

**Department of Work and Pensions – Personal Independence  
Payment: draft of assessment regulations  
Parkinson's UK submission  
August 2011**

**About Parkinson's**

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 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'.

**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 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, including<sup>1</sup>:

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

#### **Case study: impact of Parkinson's on an individual's life:**

"One of the hardest things I find living with Parkinson's is that on the outside I can and try to look well, but inside I have to continually remind myself to lift my feet when I walk and to hold my shoulders back, otherwise I would be on the floor, also if I don't take my medication I am a stiff shaking mess.

For me receiving DLA has enabled me to purchase care needs for myself, such as a cleaner, having a weekly laundry person for the bedding. Also, DLA enables one to receive other benefits such as Warm Front (England) HEES (Wales). I am currently waiting for a new boiler through this scheme. High rate mobility automatically enables one to be eligible for a Blue Badge, which makes shopping much easier".

## **Introduction**

Parkinson's UK welcomes this opportunity to make a response to the assessment criteria for the Personal Independence Payment (PIP), as set out by the Department for Work and Pensions (DWP). Our response is based on our own initial analysis of the criteria following brief consultation with people affected by Parkinson's and Parkinson's UK helpline staff and Information and Support Workers. The response also draws on our work on the Work Capability Assessment (WCA) including

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<sup>1</sup> Survey of people with Parkinson's, 2009

Parkinson's UK research<sup>2</sup> 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. We believe that the new PIP assessment is similar to the WCA and therefore the recommendations made by Professor Harrington and the subsequent review group on fluctuating conditions<sup>3</sup> should be taken into consideration.

Parkinson's UK is also a member of the Disability Benefits Consortium (DBC). We support the DBC's submission to the initial consultation and would urge the DWP to consider the DBC's alternative PIP assessment.

We have also contributed to a number of DWP seminars that have taken place over the summer on the development of the PIP assessment.

Our views are set out below. In particular, we are concerned at a number of instances where the principles stated in the consultation do not appear to be reflected in the criteria. These are highlighted below. Also included are areas where we feel the draft assessment criteria are lacking and recommendations on how these could be addressed.

## **Fluctuating conditions**

We would welcome a multidimensional approach to assessing the additional costs and barriers to participation experienced by people with conditions such as Parkinson's.

Benefits assessors often underestimate the impact of Parkinson's on a claimant's wellbeing and care and mobility needs. Proposals to reassess people with Parkinson's on a regular basis for their eligibility for PIP will cause anxiety and wastes Government resources. Parkinson's is a progressive condition. The newly published draft PIP criteria do not take fluctuation into account and are less appropriate for assessing people with Parkinson's than the system currently in place. Under new proposals, assessors will not take into account life-limiting symptoms such as problems with getting out bed, moving around indoors, the risk of falls and stumbles and night-time care needs. This will inevitably mean some people with Parkinson's who currently receive DLA will not qualify for its replacement, PIP, despite the Government's assurance that "those who are genuinely sick and disabled have nothing to fear".

According to the consultation, a person must be able to complete an activity "reliably, in a timely fashion, repeatedly and safely" to be considered able to do

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<sup>2</sup> *Of Little Benefit and Not Working: people with Parkinson's experience of Employment and Support Allowance* (Parkinson's UK, Oct 2009)

<sup>3</sup> *Employment and Support Allowance Work Capability Assessment review - making it work for fluctuating conditions* (MS Society, Parkinson's UK, NAT, Crohn's and Colitis UK, Forward-ME Group, April 2011)

the activity. However, we are concerned that on the face of the criteria, no mention is made of these points. In our work around the WCA for ESA<sup>3</sup> above, we have recommended that the assessment process asks if an individual is able to undertake an activity 'reliably, repeatedly and safely'. Without this, there is a risk that an accurate assessment of an individual's condition will not be made.

In addition, we believe that an accurate assessment of fluctuating conditions such as Parkinson's can only be made if the individual is asked about the frequency, severity and duration of the condition.

Under the mobility section, there is reference to taking into account pain, breathless, fatigue and risk. Furthermore the consultation says the choice of the descriptor will be based on consideration of a 12 month period, and the level which applies for the greatest proportion of that time. If the activity cannot be completed for more than six months aggregated over that period then it will be considered as not being able to be completed at all.

Again, there is nothing on the face of the criteria (or in the regulations) that notes these points. We know from the WCA that these considerations are not properly taken into account, particularly if they are not on the "face" of the test. Moreover, someone who can't undertake an activity for say, three months, a year is still living with significant disability. In addition, we would urge that the scoring system reflects the needs of people with long-term conditions who experience significant symptoms for some of the time (for instance, three months of the year).

The mobility criteria does not allow for enough fluctuation in ability, for example, someone with Parkinson's may be able to walk relatively well once they get going but may have severe problems with initiating movement or may freeze unexpectedly. We believe that the assessment needs to enable individuals the opportunity to explain these kinds of issues.

We are keen to ensure that PIP 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 for the WCA:

- 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.

## **Activities to be assessed**

The DLA form asks for information on getting out of bed, on moving around indoors and falls and stumbles indoors (under care). It also prompts people about their needs at night as well as daytime. These prompts appear to be missing from the new PIP criteria. We believe that these should be included in order to facilitate a more accurate assessment of an individual's condition.

We are concerned at the proposal that the assessment takes into account the mitigating impact of aids and adaptations in their entirety. This is because there is strong evidence that individuals are currently using their DLA to purchase equipment that is not available on the NHS or subject to delays. Regardless of this, we believe that aids and adaptations are unable to totally mitigate the barriers people with Parkinson's experience in participating in society – such as accessing public transport, shops etc.

## **Managing medications**

We are concerned at the proposed low scoring for managing medication. The main treatment for Parkinson's is medication and there are specific drugs which work by replacing or mimicking the actions of dopamine, the chemical that is depleted in the brain. For people with Parkinson's, their medication is essential to enable them to undertake activities of daily living. The timing of medication is tailored to the individual. 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 this reason, we believe that the scoring system should better reflect this issue, for instance by allocating a higher score to individuals where there are significant medicines management issues to be addressed.

Many individuals who do not qualify for free prescriptions currently use their DLA to support this cost. In addition, we would like to see PIP take into account and support the costs people with certain long term conditions – such as Parkinson's – have to pay for prescriptions. This is especially important in the light of the Government's decision not to make prescriptions free for all people with long term conditions such as Parkinson's.

## **Other issues**

- Parkinson's is condition which affects individuals in a unique way, with a range of symptoms impacting on all aspects of daily life. We are concerned that little mention has been made of how the assessors will be made aware of disability in general and specific conditions – such as Parkinson's – in particular.
- Mobility component for people living in residential care – in spite of recent Government assurances that people in residential care will be assessed in the same way as other applicants, the draft assessment does not contain any information on how this issue will be addressed. For people with Parkinson's, this is disappointing, since many people with the condition are likely to use residential

care as the condition progresses. We continue to urge the Government to offer concrete proposals on how this issue will be addressed, in particular with inclusion in the draft assessment for PIP.

- Migration from DLA to PIP: we would like to see steps taken to ensure that this process is not rushed and criteria not subject to incremental change whilst migration is occurring. In this respect, we believe that there are lessons to be learnt from the migration to ESA.
- In view of the fact that DLA is underclaimed, what steps will be taken to ensure appropriate uptake and awareness of PIP and encourage individuals to come forward for assessment.
- Supporting evidence - the evidence of carers and people who know the applicant should be given equal weighting to that of healthcare professionals who would not necessarily know their patient's social needs.

## **About Parkinson's UK**

Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone. We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

## **Contact details**

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