



HM Government

Recognised, valued and supported: next steps for the Carers Strategy:

Response to the call for views

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Executive Summary

On 28th July 2010, the Department of Health published a call for views on the key priorities, supported wherever possible by evidence of good practice, that will have the greatest impact on improving carers' lives in the next four years.

In total, 764 responses were received. The key messages from the responses were:

- carers need better and timely access to information – on the illness or condition of the person they are caring for; on appropriate caring; on accessing benefits and other support; and on financial and employment issues;
- carers can often feel excluded by clinicians – both health and social care professionals should respect, inform and involve carers more as expert partners in care;
- carers find accessing assessments overly bureaucratic and slow, and are often disappointed about the paucity of the services that follow;
- carers often feel forced to give up work to care;
- carers often neglect their own health and need advice to maintain their wellbeing;
- carers need breaks from caring in order to sustain their role as a carer;
- carers feel that the value of Carer's Allowance is inadequate, the rules around overlapping benefits are unfair and the earnings limit is a disincentive to work; and
- more should be done to identify and support young carers – in particular, schools should be more carer aware and the memorandum of understanding *Working together to support young carers* should be embedded.

Drawing on advice from the Standing Commission on Carers and on the responses received to the call for views, *Recognised, valued and supported: Next steps for the Carers Strategy* was developed and published on 25th November 2010.

This document provides an overview of the responses received.

Introduction

Carers at the heart of 21st-century families and communities, published in 2008, set out the following Vision:

'Carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.'

Over the summer, the Department of Health sought views on what the priorities over the next four-year period should be, supported wherever possible by evidence of good practice.

The call for views can be found at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleague/letters/DH_117249

Respondents were asked to outline their views under the five outcomes for carers contained in the strategic vision in the 2008 Carers Strategy:

carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;

carers will be able to have a life of their own alongside their caring role;

carers will be supported so that they are not forced into financial hardship by their caring role;

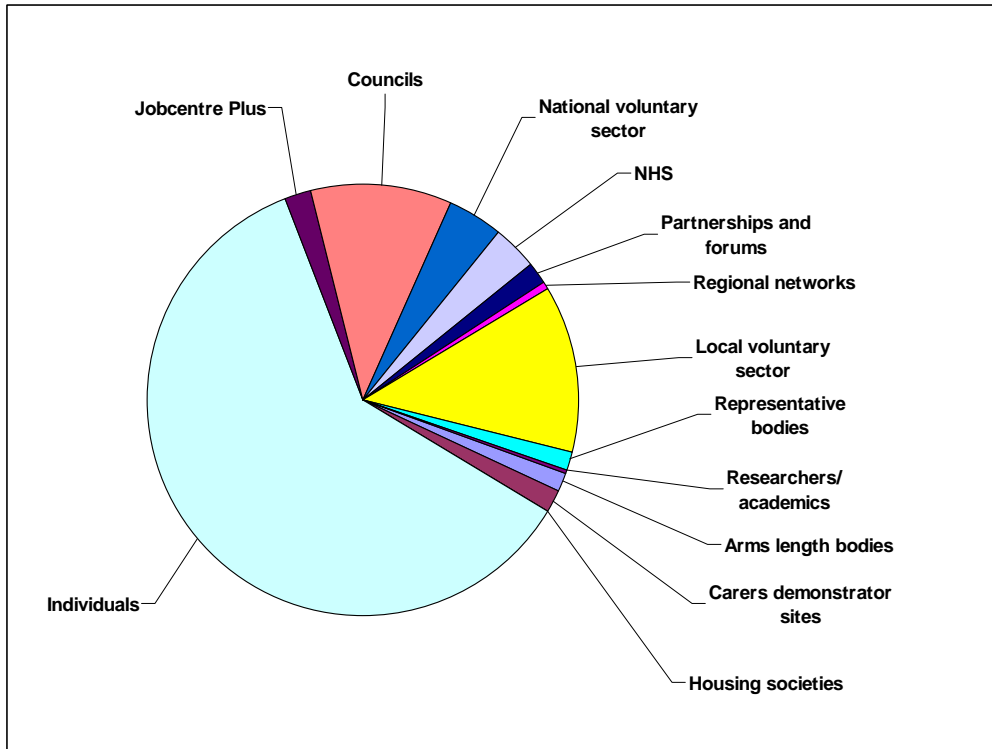
carers will be supported to stay mentally and physically well and treated with dignity;

children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.

The issue of benefits and flexible working for carers did not form part of the call for views as they are already being considered as part of the wider work on welfare reform and flexible working arrangements.

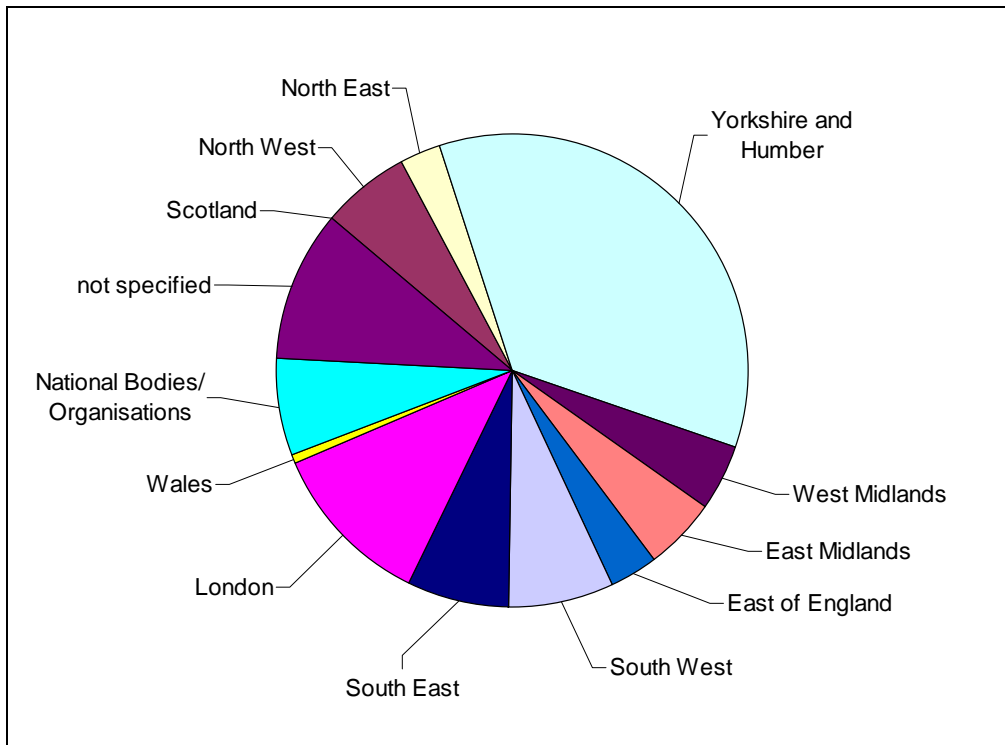
Response to the Call for Views

In total, 764 responses were received. The following chart illustrates the breakdown of individual and organisational responses.



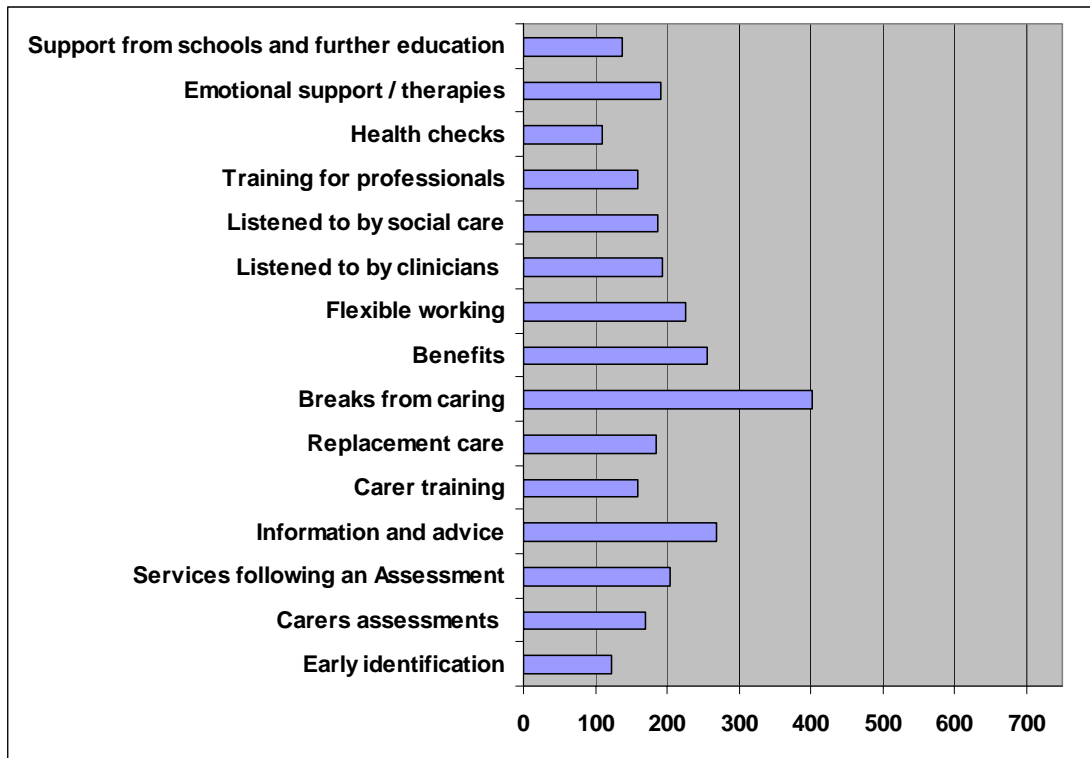
Type of respondent	Number of responses
Arms length bodies	10
Carers demonstrator sites	13
Housing society	1
Individuals	462
Jobcentre Plus	15
Local voluntary sector	97
Councils	81
National voluntary sector	31
NHS	26
Partnerships and forums	13
Regional networks	3
Representative bodies	9
Researchers/academics	3
	764

The following chart illustrates the regional breakdown of responses.



Region	Number of Responses
Scotland	1
North West	45
North East	22
Yorkshire and Humber	269
West Midlands	35
East Midlands	38
East of England	25
South West	56
South East	52
London	88
Wales	3
National Bodies/ Organisations	52
not specified	78
	764

Key themes raised in the call for views



Breaks from caring responsibilities

The theme raised most often, by over half of the respondents, is the need for breaks from caring in order to sustain carers in their role.

“There are times when I feel the need to have some time and space to myself” (quote from a carer)

Whilst the majority of responses focused on the availability of breaks, a number focused on the type of breaks on offer. In order to be beneficial, breaks need to be personalised to meet the specific needs of the carer - many felt that breaks are currently offered on a ‘one-size-fits-all’ basis.

“Respite does not always mean somewhere to send the cared for person or for respite carers to come to the home. Different people use different ways of finding respite from their caring role and this needs to be recognised and funded.” (quote from a carer)

A number of responses, particularly those about young carers, stressed the need for breaks to involve the whole family, including the person being cared for. Many felt that the provision of a break is not enough and that carers may need to be given additional support to help them to make the most of their break – for some this might be transportation, particularly for those living in rural communities, for others, socially isolated as a result of their caring role, this might be the establishment of networking events for carers.

The majority of those who had experienced a good break from caring responsibilities said that they had arranged these themselves with a direct payment.

Replacement care

Connected to breaks, 185 respondents raised concerns about the availability and quality of replacement care. Many stated that this impacts upon their ability to have a meaningful break, as replacement carers often turns up late, if at all, and plans have to be rearranged or cancelled. In particular, carers of people with challenging behaviours feel unable to take a break as paid care workers are unwilling or unable to deal with episodes of challenging behaviour and will call them as soon as they feel unable to manage.

A number of carers pointed out that the lack of reliable replacement care also impacts upon their health and their ability to work, train and carry out their caring role, as without it they are unable to attend medical appointments or do something as simple as go shopping.

“We need the feeling that we can be ill and not have to worry”
(quote from a carer)

“I am due to go in hospital soon for an operation. I am worried sick about what will happen as I can’t take my wife into hospital with me”
(quote from a carer)

A number of carers also raised concerns about councils refusing to provide replacement care when they found employment.

Information and advice

Over a third of respondents felt that there is still a lack of information, advice and advocacy available to carers. Health and social care professionals do not proactively provide carers with information on their rights or the services available to them – carers have to seek out information themselves. A number of respondents felt that social services should proactively offer carer’s assessments and do not understand why they still had to request one despite being known to social services as a carer.

“My main concern is the inordinate amount of time it takes Social Services to assess cases (this has been going on since October 2009)”
(quote from a carer)

A number of carers also raised concerns about the lack of information provided by clinicians on the treatment or care of the person that they support, confidentiality being the usual reason for withholding such information.

“There must be a balance between information and confidentiality. Confidentiality must not be used as an excuse for withholding information.” (quote from a carer)

The lack of information was often mentioned in relation to not feeling respected as expert partners in care.

“At present there seems to be a lack of information given to carers (it is almost a ‘how dare you bother me’ approach that we receive)”
(quote from a carer)

Benefits

Despite this being outside of the scope of the call for views, 255 respondents felt that benefits could not be ignored. In particular, a large number of respondents were unhappy about the rules that prevent individuals in receipt of State Pension from receiving Carer’s Allowance, as caring responsibilities do not stop at retirement.

“As soon as I took my pension the very small sum I got from Carers Allowance ceased. Why? We do the same job as before but now have to dip into our savings without any support from the Government”
(quote from a carer)

In addition to this, there was a general dissatisfaction with the value of Carer’s Allowance and the inflexible earnings limit. A number of respondents said that the £100 earnings limit is a disincentive to work and wanted to see the reduction in Carer’s Allowance, as a result of employment, tapered.

“I have never met a carer who was not hard up” (quote from a CAB adviser)

Flexible working

Similarly, a number of respondents felt that they could not ignore flexible working, despite this also being outside of the scope of the call for views – 225 respondents raised this issue. Whilst the majority welcomed the Government’s efforts to encourage flexible working, many felt that there should be a legal duty on employers to provide it. A number of carers felt that they had been forced to give up work and said that they would not have done so had the support and information been available to them when they took on their caring responsibilities.

“I would not have given up my previous job to become a full-time carer for my mum-in-law had I realised the lack of support available in my area”
(quote from a carer)

“It has been indicated by Social Services that I need to find a way Peter will be cared for while I go to work. In other words, I am being asked to give up my job as a nurse and care for Peter. I find this very unfair and not right.”
(quote from a carer)

Those that receive support felt it invaluable and did not feel that they would be able to continue to work without it.

“I find support from agencies allows me more time myself and I do not feel caring as a burden when I can delegate. I am working full time and have a family so this support is essential” (quote from a carer)

Services for carers and the people they care for

Some 204 respondents raised concerns about the services that are available to carers following an assessment. Issues were raised about the paucity of such services and the length of time that it takes to access them following an assessment.

“Another problem for carers is the person they care for being assessed as needing a service and then being put on an indefinite waiting list.”
(quote from a carer)

“Many carers are confused by the apparently uncoordinated support they receive from various organisations. There also tends to be a lack of a personal touch. A more local front line support at GP practices would offer a more personalised, cost-effective and focused service.”
(quote from a carer)

There was overall support for personal budgets, and direct payments in particular, from those that received them.

“Since my daughter started receiving direct payments life has been a lot better for both of us. She is a lot happier and has more interests as she now has paid carers to take her out, which in turn gives me a life of some sort.”
(quote from a carer)

However, a number of respondents raised concerns about the level of contribution that carers are expected to make and that the payments that they receive fall short of the cost of services. Concerns were also raised about the additional responsibilities that come with employing a personal assistant.

Respondents felt that the use of equipment or assistive technology (telehealth and telecare) could not only make the carer’s job easier and safer, but also prove good value for money in allowing carers to have a life outside of caring without the need for replacement care.

Carers’ assessments

170 respondents also raised concerns about carer’s assessments, feeling that the process is too long and overly bureaucratic.

“The assessment process takes far too long so the support is not provided at the time when it is most urgently needed.”

(quote from a Multiple Sclerosis Society carer)

“The system is completely oblivious to the impact the slow referral and assessment systems have on the lives of those it is set up to help and their carers. The system appears to create dependency, as carers are forced to give up work due to lack of support and take on the full-time carer’s role.”

(quote from a carer)

A number thought that carer’s assessments should be offered and carers should not have to request them. Others felt that the assessments currently on offer are too narrow and should be broadened to cover advice on benefits and employment.

“... many carers want to work for financial reasons but are unaware of the help available and often no other agencies engage with carers about their work options as this is not their area of expertise”

(quote from South Wales Valleys Jobcentre Plus)

Concerns were also raised about the disjunction between multiple assessments, both in respect of separate assessments for the carer and the person being supported, and when there is more than one disabled person in the family.

“Having to repeat the same details to different agencies is weakening, wasteful of time and unnecessary in these days of computerised records”

(quote from a carer)

One respondent who has two disabled children described how she was assessed twice, once for each of child.

Recognition by health and social care

Some 194 of those who responded did not feel that clinicians listen to them, and 188 respondents did not feel listened to by social care professionals. Carers feel frustrated that their contribution is not valued but also that care could be improved by the knowledge and experience that the carer has gained in their caring role.

“I do everything to care for my husband at home yet when he goes into hospital, I am just the wife!” (quote from a carer)

“Carers are part of the Health and Care Team and should be respected for their knowledge of the patient and listened to” (quote from a carer)

In particular, many feel that their exclusion from clinical discussions makes discharge from hospital more likely to fail.

“If only the health professionals at hospitals would realise that carers are the linchpin of any care plan.” (quote from a carer)

“Patients are too frequently discharged early simply because they have a family member to act as the carer, with the carer being bullied into taking the patient home, being told that they MUST do so.”

(quote from a carer)

Of those who felt excluded from clinical and social care discussions, the majority felt that health and social care professionals need additional training to make them ‘carer aware’.

Carers’ health and well-being

A quarter of those who responded were concerned about the additional stress put on carers as a result of their caring responsibilities and called for emotional support and other therapies to be made available.

“The mental and emotional support I received saved my sanity and the use of direct payments gave me a little ‘me time’. My GP has been very supportive and treats me as an ‘expert’ in my wife’s care.”

(quote from a carer)

A number of responses cited evidence of carers suffering disproportionate levels of poor health and felt that health checks should also be available to carers.

“GPs and their staff need to be encouraged to recognise that they have just as much a responsibility to attend to carers as they do for the cared-for”. (quote from a carer)

A couple of respondents commended their GPs for providing more flexible appointment times for carers, whilst others were disappointed that such services were not available to them.

“I had really good support from my GP service once I kept mentioning that I was a family carer – they opened up more convenient appointment times, and made sure I was receiving the health screening and checks that I should. However, I had to know that I was flagged as a carer, and had to remind the staff – gently.” (quote from a carer)

Carers’ training

A total of 158 respondents wanted better access to training; for many, this is training to assist them in carrying out their caring role effectively and safely. Other responses, however, highlighted other training needs, particularly around helping them to return to work and developing skills with training being a way of taking a break.

“I now have difficulty in finding employment to transfer my skills and experience to – why? – because for example my training in managing projects is out of date and I don’t have the newly recognised qualifications”. (quote from a carer)

Early identification

The early identification of carers was raised by 123 respondents, with many feeling that this is a responsibility wider than just health and social care. In relation to young carers, a number of respondents felt that schools should do more to identify and support young carers. A number also felt that more needed to be done to reach out to individuals in particular communities, including ethnic minority communities, where caring is seen as part of their family responsibilities.

“There is a problem with the term ‘carer’ as many people feel [they] are not carers – they are just doing what you should do for another family member. If labels can be avoided that would help.”
(quote from a carer)

Conclusion and next steps

The Department is grateful to respondents for their views on what the Government's key priorities should be over the next four years.

Recognised, valued and supported: Next steps for the Carers Strategy was published on 25th November 2010.

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_122106.pdf

On 25th November, emerging evidence on effective early intervention in identifying, involving and supporting carers was also made available in *Carers and personalisation: improving outcomes*:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_122107.pdf

Social Care Institute for Excellence (SCIE) will gather further examples for inclusion in their Good Practice Framework.

Annex A – List of respondents

Association of Directors of Adult Social Services North West Carer Leads Network	Carers Council
Association of Directors of Adult Social Services/Local Government Association	Carers Counselling Project
Adfam	Carers First, Layland
Admiral Nurses	Carers First, Tonbridge
Adult Mental Health, Warwickshire County Council	Carers Gloucestershire
Age Concern Leeds	Carers in Hertfordshire
Age Concern Warwickshire	Carers Leeds
Age UK	Carers LINK, Accrington
Alzheimer's Café	Carers Milton Keynes
Alzheimer's Society	Carers Network, Westminster
Ascot CBT for Carers Group	Carers Northumberland
Association of Palliative Medicine	Carers Sandwell
Barnardos	Carers Sitting Service, Derbyshire
Barnet MENCAP	Carers Support Centre, North Lincolnshire County Council
Barnet Strategy Partnership Board	Carers Together in Redcar & Cleveland
Barnsley PCT	Carers UK
Bath and North East Somerset Carers Centre	Carers Wakefield and District
Bedford Borough Council	Carerwatch
Birmingham and Solihull Mental Health NHS Foundation Trust	Central & North West London NHS Foundation Trust
Birmingham County Council	Central Bedfordshire Council
Blaby District Carers Forum	Challenging Behaviour Foundation
British Medical Association	Challenging Behaviour National Strategy Group
Bolton Care4	Cheshire East Carers' Inter-agency Strategy Group
Bolton Carer Demonstrator Site Project	Churchdown Carers Group, Gloucestershire
Bournemouth & Poole Carers	Cirencester Eating Disorders Self Help Support Group
Bournemouth & Poole LA/NHS	City of York Council
Bradford Direct Care Trust	Colebrook Housing
Bradford Metropolitan Borough Council	Connect in the North
BRAME	Contact A Family
Brighton and Hove Carers Centre	Conwy County Borough Council
Bristol Area Stroke Foundation	Cotswold Care Hospice
Bristol Princess Royal Trust for Carers	Counsel and Care
British Association of Paediatric Surgeons	Coventry Carers Centre
Bromley Carers Organisations Group	Crossroads Care
Brunel Medical Practice	Cumbria County Council
Buckinghamshire County Council & NHS Buckinghamshire	Darlington Borough Council
Burnley Council for Voluntary Service	De Montford University, Leicester
Bury Council	Derbyshire County Council/NHS Derbyshire County
Calderdale Council	Devon County Council
Cambridgeshire County Council	Devon Carers Demonstrator Site
Cambridgeshire Crossroads	Dorset NHS
Capita/NHS Choices	Dudley Carers Network
Care Quality Commission	Dudley Metropolitan Borough Council
Carers Ashford	Durham County Council
Carers Bromley	Ealing Carers Strategy Group
Carers Centre Hull	East Riding of Yorkshire Council

East Sussex County Council Carers
Demonstrator Site
Eastbourne District MENCAP
EDP Drug and Alcohol Services
Emergence Plus
Employers for Carers
Emu Evaluation Research
Enfield LINK
Equality 2025
Essex County Council
Family Tree, Wirral
Federation of Irish Societies
Flintshire Carers
Foundation for People with Learning
Disabilities/Mental Health Foundation
Friends of Chiswick Health Centre
Gateshead Carers Association
Gateshead Crossroads
Genetic Alliance
Gloucestershire Chinese Womens Guild
Gloucestershire County Council
Guideposts Trust, Watford
Halton Local Authority
Hampshire County Council
Haringey Council
Haringey Federation of Residents
Associations
Health Mirror Group
Hertfordshire Council Carers Demonstrator
Site
Hertfordshire County Council
Hull County Council
Inclusion North
In-Control
Isle of Wight Council
Islington Carers Centre
Islington Council
Jobcentre Plus Derby
Jobcentre Plus East of England
Jobcentre Plus Leicestershire and Northants
Jobcentre Plus Lincolnshire and Rutland
Jobcentre Plus London
Jobcentre Plus North East
Jobcentre Plus North West
Jobcentre Plus Nottinghamshire
Jobcentre Plus Products and Transformation
Jobcentre Plus Scotland
Jobcentre Plus South East
Jobcentre Plus South Wales Valleys
Jobcentre Plus South West
Jobcentre Plus West Midlands
Jobcentre Plus Yorkshire and Humber
Joe's Club
Kent County Council
Kirklees Council & NHS Kirklees
Lambeth Council
Lancashire County Council
Leeds City Council
Leeds Partnership NHS Foundation Trust
Leicester City Council
Leicestershire County Council
Leicestershire Learning Disability Partnership
Board
Lincolnshire County Council
Liverpool Carers
Liverpool Carers Centre
Lives Unlimited
London Borough of Barnet
London Borough of Camden
London Borough of Haringey
London Borough of Harrow
London Borough of Hounslow
London Borough of Sutton
London Borough of Tower Hamlets
London Mental Health Carers Advisory
Group
Luton Borough Council
MacMillan Cancer Support
Maidenhead Princess Royal Trust for Carers
Maidstone and Malling Carers Project
Making Space, East of England
Manchester City Council
Markfield Project, London
McMillan Speech and Language, Sunderland
Royal Hospital
Meadowbrook Carers Group, Salford
Mencap
Middlesbrough Council
Motor Neurone Disease Association
Multiple Sclerosis Society
National Council for Palliative Care
National Family Carer Network
National Institute of Adult Continuing
Education (NIACE)
National Mental Health Development Unit
(Acute Care Programme)
National Mental Health Development Unit
(Equalities Programme)
National Valuing Families Forum
National Young Carers Coalition
Norfolk Drug and Alcohol Partnership (N-
DAP)
North East Department of Health
North East Lincolnshire Care Trust Plus
Newcastle City Council
Newham Carers
NHS Barnsley
NHS Bristol
NHS Cambridgeshire
NHS Gloucester

NHS Leeds
NHS Mid Essex
NHS Northamptonshire Carers Demonstrator Site
NHS Redbridge Carers Demonstrator Site
NHS Rotherham
NHS Sheffield
NHS SW Essex Carers Demonstrator Site
NHS Swindon and Swindon Borough Council
NHS Tameside and Glossop PCT
Norfolk Young Carers, Crossroads
North East Princess Royal Trust for Carers
North Lincolnshire Carers Advisory Group
North Lincolnshire Council
North Somerset Council
North West Leicestershire Carers Project
Northamptonshire Carers
Northumberland Care Trust
Norwich Carers Forum
Nottingham City Council and Nottingham NHS
Nottinghamshire Council Carers Demonstrator Site
Nottinghamshire County Council
North West Leicestershire Carers Project
Oasis Centre
Oldham Princess Royal Trust for Carers
Oxford Carers Centre
Oxfordshire Carers Forum
Oxfordshire County Council
Oxfordshire County Council (Diversity Team)
Paignton Carers Group
Parkinson's UK
People First (Self Advocacy)
Portsmouth County Council
Walsall Princess Royal Trust for Carers
Princess Royal Trust for Carers
Royal College of General Practitioners
Reading Carers Group
Redbridge Council
Redcar and Cleveland Carers Partnership
Rescare
Rethink
Richmond County Council
Richmond MIND
Rochdale Metropolitan Borough Council
Rotherham Metropolitan Borough Council
Royal Borough of Kensington and Chelsea
Royal Borough of Windsor and Maidenhead
Royal College of Nursing
Sandwell PCT
Social Care Institute for Excellence
SE Regional Carers Network
Sefton Carers Group, Making Space
Sefton Carers Strategy Group
Sheffield Carers Centre
Shropshire County Council
Skills for Care
Skills for Health/Skills for Care
Slough Borough Council
Solihull NHS Care Trust and Solihull Council
Solihull Carers Centre
Solihull NHS Trust
Somerset County Council
Soundwell Music Therapy Trust, Bath
South & Vale Carers Centre, Oxfordshire
South Gloucestershire Council
South Tyneside Local Authority
Southampton Carers Strategy Group
Spurgeons
St Catherine's Hospice, Surrey/Sussex
St George's University and Kingston University
St Helen's Council
St Helen's Mental Health Carers
St John's Ambulance
St Richard's Hospice, Worcester
Stockport Council
Stockton Borough Council
Stockton LINK
Stoke on Trent City Council
Suffolk County Council
Suffolk Family Carers
Sunderland Carers Centre
Sunderland City Council
Surrey County Council
Sussex Partnership NHS Foundation Trust
Sutton Borough Citizens Advice Bureau
Sutton Carers Centre
Sutton Carers Support Group – Learning Disabilities
South West London and St Georges Mental Health Trust
Tameside Metropolitan Borough Council
Telford Carers Contact Centre
Telford Council
The Afiya Trust
The Carer's Resource, Harrogate
The Children's Society
Uniting Carers at Dementia UK
Voluntary Action Charnwood
Wakefield Council
Wandsworth Carers Centre
Warkwickshire County Council
Warrington Borough Council
Warwickshire County Council
West Sussex Carers Implementation Group
Wokingham Learning Disability Partnership Board
Wokingham MENCAP

Worcestershire County Council
York Carers Centre
Yorkshire and Humber Later Years Group,
Age UK
Young People's Learning Difficulties and/or
Disabilities Team