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30 April 2012

Dear Sir or Madam,

Department of Work and Pensions – Personal Independence Payment thresholds and assessment consultation

Parkinson's UK welcomes the opportunity to respond to this important consultation.

With the consultation revealing that there will be half a million less working age disabled people receiving Personal Independence Payment (PIP) than currently receiving Disability Living Allowance (DLA), there is huge anxiety caused by these reforms amongst people with Parkinson's. The question on everyone's lips is "will I lose my DLA"? Despite the Secretary of State for Work and Pensions stating the genuine sick and disabled have "nothing to fear" from the reforms¹ it is incredibly difficult to determine who the Department of Work and Pensions has in mind when it says that PIP will be targeted at those with the "greatest needs".

Someone with Parkinson's who qualifies for DLA should qualify for PIP. This is a long term, degenerative condition with no prospect of getting better unless a cure is found. We are determined that the 8,800 working age people with Parkinson's who receive DLA should also be able to access PIP, mirroring as closely as possible the rates and components they receive under DLA.

Our response is based on publicising and discussing the criteria with those affected by Parkinson's who receive DLA and Parkinson's UK helpline staff and Information and Support staff who help people with Parkinson's access DLA at a local level.

¹ Speech by Iain Duncan Smith, Conservative Party Conference, 5 October 2010.

We also undertook a survey of people with Parkinson's to find out what aspects of the condition DLA funding supports and their views on the proposals. 124 people responded to the survey. **78% of people with Parkinson's we surveyed were "seriously worried" about how the changes will affect them².** It is distressing to read some of the free text responses: some people stating that life would not be worth living if they lost their DLA and could not access PIP.

Key recommendations in this response

Our main concerns lie with the proposals for medication, for mobility, and the omission of domestic descriptors. As it stands we do not believe that the structure would be able to comprehensively identify those whose abilities are limited or severely limited by their Parkinson's.

General recommendations

- **We urge the Department of Work and Pensions to provide more caseload analysis of who is most likely to have their benefit withdrawn due to the reforms. The Department must have "in mind" who will be the winners and losers from the testing that has been undertaken and this should be revealed.**
- **Using the precedent of ESA in allowing for discretionary award where someone does not meet all the tests, a new non-functional descriptor should be created for PIP, allowing the decision maker the discretion to award PIP daily living or mobility (or both) if by reasons of the persons mental or physical condition there would be a substantial risk to their quality of life if not found eligible for PIP. This would need detailed discussion and design.**
- **If PIP criteria provide a proxy on an individuals ability to participate and their potential extra costs then it is vital that there is a criteria for "maintaining the domestic environment" for PIP to have any credibility with people with Parkinson's.**
- **Activities must be described to safe completion; there should be a published rationale for weightings; there should be unambiguous language and defined times for descriptor completion; there is a need to be consistent on supervision and assistance which can equate to similar costs; and there must be recognition that disabled people rely more heavily on "ordinary" aids and appliances and everyday objects.**

Specific activity/regulatory comments

² The remainder of those responding to the survey were worried, but said they would find a way to cope, or did not know how it would impact on their quality of life.

- **Activity 1:** This activity should be reworded as: *the ability to prepare a simple cooked meal and make a hot drink* and the descriptors reworded accordingly listed in all descriptors. If someone can do one part of the descriptor but not the other that should count as not being able to do the descriptor at all.
- **Activity 1:** Descriptor F should score 8 points. It should recognise that for someone who has to have help, or cannot feed themselves at all the consequences are the same ie. could lead to admission to hospital through dehydration or malnutrition.
- **Activity 2:** A person may still be able to convey food and drink to their mouth but a new descriptor to reflect the risk of choking should be included: *Needs supervision when taking nutrition – 8 points*
- **Activity 3:** We believe that the scoring system should better reflect a person's need for medication, for instance by allocating a higher score to individuals where there are significant medicines management issues to be addressed of at least 4 points. Different descriptors could be created for those who can manage significant medication on their own, with the use of aids and appliances or with the help of someone else with additional scoring to reflect this.
- **Activity 4:** This criteria should score higher given the importance of personal care and hygiene to someone's self esteem. It should include shaving, drying and footcare. Someone who needs assistance to bathe and groom should score 8 points.
- **Activity 5:** this criteria should be clear that incontinence pads and incontinence wear are aids/collecting devices.
- **Activity 6:** this criteria should include someone's need for supervision when dressing and undressing and should allow someone who cannot dress their upper/lower body to score higher number of points.
- **Activity 7:** this criteria should include points for difficulty or inability to write, problems with vocalisation and word recall.
- **Activity 8:** this activity should be reworded to encompass the disabling distress and anxiety that can come from a having a physical condition and symptoms that may cause social embarrassment and accrue points accordingly.
- **Activity 9:** this activity should include supervision criteria and provide for higher scores given the impact it can have on daily living.

- **Activity 10:** The descriptors should feature scores for needing assistance from another person. The activity should recognise that physical conditions as well as mental conditions can lead to anxiety, loss of confidence and therefore the need for support. These may not be classed as "overwhelming psychological distress" but can be just as inhibiting to the individual.
- **Activity 11:** Descriptors throughout should be amended to state: "Cannot move repeatedly, reliably or safely up to x metres either unaided or using an aid or appliance or without encountering severe discomfort, pain and fatigue."
- For someone who cannot move 50 metres without encountering severe discomfort, pain or fatigue they should score 12 points and therefore higher rate mobility.
- All mobilising activities should also list what average times taken should be over the distances given so people can assess whether they can do so in a "timely fashion".
- The "some stage in the day" proviso is crucial and very welcome. We feel it is vital that there is an explicit prompt in each criteria to ensure people think about the times in the day they cannot undertake the tasks listed and apply these scores.
- We believe that the assessment must reflect cumulative impact of a condition and there should be a "non functional" descriptor (as noted in our response above) to reflect upon the risks to quality of life raised by a person's condition. This would be a safety net for those who do not meet the narrow criteria on 50% of days but whose condition is all pervading over their lives.
- We think that careful consideration should be given to how people can evidence the rules around fluctuations and impact on 50% of days as a year's estimate will be almost impossible to recall or estimate for most people. We suggest that a shorter proxy period will need to be considered in terms of being most helpful to individuals as well as decision makers.
- It is vital to repeatedly state "reliably, repeatedly, safely and in a timely manner" in the regulations and the criteria. However we also believe there should be a prompt on the face of each activity otherwise there is a danger this will be overlooked.
- We believe notification of an interview should be a minimum of 21 days and that matters outside of the control of the claimant should include delays in provision of medical information from healthcare professionals.

Full response

About Parkinson's

It is estimated that 127,000 people in the UK have Parkinson's. Parkinson's is a progressive, neurological disorder, with no known cure. The three main physical symptoms associated with Parkinson's are tremor, muscle rigidity and slowness of movement. However, not everyone will experience all three.

There is also a long list of commonly occurring non-motor symptoms, which may or may not occur at different points throughout the course of Parkinson's. These include sleep disturbances, difficulties with balance, incontinence, problems with altered posture, tiredness, speech difficulties, pain and mental health problems such as dementia, hallucination and depression.

Treatment of Parkinson's is largely made up of medication to replace, enhance or facilitate the production of dopamine within the brain. However, all classes of Parkinson's drugs are associated with significant side effects which in themselves can require management. In addition to drug management there is significant benefit to be gained by therapy intervention such as physiotherapy, speech and language, occupational and psychological therapies.

Parkinson's affects people from all social and ethnic backgrounds and age groups. The average age of onset of Parkinson's is between 50-60 years of age, though one in seven will be diagnosed before the age of 50 and one in twenty will be diagnosed before the age of 40.

As a progressive, neurological condition, the severity of Parkinson's symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden 'freezing'.

As well as consulting with people affected by Parkinson's and our advisory staff, the response also draws on our work on the Work Capability Assessment (WCA) including Parkinson's UK research³ and submissions to DWP consultations including Professor Harrington's review. We were also invited to take part in a review of the WCA, chaired by the MS Society, specifically looking at how the WCA could be improved for people with fluctuating conditions including Parkinson's. As a points based system based on impact of functional impairments, PIP is shaping up to be something very similar to the WCA.

Parkinson's UK is also a member of the Disability Benefits Consortium (DBC). We support the DBC's submission to this consultation and would urge the DWP to consider this consolidated response from the disability sector.

³ *Of Little Benefit and Not Working: people with Parkinson's experience of Employment and Support Allowance* (Parkinson's UK, Oct 2009)

http://www.parkinsons.org.uk/pdf/esareport_october2009.pdf

Why do people with Parkinson's use DLA?

As part of our survey for this consultation we asked people with Parkinson's whether it affected their ability to carry out daily activities? **98.4%** said yes, it did.

The main symptoms people reported as affecting their daily activities were:

- Slowness of movement (84.5%)
- Handwriting problems (82.8%)
- Dexterity (eg. using a computer, getting dressed) (80.2%)
- Painful muscle cramps and spasms (72.4%)
- Difficulty sleeping at night (71.6%)
- Tremor (70.7%)
- Bladder and bowel problems (67.2%)
- Daytime sleepiness (64.7%)
- Speech and communication problems (62.9%)

Over half of respondents also reported anxiety, depression, difficulty with concentration, falls and dizziness, rigidity, and mild memory problems while less common (but still affecting 1 in 5 respondents or more) were issues such as freezing, excessive sweating, hallucination, eye problems, impulsive and compulsive behaviour. Less commonly reported were issues with swallowing, drooling, choking and nausea.

68.6% of respondents said there was a big difference between their "best" and "worst" times with 1 in 10 saying this could happen 10 times on a typical day. - More commonly 53% of respondents said their symptoms fluctuated between best and worst 2 to 4 times a day. In addition nearly half of people (47.5%) said they'd only had a few days within the past three months where they could really say they felt at their best. -

Additional spending requirements due to Parkinson's -

Parkinson's UK received over 13,000 responses to its members survey in 2007. Key findings were that over half of respondents (54%) felt that they had additional spending requirements due to the condition. These are listed below: -

| Additional cost | % of all respondents with extra costs |
|-------------------|---------------------------------------|
| (1) Domestic Help | 27 |

| | |
|-----------------------------------|----|
| (2) Mobility/ transport | 19 |
| (3) Heating | 19 |
| (4) Laundry | 12 |
| (5) Aids and appliances | 11 |
| (6) Incontinence supplies | 10 |
| (7) Additional insurance premiums | 8 |

DLA uses

600 people with Parkinson's took part in a Disability Benefits Consortium survey⁴ in 2010 and over 300 who responded used DLA and described the "top three" things they used their DLA for.

| DLA used for | % of DLA user responses |
|-------------------------------------|--------------------------------|
| Paying bills, eg electricity, water | 47.6% |
| Transport (excl Motability scheme) | 42.8% |
| Support/help from someone | 42.8% |
| Motability scheme | 40.9% |
| Buying essentials | 34.5% |
| Food | 28.4% |
| Health treatment | 25.9% |
| Mobility aid | 22.0% |

In our survey of 2012, although there were less respondents, when asked about the top three things DLA pays for, the answers were very similar.

| DLA used for | |
|-------------------------------------|-------|
| Paying bills, eg electricity, water | 42.3% |

⁴ See Benefitting Disabled People? (2010) Disability Benefits Consortium. 6000 disabled people responded. This data was derived from the unpublished detailed survey results on respondents with Parkinson's. <http://www.disabilityalliance.org/dbcreport.htm>

| | |
|--|-------|
| Transport (excl Motability scheme) | 36.9% |
| Support/help from someone | 36.0% |
| Motability scheme | 35.1% |
| Food | 32.4% |
| Buying essentials | 25.2% |
| Mobility aid | 25.2% |
| Home adaptations | 23.4% |
| Activities such as yoga, gym, to maintain independence | 20.7% |
| Health treatment | 18.9% |
| Prescriptions | 16.2% |

In conclusion DLA pays for a real spread of essentials that come with living with a condition like Parkinson's – **paying bills, along with transport costs, and personal support and help.** Food, other essentials, mobility aids and health treatment also feature prominently.

DLA is the difference between a reasonable life, and no life

Respondent to our survey

It can be seen from these responses that DLA meets needs that are often overlooked by statutory services, and in the current climate are subject to rationing and cuts. DLA provides a crucial role in helping people to remain independent and stop their condition and personal circumstances deteriorating. In England, DLA is also useful to pay for prescriptions which are not free for many working age people.

In all the responses we have had to these proposals a consistent theme has been the “preventative” role that DLA performs, helping people to cope with the challenges that Parkinson's brings, avoiding relying too heavily on family or local services.

How many people with Parkinson's receive DLA?

Overall around 8,800 working age people with Parkinson's receive DLA, with another 10,000 people with Parkinson's continuing to receive it after 65.

Of this 8,800 caseload, people can receive either or combinations of care and mobility elements (and therefore figures will not add to this total). Around 6,500 working age people with Parkinson's get the high rate DLA mobility, while 4,000 working age people with Parkinson's receive the high rate of DLA care. For those on lower rate mobility (400), middle rate care (2,700) and lower rate care (2,000) who live with this condition it remains absolutely vital they continue to receive the help they need.⁵

It is interesting to note that the our PIP survey response mirrored this caseload, with 75% of respondents reporting they were on high rate mobility, 41% on high rate care, 28% on middle rate care and 24% on lower rate care.

How many people with Parkinson's will receive PIP?

We note that no breakdown by condition is given in the Government figures on estimated caseload for PIP.

Therefore it is very hard to identify who will lose their DLA and be unable to access PIP under the proposed criteria. As the Work and Pensions Committee⁶ commented:

"We are unable to ascertain, from the latest figures released by DWP in January, from which DLA rate combinations the projected PIP caseload reduction of 500,000 claimants will come and therefore which current DLA recipients are likely to have their benefit withdrawn altogether. We recommend that, in its response to this Report, DWP sets out further case studies to show how the introduction of PIP is likely to affect current working-age recipients of each rate combination of DLA."

At the most the figures released in the consultation document give some indication on how caseloads at different combination rates may change. We are very concerned that those on the lower rates seem to be the obvious targets for these cuts.

Moreover the Joint Committee on Human Rights⁷ has highlighted the lack of impact assessments on the potential wider impact of 500,000 disabled people losing their DLA support. So far the Department of Work and Pensions have not answered questions about potential costs: to the NHS, to councils and to out of work benefits (if both individuals or their carer has to give up work).

⁵ All of these figures are derived from Department of Work and Pensions, Tabulation Tool. Cases in Payment (5% sample). Disability Living Allowance (August 2011) http://83.244.183.180/5pc/dla/disabled/age/a_stock_r_disabled_c_age_aug11.html This data is for Great Britain only.

⁶ See Work and Pensions Committee (2012) 7th report - Government support towards the - additional living costs of working-age disabled people <http://www.publications.parliament.uk/pa/cm201012/cmselect/cmworpen/1493/149302.htm>

⁷ See Joint Committee on Human Rights. Implementation of the rights of disabled people to independent living (2012). <http://www.publications.parliament.uk/pa/jt201012/jtselect/jtrights/257/25702.htm>

Without the financial support for taxis to work I would not be able to stay in my current job. I was out of work for eight months before finding this job when my Parkinson's was only just becoming evident. I don't hold out much hope of getting another job should I have to leave this one if I lose my DLA.

Respondent to our survey

Recommendation: We urge the Department of Work and Pensions to provide more caseload analysis of who is most likely to have their benefit withdrawn due to the reforms. The Department must have “in mind” who will be the winners and losers from the testing that has been undertaken and this should be revealed.

General comments on the criteria, weighting and thresholds

The consultation invites general comments on the second draft criteria – in particular on the changes made in the November 2011 version, the proposed weightings and the entitlement thresholds. We offer these general comments at the outset and specific questions are responded to below.

Introduce a new non-functional “quality of life” descriptor

We believe a points based system may help people understand the criteria for PIP more so than DLA, and so the basis for an appeal if they think their assessment is wrong. However the danger is that people are “pigeon holed” according to 11 basic tests. Should they not fit the criteria they will slip through the net. Or it could be the case if people with a fluctuating condition are affected for less than 50% of days but still have severe episodes of illness.

For example, sleep disturbance and nighttime care needs were mentioned regularly by people with Parkinson's as having a massive impact on life but is unconsidered in the draft PIP criteria. It leads to consequences, for example people needing more assistance in the night, for someone to supervise or assist if someone is at risk of falling if they get up to go to the toilet. It also leads to daytime fatigue.

The inability to see the “big picture” has been the experience of the Work Capability Assessment for Employment and Support Allowance which is a crude set of functional tests.

However the ESA does set an important precedent for PIP in that it recognises there will be people who don't meet criteria for a benefit but would do so based on “non functional” considerations.

ESA decisions can and are made on the basis of risk to the person's health if they are found "fit to work" or "fit for work related activity". For example, people can be considered for entry to the Work Related Activity Group (WRAG)⁸

"A claimant who does not have limited capability for work as determined in accordance with the limited capability for work assessment is to be treated as having limited capability for work if...he claimant suffers from some specific disease or bodily or mental disablement and, by reasons of such disease or disablement, there would be a substantial risk to the mental or physical health of any person if the claimant were found not to have limited capability for work"

Sadly decision makers rarely use this rule in their initial decision although tribunals do. We are taking this up separately in our campaigns.

However, the precedent set by ESA exists and we strongly recommend in PIP there should be a "non functional" quality of life test which is applied by the decision maker **only** if someone does not meet the criteria for daily living or mobility PIP.

The Unified Parkinson's Disease Ratings Scale⁹ reveals the many facets of Parkinson's and the impact that they can have on quality of life. These range from sleep disturbance, to dizziness, nausea, pain and fatigue.

Quality of life considerations for Parkinson's should include:

- clinical rating of the severity of the condition
- prognosis and progression of the condition
- pain
- fatigue
- nausea
- sleep disturbance
- side effects of medication
- length of time when symptoms are under poor control
- predictability of symptoms

⁸ Regulation 29(2)(b) of the Employment and Support Allowance Regulations 2008
<http://www.legislation.gov.uk/ukxi/2008/794/part/5/made>

⁹ Unified Parkinson's Disease Rating Scale can be found at
<http://www.mdvu.org/library/ratingscales/pd/updrs.pdf>

- involuntary or sudden loss of functions

It's not just one problem, it's all the little problems totalled up. I can still do most things but virtually everything is more difficult, time consuming and tiring than it used to be. Often I have to stop and rest. Sometimes I find it extremely difficult to do something I found relatively easy the day before and vice versa. It's so debilitating and frustrating, people who have never experience this cannot possibly understand what it is like or the devastating impact it has on everyday life.

Respondent to our survey

Recommendation: Using the precedent of ESA in allowing for discretionary award where someone does not meet all the tests, a new non-functional descriptor should be created for PIP, allowing the decision maker the discretion to award PIP daily living or mobility (or both) if by reasons of the persons mental or physical condition there would be a substantial risk to their quality of life if not found eligible for PIP. This would need detailed discussion and design.

Introduce domestic activity descriptors

Despite the clear efforts that have gone into amending the criteria from the first draft, and some welcome changes, we remain concerned that the key drivers of extra disability related costs in daily living are not captured by the 9 "daily living" activities listed.

We understand that it is not possible to consider every area where individuals face barriers or where extra costs would occur, and that the Department are operating a principle where the same measure of ability isn't counted twice.

However, every survey of DLA we have undertaken, and indeed the DWP's own research is clear about DLA's use in keeping ones environment safe, warm and clean. In fact the DWP research¹⁰ found that for both DLA and Attendance Allowance, personal care was often provided informally and the benefits were being used to cover domestic financial costs.

For many DLA and AA recipients, managing daily living also depended on finding solutions and working out ways of doing things which reduced the amount of direct help they needed, and enabled them to maintain control and some independence. Life was managed by being able to afford

¹⁰ The impact of disability living allowance and attendance allowance: findings for exploratory qualitative research (DWP 2010)
http://research.dwp.gov.uk/asd/asd5/report_abstracts/rr_abstracts/rra_649.asp

market prices for housework, laundry, garden maintenance, odd jobs and taxi rides; by buying frozen meals or buying hot meals outside the home; by relying on frequent use of telephones, and by running private vehicles.

People with Parkinson's often say all their energies have to be devoted to themselves and keeping as well as they can do, at the expense of household tasks which they have no remaining energy for such and indeed where it would be risky for them to undertake these activities.

The danger with the criteria as they stand is that someone who can maintain their own cleanliness and health scores "0" points when all else is neglected. Costs then build up to the individual and puts them at risk (for example the house gets cluttered, the kitchen becomes unhygienic, repairs can't be afforded).

We recall that the policy objective for DLA reform¹¹ is to ensure that "PIP will support disabled people to overcome the barriers they face to leading full and independent lives". A fundamental part of independent life is to live in a safe and clean environment.

An activity based on this would also help bring in abilities that are so far not covered in full by the criteria (there may be some areas of small overlap) such as bending, kneeling, pushing, lifting and reaching.

DLA allows me to have a cleaner, help with ironing and window cleaning.

Respondent to our survey

Recommendation: If PIP criteria provide a proxy on an individuals ability to participate and their potential extra costs then it is vital that there is a criteria for "maintaining the domestic environment" for PIP to have any credibility with people with Parkinson's.

Other general recommendations

The need to distinguish between "preference" and "avoidance"

Throughout and on the face of the criteria it should be explicit that these criteria are "theoretical" and are not looking at what a person does or doesn't do now. Many people manage their condition or disability by restricting what they do or avoiding situations. There is a real danger that if someone does not go out because they have a fear of eg. falling outdoors, they don't answer the question.

¹¹ October 2011 impact and equality impact assessments
(<http://www.dwp.gov.uk/docs/dla-reform-wr2011-ia.pdf>)

This is particularly important as in paragraph 7.1 Annex A it states that the assessment of ability or inability is "not simply a matter of preference by the individual". Assessors will need skills to draw out information from people so simplistic conclusions are not drawn about people "preferring" not to undertake activities when in fact they are avoiding them because of the disabling effects of their condition.

Activities must be described to safe completion

We believe that if an activity is described it should be described "to safe completion". At present some descriptors do this but some do not. For example toileting recognises people will need to get on and off the toilet and clean themselves. While bathing just considers whether someone can wash, but not dry themselves.

There should be a published rationale for weightings

We are struck by the variation in some of the weightings. While we understand that these have been developed internally by an advisory group, and tested with volunteers, very little rationale has been given with the consultation document. DWP should reveal its thinking. The scoring appear to be random in places and low scoring in others, and these are noted in our specific comments below.

Use unambiguous language and define times for descriptor completion

The language in various places throughout the criteria can be confusing and ambiguous, such as the lack of definition of what is a "reasonable standard" in terms of being able to undertake activities reliably. In addition there is no time given against activities so people understand what is meant by a "timely fashion".

The need to be consistent on supervision and assistance which can equate to similar costs

There is also variation in the use of assistance, prompting and supervision with many instances where supervision is not mentioned in criteria, which are listed in the specific comments below. In many instances supervision and assistance will involve a similar cost in terms of needing someone to be consistently present, and this should be reflected in the scoring.

Recognise that disabled people rely more heavily on "ordinary" aids and appliances and everyday objects

The approach to aids and appliances is not satisfactory: we are concerned about the definition of aids and appliances as not including "those ordinarily used by a person without a physical or mental condition". Someone with Parkinson's may rely far more heavily on mainstream devices that make life that little bit easier - for example a food processor or electric toothbrush, and this should be equally recognised.

In addition many people will rely not on what may be an “aid or appliance” but use everyday items to make life easier such as give them stability. Indeed some people with Parkinson’s find it hard to hold a walking stick because of their dexterity problems or tremor.

An example is how people using the toilet might use the sink to haul themselves up, or when in the supermarket they will be clinging to a trolley: neither can be said to be aid, appliance, nor prompting, supervision or assistance. But clearly someone is having exceptional problems manoeuvring in everyday life situations.

Specific consultation questions

Q1 – What are your views on the latest draft Daily Living activities?

We also have specific comments on the criteria

Activity 1 – Preparing food and drink

This activity is called “preparing food and drink” but contains no descriptors in respect of making a drink apart from descriptor G.

Under descriptor C there should be included the word “prepare” as well as cook.

Preparing and transfer of liquids is just as important as being able to cook a simple meal and can be more dangerous if the person spills a hot drink and scalds themselves.

Recommendation: This activity should be reworded as: *the ability to prepare a simple cooked meal and make a hot drink* and the descriptors reworded accordingly listed in all descriptors. If someone can do one part of the descriptor but not the other that should count as not being able to do the descriptor at all.

This activity is also low scoring. We think 4 points for needing assistance to prepare and cook a simple meal is too low at Descriptor F. This should be at least 8 points.

This is one of the activities where assistance is to some extent irrelevant. Unless someone gets the help they need to prepare or cook a meal they can't undertake the task. They will be at risk of malnutrition or dehydration, just as someone who cannot cook food or drink at all will be. By downgrading the role of assistance in the scoring, it also disadvantages those who have the support of a carer.

Recommendation: Descriptor F should score 8 points. It should recognise that for someone who has to have help, or cannot feed themselves at all the consequences are the same ie. could lead to admission to hospital through dehydration or malnutrition.

Activity 2 – Taking nutrition

This is an example of where supervision is not reflected in an activity and should be because of the risk that can be involved if someone chokes. This can happen to people with Parkinson's as the condition progresses and impacts on swallowing function.

Recommendation: A person may still be able to convey food and drink to their mouth but a new descriptor to reflect the risk of choking should be included: *Needs supervision when taking nutrition* – 8 points

Activity 3 – Managing therapy or monitoring a health condition

I take 12 tablets first thing in the morning. Then 9 tablets after that 3 times a day. Every day I face the onerous prospect of all that medication. My day revolves around it, I have to plan everything to ensure I get those tablets on time because I live on my own.

Melfyn

We strongly object to the proposal that if someone can take medication by themselves (regardless of how much they have to take and how many times they have to take it) they score 0 points.

We note that in earlier criteria medication and therapy was separately considered and there were two criteria. It seems the decision to combine the two in this version of the criteria has led to the need for medication to be totally downgraded, with only therapy attracting higher scores.

Without managing medication a person with Parkinson's would be unable to function. The timing of medication is tailored to the individual and crucial. If a person with Parkinson's is unable to take their prescribed medication at the right time, the balance of chemicals in their brains can be severely disrupted – leading to the symptoms of the condition becoming uncontrolled and they can become very ill. For some people with Parkinson's medication is not delivered in tablet form but by apomorphine pumps¹² to give a continuous infusion of the drug or via injections.

Having such significant medication management issues is also very disruptive to someone's ability to live independently, with the daily life often driven by when and how much medication one has to take.

The criteria also reveal an inconsistency in that there are no points given, unlike in other criteria, of the use of aids and appliances. Certainly dossett boxes, pill

¹² For more information on apomorphine see our website
http://www.parkinsons.org.uk/about_parkinsons/treating_parkinsons/drugs/apomorphine.aspx

timers and other aids are vital when someone has significant medicine management issues. However, to score any points one must need the help of an individual. This penalises those who live on their own and must rely on aids or appliances instead. These people may not have family members or paid staff to help them.

Many individuals who do not qualify for free prescriptions (in England) currently use their DLA to support this cost or use it to buy in over the counter medication. If PIP assessment provides a proxy on the additional costs of disability and impact of impairment then it makes no sense to have recognition of cost and time of therapeutic interventions but not the cost and time taken to take medication itself. This is especially important in the light of the Department of Health's decision not to make prescriptions free for all people with long term conditions such as Parkinson's in England.

Recommendation: We believe that the scoring system should better reflect a person's need for medication, for instance by allocating a higher score to individuals where there are significant medicines management issues to be addressed of at least 4 points. Different descriptors could be created for those who can manage significant medication on their own, with the use of aids and appliances or with the help of someone else with additional scoring to reflect this.

Managing therapy is also ambiguous. Many people with Parkinson's receive massage or stretching to help relieve pain: not always suggested by clinicians but identified by peers or support workers as something which will help.

Activity 4 – Bathing and grooming

Shaving and drying should be included in grooming. Shaving can carry significant risk for someone with Parkinson's. In addition, being able to dry oneself "completes" the activity and we believe this should be listed.

We also believe that footcare including nail cutting should be included in grooming, again for Parkinson's care of the feet is essential and may help prevent falls. If someone cannot look after their feet there are associated costs from getting the help they need from local footcare services or chiropodists.

We also note a similar problem to that noted for Activity 1, in that there is little difference in reality between G and H in terms of bathing. People who need assistance to bathe and groom cannot actually do the task at all without help. People will be underscoring themselves and ticking G (4 points) when in fact the person should score the higher H and 8 points.

Generally we believe the scoring for this section is very low given that it is important part of ensuring someone remains well and does not neglect themselves.

Recommendation: This criteria should score higher given the importance of personal care and hygiene to someone's self esteem. It should include shaving, drying and footcare. Someone who needs assistance to bathe and groom should score 8 points.

Activity 5 – Managing toilet needs or incontinence

In our earlier comments we made the case that having assistance to complete a task, and not being able to do a task at all, should score the same. Here it seems here the descriptors acknowledge this, which we welcome. Here F and G score equivalent 8 points ie. needing assistance to manage incontinence of bladder and bowel is recognised as the same as not being able to manage incontinence at all.

However this is an area where wording is ambiguous. We are unclear whether incontinence pads would count as an "aid" or "collecting device" for the purposes of this activity. This is vitally important because these pads are expensive and availability on the NHS is by no means guaranteed or may not be fit for purpose. Paying for discreet continence wear is an associated cost of disability which needs to be reflected in the criteria. Moreover the criteria does not recognise the frequency and severity of incontinence which can lead to higher costs as well as laundry costs.

People with Parkinson's may need to rely on incontinence wear even if they are not incontinent, to protect from accidents in case they have a period of immobility "freezing" where they cannot get to the toilet in time.

There is no mention of supervision in this section.

Recommendation: this criteria should be clear that incontinence pads and incontinence wear are aids/collecting devices.

Activity 6 – Dressing and undressing

Points for D and E should be equivalent number of points. In addition, if you cannot dress your top or bottom half then it this should score higher as effectively you cannot complete dressing yourself ie dress yourself at all.

Again supervision seems to disappear from this criteria and needs to be included as people often need someone there in case they fall or become unstable.

There is a need to define "unadapted" clothing.

Recommendation: this criteria should include someone's need for supervision when dressing and undressing and should allow someone who cannot dress their upper/lower body to score higher number of points.

Activity 7 – Communicating

This activity only seems to consider specific facets of communication around sensory loss and so is very much focussed on aids and equipment, or the need

for interpretation. As an example, there is no activity to express written communication.

For many conditions communication does not relate to sensory loss but the loss of dexterity for writing, problems with vocalisation and cognitive issues such as word recall. In Parkinson's communication can be affected in all of the above ways and DLA can pay for a person to have vocal coaching to increase volume of voice or towards a computer or technology that can avoid handwritten means of communication.

My main worry concerns written communication. My handwriting deteriorates very rapidly and becomes minute and illegible. In addition my left/right co-ordination is very poor, so this is being typed with one finger. I find it impossible to improve on this. I cannot see that this is recognised in PIP.

Andrew

Recommendation: this criteria should include points for difficulty or inability to write, problems with vocalisation and word recall.

Activity 8 – Engaging socially

A definition is needed whether the person “trained or experienced” in assisting people to engage in social situations can be the person's family member or friend. We would support their inclusion.

“Overwhelming psychological distress” is an incomplete definition.

“Overwhelming” is a subjective word. We would prefer it to be “disabling distress” as anxiety and panic attacks can arise not just from mental health conditions or cognitive and intellectual impairments but as a side effect of both a physical condition and also medication. Non motor symptoms of Parkinson's are often overlooked or not even recognised by assessors.

This should include anxiety, as people with Parkinson's can often suffer from anxiety and panic attacks due to the condition and the side effects of medication. Or they may simply have a real fear of falling, freezing or displaying other symptoms of Parkinson's and consequently the social embarrassment this could cause them.

You cannot say when you are going to have a good spell or bad spell, it just happens. We have been out and I have suddenly lost mobility. I end up shuffling and I feel embarrassed because people stare so I find I spend a lot of time at home now.

Recommendation: this activity should be reworded to encompass the disabling distress and anxiety that can come from a having a physical condition and symptoms that may cause social embarrassment and accrue points accordingly.

Activity 9 – Making financial decisions

This is another area where we are unclear as to why someone who would need prompting to make simple financial decisions is not classed as someone who cannot make a financial decision at all. Without prompting they amount to the same thing.

This activity is also low scoring despite the major impact and implications there are for someone living with an impairment that means they could not pay for a newspaper or cup of tea. They score only 6 points. If they cannot do this then it can be implied that they will need much support and supervision, with the onus on a family member, friend or services to provide the support to get the goods and services they need to function and keep a roof over their head.

We query why supervision is not included in this criteria. If someone does not have someone to supervise them in making decisions and transactions there could be serious risk to that person, to the extent that the person could end up bankrupt or destitute.

Recommendation: this activity should include supervision criteria and provide for higher scores given the impact it can have on daily living.

Q2 – What are your views on the weightings and entitlement thresholds for the Daily Living activities?

Please see our responses to Question 1

Q3 – What are your views on the latest draft Mobility activities?

Activity 10

The activity is too focussed on psychological issues and sensory loss. It needs to recognise that people with other physical conditions will have the need for help in planning and following a journey, for reasons of reassurance, loss of confidence, or anxiety, as well as the potential danger to them from eg. a risk of falls or unpredictable physical symptoms. An example with Parkinson's is "freezing" when the person becomes unpredictably immobile. Just as with epilepsy, this unpredictability is an important feature of the condition.

The activity completely omits to consider the need for assistance from another person, a significant "gap" given Activity 11 only covers those who use aids and

appliances to mobilise or can mobilise unaided. Someone who needs an arm for support and stability, or help up and out of a bus or train seat should score points in this section.

Recommendation: The descriptors should feature scores for needing assistance. The activity should recognise that physical conditions as well as mental conditions can lead to anxiety, loss of confidence and therefore the need for support. These may not be classed as "overwhelming psychological distress" but can be just as inhibiting to the individual.

In addition, generally this activity is difficult to interpret or the rationale for scores is unclear. Descriptor B is particularly confusing. If someone can't leave home unaccompanied on all journeys without getting distressed then they only score 4 points. This is no different to needing supervision to follow a familiar journey though - and this scores 15 points. Both need someone with them to get out of the house and follow a journey: an additional cost.

The reference to **all** journeys will also make it difficult for someone living with a fluctuating condition such as Parkinson's to "score" themselves, and should be removed to be consistent with the approach to fluctuating conditions.

Another area which confused people with Parkinson's was the common scenario that they feel comfortable going out of the house in a car. They might be able to do this on their own, but with the use of a sat nav. Would this count as "a journey to an unfamiliar or familiar destination to have planned entirely by another person?" (Descriptors C and E).

Activity 11

In the mobility section there is no mention of pain and discomfort. On a good day I could walk well over 200m but with considerable pain. I tend not to walk far since there is a knock on effect in pain and lack of movement in subsequent days.

Andrew

This quote highlights our serious concerns with this activity. Many people with Parkinson's receive higher rate mobility DLA. This is because DLA takes account of whether someone is virtually unable to walk by assessing the severe discomfort someone may encounter and at what point in the journey they encounter it.

In the PIP criteria it seems only those who need a wheelchair would qualify for the higher rate of the benefit. Those who can mobilise 100 metres but no further would score only 4 points and potentially not qualify for mobility payments at all.

This is despite the high transport costs of getting around and barriers to participation for only being able to walk 100 metres.

For this activity it is absolutely essential that the descriptors talk about pain, discomfort and fatigue just as the other activities list effects in other descriptors eg. of overwhelming psychological distress.

In our experience people with disabilities are very good at ignoring their own pain when it comes to filling in forms, having lived for many years with a condition a person may have come to terms with their pain and “learnt to live with it”. People may also want to “struggle on” without using an aid or appliance, and feel that it’s a sign they’ve “given in” if they need a wheelchair or mobility scooter. In addition, the significant “gap” in both mobility activities (10 and 11) is the person who does not use an aid or appliance but does not do activities “unaided” because they have help from another person, or lean on objects like a supermarket trolley when out.

The criteria must also be most explicit here about the physical exertion involved and whether someone could do the activity repeatedly, reliably, safely and in a timely fashion. On the latter the amount of time the government estimate the activity to be undertaken should also be explicit eg. the average non disabled person would be able to walk 50 metres in 36 seconds (based on 5km/hour walking speed). Therefore a person who takes twice as long would not be counted as able to walk this distance in a timely fashion.

We note the change in language from being able to “walk” to in places in the criteria being able to “move”. We believe it should be explicit that this is about assessing walking ability.

Lastly, although DLA did not assess walking ability indoors in terms of the criteria, when filling in the form people were asked about this ability. We believe there is a missed opportunity in PIP to look at people’s ability to move around other than a flat surface inside or out: for example navigating steps, uneven surfaces, cobbles, hills, all of which can be problematical for people with Parkinson's with mobility issues.

If I can get a clear area I can walk quite well but in a confined space, eg. crowded shop, narrow isles, where a constant change of direction is needed is where it becomes difficult. Sometimes I cannot go into a shop.

Dave

Activity 12: Recommendation: Descriptors throughout should be amended to state: “Cannot move repeatedly, reliably or safely up to x metres either unaided or using an aid or appliance or without encountering severe discomfort, pain or fatigue.”

For someone who cannot move 50 metres without encountering severe discomfort, pain or fatigue they should score 12 points and therefore higher rate mobility. All mobilising activities should also list what average times taken should be over the distances given so people can assess whether they can do so in a “timely fashion”.

Q4 – What are your views on the weightings and entitlement thresholds for the Mobility activities?

This has been covered in our response above.

Q5 – What are your views on how the regulations work regarding benefit entitlement? Draft Regulations 1 to 4 set out how the assessment will work to prioritise individuals and determine entitlement to the benefit. How well do you think the draft regulations achieve the intent of the assessment set out in the explanatory note? Do we need to make any changes?

Our comments here relate to our overall comment about the “points based” system and how it may fail to reveal the bigger picture about an individual’s level of need.

Until the criteria are more nuanced we cannot agree that the regulations, as worded, will reveal the claimants ability is either “limited” or “severely limited” by their condition.

Q6 – What are your views on how we are dealing with fluctuating conditions?

We welcome the proposal that a person will score points against an activity if they are unable to complete or perform it **at some stage of the day** ie over a 24 hour period. This addresses a major concern in respect of fluctuations as in respect of Parkinson’s many people find that they cannot manage to undertake many activities first thing in the morning until their medication begins to have an effect. It is a good way of recording the disruptive impact of such impairments on people’s lives. However, people we consulted often overlooked this proposal.

Recommendation: We feel it is vital that there is an explicit prompt in each criteria to ensure people think about the times in the day they cannot undertake the tasks listed and apply these scores.

Our main concern is that we think the “cumulative” impact will be missed using the 50% of days rule, people can have times where their Parkinson’s is having a serious impact on their lives but it won’t be “enough” of the time to score.

For example someone who can meet (A) ie dress and undress unaided for 51% of days will score 0 points, even if there are days when they find it really difficult because of their Parkinson’s. In other words, they might score under (E) for 20% of days and (F) for 29% of days but together they don’t add up to more than 50% of days and (A) effectively “trumps” everything.

Recommendation: We believe that the assessment must be nuanced to reflect cumulative impact of a condition and there should be a “non functional” descriptor, as with Employment and Support Allowance that allows the assessor to reflect upon the risks to quality of life raised by a person’s condition. This would be a safety net for those who do not meet the narrow criteria for 50% of days but whose condition is all pervading over their lives.

A common response from people affected by Parkinson’s and our advisory staff was just how easy it would be for a person to recollect whether they have been able to complete an activity over a 12 month period. A further question was how will someone be able to “prove” they are affected for different percentages of time? What will the assessors take as evidence?

Recommendation: We think that careful consideration should be given to how people can evidence the rules around fluctuations and impact on 50% of days as a year’s estimate will be almost impossible to recall or estimate for most people. We suggest that a shorter proxy period will need to be considered in terms of being most helpful to individuals as well as decision makers.

Q7 – What are your views on the definitions of ‘safely’, ‘timely’, ‘repeatedly’ and ‘in a timely’ manner?

The fact that people aren’t classed as being able to do tasks if they can’t do them reliably, safely, repeatedly and timely will be helpful given the symptoms of Parkinson’s. For example we know people sometimes prefer to have someone with them while they are dressing, for example, in case they have a fall, or will take a very long time to get ready and going at the beginning of the day.

Living on my own, is particularly difficult. Dressing and undressing can take up to an hour. Dizzy spells and exhaustion come on very quickly.

Melfyn

Although these are very welcome there is much to learn from the Work Capability Assessment and the fact that these terms should be on the face of the criteria. It is very apparent from face to face assessments that assessors have failed to make this judgement call and took the decision on the basis of what a person was able to do in the interview.

This is one of those areas where the language of the criteria is also ambiguous. Reliably is said to mean “to a reasonable standard”. There is no definition of what this means leaving it open for individuals and decision makers to interpret matters very differently.

Similarly “in a timely manner” is described as more than twice the time it would take a non disabled person. It is therefore vital the government places figures on all activities so people know what estimated time is – particularly on the walking activity.

People need to be encouraged to ask themselves “At some point in the day, am I unable to do this activity? If I’m able to can I still do it without putting myself in danger? How long does it take me compared to what the government estimate a “non disabled person” could do the activity? And could I do it as many times as needed without causing discomfort or fatigue?”

Recommendation: It is vital to repeatedly state “reliably, repeatedly, safely and in a timely manner” in the regulations and the criteria. However we also believe this should go a further step and provide a prompt on the face of each activity otherwise there is a danger this will be overlooked.

Q8 – What are your views on the definitions in the regulations? The draft regulations contain a number of definitions in Regulation 1 (Interpretation) and Schedule 1. Do we need to make changes to any of these?

We have offered comments in our response to the detailed activities but to reiterate:

“groom” should include shaving and drying oneself, as well as footcare, such as the ability to cut one’s toenails.

“managing incontinence” it must be explicit that incontinence pads and wear are collecting devices.

“overwhelming psychological distress” is an incomplete definition.

“Overwhelming” is a subjective word. We would prefer it to be “disabling distress” as anxiety and panic attacks can arise not just from mental health conditions or cognitive and intellectual impairments but as a side effect of both a physical condition and also medication. Non motor symptoms of Parkinson’s are often overlooked or not even recognised by assessors.

“social support” it is unclear whether this trained or experienced person can be a professional or someone who is an informal carer (in our view it should be both)

At present there is no definition of unadapted clothing.

Q9 – Do you have any other comments on the draft regulations? Regulations 5 to 10 of the draft regulations relate to elements of the assessment process for Personal Independence Payment, around the requirement to provide information and attend face-to-face consultations, the consequences of failing to meet these requirements and when individuals might have good reason for not meeting these. Do you have any comments on these regulations?

We note that Regulations 11-13 are not open for comment due to the consultation on detailed proposals for PIP.

For Regulations 5 – 10 we note that the proposal to provide information to the Secretary of State is one month. We believe this may be too short for many individuals with Parkinson's and there should be an explicit addition subsection to Regulation 8 (Matters to be taken into account in determining good reason) to include:

“c) matters outside of the control of the claimant, such as provision of medical information from healthcare professionals.

We also believe that Regulation 7 has an exceptionally short minimum timescale for written notice of a consultation to be given. If people are only contacted 7 days in advance of their interview (by face or phone) they may be away on holiday, or will need to arrange a day off work (likewise for those who would support them at their interview).

Recommendation: We believe notification of an interview should be a minimum of 21 days and that matters outside of the control of the claimant should include delays in provision of medical information from healthcare professionals.

Contact details

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