

**Disability Living Allowance reform
Consultation response from Parkinson's UK
February 2011**

"I can't do my garden any more, so I have to pay for help. I can't stand and iron any more, so I have to pay someone to do it. I can't wash my floors, I have to pay someone to do it. Without DLA I would be dirty, unkempt and living in a jungle."
Person with Parkinson's

It's impossible in advance to know what state I'll be in at the time of the assessment (although the stress won't help), but whatever the assessor believes he/she has observed is going to permanently affect my income thereafter.
Person with Parkinson's

Parkinson's UK welcomes the opportunity to respond to this consultation. We believe that it is important to retain the financial support via disability benefits as an effective, flexible and popular means of meeting an individual's disability related costs. Government must create the right financial framework to make sure that no one with a complex condition like Parkinson's is denied access to vital benefits.

DLA is a benefit for people who have care needs and/or have difficulty walking. As Parkinson's is a fluctuating and degenerative condition, this will apply to all those affected at some stage.

The lack of clarity over whether those over the age of 65 will be reassessed is of extreme concern to a large number of DLA recipients. We call on the Government to clarify its position on this as a matter of urgency

About Parkinson's disease

It is estimated that 120,000 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 point 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.

People with Parkinson's face additional costs because of their condition. Although some of these costs, such as domestic help and aids and appliances, could be met through social care support, disability benefits are needed to help with those costs that would not be met through social care, including incontinence supplies, laundry, heating, additional insurance premiums and prescription charges. Transport costs are a particular issue with Parkinson's, because many people have to give up driving because of the condition.

A recent survey of people with Parkinson's revealed that sixty three per cent of respondents identified specific extra living costs due to their disability, including¹:

- Transport costs
- Heating costs
- Help with gardening
- Extra laundry or cleaning costs

1. What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?

People with Parkinson's face a number of barriers to participating fully in society and leading independent lives:

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'. Appropriate health and social care provision is crucial to enabling those affected to manage their symptoms, maintain quality of life and maximise their independence.

Main symptoms that restrict people with Parkinson's:

- slowness of movement (91%)
- problems with handwriting (83%)
- Around two thirds said that tremor, rigidity, getting around in public and getting ready to go to work caused problems.
- The most common non motor barriers were problems with concentration (60%), sleep problems (60%), staying focussed (54%) and feeling anxious and panicky (50%) and memory (50%).

As the condition progresses and there is a greater impact on daily living activities, this can result in increased dependency for support from care providers, either family members or private or statutory care services. Maintaining normal activities such as work, family responsibilities or hobbies becomes increasingly difficult and assistance may be required in all activities of daily living to allow the person to maintain mobility and independence as far as possible. Without this assistance and support, the person with Parkinson's may often become socially isolated and this will result in a further deterioration in their quality of life.

People with Parkinson's also face discrimination by society at large. This impacts on individuals' ability to secure and retain paid employment and consequently their financial situation is likely to suffer further.

¹ Survey of people with Parkinson's, 2009

2. Is there anything else about Disability Living Allowance (DLA) that should stay the same?

Parkinson's UK believes that the mobility component for people in residential care should remain. We therefore call on the Government to reverse their proposal and not remove DLA mobility component from people with Parkinson's and other disabled adults in residential care who rely on it to maintain their independence. The proposed change is not only of detriment to peoples' quality of life and human rights, but runs counter to Government policy and economic common-sense, in terms of facilitating independent living.

People with Parkinson's attach enormous value to the mobility component of DLA as the condition has an increasing impact on mobility as it progresses. Symptoms can include rigidity and muscle cramp, involuntary random movement ("dyskinesias"), sudden loss of movement ("freezing"), slowness of movement or difficulty beginning movement ("start hesitation") and loss of balance. Due to the impact of the condition, a significant proportion of people with Parkinson's live in residential care.

We are also concerned with the focus on 'those with the greatest need'. We believe that this risks leaving a large number of people with no help at all. This approach neglects that the additional costs of living with a disability do not necessarily correlate with the functional impact of someone's disability. DLA is a vital source of support for those whose needs do not qualify for social care, but nevertheless face significant additional costs and barriers to participation as a result of their condition.

3. What are the main extra costs that disabled people face?

Parkinson's UK research has shown that over half of people with Parkinson's (54%) feel they have additional spending requirements due to having the condition. DLA provides important support towards meeting these costs².

In order to facilitate activities of daily living, people with Parkinson's are likely to need to pay for this support. Recent research has highlighted the high costs of living for disabled people and how these are caused by a range of factors³.

People with Parkinson's have told us that they use extra money to cover the 'costs' of disability, in some of the following ways⁴:

Support / help from someone	42.8%
Health treatment	25.9%
Mobility aid	22.0%
Transport	42.8%
Motability	40.9%

4. The new benefit will have two rates for each component:

- Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?

² *Life with Parkinson's today – Room for Improvement* (Parkinson's UK, 2008)

³ Wood and Grant; *Counting the Cost*, Demos 2010

⁴ Disability Benefits Consortium survey (unpublished), Autumn 2010

- **What, if any, disadvantages or problems could having two rates per component cause?**

Parkinson's UK believes that everyone with Parkinson's should get the support they need to manage the costs of living with the condition, and we therefore oppose the arbitrary target of cutting the number of DLA claimants by 20 per cent. A high proportion of people with Parkinson's rely on disability benefits for their income. Although some of the additional costs they may face could be met through social care support, disability benefits are essential for costs that would not be covered by care services.

We are very concerned about the focus on those 'with the highest needs', and particularly what this may mean for people who currently receive the lower rates of DLA. It is important that the Government clarifies exactly what is meant by the 'greatest need'. As stated above, the recent Demos report demonstrated that there is little clear correlation between high costs of disability and the functional impact of a person's impairment or disability. For example, the study found that disabled people who claim Job Seekers Allowance had higher disability costs, despite being medically 'fit to work'. We are concerned that groups like this are likely to lose out under the new PIP regime, although to deprive these people of this vital support would be against the original purpose of DLA as an equality measure to compensate people for the extra costs of living with a disability.

We oppose cutting DLA for people in residential care: this regressive step will have a huge impact on the lives of people in care homes, compared to the relatively small savings expected

5. Should some health conditions or impairments mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual applying?

We believe that if someone is diagnosed with a long-term, progressive condition such as Parkinson's, this should be taken into account to determine the type of assessment required to gain access to benefits and also the frequency of future assessments.

We would also recommend that people with long-term, progressive conditions should either be exempt from reassessment or alternative methods of assessment be found in place of a face-to-face interviews. We are keen to ensure that the challenges faced by people when applying for Employment Support Allowance (ESA) – including the stress caused by the assessment process itself – are not replicated with the changes to DLA.

7. How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?

We are concerned that the introduction of a blanket medical assessment could mean that people are wrongly assessed as not needing the allowance. Any DLA assessment needs to take into account the complex needs of people with a degenerative and fluctuating condition such as Parkinson's. We are concerned this medical reassessment process may mean people are assessed as not needing the support which they rely on.

In addition, we are mindful of the challenges that people with Parkinson's have faced when undergoing assessment for other benefits, notably Employment Support Allowance (ESA). We are therefore keen to ensure that the new assessment adequately addresses the challenges faced by people with fluctuating conditions such as Parkinson's. In this respect, the following recommendations have been made by Parkinson's UK with regard to recording fluctuating conditions for ESA:

- The use of supporting evidence from GPs / consultants should be a formal part of the process.
- For people with more than one health condition, a report from the individual's GP is a good starting point since their patient notes will record all aspects of the individual's healthcare.
- Another mechanism for recording the impact of fluctuating conditions is a diary kept by the claimant over a 7-14 day period.
- The diary should be used as part of the evidence collected in the assessment.
- Finally, the assessment should include a list of open questions to give GPs/consultants scope to describe their patient's condition in full.
- In addition, the possibility of having the assessment spread out over more than one day should be considered.

8. Should the assessment of a disabled person's ability take into account any aids and adaptations they use?

- **What aids and adaptations should be included?**
- **Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?**

We do not believe that the assessment should take into account aids and adaptations due to evidence showing how people with Parkinson's face difficulties securing access to the appropriate support. Our research has shown that in the face of these difficulties, one in five people with Parkinson's have resorted to purchasing their own aids and equipment⁵. These purchases are financed through individuals' own money, often supported by DLA.

We do not believe it is correct that an individual's disability or long term condition and its financial impact is mitigated by the very fact of having an aid or adaptation such as a wheelchair or other walking aid, for example. In addition, despite equality legislation, people with Parkinson's continue to experience barriers when accessing services such as public transport, shops etc.

10. What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?

See above (q7).

11. An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.

- **What benefits or difficulties might this bring?**
- **Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?**

⁵ *Life with Parkinson's today – Room for Improvement* (Parkinson's UK, 2008)

Parkinson's UK is opposed to people with Parkinson's, and particularly advanced Parkinson's, to have to go through a face-to-face test for DLA/PIP: we are concerned this will bring in unnecessary bureaucracy and may disadvantage people who have difficult-to-assess, unpredictable symptoms.

We would urge the Government to take into account the challenges faced by people with long term, progressive and fluctuating conditions such as Parkinson's, when being assessed by healthcare professionals for ESA. In particular, we feel that consideration needs to be given to the following issues which people with Parkinson's have faced with the ESA assessment and steps taken to ensure that similar issues do not arise with DLA/PIP assessment:

- Lack of awareness of Parkinson's and its many and varied symptoms amongst assessors. We recommend that condition-specific training of assessors.
- Ensuring that there is a legitimate way of recording the fluctuating and unpredictable nature of an individual's condition. Due to the fluctuating nature of the condition, it is very difficult for a person with Parkinson's to predict their ability to carry out any particular task (including employment) with any kind of accuracy.
- Ensuring that provision is made to allow for appropriate recording of all the symptoms of Parkinson's and the way they impact on an individual's life.

12. How should the reviews be carried out? For example:

- **What evidence and/or criteria should be used to set the frequency of reviews?**
- **Should there be different types of review depending on the needs of the individual and their impairment/condition?**

For someone with a progressive condition like Parkinson's – where, by definition, their condition will deteriorate over time – it is unlikely that their condition will improve to the extent that they no longer need to claim DLA/PIP.

We are concerned that repeated assessments for people with progressive conditions such as Parkinson's will cause unnecessary stress for individuals concerned. In addition, given the nature of the condition, we believe repeated assessments to be unnecessary and in this respect, potentially wasteful in terms of public expenditure.

It would therefore be more appropriate to require individuals to report to the DWP any changes to their condition – this would include any deterioration to their condition which might result in an individual receiving a higher level of DLA.

13. The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?

We would favour the Government introducing positive incentives to encourage people to report changes in circumstance. Clear, concise information is crucial in order to facilitate this.

The proposal to introduce penalties for failing to report changes in circumstance are concerning. Further clarification is needed in order to communicate with people with

conditions like Parkinson's, when it would be appropriate to report a change in circumstance.

14. What types of advice and information are people applying for Personal Independence Payment likely to need and would it be helpful to provide this as part of the benefit claiming process?

Advice and information needs to be personalised to the individual. Efforts should be made to ensure the individual has all the information they need to make informed decisions and manage their situation to achieve the best possible outcome and maximise quality of life.

In addition, information should be tailored to the needs of individuals at varying stages of a progressive, neurological condition such as Parkinson's. Consideration should also be given to making information available in accessible formats, particularly audio, large print and translated versions.

15. Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action?

A requirement to access advice and support would not necessarily resolve any issues alluded to. We believe that more action needs to be taken to provide appropriate information and target it at hard-to-reach groups, as the primary method of resolving this issue.

16. How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?

See above (question 8)

19. What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?

- If a substantial number of DLA claimants see their benefits reduced or removed as a result of the proposed cut of £1 billion to the DLA budget, this could have a significant impact on Carer's Allowance and other passported benefits, particularly disability premia. The Government must publish an urgent analysis of the knock-on impacts of this cut on family incomes – which could be devastating for families as they lose disability and carers' benefits.
- Carers of people with Parkinson's already face significant financial challenges: Parkinson's UK research has shown that over one in five carers gave up work because they were caring for someone with Parkinson's and the financial situation of 28% of carers has worsened^{5 above}.
- The consultation paper does not examine where eligibility for Carer's Allowance would be established within the new Personal Independence Payment. As a result, it is impossible to assess the impact of these changes on carers and the ability of families to care for ill or disabled friends and relatives.
- Carer's Allowance must remain outside of the Universal Credit. Carers already in receipt of means-tested benefits (the carer premium to Income support, for example) may benefit from moving onto Universal Credit. However, introducing a means-test for carers who receive non means-tested Carer's Allowance by

moving them onto Universal Credit would be a huge step backwards in carers' right to an independent income. It would leave some carers financially dependent on partners or family members and risks making family care financially untenable for others.

20. What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?

We believe that any sharing of information should be conducted in a way that is open and transparent and individuals concerned have access to their own records prior to benefits decisions being finalised, in order to allow an opportunity for corrections to be made if necessary.

Further information:

For further information, please contact the Social Policy and Campaigns team: 020 7932 1323 or campaigns@parkinsons.org.uk