis.

**Ageing & disease**

In many older people, the ageing process is compounded by overt disease, which may affect functional capacity, quality of life and independence, cause frailty, a reduction in well being and independence and which may result in increased care and mobility needs.
Some of the commonest disease processes affecting older people are described below:

**Nervous System (Physical)**
- Parkinson’s disease
- Strokes – paralysis/weakness
- Epilepsy often as a result of a stroke

**Nervous system (mental)**
- Depression
- Cognitive impairment (Alzheimer’s, diffuse vascular disease)
- Confusion – acute or chronic
- Paranoia

**Cardiovascular**
- Ischaemic heart disease
- Peripheral vascular disease
- Aortic stenosis and Valvular heart disease
- Arrhythmias (such as atrial fibrillation)
- Varicose Veins

**Skin**
- Pressure sores
- Delayed wound healing
- Varicose ulcers
- Easy bruising

**Immune System**
- Increased prevalence of cancers
- Increased prevalence of autoimmune diseases
- Increased infection

**Genitourinary**
- Prostatic enlargement
- Incontinence (weak bladder)

**Lungs**
- COPD (Chronic bronchitis & emphysema) usually from smoking and mining
- Bronchiectasis
- Lung Fibrosis (Silicosis & Asbestosis)
**Bones**
- Osteoarthritis
- Rheumatoid Arthritis
- Joint problems
- Foot problems
- Osteoporosis and fracture

**Metabolic**
- Adult – onset diabetes (NIDDM)
- Thyroid disease – hyper or hypothyroidism

**Incontinence**
Many elderly people not only have problems with disturbance of urinary function but have problems with incontinence. It affects around 50% of residents in care homes [and is often a reason for institutionalisation because of the extra burden it imposes on carers] and around 30% living at home. It causes a great deal of embarrassment and can significantly limit the person’s lifestyle.

The four main types of incontinence are:

- Stress
- Urge
- Overflow
- Functional

**Stress incontinence:**

Urinating regularly to avoid a full bladder,
Kegel (pelvic muscle) exercises,
Oestrogen tablets or cream,
Surgical procedures (lift bladder and tighten bladder outlet).

Usually occurs in women, as a result of weakness of muscles in the pelvis or at the neck of the bladder. It results in leakage of urine in certain specific situations, such as when coughing, laughing, sneezing or during exercise. It tends to affect older women, particularly after the menopause and the tendency may be increased by stresses to the pelvic muscles during childbirth many years ago.

**Urge incontinence:**

Regular urination,
Pelvic muscle exercises,
Drugs to relax the bladder (such as Oxybutinin).

Is the result of instability of the bladder muscles, and is more common in older people. It results in an urgent need to pass urine at frequent intervals both day and night; incontinence results if there is delay in reaching a toilet or suitable receptacle. Urge incontinence may result from a problem with the bladder itself, or it may arise as a consequence of damage to the central nervous system and nerves controlling bladder function.

**Overflow incontinence: -**

Surgery to treat a blockage,
Drugs to relax bladder outlet,
Manual pressure on abdominal wall,
Catheterisation.

Occurs when the bladder fails to empty completely; urine builds up and in the end overflows resulting in either intermittent or continuous dribbling. It may result from obstruction to the neck of the bladder, as occurs in older men due to enlargement of the prostate gland at the base of the bladder. It may also result from disease or injury of the brain or spinal cord, e.g. multiple sclerosis, traumatic paraplegia, which affects the nerves that control bladder function. In such cases there may be complete lack of control of bladder function.

**Functional incontinence: -**

Regular toileting,
Physical and psychological support.

Is the passing of urine in inappropriate places. It may be a result of varying degrees of immobility, for example making it difficult or impossible for the person to reach a toilet or to manage their clothing. It may also be the result of disturbed mental function, e.g. dementia, severe behaviour disorders, in which normal awareness of acceptable social behaviour is lost.

These factors may be alleviated considerably with treatment.

**Clinical features of normal ageing**

Cardiovascular system
Muscles
Immune system
Genito-urinary system
Liver
Sensory - Ears
Cardiovascular system
There are various effects of ageing in the cardiovascular system, which include:

- A slightly enlarged heart, which does not pump as efficiently during exercise.
- Stiffer arteries.
- Isolated systolic hypertension (where the blood pressure rises when the heart contracts).

Muscles
There is a decrease in muscle strength and power, and lean body mass (up to 30 to 40%), and an increase in fat body mass, with ageing. The process is known as sarcopenia, and results in decreased functional capacity.

Immune system
The immune system changes, and becomes more dysfunctional. There is an age-related decline in a particular cell, which combats infection, and this is a consequence of shrinkage, and greatly reduced function of the thymus gland (behind the breastbone or sternum).

Infectious disease, such as bronchopneumonia and influenza, is up to 10 times more likely to be the cause of death in older people, and people are more likely to have a reactivation of certain diseases such as shingles, and tuberculosis. There is an increase in occurrence of autoimmune diseases and cancers.

Genito-urinary system
By the age of 80 years, between 10 to 30% of the glomeruli in the kidneys, (which filter waste products from the blood) no longer work. 25% of the kidney mass is lost, due to shrivelling of the outer part of the kidney. Generally the kidneys are still able to regulate the fluid levels in the body, and reduced function will only be apparent in times of stress to the body. Benign enlargement of the prostate gland occurs in 25 to 50% of men over 65 and this leads to incomplete emptying of the bladder and a weak stream of urine, or signs of irritation with frequency of urination. Because of age-related atrophy of the uro-genital system in females, there is more susceptibility to urinary and vaginal infections.
Liver

Though there is a 25% reduction in the mass of the liver, function remains within normal limits, protein (albumin) production is slightly reduced, and there is an impaired metabolism of some drugs through the liver.

Sensory - Ears

There is impaired hearing in a third of over-65’s and 80% of 80 year-olds and this is known as presbyacusis—decline in hearing with age is a very common age-related change. Loss of high-frequency sounds occurs first, and hearing loss is more common in older men than women. Degenerative changes in the inner ear may also lead to some impairment of balance, resulting in falls, which again is a common problem in older people.

Sensory - Eyes

Normal Age-Associated Changes in the Eyes:

- The lens stiffens, and this causes presbyopia (difficulty in focusing on near objects) and from around the age of 40, people find that they need reading glasses to focus easily,
- The retina becomes less sensitive to light, which causes older people to have difficulty seeing in low or dim light, and to distinguish objects of low contrast from each other,
- The pupils react more slowly, which means that an older person has difficulty adjusting to changes in light levels. This could result in difficulty with night driving,
- Peripheral and colour vision may become less sensitive with age. A change in peripheral vision is due to a smaller pupil, more opaque lens and less sensitive retina, while colour perception is a result of yellowing of the lens, which occurs with age.

Lungs

The changes in the ageing lung (in healthy older people) are similar to the changes seen in mild chronic obstructive pulmonary disease, with decreased elastic recoil of the lung tissue, stiffening of the chest wall, weakening of the muscles of respiration, resulting in reduced lung volumes and flow rates. The ability to exercise is reduced by around a third, between the ages of 20 and 70.

Bones

Osteoporosis (thinning of bones) is a reduction of bone mass with a deterioration of bone tissue, causing increased fragility of the bones, and a susceptibility to fracture. Women are especially affected after the menopause; osteoporosis affects men more slowly. With increasing age, blood calcium comes from bone more than from diet. Calcium
supplements can be very helpful in this age group and along with vitamin D has been noted to reduce incidence of falls in patients living in residential homes.

**Nervous system**

There is a decline in performance, and many changes occur in both the central and peripheral nervous system. Some are:

- A decrease in the size and mass of the brain,
- Loss of neurones (nerve cells) with fewer connections in both the brain and spinal cord,
- Slower thought processes,
- Slower reaction time,
- Decreased vibration and position sense,
- Reduced sensitivity to temperature changes.

**Skin**

There is the formation of wrinkles, thinning and reduced strength, and elasticity of the skin. It is more fragile and more susceptible to damage. Wound healing takes longer. The fat layer generally lessens, but fat accumulates in particular areas (stomach, under the chin). Pigment cells are fewer but clump together, giving an appearance of paler skin with age spots. The skin is drier and more susceptible to flakiness, sense of pain is lessened and temperature regulation is less efficient. Hair and nail growth slows down, hair thins, nails thicken and become more yellow. The skin is less able to withstand infections and malignant change as the immune function declines. Skin becomes dry, itchy and bruises more easily.

**Effects of multiple conditions**

As people get older they are more likely to have multiple pathology (that is, to suffer from more than one condition), which can have considerable impact on their care and mobility needs. For instance, a person may have weakness or paralysis of one side of the body because of a stroke, which affects walking ability but this will be compounded if the person has co-existing osteo-arthritis of the hip. The overall disabling effect will be worse than the sum of the effects of each condition.

**Side effects of treatment**

Older people are more likely to be on medication for more than one condition, (poly-pharmacy) and, apart from the side effects of the medication there is the likelihood of interactions from the medication
combinations and the effects of medications on existing physical conditions.

Examples are:

ACE Inhibitors in older people may induce a profound fall in blood pressure, and should be introduced with caution, especially if they are already taking diuretics.

Older people are more susceptible to collapsing and falling, than younger persons. There are other factors involved in why they fall, but medicines may also play a role, for example:

They are more likely to be taking diuretics, therefore have electrolyte imbalance, or have impaired kidney function.

If a person has congestive heart failure, the impact of diuretic use would be much greater in a person who has urinary problems (for example, incontinence of urine, or frequency and poor stream, due to enlargement of the prostate gland) than one who has not.

**Case example**

Mr Jones is 85 years old and lives alone in a two-storey house. He sleeps upstairs but has great difficulty getting to bed because of severe osteoarthritis of his left hip and the effects of a stroke 2 years previously causing mild, left-sided weakness.

His doctor has aggressively treated his raised blood pressure to try to reduce the chance of further stroke but this results in giddy spells, particularly when he rises. This happens because of postural hypotension (sudden drop in blood pressure) when changing posture to a standing position.

He suffered a fractured wrist last year and he was noted to have osteoporosis.

During one night, he got out of bed quickly, as he needed to pass urine urgently. He felt dizzy and tripped over a loose rug onto his left hip causing extensive grazing, bruising and a fracture of the hip. He could not get up and lay on the floor overnight, which caused pneumonia (lung infection).

Back to A - Z
Falls in older people

Introduction

Elderly people are more prone than younger people to unpredictable and unexpected falls.
Falls are common in older people and the risk of falling increases with increasing age.
Falls affect a third of those aged 65 years and over rising to over 40% in those aged 80 years and above.

A fall may be the result of a simple "trip" in which case the environment needs to be looked at, in order to reduce hazards such as wet and slippery floors, loose rugs and poor lighting but often in the elderly, a fall may be caused by a combination of several factors. A condition may present itself in an unusual way in an older person [for instance, infection, transient ischaemic attack, heart disease] and the poor general condition of the person may manifest itself in a fall or it may be the result of very poor compensatory mechanisms to maintain balance such as stiff and arthritic joints, weak muscles and slower reflexes.

There are many risk factors associated with falls in older people and a combination of apparently trivial factors may “tip the balance” in an older person, who, as well as manifesting the effects of “normal” ageing may also be frail and/or have a disease condition such as Parkinson's Disease, in which gait is already affected (short, shuffling steps and altered centre of gravity). Also, the more risk factors the person has, the higher the risk of falling.

Causes of Falls

<table>
<thead>
<tr>
<th>Weakness and frailty</th>
<th>Medication side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Musculo – skeletal: -</td>
<td>Heart problems: -</td>
</tr>
<tr>
<td>• Arthritis,</td>
<td>• Drop attacks,</td>
</tr>
<tr>
<td>• Stiffness of joints,</td>
<td>• Arrhythmias,</td>
</tr>
<tr>
<td>• Weak muscles,</td>
<td>• Blood pressure drops on changing position,</td>
</tr>
<tr>
<td>• Giving way of knee,</td>
<td></td>
</tr>
</tbody>
</table>

- Deconditioning due to immobility.
- Medication side effects, Syncope.
- Vision defects including cataracts and reduced visual fields. Mental Health: - Alzheimers disease, Confusion, Paranoia, Psychosis, Medication side effects.
- Reduced position and vibration sense. Other factors: - Use of stick, Previous falls.
- Slow reactions

### Effects of falls

Falls are not only more likely to happen in older people but they are also more likely to result in serious injury. Elderly people are not as well able to save themselves from a fall as younger people. They are less stable with slower reflexes and are therefore less effective in preventing falls.

### Injury

Approximately one in ten falls results in serious injury and 10% of visits to hospital emergency are as a consequence of falls. The most common fractures are fractured hip or femur (thigh bone) and Colles fracture (involving the end of the forearm) but other serious injuries can occur such as skull fracture, head injury, sub-dural haematoma, (bleeding on the brain following a head injury) other fractures and soft- tissue injuries. Burns can be sustained if he/she falls against a radiator and is then unable to move.

Fracture of the femur is an example of a very serious complication of a fall as it involves hospitalisation, surgery and a convalescent period. The treatment can itself be complicated by an adverse reaction to the anaesthetic, infection of the wound, post-operative pneumonia, immobility and pressure sores, slow and delayed recovery, pain and stiffness of the hip joint and reduction of future activity for fear of further falls.

The consequences of the fall itself may be made more serious by a delay in discovery when the person stays on the floor or ground for a long time and this can lead to hypothermia (especially in the winter) or dehydration from lack of fluids. The time from injury to discovery may be the difference between life and death.
**Immobility, mental and social**

The average person of 70 to 80 years is now much fitter than ever before. Continuing activity and exercise helps maintain muscular strength, balance, joint position sense and the strength of bones. However, a hidden and often under-recognised consequence of falls is fear, loss of confidence and restriction of activities in order not to put themselves in the position of risking further falls. The person may seriously restrict outings, hobbies and activities such as attending religious services. This can lead to detrimental effects such as social isolation, loneliness and immobility leading to further reduced strength and muscle tone and stiffer joints. Because of a limitation of lifestyle and being confined to the home, the person can become very depressed and withdrawn.

Frequent falls and the fear of further incidents may cause the elderly person to be admitted into long-term care. This may not be the ideal solution as the environment may well have its own hazards (polished floors, unfamiliar bathrooms, rugs, steps and stairs) with which the person will not be familiar leading to an increased risk of falls and the loss of independence. This change of circumstances (including distance from important relatives) may lead to serious depression, decline and ultimately death.

**Effects of falling**

<table>
<thead>
<tr>
<th>Physical</th>
<th>Mental</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bruising, Fracture (especially femur), Brain haemorrhage, Burns (fall against a radiator), Dehydration, Pneumonia, Death, Immobility causing reduced activity, loss of muscle tone, stiffer joints.</td>
<td>Depression, Loss of confidence, Fear, Restriction of lifestyle.</td>
<td>Inability to leave home (real or imagined), Long term care, Inability to travel, Inability to follow hobbies.</td>
</tr>
</tbody>
</table>

**Risk factors associated with falls**

- Mental health
- Weakness and frailty
- Vision defects
- Musculo-skeletal factors
- Neurological factors
- Heart / circulatory problems
- Environmental factors
- Other factors
Mental health

Mental and intellectual processes are altered by ageing and may be manifested in various ways but there is considerable individual variation. Short-term memory may be affected with difficulty in remembering new information or recalling recent events, though long-term memory will be unaffected. There may be less problem-solving ability, slower reaction times and speech may be slower. There may be more caution and rigidity in personality and attitudes.

Elderly people may be “confused”. This may be as a result of dementia, cerebro-vascular disease affecting the brain ["hardening of the arteries"], mental illness such as depression or chronic diseases such as COPD with chronic oxygen lack. This may be demonstrated on the “Mini Mental Score Examination (MMSE). More severe mental illness such as psychosis may be present where reality and fiction are blurred, there is no real concept of time and day may be confused with night.

An elderly person who is not normally confused may suffer “acute confusion” in response to a specific event such as hospital admission, operation or an infection such as a urinary tract infection or pneumonia.

The effects of medication can also put elderly people at risk. Sedative drugs such as sleeping pills are particularly important. Anti-depressants and sedatives may slow the reaction - time and thus may prevent the older person from responding quickly or appropriately. Drugs, which lower the blood pressure either intentionally e.g. medication for high blood pressure or as a side effect e.g. water tablets (diuretics), may cause a fall in blood pressure on standing, making the elderly person feel dizzy and falls may result.

Weakness and frailty

Frail people are at risk of unpredictable falls because of a generally more vulnerable state and a combination of factors, which lead to a predisposition to falling, being less able to avoid a fall and problems getting up unaided after a fall, which could lead to dangerous consequences, such as dehydration, hypothermia, pneumonia, fractures or sub-dural haematoma (bleeding on the brain).

Vision defects

Vision is often impaired in older people, (see “Effects of Normal Ageing”). It is not only the visual acuity and ability to focus but also contrast sensitivity (the ability to adapt to light changes) and peripheral vision, which may be affected. This reduces the ability to see hazards and avoid a fall.
Musculo-skeletal factors
In older people, changes in gait and balance can occur. With stiffness and pain in weight-bearing joints and weak musculature, (as a result of osteoarthritis or from normal ageing) there is less ability to lift feet up properly (steps become short and shuffling) and a greater tendency to trip and stumble. A lower limb may be weak or paralysed (as the result of a stroke) and thinner bones (a result of osteoporosis) are more likely to break. The feet themselves may have reduced sensation and/ or ulcers for example, as a result of diabetic neuropathy, alcoholism or medication.

Neurological factors
Neurological factors, which may lead to a danger of falling are: -

- Cerebro-vascular disease and stroke with resultant impaired gait and balance,
- Reduced position sense,
- Reduced vibration sense,
- Peripheral neuropathy, with loss of feeling in the feet,
- Slower reflexes,
- Slower reaction time,
- Abnormalities of gait, as in Parkinson’s Disease,
- Dizziness,
- Epilepsy,
- Effects of medications. Falls are associated with the use of 4 or more medications at the same time, sedative-hypnotic drugs, especially long-acting benzodiazepines, some antidepressants and some major tranquillizers.

Heart / circulatory problems
Some heart / circulatory problems which can lead to falls are :-

- Arrhythmias, such as atrial fibrillation,
- Heart block,
- Heart failure,
- Aortic stenosis,
- Syncope (faints) and low blood pressure on standing (postural hypotension). (All of these may cause a sudden loss of consciousness because of reduced blood circulating in the brain),
- Medications such as digoxin, diuretics, some anti-arrhythmics and some medications that reduce blood pressure for example, ACE inhibitors.

Environmental factors
Many of these factors are hazardous, and can be changed to minimize risk to the person: -

- Steep stairs,
- Slippery surfaces such as polished and wet floors,
- Loose rugs,
- Trailing cords and flexes,
- Poorly - lit areas,
- Incorrect height of furniture,
- Unfamiliar environments.

Measures such as the use of grab rails, raised toilet seats, installation of proper lighting and stair lifts (if necessary), the use of brightly - coloured strips around light switches and on the edges of steps and the installation of personal and home alarms all help to minimize environmental risk and restore some confidence.

Other factors
Other factors to be considered are: -

- Previous falls (an elderly person who falls more than twice in a six- month period should be evaluated for treatable causes).
- The use of mobility aids (stick or walking - frame), which may indicate some difficulty with mobility (but also the aid may be unsuitable or not safe).

Prevention of falls

Falls in older people are very often found to be multi-factorial.

If an elderly person has had 2 or more falls in a 6-month period, an evaluation of the person’s health, environment and lifestyle should be undertaken with a view to removing treatable causes.

This can be done in specialist Falls Clinics where there is a multidisciplinary approach to the person, involving a team with special knowledge and expertise.

- Hazards in the home and environment can be modified, and safety features such as non- slip surfaces and grab rails installed. An occupational therapist is usually the appropriate person to assess home safety.
- An evaluation of medication is important especially if the person is taking four or more prescription medications, is on new medication or is taking medications, which have a sedative effect or are likely to cause a sudden drop in blood pressure.
- Reduced vision and hearing may be treated, as much as possible, and safety features such as good lighting, fluorescent safety strips put in to make the environment safer.
• Strength and balance training can be taught to optimise joint position sense, muscular strength and balance. A physiotherapist may do this or there may be special (exercise or Tai Chi) classes in some areas.
• Walking aids may not be used and may be needed to restore balance and confidence.

Back to A - Z
Frailty

Introduction

A person who is frail is said to be “physically weak and delicate (fragile)”. Frailty is defined as “infirmity - the state of being weak in health and body (especially in old age)”. It is understood to be an increased vulnerability to loss of function whereas disability is actual loss of function. It is a loss of resilience and the loss of ability to withstand physical and psychological stressors.

Frailty is a combination of factors and can occur in younger persons (but in these cases usually a disease process such as cancer or a condition such as Anorexia Nervosa is present).

Dr Linda Fried produced the Fried Framework of Frailty and the definition suggested that for anyone to be considered frail, the person should have 3 or more of the following 5 factors: -

- Unintentional weight loss (10 pounds or more in a year).
- General feeling of exhaustion (as self-reported).
- Weakness (as measured by grip strength).
- Slow walking speed.
- Low levels of physical activity.

Frailty occurs on a background of natural ageing and can be precipitated by a factor such as anaemia, joint pain or loss of muscle mass (sarcopenia).

The domains whose functions are usually affected in frailty are: -

- **Musculo-skeletal** - such as reduced muscle mass [known as sarcopenia], joint pain as in arthritis (leading to reduction in activity, and immobility), polymyalgia rheumatica (painful hip and shoulder muscles with weakness).
- **Cardio-respiratory** - such as chronic obstructive pulmonary disease, heart failure, anaemia, atherosclerosis and peripheral vascular disease.
- **Cognitive** - such as cognitive impairment, slower reaction times, depression, [leading to feelings of fatigue, and slower thought processes, reduced activity and motivation, and anorexia].
- **Balance and Gait** (impaired balance can lead to an increased risk of falling, loss of confidence, and reduced mobility).
• **Nutritional Status Anorexia** - can often occur as part of the ageing process and also as a consequence of certain diseases such as COPD where eating becomes difficult due to lack of breath. The consequence is chronic under-nourishment, vitamin deficiency and a decline in health.

It is recognised that other factors play a part, and these can include:

• Diabetes mellitus.
• Chronic diseases (such as congestive cardiac failure, COPD).
• Endocrine disorders (such as hyper and hypothyroidism, adrenal gland dysfunction and low testosterone levels (testosterone builds up muscle tissue).
• Pain (leading to restriction of movement and depression).

**Needs in frailty**

The Canadian Study of Health and Ageing describes frail people as below (category 4,5,6 and 7).

<table>
<thead>
<tr>
<th>Category</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category 1</td>
<td>Very fit (the most fit)</td>
</tr>
<tr>
<td>Category 2</td>
<td>Well (without active disease)</td>
</tr>
<tr>
<td>Category 3</td>
<td>Well, with treated (well-controlled) co-morbid disease</td>
</tr>
<tr>
<td>Category 4</td>
<td>Apparently Vulnerable – although not frankly dependent, these people commonly complain of being “slowed down”, or have disease symptoms.</td>
</tr>
<tr>
<td>Category 5</td>
<td>Mildly Frail – with limited dependence on others for instrumental activities of daily living.</td>
</tr>
<tr>
<td>Category 6</td>
<td>Moderately Frail – help is needed with both instrumental and non-instrumental activities of daily living.</td>
</tr>
<tr>
<td>Category 7</td>
<td>Severely Frail – completely dependent on others for the activities of daily living, or terminally ill.</td>
</tr>
</tbody>
</table>

(From the CSHA Clinical Frailty Scale, CMAJ)

Other studies have used a frailty index, obtained by comprehensively assessing physical, psychological and mental health and function.

In the assessment of a frail elderly person and their needs, all factors need to be taken into consideration including:

• Medical history and present state of health.
• Current medications and side effects/interactions.
• Social circumstances and level of support needed (for example, social isolation, having to give up driving).
• Current level of functional ability (ability to self-care, and to get about).
• Physical and mental state, including musculo-skeletal, cardiovascular, cognitive, balance and gait, and nutritional status.

A multidisciplinary approach with information from all professionals (doctor, physiotherapist, occupational therapist, carers, nurses and dietician) involved with the person is important in order to get an overall view.

Frailty is common in older people and may be an indication of future prognosis (gradual decline and death) but the process can be reversed by treating those conditions, which are not irreversible and which are a contributory factor to frailty. For example, loss of muscle mass can be reversed by an exercise programme, which builds muscular strength. Poor eating habits may be changed and anaemia can be treated by the appropriate medication.

Back to A - Z
Audiological Reports

An Audiological report (audiogram) is a technical assessment to establish the extent of a customer’s deafness.

An audiogram demonstrates the level of hearing loss at different frequencies and shows whether the hearing loss is due to a conductive, sensorineural or mixed cause. The level of disability in the CCM guidance is based on audiograms carried out without hearing aids being worn by the customer.

An audiological report can be used as further evidence when a customer claims the DLA higher rate mobility component because of a combination of hearing loss and blindness (deaf / blind deeming provisions).

Departmental Decision Makers can request an Audiological report but only when the customer has not had an Audiogram in the last six months.

Back to A - Z
Care Programme Approach (CPA)

Introduction
The term Care Programme Approach (CPA) has been used since 1990 to describe the framework that supports and co-ordinates effective mental health care for people with severe mental health problems in secondary mental health services.

Where a service user has straightforward needs and has contact with only one agency then an appropriate professional in that agency will be the person responsible for facilitating their care. Formal designated paperwork for care planning and the review process for these service users, is not required. However, a statement of care agreed with the service user should be recorded. This could be done in any clinical or practice notes, or in a letter, and this documentation will constitute the care plan.

From October 2008, the term Care Programme Approach describes the approach used in secondary mental health care to assess, plan, review and co-ordinate the range of treatment, care and support needs for people in contact with secondary mental health services who have complex characteristics (as outlined below). It is called an “approach”, rather than just a system, because the way that these elements are carried out is as important as the actual tasks themselves. Active service user involvement and engagement will continue to be at the heart of the approach, as will a focus on reducing distress and promoting social inclusion and recovery.

Who will need CPA?
In the main, the individuals needing the support of CPA should not be significantly different from those who needed the support of enhanced CPA in the past. The current characteristics of those needing enhanced CPA are described as individuals who need: multi-agency support, active engagement, intensive intervention, support with dual diagnoses and who are at higher risk.

CPA and eligibility for services
The list in the table below is used to decide if, having been accepted as needing secondary mental health services, further support is needed with engagement, co-ordination and risk management (i.e. needing CPA).

<table>
<thead>
<tr>
<th>Characteristics used to decide if CPA support is needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Severe mental disorder (including personality disorder) with high degree of clinical complexity</td>
</tr>
<tr>
<td>• Current or potential risk(s), including:</td>
</tr>
<tr>
<td>Suicide, self harm, harm to others (including history of offending)</td>
</tr>
<tr>
<td>Relapse history requiring urgent response</td>
</tr>
<tr>
<td>Selfneglect/non concordance with treatment plan</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Vulnerable adult; adult/child protection e.g.</td>
</tr>
<tr>
<td>exploitation e.g. financial/sexual</td>
</tr>
<tr>
<td>financial difficulties related to mental illness</td>
</tr>
<tr>
<td>disinhibition</td>
</tr>
<tr>
<td>physical/emotional abuse</td>
</tr>
<tr>
<td>cognitive impairment</td>
</tr>
<tr>
<td>child protection issues</td>
</tr>
</tbody>
</table>

- Current or significant history of severe distress/instability or disengagement
- Presence of non-physical co-morbidity e.g. substance/alcohol/prescription drugs misuse, learning disability
- Multiple service provision from different agencies, including: housing, physical care, employment, criminal justice, voluntary agencies
- Currently/recently detained under Mental Health Act or referred to crisis/home treatment team
- Significant reliance on carer(s) or has own significant caring responsibilities
- Experiencing disadvantage or difficulty as a result of:
  - Parenting responsibilities
  - Physical health problems/disability
  - Unsettled accommodation/housing issues
  - Employment issues when mentally ill
  - Significant impairment of function due to mental illness
  - Ethnicity (e.g. immigration status; race/cultural issues; language difficulties; religious practices); sexuality or gender issues

**Social Services (Social Care and Health) Care Plan**

Services are provided for customers who may have physical, sensory or learning disability or are an older person. They can provide the following services:
- Specialist advice and information
- Help to manage personal care in the customer’s own home
- Help with meals
- Equipment and adaptations to help the customer live at home
- Disabled parking scheme (blue badge)
- Support for the visually impaired or the deaf of hard of hearing
- Information about other services and organisations who can help

Social Services (Social Care and Health) can arrange services to help the customers with daily living tasks so that they are as independent as possible.

A specially trained assessor gathers the information and this assessment forms the basis of planning how the customers needs can be met and a Care Plan is developed.

The Care plan describes:
Who is responsible for providing services
What they have agreed to do
When they will do it
Who is responsible for making sure things go according to plan
The names of key people and how to contact them

Services may not always be provided by Social Services (Social Care and Health), they may arrange for private or voluntary agencies to do so on their behalf.

A copy of the Care Plan is given to the customer and a copy should be obtained as it is important that the Departmental Decision Maker is aware of the details of the arrangements in place for the individual.

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Examining Health Care Professional (EHCP) Reports

A Health Care Professional (HCP) is a practitioner involved with patient care. This would include doctors, nurses, occupational therapists and physiotherapists. They will have received training in disability assessment medicine. In addition they are instructed in the assessment of care and mobility needs relating to the entitlement to DLA/AA.

An EHCP report will provide details of the diagnosis (where known), brief history of the condition, treatment, a record of clinical examination, severity and likely disabling effects of the condition on day-to-day living. The EHCP report is able to provide a critical appraisal of whether a person's claimed care and mobility needs are reasonable in the light of the disabling condition(s).

An EHCP report can be particularly helpful in situations where the existing medical evidence (usually factual reports) appear to be contradictory, or where factual reports do not appear to cover areas relevant to entitlement.

When the Departmental Decision Maker decides to request an EHCP report, it is worth considering the exact nature of the information required and to formulate a submission with some specific questions for the HCP. It may also be useful to enclose copies of factual reports, especially if existing evidence is contradictory.

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The Educational Psychology Service

What is an Educational Psychologist?

Educational Psychologists (EP’s) provide guidance and support to schools on a range of issues including Special Educational Needs (SEN). They work with parents, carers and teachers to identify and support the SEN of individual children at home and at school.

All EP’s have qualifications in Psychology and Educational Psychology and are not usually medically qualified. They may also be qualified teachers with teaching experience.

What does their work include?

EP’s help children from Nursery school to age 19. They assess how best to help by observing and working with children at home and at school. The EP works closely with parents and school staff to plan a programme of support.

Usually the Special Educational Needs Coordinator (SENCo) at school will contact an EP after deciding the child might benefit from their help. The school then contacts parents for permission to provide the specialist support.

Parents / carers, the school and the EP review the plan to make sure the child’s needs are being met.

Back to A - Z
General Practitioner Reports (GP Reports)

GPs are the first point of contact for people with a health condition and provide ongoing care to their patients. They are responsible for diagnosing and treating illnesses and may refer the patient to hospital for specialised care, in which case a report is usually sent back to the GP. GPs will have long term knowledge of the patient and hold the patient's records including hospital correspondence. GPs generally are not trained and do not assess a patient's function and are therefore not usually in a position to give information about their patients' ability to perform daily living activities.

It is reasonable to expect a GP's report to contain factual information such as diagnosis, history of the condition, clinical findings, results of special tests, medication and treatment plan.

The GP may have very limited information on people who have had stable, long-term disabilities, often since childhood, for example children and adults with learning disabilities. Claimants with mental health problems or learning disabilities may be mainly under the care of community psychiatric services or other specialist teams and it is often more appropriate to make an initial request for a factual report from another agency or professional.

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Health Care Professional

The term "health care professional" means an individual who has had specialised training to provide health care items or services, treatment, assistance with activities of daily living or medications to patients.

Hospital Departments/Specialism

The table below lists the names of Hospital Departments and the types of conditions / services that they are responsible for treating / providing.

Back to A - Z
<table>
<thead>
<tr>
<th>Department Name</th>
<th>Area of Specialism</th>
<th>Types of condition treated / services provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accident &amp; Emergency</td>
<td>Initial management of all types of trauma and serious acute illnesses.</td>
<td>Results of trauma – fractures, head injuries etc. Acute serious illnesses – myocardial infarction etc.</td>
</tr>
<tr>
<td>Alcohol &amp; Substance Misuse</td>
<td>Treatment of drug/alcohol dependency. Usually part of the psychiatric department.</td>
<td>Mental health aspects of drug/alcohol dependency.</td>
</tr>
<tr>
<td>Audiology</td>
<td>Assessment of hearing disorders</td>
<td>Provides services such as hearing tests (e.g. audiograms), hearing aid fitting and general rehabilitation of people with hearing difficulties.</td>
</tr>
<tr>
<td>Cardiology</td>
<td>Medical assessment and treatment of heart disorders</td>
<td>All diseases &amp; disorders of the heart incl. Arrhythmias, Cardiomyopathy, Heart failure, Ischaemic Heart disease, Myocardial Infarction etc.</td>
</tr>
<tr>
<td>Care of the Elderly (Geriatric)</td>
<td>Medical management of medical conditions in the elderly.</td>
<td>Acute and chronic medical conditions – strokes, heart failure. Rehabilitation with management of falls, bladder and bowel problems.</td>
</tr>
<tr>
<td>Child &amp; Adolescent Psychiatry</td>
<td>Mental Illness in children and younger people.</td>
<td>Mental health conditions - Learning difficulties, Autism, ADHD etc.</td>
</tr>
<tr>
<td>Specialty</td>
<td>Management</td>
<td>Diagnoses</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Dermatology</strong></td>
<td>Management of skin disorders.</td>
<td>Eczema, Acne, Psoriasis, dermatitis. Diagnosis of skin tumours (malignant melanoma, basal cell carcinoma) but usually refers to surgeons/radiotherapist for treatment.</td>
</tr>
<tr>
<td><strong>Diabetes</strong></td>
<td>Diabetes.</td>
<td>Management of Diabetes and its complications.</td>
</tr>
<tr>
<td></td>
<td>May be part of Endocrinology department</td>
<td></td>
</tr>
<tr>
<td><strong>Endocrinology</strong></td>
<td>Management of conditions connected with the hormone producing glands</td>
<td>Diabetes Mellitus, Thyroid gland disorders (Hypothyroidism, Myxoedema, Thyrotoxicosis, and pituitary disorders etc.</td>
</tr>
<tr>
<td>Department</td>
<td>Description</td>
<td>Conditions</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td>General Medicine</td>
<td>Medical management of all medical conditions.</td>
<td>All medical conditions found in gastroenterology, cardiac and respiratory medicine, endocrinology etc. (Such Departments found in smaller hospitals).</td>
</tr>
<tr>
<td>General Surgery</td>
<td>Management of common surgical conditions</td>
<td>Gastro-intestinal, hernia and cancer surgery. Would exclude cardiac, respiratory and neurosurgery. (Such Departments found in smaller hospitals).</td>
</tr>
<tr>
<td>Genetics</td>
<td>Offers a genetic counselling, diagnostic and testing service to people affected or have offspring affected by genetic disorders. They will advise pre conception about the chances of having a child with the genetic condition</td>
<td>Down’s syndrome, Cystic Fibrosis, Myotonic dystrophy etc.</td>
</tr>
<tr>
<td>Genito-urinary Medicine</td>
<td>Medical management of diseases (usually infections) of the Reproductive organs and related conditions.</td>
<td>Sexually transmitted diseases – HIV/AIDS, Clamydia etc.</td>
</tr>
<tr>
<td>Haematology</td>
<td>Management of Blood disorders</td>
<td>Anaemias, Leukaemia, Haemophilia etc.</td>
</tr>
<tr>
<td>Hospice</td>
<td>Management (usually by a multidisciplinary team) of serious progressive illnesses where there is no curative treatment or such treatment has failed. The hospice staff may also supply support in the community.</td>
<td>Malignancies, progressive neurological diseases.</td>
</tr>
<tr>
<td>Neurology</td>
<td>Medical management of Nervous system disorders.</td>
<td>Epilepsy, Multiple Sclerosis, Motor Neurone disease, Parkinson’s disease etc.</td>
</tr>
<tr>
<td>Neurophysiology</td>
<td>Study of the central and peripheral nervous systems usually by measurement of electrical impulses in the nervous system.</td>
<td>Electroencephalogram (EEG) in epilepsy. Nerve conduction studies to diagnose carpal tunnel syndrome.</td>
</tr>
<tr>
<td><strong>Neurosurgery</strong></td>
<td>Specialises in surgery on any part of the nervous system.</td>
<td>Brain tumours, Spina Bifida, nerve compression neck and lower back (orthopaedic surgeons may also perform such surgery).</td>
</tr>
<tr>
<td><strong>Nuclear Medicine</strong></td>
<td>Diagnostic and treatment of diseases using radioactive compounds May be part of Department of Radiology</td>
<td>Diagnosis – thallium scan to assess IHD, Radioactive iodine scan for thyroid disease. Treatment – radioactive iodine for thyrotoxicosis.</td>
</tr>
<tr>
<td><strong>Occupational therapy</strong></td>
<td>Treatment of conditions through activities. The aim is to achieve independent living</td>
<td>Chronic physical and psychiatric conditions.</td>
</tr>
<tr>
<td><strong>Ophthalmology</strong></td>
<td>Management (mainly surgical) of eye disorders.</td>
<td>Amblyopia, Cataracts, Myopia, Nystagmus, retinal detachment, Retinopathy etc.</td>
</tr>
<tr>
<td><strong>Click on the link below for details of:</strong></td>
<td><strong>List of NHS hospitals with Ophthalmology departments</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Oral &amp; Maxillo-facial Surgery</strong></td>
<td>Specialising in surgery of the mouth and upper jaw</td>
<td>Oral cancers, trauma to the face etc.</td>
</tr>
<tr>
<td><strong>Orthopaedics</strong></td>
<td>Surgical management of disease of bones, joints, muscles and tendons</td>
<td>Fractures, Osteo-arthritis – joint replacement.</td>
</tr>
<tr>
<td><strong>Paediatrics</strong></td>
<td>Medical management and prevention of Children's illnesses. There is usually a separate Department, Child Psychiatry dealing with mental illnesses, learning disability in childhood</td>
<td>Developmental delay, failure to thrive. Acute medical conditions – chest infections, meningitis Childhood cancers and leukaemias (may be specialised unit). Chronic illnesses – asthma, diabetes.</td>
</tr>
</tbody>
</table>
| **Pain clinic**  
May be part of an anaesthetic department | Treatment of chronic pain | Chronic pain and pain due to cancer. |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Palliative Medicine</strong></td>
<td>Treatment aimed to relieve symptoms e.g. pain breathlessness of a person with a terminal illness. There is usually no prospect of a cure.</td>
<td>Cancers and progressive neurological diseases e.g. Motor Neurone Disease.</td>
</tr>
<tr>
<td><strong>Physiotherapy</strong></td>
<td>Treatment of conditions by prescribed physical exercise and other physical treatments</td>
<td>Musculo-skeletal conditions, strokes etc.</td>
</tr>
</tbody>
</table>
| **Podiatry** | Treatment (including minor surgery) of foot conditions | Fitting and supply of specialised foot-ware  
Treating diabetic foot disease – ulcers etc  
Dealing with calluses. |
| **Psychiatric** | Management of mental illness  
There is usually a separate Department, mental health for the elderly dealing with mental health problems in old age including dementia | Bipolar disorder, Depression, Schizophrenia etc. |
| **Psychology**  
Usually part of the Department of Psychiatry | Study of the function normal and abnormal of the human mind (thought processes cognition etc) | Treatment of mental illness usually by ‘talking therapies such as Cognitive behaviour therapy. |
| **Radiology** | Imaging of internal body organs and structures using X rays and ultrasound | X- Rays, CT & MRI scans, ultrasound scans etc. |
| **Radiotherapy & Oncology**  
May be separate departments | Radiotherapy – treatment of cancer using radiation  
Oncology – treatment of cancer using drugs | Treatment of all malignancies. |
<table>
<thead>
<tr>
<th>Renal Medicine</th>
<th>Kidney disorders</th>
<th>Treatment of kidney disorders. Care often shared with department treating underlying condition e.g. diabetology for diabetic kidney disease. Haemodialysis, Continuous Ambulatory Peritoneal Dialysis (CAPD).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory</td>
<td>Lung disorders</td>
<td>Asthma, COPD, Emphysema, occupational disorders e.g. asbestosis, pneumoconiosis lung malignancies etc.</td>
</tr>
<tr>
<td>Rheumatology</td>
<td>Medical management of disorders of bones, joints, tendons and muscles</td>
<td>Osteo-arthritis, Osteoporosis (also see Orthopaedic), Rheumatoid arthritis (also see Orthopaedic), Tendonitis.</td>
</tr>
<tr>
<td>Urology</td>
<td>Surgical management of disorders of the kidneys, ureters, bladder, prostate and male reproductive organs</td>
<td>Kidney tumours, renal transplant, stones in ureter, bladder tumours. Prostate disease – cancer and benign hypertrophy.</td>
</tr>
</tbody>
</table>

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Hospital Reports

National Health Service hospitals and trusts are required by the NHS Executive to provide factual reports incidental to the claimant's treatment when requested by the Benefits Agency. The hospitals or their employees are not paid on an individual basis for the reports. It is the responsibility of the hospital or trust management to ensure that the information is supplied.

Although patients are under the care of a designated consultant, this doctor does not necessarily have to complete the report. An alternative member of the medical team, another consultant or other healthcare professional may carry out the task.

The hospital report will contain information obtained from the medical records and the professional's knowledge of the patient. It will consist of detail relating to diagnosis, special tests, clinical findings, medication etc.

A hospital doctor will not have the background knowledge to answer specific questions relating to the criteria for benefit entitlement.

Hospitals are likely to be the most appropriate source of information when the medical diagnosis is uncommon or treatment is very specialised.
Individual Education Plan

The child’s teacher is responsible for working with the child on a day to day basis, but may decide to write down the actions of help in an IEP. The IEP will include details of the conditions giving rise to the child’s needs and could also include -:

- what special or additional help is being given
- who will provide the help and how often
- what help the child could be given at home
- the child’s targets
- how and when progress will be checked

Other names for an IEP, which may also be used, are -:

- Individual Behaviour Plans (IBP),
- Individual Behaviour Management Plans (IBMP),
- Behaviour Support Plan (BSP), and
- Behaviour Target Report (BTR).

Formal reviews of the plan should be held at least twice a year.
<table>
<thead>
<tr>
<th>Name</th>
<th>Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Area/s of concern</td>
<td>Yr group IEP No</td>
</tr>
<tr>
<td>Class Teacher</td>
<td>Start date</td>
</tr>
<tr>
<td>Supported by</td>
<td>Review date</td>
</tr>
<tr>
<td>Proposed support</td>
<td>Support began</td>
</tr>
</tbody>
</table>

Targets to be achieved

Achievement criteria

Possible Resources and Techniques

Possible strategies to use in class

Ideas for support teacher / assistant

Parents / carers need to

Student needs to

Back to A - Z
Medical Services Doctors

The doctors employed by Medical Services are particularly skilled and knowledgeable in the field of medical disability analysis. Most carry out regular examinations for benefit including the Personal Capability Assessment, Severe Disablement Allowance, Industrial Injury Disablement Benefit and DLA/AA. They also train contracted doctors to carry out the above types of examination and monitor the reports of these doctors, providing further training if needed.

Advice is given to Departmental Decision Makers on request in all the benefit strands.

Medical Service doctors also liaise with general practitioners, hospital doctors and other external bodies with regard to individual claims or other benefit matters.

Their experience in all strands of the medical benefits enhances their expertise in interpreting the effects of functional impairment across a wide range of disability.

Medical Services doctors can advise Decision Makers in a number of ways:

- They can identify who is likely to be the best person to approach for a medical report, whether a doctor or other healthcare professional and provide advice on the basis of the reply.

- They can explain and interpret medical terminology in all types of medical reports. This can include the nature of diagnoses, the use of medication, the meaning of clinical examination findings and the likely disabling effects of any given condition.

- They will be able to interpret clinical information, analyse it and describe the extent of care or mobility restrictions likely to arise from a specific medical or disabling condition.

- They can identify inconsistencies or contradictions in the evidence and advise if further evidence is likely to be useful.

- They can give advice regarding response to treatment and prognosis.
Common Medical Tests

<table>
<thead>
<tr>
<th>Bruce Protocol</th>
<th>Coronary Angiography</th>
<th>Endoscopic Examination of the GI Tract</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spirometry Tests</td>
<td>Peak Flow Meters</td>
<td>The Medical Research Council (MRC) dyspnoea scale</td>
</tr>
</tbody>
</table>

Bruce Protocol (Treadmill Exercise) Test

Formal exercise testing is undertaken when the diagnosis of angina needs to be confirmed in suspected individuals and indeed the severity of the coronary disease.

A standard treadmill or, more rarely, a bicycle ergometer is used and a formal exercise test (ETT) is performed. It is carried out according to a standard protocol.

The patient walks on the treadmill, which has a varying speed (which can be altered, i.e. made faster or slower) and a variable gradient (slope), which can mimic going uphill or upstairs. (The Bruce Protocol is a description of the protocol for the increments in speed and gradient in the treadmill test).

During the time of testing, continual monitoring of the patient's general condition, ECG and blood pressure take place.

A specialist must supervise and full resuscitation facilities must be available. The patient stops when chest pain or discomfort occurs, or when advised to, by the Specialist.

For the Full (Standard) Bruce Protocol, each stage lasts 3 minutes and the speed and gradient are increased at each stage.

For the modified Bruce Protocol, the gradient, but not the speed, is increased at each stage (see table).

Specific ECG changes indicate myocardial ischaemia.

The modified test is used in cases where standard testing would be too strenuous for the patient. The patient may not be able to participate in
exercise testing because of co-existing problems (i.e. severe OA of the hip, or severe chronic obstructive airways disease).

**Modified Bruce Protocol**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Speed (Metres per Min)</th>
<th>Gradient</th>
<th>Duration (Min)</th>
<th>Cumulative Time (Min)</th>
<th>Cumulative Distance (Metres)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>46</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>138</td>
</tr>
<tr>
<td>2</td>
<td>46</td>
<td>5</td>
<td>3</td>
<td>6</td>
<td>276</td>
</tr>
<tr>
<td>3</td>
<td>46</td>
<td>10</td>
<td>3</td>
<td>9</td>
<td>414</td>
</tr>
<tr>
<td>4</td>
<td>67</td>
<td>12</td>
<td>3</td>
<td>12</td>
<td>615</td>
</tr>
</tbody>
</table>

If the patient can complete Stage 1 of the test they are able to walk 138 metres on the flat.

**Coronary Angiography**

Coronary angiography is performed in order to demonstrate the exact anatomy of the coronary arteries, usually with a view to progression to PTCA (percutaneous transluminal coronary angioplasty) with or without stents, or CABG (coronary artery bypass graft).

Indications for angiography are:
- Where the diagnosis is not clear,
- Angina not responding to medical therapy,
- Strongly positive exercise test according to the Bruce Protocol,
- Moderate or severe angina,
- Unstable angina (very severe angina),
- After an infarct (M.I), if well enough.

**Endoscopic examination of the GI Tract**

**Sigmoidoscopy**

Sigmoidoscopy is a special internal investigation of the lower third of the large bowel (colon). An instrument called a sigmoidoscope is inserted via the anus and allows direct visual examination of back passage (rectum) and the sigmoid and descending colon (the last part of the colon).

The sigmoidoscope is a small camera attached to a flexible tube about twenty centimetres long (flexible sigmoidoscope). In some circumstances a rigid tube is used (rigid sigmoidoscope). The sigmoidoscope allows the operator to see any bleeding, inflammation, abnormal growths or ulcers in the colon and rectum. During the procedure the operator is also able to
remove small samples of any abnormal tissue identified (biopsy) for more
detailed examination under the microscope to confirm diagnosis.

Colonoscopy
Colonoscopy is a special investigation that permits internal examination of
the entire large bowel (colon). A long flexible fibro-optic tube, the
colonoscope, is inserted via the anus and slowly guided through the large
bowel under sedation. The colonoscope transmits pictures of the inside of
the bowel on to a video screen.

The operator is able to visualize any bleeding, inflammation, abnormal
growths or ulcers in the colon. Abnormal growths arising from the inner
surface of the bowel, such as polyps, can be removed via the
colonoscope. In addition small samples of any abnormal tissue identified
(biopsy) may be removed for more detailed examination under the
microscope to confirm diagnosis.

Gastroscopy
Gastroscopy is a special investigation that permits internal examination of
the upper parts of the gastrointestinal tract. It allows direct examination of
the oesophagus, stomach and duodenum. The gastroscope is a long
flexible fibro-optic tube that transmits pictures of the inside of the gut on to
a video screen. It is passed from the mouth, via the throat, into the
oesophagus and then on to the stomach and duodenum. The fibro-optic
tube is also referred to as an endoscope and the examination as
endoscopy.

The operator is able to identify any abnormal inflammation, bleeding or
growths, and to locate stomach or duodenal ulcers. Small samples of any
abnormal tissues identified (biopsy) may be removed via the gastro scope
for more detailed examination under the microscope to confirm diagnosis.

Gastroscopy is commonly used investigate symptoms of dyspepsia and
locate peptic ulcers in the stomach and duodenum. It also used to
investigate inflammation in the oesophagus and to diagnose oesophageal
and stomach tumours.

Peak Expiratory Flow (PEF)

This is usually used for asthma.

It is the maximum rate of air breathed out as hard as possible through a
measuring device called a peak flow meter, (after a full breath taken in).
The reading is measured in litres/minute (l/min). Three readings are taken
and the best of three is recorded.
A measured peak flow of less than 80% predicted indicates that airways obstruction is present but the diagnosis of asthma cannot be made on a single peak flow measurement as PFR may vary throughout the day as well as on a day-to-day basis, a series of sets of readings should be considered. Also, having a normal one-off peak flow reading does not exclude asthma.

Peak flow measurement is done very commonly, and many patients test their peak flows on a daily basis, having their own peak flow meters. They then may record the reading in a graph form, which then easily highlights any change especially morning and evening. It is a very easy test to do. GPs and Specialist Asthma nurses can do an on-the-spot reading to quickly check a patient’s status.

**EU Standard for Peak flow Meters**

**Background**

Studies have identified that existing scales on hand held mini-Peak Flow Meters are accurate in the mid range but at the high and low ends of the range they are less accurate, with a result that asthma may be under-diagnosed and treatment may not be optimal. As a consequence, a new EU standard has been introduced for mini peak flow meters, which is now in force. Any PF meter purchased or prescribed in the UK will from now on be EU standard compliant. Peak flow meters, which are well maintained, and in good condition can still, be used, since it is possible to apply an algorithm, which converts old to new readings.

It is important to determine the type of meter with which the reading was taken. Therefore, when documenting Peak Flow, it should be recorded whether an existing “Wright” or new “EU” meter has been used, like this: PFR 450l/min (Wright) or PFR 450 (EU)

Examples of comparable peak flow values are:

<table>
<thead>
<tr>
<th>WRIGHT (value in litres/minute)</th>
<th>EU (value in litres/minute)</th>
</tr>
</thead>
<tbody>
<tr>
<td>130</td>
<td>117</td>
</tr>
<tr>
<td>150</td>
<td>130</td>
</tr>
<tr>
<td>200</td>
<td>165</td>
</tr>
<tr>
<td>249</td>
<td>203</td>
</tr>
<tr>
<td>250</td>
<td>204</td>
</tr>
<tr>
<td>299</td>
<td>246</td>
</tr>
<tr>
<td>300</td>
<td>247</td>
</tr>
<tr>
<td>350</td>
<td>294</td>
</tr>
<tr>
<td>400</td>
<td>344</td>
</tr>
<tr>
<td>450</td>
<td>399</td>
</tr>
</tbody>
</table>
The average range for an adult for peak flow lies between PFR 450 (EU) and PFR 600 (EU), but because the peak flow depends on age, gender, race and height, the measured result is compared to that predicted for a person’s age, gender, and height, using special charts and the measurement is compared with what would be expected.

Below are some approximate result ranges indicating the level of peak flow reduction.

<table>
<thead>
<tr>
<th>Male Peak Flow Reading range</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild peak flow reduction</td>
<td>More than 300 litres per minute (l/min) Wright More than PFR 247 (EU)</td>
</tr>
<tr>
<td>Moderate peak flow reduction</td>
<td>200 – 299 litres per minute (l/min) Wright PFR 165 (EU) to PFR 246 (EU)</td>
</tr>
<tr>
<td>Severe peak flow reduction</td>
<td>Less than 200 litres per minute (l/min) Wright Less than PFR 165 (EU)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Female Peak Flow Reading range</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild peak flow reduction</td>
<td>More than 250 litres per minute (l/min) Wright More than PFR 204 (EU)</td>
</tr>
<tr>
<td>Moderate peak flow reduction</td>
<td>130 – 249 litres per minute (l/min) Wright PFR 117 (EU) to PFR 203 (EU)</td>
</tr>
<tr>
<td>Severe peak flow reduction</td>
<td>Less than 130 litres per minute (l/min) Wright Less than PFR 117 (EU)</td>
</tr>
</tbody>
</table>

With the new EU values, a new Nomogram has been provided, which should be used to determine whether the claimant has mild, moderate or severe asthma.

“In men, readings up to 100 litres/minute lower than predicted are within normal limits.
For women, the equivalent figure is 85 litres / minute.

Values are derived from Caucasian populations.”
**Special Peak Flow Monitoring**

The patient is asked to measure their peak flow on a peak flow meter, every morning and evening for 1 to 2 weeks, to measure variability. A variation between the morning and evening readings of more than 15% is diagnostic of asthma.

**Spirometry Test**

A Spirometry Test measures the volume of air blown out against time and gives more specific information about lung function. This is done by a special technician or specialist using a machine into, which the patient’s age, gender, and height have been entered, so that a predicted value has already been made. The patient blows out into a mouthpiece connected to the machine, as fully and as long as possible, after a deep breath in. Various readings can then be taken and compared with the predicted values.

It is the single best diagnostic test for patients with airflow limitation. All new diagnoses of COPD have to be tested to fulfil scores in the new GP General Medical Services contract. Most GPs are now becoming familiar with this and have nurses who perform spirometry and reversibility testing.

A value is calculated for the amount of air blown out in one second (this is known as the “Forced Expiratory Volume” or FEV1). This is divided by the total amount of air blown out until all air is expired (known as Forced Vital Capacity or FVC). This is expressed as a percentage value and a value of less than 70% indicates COPD.

In asthma, the readings will be reduced, returning to normal between episodes, and again, the recorded result would be compared with what is predicted (according to age, height and gender, by the machine) and the results are then printed out.

Below are some approximate result ranges indicating the level of reduced FEV1. These can only be considered approximate as factors such as height, age and weight are not considered.

<table>
<thead>
<tr>
<th>Male Spirometry reading range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild reduction</td>
</tr>
<tr>
<td>Moderate reduction</td>
</tr>
<tr>
<td>Severe reduction</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Female Spirometry reading range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild reduction</td>
</tr>
<tr>
<td>Moderate reduction</td>
</tr>
</tbody>
</table>
FEV1 and Functional restriction table
This table shows the predicted FEV1 as a percentage figure and the likely level of corresponding functional restrictions.

<table>
<thead>
<tr>
<th>FEV1 % predicted</th>
<th>Severity of airflow obstruction (Post-bronchodilator)</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥ 80%</td>
<td>Stage 1 – Mild</td>
</tr>
<tr>
<td>50–79%</td>
<td>Stage 2 – Moderate</td>
</tr>
<tr>
<td>30–49%</td>
<td>Stage 3 – Severe</td>
</tr>
<tr>
<td>&lt; 30%</td>
<td>Stage 4 – Very severe*</td>
</tr>
</tbody>
</table>

*Or FEV1 < 50% with respiratory failure.

[Adapted from updated NICE Guidance 2010]

Please note that FEV1 % predicted while indicative is not a perfect predictor of level of disability.

Forced Vital Capacity (FVC)
This is the total volume of air breathed out by the person after a full inspiration (breath in) into a spirometer. This is not generally used as a diagnostic test in COPD.

The FEV1 / FVC Ratio
This is a useful diagnostic aid and is a measure of airflow limitation.

Normally, the FEV1 / FVC ratio is approximately 75%.

A value of below 70% is indicative of airflow obstruction (obstructive airways disease). This could be either asthma or COPD. The difference is that asthma is reversed when a short-acting beta agonist such as salbutamol or terbutaline are used (this is known as reversibility), whereas COPD is not reversible.

A value of between 70% and 75% is indicative of restrictive lung disease such as lung fibrosis, asbestosis etc.

The Medical Research Council (MRC) dyspnoea scale
Although not strictly a test or investigation, this is a scale often quoted by General Practitioners in medical reports completed for Chronic Obstructive
Pulmonary Disease (COPD) / Chronic Obstructive Airways Disease (COAD).
Please see the link below:
http://www.gp-training.net/protocol/respiratory/copd/dyspnoea_scale.htm

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Note in Lieu

A note in lieu is issued if, after a statutory assessment, the LEA decides that the needs can be met with the support being provided by the child’s school.

A Note in Lieu describes -:

- the child’s special educational needs
- gives the reasons why a Statement has not been written
- provides suggestions for the school about how to meet the child’s needs
- describes any non-educational needs the child has and the support which might be helpful

Copies of all the advice and reports received as part of the statutory assessment will be sent along with the Note in Lieu to parents / carers.

The Note in Lieu will be used by the school to help them provide the most appropriate support for the child. The note contains advice which has been based on the assessment reports, but it is not a legally binding document.

Explanation – in lieu means ‘instead of’ - in this case instead of a SSEN.

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Occupational Therapists (OTs)

The prime function of OTs is to maximise the independence of the patients through assessing their needs and prompting the restoration of the maximum use of function. As specialists in the provision of disability equipment they offer practical advice on adapting the environment to the needs of the individual.

OTs will be found working in many areas of health care; learning disability, mental illness, geriatrics, physical disability, paediatrics, day care and rehabilitation centres. They work in a variety of settings including hospitals, day centres, claimant’s own homes and residential accommodation.

Their work focuses on enabling people to perform every day activities such as washing, dressing, cooking and shopping. They help people to readjust to independent living after discharge from hospital.
Where OTs work with people with mental health disorders or learning disabilities, they prepare these patients to return to as full a life as possible in the community. This may involve psychology or behavioural programmes including group work, for example, desensitisation programmes for agoraphobia or social skills training for people with long-term mental disorders.

**Reports from Occupational Therapists**

Reports from occupational therapists can provide very useful information since they link disability to need.

Sometimes OTs can prove difficult to identify as a source of information, especially if the patient is only seen on one or two occasions before discharge or in their own home.

If an elderly person is assessed at home a copy of the report may be available in his or her general practice records.

Claimants themselves may also have a copy of their assessment report.

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Physiotherapists

A physiotherapist has expertise in preventing and treating diseases/disabilities, particularly in relation to the neuromuscular, musculoskeletal, cardiovascular and respiratory systems.

Physiotherapists have a major contribution to make in restoring independence after a traumatic incident such as a stroke or head injury, after major surgery such as amputation, joint replacement or organ removal.

They also provide treatment for muscle, ligament, or tendon injuries, spinal conditions and rehabilitation after fractures.

When a physiotherapist treats a person for a minor illness/injury e.g. ankle injury or mechanical low back pain, the course of treatment is relatively short-lived involving two to six sessions over a similar number of weeks. Treatment after a major surgery e.g. joint replacement or amputation will be more prolonged but will be finite in length.

A few long-term disabilities may require continuing treatment on a regular basis, but this is not frequently the case. In these situations the patient may be able to carry out the exercises themselves or their carer is taught to do the procedure e.g. chest physiotherapy in cystic fibrosis.

Review of posture, pattern of walking and mobility in general is very much part of the role, together with pain-reducing and muscle-strengthening techniques.

Physiotherapists assess patients for and can prescribe appropriate aids. These include walking sticks, crutches, frames and wheelchairs. Other equipment might include TENS machine for pain relief, incontinence aids, splints, neck collars and calipers.

Reports from Physiotherapists

A report from a physiotherapist could be expected to contain a brief medical history, diagnosis of the disabling condition and details of clinical examination and treatment plan.

Information about limb function and ability to walk with appropriate appliances will often be available.

In milder conditions information will relate to a specific episode of treatment relating to the affected area of the body, and the report is unlikely to cover the disabling effects of other generalised conditions.
Special Educational Needs (SEN)

School & early education settings place great importance on identifying SEN so they can help the child as early as possible. Children learn in different ways & can have different levels or kinds of SEN. So if a child has SEN, the school will increasingly, step by step, bring in specialist expertise to help with the difficulties they may have.

The school must inform parents /carers if they start giving extra or different help to the child because of their SEN. The basic level of extra help is known as School Action & could be:

- A different way of teaching things
- Some extra help from an adult
- Using particular equipment like a computer or specialist desk.

The equivalent in Scotland is called Additional Support Needs (ASN). The principle difference being not confined to children whose need for special attention arises from disability or learning difficulties but from a range of factors e.g. being in hospital, death of a close family member.

Individual Education Plans (IEP)

The child’s teacher is responsible for working with the child on a day to day basis, but may decide to write down the actions of help in an IEP. The IEP could include:

- what special or additional help is being given
- who will provide the help & how often
- what help the child could be given at home
- the child’s targets
- how & when progress will be checked

Sometimes the school will not write an IEP but will record how they are meeting the child’s needs in a different way, perhaps as part of the lesson plans.

If the child does not make enough progress under School Action, the teacher or SEN coordinator (SENCO) will ask for advice from other people outside the school. This could include a specialist teacher or a speech & language therapist. This kind of extra help is called School Action Plus.

The equivalent in Scotland is called an Individualised Educational Programme. There is no difference to the English IEP.

Click here for more information about the Individual Education Plan
Statement of Special Educational Needs (SEN)

When SEN cannot be met by resources generally available to local schools, the assessment will identify the child's needs and any special help that is required and will be produced in the following format:

- Part 1 – Child’s details (e.g. name, address, parent / carer) and a list of the advice the authority received as part of the assessment
- Part 2 – Gives details of the child’s special educational needs
- Part 3 – Describes all the special help to be given for the child’s needs
- Part 4 – Gives the type & name of the school the child should go to & how any arrangements will be made out of school hours or off school premises
- Part 5 – Describes any non-educational needs the child has
- Part 6 – Describes how the child will get help to meet any non-educational needs.

A child’s statement of Special Educational Needs (SEN) should include mandatory information which Local Authorities (LAs) must request & consider when producing a statement of SEN. In addition to the actual statement, which will set out emotional & behavioural problems which may impact on learning as well as other conditions & health problems, parents will also have the reports considered to assist the LA to produce the statement. This will always include a medical report, a report from Nursery / School & a report from the Educational Psychologist.

Children who have learning support needs may not necessarily have a statement of SEN. The threshold for consideration of a statement is high & is variable from LA to LA. It may take several years before the LA accepts the need to prepare a statement even where a child clearly merits a statement being considered.

Those children whose condition may impact on attendance but not their learning support would not have one e.g. a child being treated for cancer may miss a whole year of school but they would not have a statement because the health problems do not impact on learning ability, only attendance.

Many children who have ADHD/ADD & other significant conditions may not have a statement because the condition does not impact sufficiently on their learning abilities. They would not usually have a statement unless they also had other conditions that impacted on their education such as dyslexia.

If a child does have a statement, this is a reliable indicator that the child does require a high level of additional support because they have a significant condition. However, the absence of a statement does not mean that the child does not have a significant learning impairment.

The equivalent in Scotland is called Co-ordinated Support Plan (CSP). There is no difference to the English statement of SEN.
Click here for more information about the statement of Special Education Needs

**Note in Lieu**
If, after carrying out an assessment, the LEA decides not to draft a statement, they may issue a note in lieu. It may resemble a SEN but it has no legal force & does not necessarily provide any additional funding to meet the child’s needs.

Click here for more information about the **Note in Lieu**

**Transition Plan**
This is for children moving from Secondary school to further or higher education. It outlines what the child wants to achieve in the next few years & what support they will need to live as independently as possible. It covers every aspect of their life, including education, employment, housing, health, transport & leisure activities. Most plans are drawn up in year 9.

The equivalent in Scotland is called Transition Planning / Future Needs Assessment. There is no difference to the English TP.

Click here for more information about the **Transition Plan**

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Social Workers

The title social worker is currently used to describe a variety of people employed in the public, private and voluntary sectors. There are great differences in the level of professional training and the type of work undertaken.

The biggest employers of professionally qualified social workers are local authority Social Services Departments. The social workers may be based in fieldwork offices or in hospital. Some specialise in areas of work such as learning disabilities, mental health, physical disabilities, childcare and hearing and sight impairment.

Social workers carry out assessments on disabled people to determine the level of care needed at home or the requirement for day care or residential services. These assessments will include information about the client’s ability to do day-to-day tasks and to perform personal care. The social workers may work closely with occupational therapists that are employed on the social work team by the same local authority.

Residential social workers and day care workers are employed in residential settings and day care centres. A care co-ordinator may have specific responsibility for a particular client. Many are very experienced in their field of care but are not professionally qualified. They usually have detailed first hand knowledge of a client’s disability and day-to-day functioning.

Reports from Social Workers

In those clients with disabilities who have undergone a formal assessment to determine the level of help which they need in their own homes or other residential settings the social worker can provide useful knowledge in determining benefit entitlement.

Some of the information will relate to activities such as the ability to shop or clean the home, which are not relevant to entitlement. In those with more severe disabilities evidence pertaining to personal care may be available.

Residential social workers will be able to give detailed information about care, including at night, similar to that provided by other relatives or carers living in the home.

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Specialist Nurses

Specialist nurses play a key role in the management of patient care. Working closely with doctors and other members of the multidisciplinary team, they educate and support patients, relatives and carers.

The specialist nurse has in depth knowledge of the physical, psychological and social effects of a specific condition.

Most specialist nurses are hospital based and have access to patient's medical records.

Some will visit patients in their own homes following discharge from hospital.

Some hospitals employ nurse specialists for:

- Blood disorders
- Gastro-enterological
- Gastro-intestinal
- Cardiac
- Respiratory
- Care of the Elderly
- Diabetes
- HIV/AIDS
- Incontinence
- Learning disability
- Oncology
- Neurology
- Pain Management
- Paediatrics
- Psychiatry
- Renal Medicine
- Skin Disease

Community Psychiatric Nurses (CPNS)

CPNs are specialist nurses with the treatment and care of people with mental health disorders. They work both in hospitals with inpatients and with outpatients in the community where they see patients in clinics or visit in their homes.

CPNs work closely with general practitioners, psychiatrists, social services and voluntary groups. Some specialise in drug and alcohol dependency.
People with more severe mental health problems may be on supervised discharge from hospital and the community psychiatric nurse acts as the care co-ordinator.

CPNs administer drug treatment by regular injection, monitor the effects of treatment, and carry out psychotherapeutic techniques such as behaviour therapy and counsel patients and their carers.

Community Matrons
Community matrons are highly experienced, senior nurses who work closely with patients (mainly those with a serious long term condition or complex range of conditions) in a community setting to directly provide, plan and organise their care.

For further information click on the following link -:


Reports from Specialist Nurses
Reports form the specialist nurse can provide details of the diagnosis, brief medical history, clinical examination findings, medication, treatment plan and response, variability of the condition, disabling effects and prognosis.

In people who have more than one medical condition, the specialist nurse may not be able to provide detailed information outside their own area of expertise or to be able to comment on multiple disabilities.

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Statement of Special Educational Needs

When Special Education Needs (SEN) cannot be met by resources generally available to local schools, the assessment will identify the conditions giving rise to needs, detail the child’s needs and any special help that is required and will be produced in the following format:

- Part 1 – Child’s details (e.g. name, address, parent / carer) and a list of the advice the authority received as part of the assessment
- Part 2 – Gives details of the child’s special educational needs
- Part 3 – Describes all the special help to be given for the child’s needs
- Part 4 – Gives the type & name of the school the child should go to & how any arrangements will be made out of school hours or off school premises
- Part 5 – Describes any non-educational needs the child has
- Part 6 – Describes how the child will get help to meet any non-educational needs.

The equivalent in Scotland is called Co-ordinated Support Plan (CSP). There is no difference to the English statement of SEN.

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The statement of SEN Report

Part 1.

<table>
<thead>
<tr>
<th>Child</th>
<th></th>
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<tbody>
<tr>
<td>Surname :</td>
<td>Other names :</td>
</tr>
<tr>
<td>Home Address :</td>
<td>Sex :</td>
</tr>
<tr>
<td>Date of birth :</td>
<td>Home Language :</td>
</tr>
<tr>
<td>Child’s parent or guardian</td>
<td></td>
</tr>
<tr>
<td>Surname :</td>
<td>Other names :</td>
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<tr>
<td>Home address :</td>
<td>Relationship to child :</td>
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<tr>
<td>Telephone :</td>
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</table>

Part 2. Special Educational Needs

This section will give details of the child’s special needs.

Part 3. Special Educational Provision

This section will describe:

- the long term objectives for the child
- the support the local authority thinks the child will need to meet their learning objectives
- The arrangements to be made for setting short term targets and regularly reviewing the child’s progress towards those targets.

Part 4. Placement

This section will name the school where the support will be made or the local authority’s arrangements for support if this is not to be in school.

Part 5. Non-Educational Needs
This section will give details of the relevant non-educational needs the child may have as agreed between health services, social services or other agencies and the local authority.

**Part 6. Non-Educational Provision**

This section will describe how the child will get the help required to support their non-educational needs.

A child’s statement of Special Educational Needs (SEN) should include mandatory information which Local Authorities (LAs) must request & consider when producing a statement. In addition to the actual statement, which will set out emotional & behavioural problems which may impact on learning as well as other conditions & health problems, parents will also have the reports considered to assist the LA to produce the statement of SEN. This will always include a medical report, a report from Nursery / School & a report from the Educational Psychologist.

Children who have learning support needs may not necessarily have a statement. The threshold for consideration of a statement is high & is variable from LA to LA. It may take several years before the LA accepts the need to prepare a statement even where a child clearly merits a statement being considered.

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Many children who have ADHD/ADD & other significant conditions may not have a statement because the condition does not impact sufficiently on their learning abilities. They would not usually have a statement unless they also had other conditions that impacted on their education such as dyslexia.

If a child does have a statement, this is a reliable indicator that the child does require a high level of additional support because they have a significant condition. However, the absence of a statement does not mean that the child does not have a significant learning impairment.
Transition (14+) Plan / Review.

This is for children moving from Secondary school to further or higher education. It outlines what the child wants to achieve in the next few years and what support they will need to live as independently as possible. It covers every aspect of their life, including education, employment, housing, health, transport and leisure activities. Most plans are drawn up in year 9.

<table>
<thead>
<tr>
<th>Transition needs</th>
<th>Action</th>
<th>Agencies responsible</th>
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<tbody>
<tr>
<td>Academic</td>
<td></td>
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<tr>
<td>Career / Future</td>
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<td>Health / Therapy</td>
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<td></td>
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<tr>
<td>Personal / Family / Social</td>
<td></td>
<td></td>
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<tr>
<td>General Action</td>
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</tbody>
</table>

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Cerebral Palsies in Adults

Introduction

Cerebral palsies are disorders of posture, movement and muscle tone resulting from abnormal structural development or non-progressive lesions of the immature brain, which in the majority of cases arise at, around or before birth. Cerebral palsies are not specific diseases but are groups of disorders of varied causes and commonly associated with sensory defects (i.e. impairments of vision, or hearing, or touch, etc), learning difficulties and epilepsies. Cerebral palsies affect one adult in 400.

Cerebral palsies arise from abnormalities of brain development before birth or from damage to the brain in the womb, during birth or in infancy. The predominant features of the resulting disability are impairments in self-care, independent mobility and social interaction, which include communication. In late middle age, there is an increased risk of memory loss, dementia and osteoarthritis.

Clinical Features

Adults with cerebral palsies may show laborious movements due to spasticity (stiffness of muscles of the limbs). If this affects one side of the body it is called a hemiplegia, if it affects all 4 limbs it is called a quadriplegia, if it affects the mouth muscles it is called a bulbar palsy. Others show involuntary movements of a writhing (athetoid) and/or jerking nature (chorea). If there is unsteadiness or lack of balance this is known as ataxic cerebral palsy. Some people have mixed forms of cerebral palsy – e.g. ataxia and spasticity. Skeletal deformities are common e.g. curvature of the spine (scoliosis), dislocation or restricted mobility of the hip(s), deformities of the ankle or foot requiring use of appliances e.g. callipers or special footwear.

About a third of adults with cerebral palsies have associated learning disability in the moderate to severe range. A further third have ‘patchy’ or specific learning disabilities (e.g. in literacy, numeracy or perception). The remainder are of normal intellectual ability or above average ability. In some the severity of the physical disability (e.g. athetosis) may bear little relation to intelligence.

Communication difficulties are common in adults with cerebral palsies; reasons include specific difficulties in comprehension or expressive language, impaired speech articulation and associated hearing loss, learning disability or autism. Augmented communication with symbol systems, word processor or a speech synthesizer may be used. Visual impairments are much more common than in the general population. Refractive error may be correctable by glasses. There may be retinal disorder in the eye, either from developmental disorders, damage by viral
infection in the womb, cataracts or cortical visual impairment from developmental abnormality or damage to the brain.

About 10 per cent of adults with cerebral palsy have epilepsy, often severe.

Life expectancy for adults with cerebral palsy depends on the type, severity and associated disabilities as well as the quality of care. It ranges from about 30 years for those with rigidity or severe spasticity associated with epilepsy and feeding difficulties, to 60-70 years for those with moderate cerebral palsy, and to a normal life expectancy for those with mild disability and no associated impairments.

**Further Evidence**
Families of adults with cerebral palsy are often closely involved in their care and support and can provide much of the information required in determining care and mobility needs. Further evidence may be sought from the social worker, a therapist, the GP or a consultant in rehabilitation medicine who has been involved in the management of the disabled person.

**Care Considerations**
About one third of adults with cerebral palsy may be expected to be independent and self-supporting with suitable education and support in childhood adolescence and early adult life. More severely affected people may require help with dressing and undressing, and with personal hygiene. Help may also be needed with cutting, mashing or blending food. Those most severely affected may be unable to feed themselves without help from another person.

**Mobility Considerations**
About 75% of adults with cerebral palsy can walk in the home and for varying distances out of doors. The manner in which progress is made, the gait adopted and the effort required may among other factors result in substantial limitations of walking abilities. Aids such as a walking stick, elbow crutches or a walking frame may be required, with a wheelchair for longer distances.

**Duration of Needs**
Care and mobility needs are ongoing in adult cerebral palsy.

<table>
<thead>
<tr>
<th>Cerebral palsy - quadriplegia</th>
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</thead>
<tbody>
<tr>
<td>Spastic diplegia</td>
</tr>
<tr>
<td>Cerebral palsy - athetoid</td>
</tr>
</tbody>
</table>
Cerebral palsy - causing hemiparesis
Cerebral palsy - ataxic
Cerebral palsy - Other / type not known

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

This text is an extract from the Disability Handbook. Extracts from the DHB are provided for a small number of topics where there is no suitable CCM guidance or NHS choices page. Adapted from the DHB – August 2011.

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Compartment Syndrome

Compartment syndrome is an acute condition affecting the muscle compartments usually of the lower limb or forearm. It is caused by any condition that results in inflammation and swelling of the tissues inside the muscle compartments especially severe trauma. Common causes are crush injury, certain fractures and vascular injury.

The swelling results in high pressure in tissue fluid around cells and the normal flow of oxygen and nutrients from blood is interrupted. If not treated quickly by decompression using a surgical operation called fasciotomy, many of these cells will die. This is called necrosis. Death of cells results in permanent disability.

If treatment is instituted quickly there will be scarring but no disabling effects. Without treatment or delay in treatment there will be disabling effects related to death of muscle or nerve cells. In the leg there are likely to be visible changes in the appearance of the calf muscle and some movements may not be possible because the appropriate muscle or its nerve is damaged, a good example of this is foot drop. This condition may be associated with disabling and difficult to treat pain syndromes relating to ischaemic nerve damage. Any resulting disability associated with this condition is permanent and may be called post compartment syndrome.

In the arm, the most well known example of compartment syndrome is caused by fracture of the elbow in children. Acute swelling causes long term damage to the muscles and nerves of the forearm. This typically ranges from flexion contracture of the fingers to complete paralysis of the forearm wrist and fingers. Long term damage caused by compartment syndrome after elbow fracture is called ‘Volkmann’s Ischaemic Contracture’.

The effects of this condition should not be confused with exercise induced compartment syndrome.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Award Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compartment syndrome -:</td>
<td></td>
</tr>
<tr>
<td>Treatment administered appropriately</td>
<td>N/A</td>
</tr>
<tr>
<td>Delayed treatment / no treatment resulting in necrosis</td>
<td>Indefinite</td>
</tr>
</tbody>
</table>
Joint Hypermobility Syndrome

Introduction
Hypermobile joints (JHM) are common, occurring in 10-20% of Western populations and even more common in people of Indian, Chinese and Middle Eastern origin.

If they are asymptomatic, these are simply people with hypermobility. It is important to distinguish them from patients with Joint Hypermobility Syndrome (JHS), where there are symptoms associated with the hypermobility and they meet the Brighton Criteria for diagnosis of this condition.

The Joint Hypermobility Syndrome (JHS) is a multi-system inherited connective tissue disorder thought to be caused by faulty fibrous tissue matrix proteins such as collagen. It is indistinguishable from Ehlers-Danlos Syndrome – Hypermobility type (previously known as Ehlers-Danlos type III). Musculoskeletal problems include joint pain, recurrent sprains, dislocations, fractures, tendonitis, bursitis, premature osteoarthritis, osteoporosis and chronic pain syndrome. Symptoms also may include fatigue, autonomic disorders, proprioceptive (awareness of joint movement and position) problems, skin abnormalities, uterine and rectal prolapse, herniae and gastrointestinal dysmotility.

Symptoms and signs
Tissue laxity results in increased flexibility, an asset to some dancers, gymnasts, musicians and athletes. However, fragile tissues are prone to overuse injury, rupture and healing is poor and often delayed.

Muscle and joint complications – joint pain, sprains, tendonitis, bursitis, recurrent dislocations, fractures, early arthritis and osteoporosis, flat feet,
chronic spinal disc problems with back and neck pain, chronic pain syndrome.

Other complications – Smooth but stretchy, poor healing skin, papyraceous scarring, stretch marks, easy bruising, lax eyelids, bruising, uterine and rectal prolapse, stress incontinence, proprioceptive impairment leading to clumsiness and falls, varicose veins, fatigue.

Gastro-intestinal problems: abdominal pain, constipation, gastroparesis, reflux – can require multiple medications and even naso-gastric tube or PEG feeding.

Autonomic Disorders occur in 78% of patients and include Vasodepressor Syncope and Postural Orthostatic Tachycardia Syndrome (PoTS - increased pulse rate on standing or prolonged sitting can result in reduced blood supply to the brain and compensatory high adrenaline levels. Symptoms include fainting, dizziness, fatigue, poor concentration and memory problems, headaches, palpitations, tremor, sense of anxiety, nausea, sweats and visual problems. PoTS can produce functional impairment similar to that found in COPD and heart failure).

**Causes**

Joint Hypermobility Syndrome is probably an inherited (genetic) condition that is passed to an average of 50% of a patient’s children (autosomal dominant). By chance, an affected parent may pass JHS to none, some or all of their children. A single gene defect has not yet been identified—several factors may be involved. Consequently, affected patients may become carers for affected relatives.

**Diagnosis**

Joint Hypermobility Syndrome is under-diagnosed. In one survey, over 50% of patients waited over 10 years from onset of symptoms to receive a diagnosis. Diagnosis is clinical—there are currently no blood tests or other markers available. It is made on the basis of satisfying the BRIGHTON CRITERIA.
Major Criteria
- A Beighton score of 4/9 or greater (current or historical)
- Arthralgia for longer than 3 months in more than 4 joints

Minor Criteria
- A Beighton score of 1, 2 or 3/9 (0-3 if age 50+)
- Arthralgia >3 months in 1-3 joints or back pain >3 months, spondylosis/spondylolisthesis
- Dislocation/subluxation in >1 joint, or 1 joint more than once
- Soft tissue rheumatism (e.g. epicondylitis, tenosynovitis, bursitis) >3 lesions
- Marfanoid habitus (tall, slim, span/height ratio>1.03, upper/lower segment ratio less than 0.89, arachnodactyly-positive Steinberg/wrist signs)
- Abnormal skin: striae, hyper-extensible, thin, papyraceous scarring
- Eye signs: drooping eyelids or myopia or antimongoloid slant
- Varicose veins or hernia or uterine/rectal prolapse

JHS diagnosed in presence of 2 major or 1 major + 2 minor or 4 minor criteria
(2 minor will suffice if there is an unequivocally affected 1st degree relative)

BEIGHTON SCORE (maximum score 9)

Opposition of the thumb to the volar aspect of the ipsilateral (same side) forearm (1 point for left; 1 for right)
Passive dorsiflexion of the fifth mp joint to ≥90° (1 point for left; 1 point for right)
Hyperextension of the elbow to ≥10° (1 point for left; 1 point for right)
Placing of hands flat on the floor without bending knees (1 point)
Hyperextension of the knee to ≥10° (1 point for left; 1 point for right)

Differential Diagnosis
It is important not to miss other conditions that manifest as hypermobile joints e.g.
- Marfan's Syndrome (may be suggested by family history of early death from dissection or ruptured aortic aneurysm).
- Vascular types of Ehlers-Danlos Syndrome (can cause spontaneous rupture of artery, gut or uterus).
Treatments
People with JHS often respond poorly to analgesics and local anaesthetics. With frequent and persistent painful episodes and poor pain control, they often develop widespread chronic pain with pain amplification and kinesiophobia (avoidance of movement to avoid pain). Deconditioning develops.

A multidisciplinary team approach can be helpful where available (e.g. rheumatologist, specialist nurse, physiotherapy, podiatry, occupational therapy, pain management team).

Depression is common due to chronic uncontrolled pain, difficulty with tasks of daily living, diagnostic delay and failure to recognise symptom severity.

In general, surgery and steroid injections are not recommended for hypermobile joints

Physiotherapy
Overenthusiastic physiotherapy from practitioners inexperienced with JHS may exacerbate symptoms. Treatment should focus on:

- Core and joint stabilising and proprioception enhancing exercises;
- Mobilising techniques;
- General fitness training.

Support Organisations
The Hypermobility Syndrome Association
Ehlers-Danlos Support UK
Marfan Association UK
Syncope Trust And Reflex anoxic Seizures (STARS) (autonomic problems / syncope)
Postural Orthostatic Tachycardia Syndrome (POTS)

Further Evidence
Because of the wide range of clinical manifestations and spectrum of disability and needs it may often be necessary to obtain further evidence, in the form of a GP or physiotherapist report or a report by an examining medical practitioner. A rheumatologist’s report may be particularly helpful.

Care and Mobility
People with severe forms of the JHS may be in frequent or constant pain that is worsened by movements, especially those involving physical effort
such as lifting. Joints may dislocate following minimal movement. When
the tissues are damaged, physically demanding activities are also painful
and may give rise to care needs from another person. Periods of rest
throughout the day may be required after only a modest amount of
physical activity.

Falls and/or faints may occur so that certain activities such as bathing,
using stairs, etc may need to be supervised, particularly in elderly people
with this syndrome.

Main meal preparation, especially cutting up vegetables, opening jars,
lifting pans and using taps may prove to be difficult. At times assistance
may be required with toileting and personal hygiene.

Workplace considerations: Chairs may need to be adapted to suit
individual’s need e.g. high back, lumbar support, elevated seat. It may be
necessary to adapt taps and door-handles. Repetitive use of susceptible
joints should be avoided. Special transport considerations may be
necessary. Advice from an occupational therapist, physiotherapist or
occupational health department may be helpful.

Employees with autonomic complications may require a cool environment
with the ability to take short regular breaks to eat and drink. Prolonged
standing and sitting should be avoided. They may have special dietary
requirements. Profound fatigue is a common problem and can impair
stamina and concentration.

Mobility considerations: Because the connective tissues are lax and fragile
they may be easily injured or dislocate. The combination of unstable,
painful joints and balance problems may make walking difficult. People
with severe forms of the syndrome require the use of walking aids (cane,
crutches) or wheelchair. Patients can become bed-bound.

**Prognosis and duration**

Pain can result from sudden injuries to the soft tissues which take weeks
or months to heal. Long delays in diagnosis means that many patients (for
example 24% of patient attending their first appointment at UCH
Hypermobility Clinic) have established chronic pain syndrome and
requiring a multi-disciplinary team approach to management.

| Hypermobility/Hypermobility syndrome |

**Over 65s**
People over 65 with this condition are likely to have accrued long term joint
damage. They are likely to have more pain and symptoms than a younger
person with this syndrome.
All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

Approved by
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August 2011

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Muscular Dystrophy

Introduction
There are several different types of muscular dystrophy, most of which are rare. All are progressive, hereditary disorders, in which muscle fibres degenerate and are replaced by fibrous tissue and fat, resulting in gradually increasing weakness. Only those muscular dystrophies most commonly encountered are described in detail. Their effects depend on the muscles involved and on the rate of progress of the disease.

Duchenne Muscular Dystrophy
This is the commonest and most severe form of muscular dystrophy. In about two-thirds of affected individuals, the condition is inherited through the mother, who is a carrier. In the remainder, the condition is a result of a change in genetic structure (mutation) in the egg (ovum). Only boys are affected by the disease - although a few female carriers show some of the symptoms, which rarely, is severe enough to cause wheelchair-dependency.

The condition usually becomes apparent between one and four years old, with delay in walking, a clumsy gait, inability to run properly, frequent falls and difficulty managing stairs. Learning difficulties and behavioural problems are relatively common, but usually mild to moderate.

Weakness of the leg and hip muscles gradually increases, and walking becomes more difficult, despite the use of aids until a wheelchair is necessary. All boys become completely wheelchair-dependent by the age of 12 years. There is progressive weakness of the upper limbs and by mid-adolescence the only useful residual function is finger movement, which allows use of a keyboard and control of an electric wheelchair. Progressive spinal weakness leads to increasing curvature of the spine (scoliosis) which compromises breathing and causes difficulty with posture in the wheelchair. Spinal surgery (insertion of steel rods) may be necessary. Breathing difficulties increase due to progressive chest muscle weakness and spinal curvature. Untreated, boys used to die in their late teens from ventilatory failure. The introduction of night-time, non-invasive ventilation over the last 20 years has led to marked prolongation of life (into the 30s) but with the added complication of increasing physical disability and heart involvement. Heart muscle involvement (cardiomyopathy) is inevitable and requires drug treatment to prevent and treat heart failure. Although survival has been prolonged with the use of ventilation, those living longer are more likely to develop symptomatic cardiomyopathy, which may be fatal. There is more information about cardiomyopathy in the CCM guidance.

Becker Type Muscular Dystrophy
This is a variant of Duchenne dystrophy, again usually only affecting boys, although there are rare cases of symptomatic female carriers who may
also develop cardiomyopathy. It is extremely variable in severity. At the mildest end of the spectrum, the only complaint may be of muscle pain on exercise or weakness may appear for the first time in middle age and progress only slowly. At the most severe end, it is essentially indistinguishable from Duchenne dystrophy – wheelchair dependency being a little later than in Duchenne i.e. in mid to late-teens. The most common form presents with weakness in childhood, affecting first the legs and later the arms. It progresses slowly and boys may remain ambulant (able to walk) with aids for many years. Wheelchair use becomes increasingly necessary from about the age of 40 years, but sometimes earlier. Heart muscle involvement (cardiomyopathy) is common and again variable in severity. In some, the cardiomyopathy is far more severe than limb involvement – rare cases require cardiac transplantation. More information on the effects and treatment of cardiomyopathy is provided in CCM guidance.

**Limb Girdle Dystrophy**
This broad term covers more than twenty specific genetic entities and affects both sexes. In terms of severity, the range is from a condition as severe as Duchenne dystrophy, to first presentation in late-middle age. Most commonly it presents in adolescence and early adult life. Muscle weakness is usually noticed in the lower limbs before the upper. Progression is relatively slow. Significant numbers eventually become wheelchair-dependent. Some are associated with cardiac involvement, which may be severe. Many are associated with ventilatory insufficiency, which may require the use of non-invasive ventilation. In some, ventilatory failure may occur when the patient is still able to walk, but usually it develops when they have been wheelchair dependent for many years.

**Facioscapulohumeral Dystrophy**
This is generally a milder disorder than those already mentioned, and affects both sexes. Onset may be at any age from childhood to adult life, but comes on most commonly during adolescence. The muscles of the face and shoulders are most affected, causing increasing difficulty in lifting the arms, weakness of eye closure and lack of facial expression. Despite the name, lower limb involvement is common. Initially this is most commonly in the form of foot drop, but in the later stages of the disease there may be marked weakness around the hips causing major walking difficulties. It is commonly associated with spinal muscle weakness and abnormal curvature of the lumbar spine – low back pain is a common feature. About 10% of patients become wheelchair-dependent, and some of those will develop ventilatory insufficiency requiring non-invasive ventilation.

**Myotonic Dystrophy (dystrophia myotonica)**
This condition is extremely variable in severity and differs from other forms of muscular dystrophy in being a multi-system disorder. The muscular problems may be accompanied by others involving the eyes, heart, lungs, hormone and immune systems and the brain. As well as weakness, there is difficulty in relaxing muscles after voluntary effort (myotonia).
It affects both sexes and is commonly found in adults, developing between the ages of twenty and fifty, though it may occasionally arise in childhood or even at birth (in children of affected women) when it tends to be very severe and associated with major learning disabilities. The first symptoms in adults are usually weakness of the hands and difficulty with walking. The major non-muscle symptoms relate to brain function. Many have excessive daytime sleepiness very similar to narcolepsy. This may greatly interfere with employment and domestic activities. In those with adult onset, IQ tends to be lower than average, but in addition, specific cognitive dysfunction is very common. This may be seen as “apathy”, and look superficially like depression, but there are characteristic features of frontal lobe dysfunction (e.g. difficulties planning and completing simple tasks – dysexecutive problems) which may significantly affect work performance as well as social functioning. Unlike other physical effects of the condition, cognitive function does not tend to worsen significantly during life.

The distribution of muscle weakness is unusual, affecting the extremities more severely than the shoulder and hip girdle muscles. Although the rate of progression of weakness is relatively slow, the specific involvement of the hands and ankles leads to profound functional disability, despite strong proximal muscles. In late stages, there may be wheelchair-dependency, but by then there will have been years of substantial disability due to distal weakness.

Breathing muscles are affected early and cause hypoventilation which increases the risk of chest infection, the risk of which is also exacerbated by the involvement of the swallowing muscles which leads to aspiration of food and fluids. Pneumonia is the commonest cause of death. The heart conduction system is involved and may lead to blackouts requiring pacemaker insertion. In addition, malignant cardiac arrhythmias are a relatively common cause of premature death. The effects and treatment of cardiac arrhythmias are covered in CCM guidance.

**Duration of Needs**

All these conditions are progressive, and cause gradually increasing disability. Needs, once established do not abate. The level of need will increase as the disease progresses.

<table>
<thead>
<tr>
<th>Condition</th>
</tr>
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<tbody>
<tr>
<td>Myotonic Dystrophy (Dystrophia myotonica)</td>
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<tr>
<td>Duchenne Muscular Dystrophy</td>
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<tr>
<td>Becker Type Muscular Dystrophy</td>
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<tr>
<td>Limb Girdle Type Muscular Dystrophy</td>
</tr>
<tr>
<td>Facioscapulohumeral Muscular Dystrophy</td>
</tr>
<tr>
<td>Muscular dystrophy – Other / type not known</td>
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</tbody>
</table>

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects.
must be based on the particular circumstances of the individual claimant.

Updated – July 2016

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The Painful Neck

Introduction
Injury to the bones and soft tissue of the neck or "degenerative" disease of the bones and joints (spondylosis) are the frequent causes of neck pain. Pain in the neck can be acute (sudden) or chronic (longstanding). Common examples of the former are acute cervical disc prolapse and whiplash injury; the most common cause of chronic pain and stiffness in the neck is cervical spondylosis. This condition is due to degenerative changes in the neck vertebrae and the discs in between the vertebrae.

Symptoms
The symptoms and any limitation of neck movements due to an acute disc prolapse or strain injury generally last for no more than a few weeks. The pain is in the region of the neck, shoulder blades and may be felt in the shoulders and the arms. The pain may be accompanied by numbness and tingling or muscle weakness resulting in a poor grip and varying degree of muscle weakness of the upper limb muscles. Neck movements may also be stiff and limited. Very rarely a disc may press on the spinal cord leading to weakness and loss of sensation in upper and lower limbs, along with difficulty controlling the bladder and bowel.

Cervical spondylosis is part of the ageing process. It is a form of osteoarthritis. On X-ray there may be well developed bony and disc changes in cervical spondylosis which cause no significant pain or disability. Most people over the age of 50 years will show some changes due to cervical spondylosis on X-ray of the neck. The condition comes on gradually, in some cases it may be made worse by trauma. The symptoms are similar to those in acute lesions but are usually less severe. In some cases due to progressive compression of the nerve roots there may be muscle wasting and weakness of the upper limbs.

Further Evidence
Further evidence is most appropriate in these cases: a factual report from the hospital or GP or an examination by an examining medical practitioner should be helpful.

Care Considerations
The help that is needed generally relates to tasks that involve the use of upper limbs i.e. dressing, washing hair and impairment of grip in using household utensils. The symptoms from cervical spondylosis can often subside spontaneously, or in response to treatment like a collar, analgesics or physiotherapy. In all but acute episodes of pain and stiffness
due to a prolapsed disc or following severe neck strain, which rarely last longer than a few months, the pain and disability due to cervical spondylosis rarely gives rise to significant care needs. When there is evidence of muscle wasting or significant loss of sensation in the upper limbs and hands care needs as described above may be present.

**Mobility Considerations**

There may be difficulty in walking in cases of acute cervical disc prolapse when pressure on the spinal cord has produced leg muscle weakness. In people with cervical spondylosis it is unlikely that there will be any significant effects on the ability to walk unless there is evidence of irreversible damage to the spinal cord. In all such cases there will be a history of hospital admission, and in the acute cases, frequently of surgical intervention. In elderly people with advanced cervical spondylosis there may be pressure on the vertebro-basilar arteries providing blood to the brain. Certain movements of the neck can result in brief episodes of dizziness and/or unsteadiness. Rarely such episodes of vertebro-basilar insufficiency can result in brief altered consciousness or loss of consciousness.

**Duration of Needs**

In cases of acute disc prolapse the condition is likely to settle within a few weeks to months with treatment (including surgery). In cervical spondylosis, the established needs tend to be long-standing though they may be intermittent.

| Cervical disc lesion | Cervical spondylosis | Whiplash injury | Neck disorder - Other / type not known |

All information must be taken into account when considering the duration of disabling effects and the duration of disabling effects must be based on the particular circumstances of the individual claimant.

This text is an extract from the Disability Handbook. Extracts from the DHB are provided for a small number of topics where there is no suitable CCM guidance or NHS choices page. Adapted from the DHB – August 2011.
Postural Tachycardia Syndrome (PoTS)

Introduction
Postural Tachycardia Syndrome is also called Postural Orthostatic Tachycardia Syndrome or PoTS. It is an abnormal response by the autonomic nervous system to upright posture. When humans stand up, there should be minimal change in their blood pressure and heart rate. In PoTS, it is thought that blood vessels fail to narrow to maintain blood pressure. Blood descends with gravity into the abdominal cavity and limbs. The heart races and, in some people, noradrenaline levels increase in an attempt to compensate. Symptoms result from reduced blood flow within the brain and increased blood levels of noradrenaline.

Definition and Symptoms
Definition:
PoTS is defined as a sustained increase in heart rate of 30 or more beats per minute within 10 minutes of moving from a lying to standing position (40 beats per minute for those age 12-19 years). Heart rate often increases to more than 120 beats per minute and blood pressure does not usually drop. There must also be symptoms of orthostatic intolerance (symptoms provoked by standing and relieved by lying down).

Symptoms include:
- **Cardiovascular** - light-headedness, syncope (fainting), palpitations, breathlessness, chest pains, puffiness and purplish discolouration of feet and hands.
- **Gastrointestinal** - nausea, diarrhoea, abdominal pain, bloating.
- **General** - Tiredness, weakness, headache, tremors, sleep disturbances, difficulty exercising.

Symptoms tend to be worse on standing or prolonged sitting and improve upon lying flat. They are worsened by heat, alcohol, exercise, large meals and lack of fluids.

Disability has been shown to be similar to that found in chronic obstructive airways disease and heart failure.

Causes
Primary PoTS
PoTS may be provoked by viral infection, pregnancy, immunisation and traumatic events. The ‘developmental’ form of PoTS is usually of gradual
onset in teenagers. In ‘Hyperadrenergic’ PoTS, patients may have very high noradrenaline levels and experience a sense of anxiety, tremor and cold sweaty hands and feet.

**Secondary PoTS**

PoTS is associated with the following illnesses:
Joint Hypermobility Syndrome, Chronic Fatigue Syndrome, Diabetes, SLE, Amyloidosis, Sarcoidosis, Cancer, Alcoholism and poisons such as lead and chemotherapy.

**Diagnosis**

Diagnosis is usually made by Tilt Table Test or Stand Test. There should be a sustained increase in heart rate of 30 beats per minute within the first 10 minutes of upright tilt or active standing. Blood pressure usually remains stable or increases slightly, although some patients will also experience a drop in blood pressure.

**Differential Diagnosis**

As there is limited awareness of PoTS within the medical communities, it can be mistaken for other conditions including vaso-vagal syncope, chronic fatigue syndrome, anxiety, panic attacks or depression. Symptoms are similar to those found in pheochromocytoma (noradrenaline secreting tumour) and hyperthyroidism and it may be necessary to exclude these conditions.

**Treatments**

- **Physiological:** High fluid (and sometimes salt) intake, support tights, graded exercise programme.

- **Medical:** A number of drugs are used to treat symptoms; all are unlicensed for this use. They include fludrocortisone, desmopressin, midodrine, beta blockers, ivabradine, SSRIs and SNRIs, pyridostigmine and octreotide.

- **Psychological:** CBT can help patients come to terms with their illness and disability. Although antidepressants (SSRIs and SNRIs) can be used in PoTS to improve heart rate and blood pressure control, they may also be necessary for co-existing depression.

**Support Organisations:**
PoTSUK: Postural Orthostatic Tachycardia Syndrome (PoTS)
STARS (Syncope Trust): Syncope Trust And Reflex anoxic Seizures (STARS)

**Further Evidence**

Because of the wide range of symptoms and spectrum of disability and needs, it may often be necessary to obtain further evidence, in the form of a GP or hospital consultant report.
Care and Mobility
While some people with PoTS have minimal symptoms with little impact on their daily activities, others may become wheelchair users or bed-bound. Many patients can live independent lives, but some require constant supervision and assistance with many aspects of daily living. Symptoms can fluctuate significantly and people with PoTS can have good and bad days.

- **Fluid intake** should be at least 2-3 litres per day. Frequent toilet breaks may be necessary.

- **Food intake** should preferably be in the form of small frequent meals, low in refined carbohydrates.

- **Posture** should be monitored. Prolonged standing should be avoided where possible. If patients experience problems with prolonged sitting, elevation of legs with a footstool can be helpful.

- **Fatigue** is a common symptom and short frequent breaks during activities may be helpful. At times, concentration and stamina may be reduced. Periods of rest throughout the day may be required after only a modest amount of physical activity.

- **Mental clouding** (‘brain fog’) can significantly impair concentration, especially when people with PoTS are upright ie standing or prolonged sitting.

- **Recurrent fainting** occurs in 40% of patients and injuries can occur. Certain activities such as bathing, using stairs, etc may need to be supervised.

- **Family members** may also have PoTS as some forms are inherited. Therefore affected people may also be carers for affected relatives.

Workplace considerations
Employees with PoTS may require a cool environment and a fan or air conditioning may be necessary. Prolonged standing and sitting should be avoided. They may have special dietary requirements. If fainting is a problem, work colleagues/ first aiders should be instructed in how to manage an unconscious person.

Mobility considerations
It may be necessary to adapt the home or workplace for use of a wheelchair.
Prognosis and duration

Many people will improve with time, especially those with the developmental and post-viral forms of PoTS. Those with the auto-immune or inherited types are likely to be affected for life.

Although 25% of people with PoTS are unable to work or attend education, 80-90% will improve with treatment and 60% will return to previous levels of functioning.

Approved by

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July 2012

Pain Management Clinic

Not to be confused with Pain Clinics, which are usually run by anaesthetists and aim to treat the pain.

Pain Management Clinics are run by a professional multi disciplinary team, usually consisting of a psychologist, physiotherapist, nurse and doctor. Pain management programmes are offered to people who have chronic pain of at least 6 months duration and where all other appropriate treatments have been undertaken. Referral from a GP or local hospital is required, and an initial assessment is carried out by the clinic to confirm suitability for the programme before a place will be offered.

The programme lasts between 8-10 weeks and consists of small groups who meet weekly for a half - day session. Usually this is conducted on a non - residential basis, but in severe cases a residential option may be offered.

A variety of methods are employed by the multi disciplinary team. The basis of the programme is aimed at introducing coping strategies, which help individuals manage their pain and improve their quality of life. This will include psychological, physical and practical techniques, known as Cognitive Behavioural Therapy (CBT).

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Skin Disease

Introduction
The skin is frequently affected by disease, whether as primary disease of the skin itself or as a secondary effect of other conditions. There are an enormous number of different skin diseases and their classification is complex but this is not important in this context as the effects of skin disease often follow similar patterns whatever the cause.

The severity of skin conditions varies enormously. At one extreme, there may be nothing more than a small patch of redness on a finger resulting from sensitivity to a particular metal in a ring. At the other extreme, weeping blisters may cover an individual from head to foot, resulting in fluid loss to a degree, which may be life threatening.

Some conditions resolve, never to return, when the cause is discovered and removed, as in the case of a specific allergy, whilst others follow a relapsing course throughout life requiring long-term treatment.

Further Evidence
If disability appears to be severe a factual report from the GP or hospital may help to assess the level of need. An examining medical practitioner report may also be useful in this respect.

Care Considerations
Even when skin disease is widespread and severe, in the absence of complications, an affected adult should to a very large extent, be able to cope with any necessary treatment unaided. Local treatment of the skin itself may require the application of lotions, creams, ointments, sprays, powders, or dressings. Only when the disease affects areas of skin which the individual cannot reach or when the hands are affected is there likely to be a need for attention. Even then, this may be brief and confined to mornings and evenings only. There is unlikely to be a need to treat the skin condition during the night hours.

If skin disease is secondary to other conditions there may be additional problems that make treatment more difficult. There may also be secondary problems caused by the skin disease, or by general treatments, particularly when oral steroid preparations are used. Such additional problems may have an effect on the overall disability.
Mobility Considerations

Mobility needs may arise when the soles of the feet are badly affected, and in those rare instances where the lower limbs have to be extensively bandaged. In addition, some skin diseases, particularly psoriasis, may be associated with a widespread form of arthritis. Involvement of the joints of the lower limbs in such cases might well give rise to mobility needs.

Duration of Needs

By the time adult life is reached the skin disease may be long-standing and all available avenues of treatment may well have been explored. However, it is unusual for skin disease to be so serious that an adult is severely disabled by it for any length of time.

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Spinal Injury

Introduction
Damage to the spinal cord results in paralysis and loss of sensation below the level at which the cord has been injured; together with loss of ability to control bladder and bowels. The type of paralysis depends on the level of the injury.

Paraplegia
Paraplegia is paralysis involving both lower limbs, results from damage to the thoracic (middle) or lumbar (lower) sections of the cord. Part, or all of the ‘trunk’ may also be affected.

Tetraplegia
Tetraplegia, also called quadriplegia, is paralysis involving all four limbs. It results from damage at the cervical (neck) level. The whole trunk may also be affected.

Paraplegia resulting from other causes
The effects of paraplegia which is not of traumatic origin will depend on the cause. In conditions which, when successfully treated, do not lead to progressive disability, the care and mobility needs will be similar to those arising from traumatic paraplegia. Where paraplegia is due to progressive disease such as cancer, there will usually be progressive deterioration with accompanying high dependency on help from others.

In persons with paraplegia not due to trauma, the cause of the condition will have to be identified, since this will give an indication of the likely care needs and their duration. If further evidence on this point is required, it should be sought from the GP or from a consultant at the hospital which the person is attending.
Further Evidence
In cases in which there is difficulty in deciding the degree of a person's disability and what help is needed, a report from the spinal injuries unit with which the person has regular contact, would be helpful.

Care Considerations
Rehabilitation of the person with paraplegia depends on the person learning to transfer from bed to wheelchair or other surface at a similar level. The ability to do so requires normal function in the upper limbs. With the use of appropriate aids, the person can then swing the lower part of the trunk and lower limbs to effect the transfer. The ability to balance whilst sitting, and to lean short distances forward, background, and sideways, may also be developed during the course of rehabilitation.

Because of the loss of sensation the person is constantly exposed to a risk of damage to the skin and to the development of pressure sores. To avoid this danger they are taught to regularly change position both by day and by night.

Loss of bladder and bowel control is dealt with in various ways. Mechanical pressure exerted by the person on the lower abdomen may be used to empty the bladder at pre-determined intervals. More commonly, intermittent self-catheterisation is employed. Alternatively, in men a penile sheath may be connected to a urinal strapped to the thigh if the bladder automatically empties when it is full. Emptying of the bowel may be assisted by use of suppositories or enemas, or by manual evacuation.

A person with traumatic paraplegia who has normal function in the upper limbs would therefore usually be expected to attain a considerable degree of independence in attending to bodily functions. However, a significant amount of help may still be needed with tasks which are performed at the beginning and end of the day.

As far as night is concerned, a person who, with suitable aids, can turn in bed should be able to do so at prescribed intervals by setting an alarm. If they cannot turn unaided, attention will be required.

On occasion, a seemingly independent person does in fact require assistance. For example, repeated breakdown of the skin with the formation of pressure sores, or repeated urinary infection, may indicate that though the person appears to be coping with their own bodily functions, care is not adequate and help is required from another person.

There are factors which may prevent successful rehabilitation. The majority of persons with traumatic paraplegia are young, previously healthy and possess the considerable and sustained motivation necessary for successful rehabilitation. Older persons may lack the requisite strength
and stamina. Young people, who at the time of their accident suffer significant brain as well as spinal damage, may not be able to achieve independence. Some young people without brain damage may be unable to adjust psychologically to the radical change in their entire way of life, and in these circumstances continued assistance may be necessary.

In people with tetraplegia, the upper limbs are also weak to a greater or lesser extent, and therefore cannot be used to effect transfers from bed to wheelchair, to change position in bed, or to cope with bodily functions. People with tetraplegia will therefore require a great deal of help both by day and by night.

**Mobility Considerations**
The person with a spinal injury resulting in paraplegia or tetraplegia is unable to walk but may be an independently mobile wheelchair user.

**Duration of Needs**
Rehabilitation in respect of care needs, during which the affected person has to ‘master’ all the new tasks which have to be learned, commonly takes about two years following the injury. During the rehabilitation phase, there is likely to be a need for considerable help, at least by day. At the end of this period a well-rehabilitated person with paraplegia should be able to perform most, or all, of these tasks without the assistance of another person, although assistance may still be required with tasks at the beginning and end of the day.

The care needs of a person with tetraplegia will be ongoing.

A person with paraplegia or tetraplegia resulting from an injury which severs the spinal cord will remain permanently unable to walk.

| Spine - Injury/Fracture/Dislocation of | Paraplegia/Quadriplegia/Tetraplegia - Traumatic |

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