

Parkinson's UK response to the Harrington review September 2010

Parkinson's UK conducted a consultation of people with Parkinson's to find out about their experiences of the Work Capability Assessment (WCA). In addition, a survey had also been conducted in 2009 which is included as an appendix to our submission.

These have helped inform our response to the review and this is detailed below

About Parkinson's

It is estimated that 120,000 people in the UK have Parkinson's. Parkinson's is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. People with Parkinson's often find it hard to move freely. Their muscles can become stiff and sometimes they freeze suddenly when moving. There are also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact on people's day-to-day lives. The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden 'freezing'.

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, although one in seven will be diagnosed before the age of 50 and one in 20 will be diagnosed before the age of 40.

Parkinson's UK views on the WCA and the descriptors

Whilst supporting the principle of enabling disabled people and those with long term conditions to work where appropriate, we have previously raised concerns about the accuracy of the outcomes from the WCA for people with Parkinson's. For this reason we welcomed this independent review and the opportunity to comment. Many people of working age who are diagnosed with Parkinson's are unable to continue in their existing jobs, need additional support to work or cannot work at all. Our research has shown that people with Parkinson's are repeatedly reporting concerns about the way their WCA has been undertaken, thereby resulting in inaccurate outcomes^{1 2}. For this reason, we believe the WCA is not fit for purpose for people with long term, fluctuating conditions such as Parkinson's.

Our research has highlighted the following problems with the current system:

- Lack of flexibility in the WCA process resulting in inaccurate outcomes for people with Parkinson's. In particular, we are concerned at the lack of 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. We believe that the issue of fluctuating conditions needs to be addressed in the WCA review as a matter of urgency.

¹ *Of little benefit and not working: People with Parkinson's experience of Employment and Support Allowance*, Parkinson's UK, 2009

² Appendix 1 to this submission

- We are concerned that the WCA assessment does not allow for appropriate recording of all the symptoms of Parkinson's and the way they impact on an individual's life.
- Lack of consistency in terms of the way in which supporting evidence from claimants' own General Practitioners (GPs) and hospital consultants are used in terms of making the final decision.
- Lack of information amongst claimants about the process overall, their rights at specific stages and the way the process can be adapted to suit individual needs. For instance one person with Parkinson's was unaware of the ability to request an assessment to take place at home. As a result, the claimant had to travel to the assessment centre – a journey which caused considerable physical difficulty as well as additional stress. In addition, people are unaware of the implications of giving specific answers to the descriptor questions. For instance, if an individual gives no answer to a question, their response is recorded as a 'default' answer, meaning that their condition is often recorded as better than it is in reality. One way of addressing these issues would be through better signposting to sources of advice / advocacy such as those provided by the voluntary sector.
- Lack of awareness of Parkinson's and its many and varied symptoms amongst ATOS assessors. We recommend that condition-specific training of assessors is looked at as a priority.
- We are concerned about the impact on disabled people of the heavy workload ATOS is likely to have over the next few years and the speed at which the Government is moving. The assessment of an estimated 1.6 million existing Incapacity Benefit claimants over the next three years is ambitious. We would be concerned at the capacity of ATOS to undertake these assessments in an accurate and appropriate way, sensitive to the needs of potential claimants.

With regard to the descriptors themselves, we would recommend that the following amendments are made:

- More scope needs to be provided to record multiple conditions / co-morbidities.
- The report produced as a result of the WCA carried out for each claimant, should be sent to the claimant, as a matter of routine. Provision should be made for this to be a formal part of the WCA process.
- In terms of recording the impact of fluctuating conditions on a claimant's quality of life, the use of supporting evidence from GPs / consultants should be a formal part of the process. Our evidence points to instances where this evidence has not been considered. 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. These should be used as evidence as part of the WCA process. Our evidence highlights how the WCA can have an impact on claimants' health (eg by exacerbating stress) and GPs / consultants have an interest in protecting the health of their patients. By undertaking this work, GPs / consultants are helping improve their patients' health in the long term. In addition, in order to facilitate this work, ATOS could produce 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.
- With the mental health descriptor, amends need to be made to reflect the fact that a claimant might have a mental health condition as a result of the side-effects of medication, not just as a condition in its own right. This therefore

needs to be built into the descriptor so that it is not solely down to the individual claimant to make this point.

- The descriptors lack detail on the following symptoms:
 - Pain
 - Fatigue
 - Varying degrees of difficulties with physical tasks
 - There is no reference to the self-care mechanisms that a claimant might need in order to manage their own condition.
 - The assessment focuses on capabilities involving a variety of tasks at single incidences and then assumes that this capacity can be repeated throughout a period of work without any adverse consequences. It therefore does not allow for any way of recording the cumulative effective of a number of symptoms that might be experienced.

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