

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

It is estimated that 120,000 people in the UK have Parkinson's. Parkinson's is a progressive, neurological disorder, with no known cure. 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

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, such as pain, sleep problems, depression and dementia. The severity of symptoms can fluctuate, both from day to day and during the course of the day, including rapid changes in functionality such as sudden 'freezing'.

Question 1

Have you noticed changes to the WCA process as a result of the Year 1 recommendations? If so, what are these changes?

- A. Process has improved
- B. Process has broadly stayed the same**
- C. Process has got worse
- D. Not noticed / not sure

Answer

B (delete as appropriate) and provide any written comments

Parkinson's UK believes that it is difficult to assess whether the Year 1 recommendations, which we strongly welcome, have yet made a difference.

The evidence so far is that the process is still broadly the same one that people with Parkinson's have experienced since ESA's inception in 2008.

This may be because many of the Year 1 changes have only been implemented in the summer period of 2011 and have yet to be embedded in working practices. In addition some of the Year 1 review is still in the process of being implemented, such as the issuing of a personalised summary of the ATOS report to those assessed by the end of 2011 (subject to piloting).

Unfortunately there are also issues "outside" of the Year 1 review which we

believe are damaging the progress that could be made:

- 1) The government took the retrograde step to reduce the numbers of descriptors (following the internal government review, and separate to the independent review). This has made the WCA an even cruder tool for functional assessment than had previously been the case.
- 2) The language used by government and media have created such negative connotations around the WCA that many people are incredibly anxious about the process. People with Parkinson's have told us that they are extremely fearful of being labelled "a scrounger" for claiming the benefit, or being granted ESA then "reported" as a fraud if they are being seen to be having a good day.
- 3) There is the proposal to time limit contributory ESA for people in the Work Related Activity Group in the current Welfare Reform Bill, making it even more important that people put in this group are those which realistically are able to re-enter work with appropriate support. The connotations are that those in the WRAG are those who will be able to work after a year's support because they will have "recovered" from illness, which clearly does not reflect the reality of living with a progressive neurological condition such as Parkinson's.

We are members of the Disability Benefits Consortium (DBC), which will be submitting its own survey of the impact of the Year 1 recommendations amongst welfare and benefits advisors. This included views from our own Information and Support Workers who offer support to people with Parkinson's. The feedback confirms our view that it is taking time for the Year 1 review reforms to translate into practice. A summary of that feedback is enclosed at **Appendix A**.

If further evidence is needed, then we believe it would be beneficial for the independent review team to consider a "mystery shopping" exercise where people were able to report whether customer care is improving throughout the process. This would bolster the independent evidence base. We understand that Professor Harrington is considering spot visits to Jobcentre Plus, and welcome this.

Question 2

Are there further areas of work that you think should be added to the programme of work for Year 3? If so, what should these consider?

- A. Major areas of work required**
- B. Minor areas of work required
- C. No more areas of work required

D. Don't know

Answer

A (delete as appropriate) and provide any written comments ...

Parkinson's UK, along with 5 other charities, has offered a comprehensive report *Making it work for fluctuating conditions* to the independent review team and look forward to the acceptance and implementation of changes to benefit people with fluctuating conditions. Those recommendations are briefly summarised at **Appendix B**. However we understand that such recommended changes may not fully be in place until 2013.

The potential changes will not benefit people with Parkinson's who are **currently** going through the process and fundamental questions remain over the appropriateness of the WCA for someone with a progressive and fluctuating neurological condition such as Parkinson's.

We make some key proposals in our response to Question 9 on how the WCA could change to rely more on medical and written evidence, along with ensuring the WRAG and Support Groups are more appropriately defined and used. In the absence of changes to the descriptors we feel an immediate shift further away from the face to face assessment is justified. Therefore more detail of how this might work is in our response to Question 9.

We believe that in addition the **Year 3 review** should take the opportunity to assess:

- Whether there is any greater clarity over government communications on the WCA (picking up on the criticisms made by the Work and Pensions Select Committee's recent report *The role of incapacity benefit reassessment in helping claimants into employment* (13 July 2011).
- The potential to involve disabled people and those with long term conditions to provide independent advice to DWP on decision making and appeals as well as through peer support through the process.
- The support being made available to people to assist with the appeals process.
- The length of time people are having to wait during the appeals process.
- The charges being made by medical professionals to supply written evidence
- Quality control and benchmarking
- A definition of what is meant by "work", building on Year 2 recommendations for work to be undertaken on a "real world" test to accompany the WCA. At present "work" is an undefined concept in the

WCA. This is problematical because there is no recognition that the necessary components of work involve being able to reliably perform work, on a sustainable basis, for a meaningful amount of time. Even in the era of homeworking, the majority of work also involves being able to travel.

Question 3

At what stage should we stop making changes to the system and let the changes already being made bed in to ensure they are having the desired impact?

- A. Don't stop making changes until the process is considered theoretically perfect**
- B. A few more changes are needed, but then pause to see their impact
- C. After Year 2 changes it will be time to assess what impact changes to date have had before making more
- D. Don't know

Answer

A B C D (delete as appropriate) and provide any written comments ...

We are mindful that incremental change it is inherently unfair. It leaves different cohorts of people made to go through different "versions" of the WCA, with the current version being particularly crude and blunt.

However in the absence of abandoning the WCA and starting again, our preference is that DWP should continue to strive to improve the current system.

Question 4

Does the Year 1 recommendation go far enough in placing the right emphasis on the face-to-face assessment?

- A. Does not go far enough – still too much emphasis on the face-to-face assessment**
- B. Balance between the face-to-face assessment and the rest of the process now about right
- C. Goes too far – now too little emphasis on the face-to-face assessment
- D. Don't know

Answer

A (delete as appropriate) and provide any written comments ...

There are two areas which need to be considered with the face to face to assessment.

Firstly, there are practical problems that people are experiencing with the venues, either their location, or the disabled facilities on offer. There are also organisational issues with waiting times (having been asked to turn up ten minutes early, there have been a substantial number of complaints about the waits and even cancellations once arrived). All of this adds to the anxiety and stress of people with Parkinson's (and their families). This was picked up the Work and Pensions Select Committee's report *The role of incapacity benefit reassessment in helping claimants into employment* (13 July 2011).

Secondly, and more importantly, the face to face assessment continues to be a time limited process which cannot hope to assess a complex and fluctuating condition such as Parkinson's in the time given. People with Parkinson's find there is not enough time accurately convey, in the average 46 minutes that an assessment takes, the way in which the condition affects their ability to function in a workplace. While we understand the arguments for a face to face to assessment, we believe that there is still too much emphasis on this snapshot process when someone has a progressive, neurological condition like Parkinson's.

We believe that there should be much more emphasis on the gathering of medical evidence **before** a decision is taken on whether there is a need for a face to face assessment. People with Parkinson's report attending tribunals and within a matter of minutes they are told they have won their appeal, often with reference to the wealth of medical evidence they have supplied.

The use of medical evidence is still very variable with some people reporting that it seems to have been comprehensively taken into account and leading to inclusion in the Support Group.

For example, Mr L wrote to us following the call for evidence with this experience:

"My wife has had Parkinson's for 9 years now. In 2009 on top of the Parkinson's she developed a prolapsed bowel. I had to give up work overnight. We applied for ESA and just after the assessment phase ended we received a letter to say she was being put in the support group. From applying to receiving the letter we did not get any requests to attend any medicals. A year later we received another received another assessment form to fill in. We filled in the form and sent it off. My wife had had a operation to sort out the bowel. She had by this time also developed memory problems and her balance had gotten worse. I was expecting her to have to attend a medical which looking at some of the reports I have

seen if she had been sent for would have passed as fit to work even though she needs someone with her most of the time and does have other problems which I do not think would not have been picked up at an assessment. About 8 weeks later we received a letter to say she was staying in the support group indefinitely.

What I think may have also helped us we put down the names addresses and phone numbers of any one she has been to see not just the doctor. We even put down the speech therapist, and the falls clinic she has been to and sent in copies of the visit to the neurologists."

At the other end of the spectrum, Mrs B reported attending her husband's assessment and also a Job Centre plus interview (following him being declared fit for work") despite a wealth of evidence from his consultant neurologist it clear that the impact of his Parkinson's on his capability was in doubt. Indeed at the JCP the interviewer stated "you look well, I can tell you are fit for work".

Question 5

Do you have any robust evidence about the face-to-face assessment processes and outcomes which will help us make recommendations for future improvements?

Answer

Please provide any written comments ...

In the main the reports we get are individual reports, and not of the quantity which would lend itself to statistical analysis. Indeed it would be helpful if the DWP undertook greater statistical analysis of the outcomes of the WCA, particularly condition specific data as there may be patterns relating to certain conditions.

But those individual reports continue to highlight variability of experiences. Obviously we hear more of the negative experiences primarily because people are aggrieved by the process and/or the result.

Some people continue to report on the lack of interaction between the assessor and the claimant, due to entry of information on the computer, while some report that assessors have put them at ease and interacted well. Some report on the lack of understanding of Parkinson's shown by some assessors, while others have been reassured that the assessor has a good understanding. For some people the environment itself has not been conducive and the impact of issues prior to the assessment (such as the wait, or lack of facilities for disabled people) has added to the distress of the experience.

We believe it would be beneficial for the review team to consider a "mystery shopping" exercise where people were able to report whether the face to face assessments are improving but also on the issues prior to the assessment, such as long waits. This would bolster the independent evidence base.

Question 6

Are you aware of any concerns about the face-to-face assessment, and if so where have these been focused?

- A. HCPs approach and the way they carry out assessments
- B. HCPs understanding of conditions
- C. The report created during the assessment and the IT supporting the assessment
- D. All three of these**
- E. Don't know

Answer

D (delete as appropriate) and provide any written comments ...

[Please see our answers to Question 5 and 7.](#)

Question 7

If you have heard specific concerns about the IT supporting the assessment (i.e the Logic Integrated Medical Assessment or LiMA system), do you have any robust evidence about how this adversely affects the assessment or its outcome?

Answer

We were very grateful to be invited to a LiMA seminar by ATOS and organised by the independent review team. For the first time, we were able to see the questions and boxes that professionals are being asked to fill in.

Based on that seminar, and from feedback from people with Parkinson's we feel there are major opportunities to improve the LiMA system.

Typical day activities

Our observations are that LiMA drives conclusions on an individual's capability due to the programme's focus on a "typical day". It was a revelation to see that the activities listed bore no relation to a job of work and were focussed around a

discussion with the individual on their daily living and leisure activities. Any data gathered on occupational health was limited to the types of work the claimant had previously been involved in.

It is therefore clear that this is a major limitation to the WCA, and why conclusions are so often wrongly drawn about someone's functional ability. It also gives the perception that the questions are there to "trick" people. For example, we heard from ATOS that if someone was able to watch a full episode of Eastenders that could be used as evidence of good concentration and ability to sit without discomfort.

One of our Information Support Workers provided this example of "extrapolation"

"My client said he was able to go to the supermarket and this was reported on his assessment as such, which no doubt was a factor in concluding fitness to work. What he didn't say, or was not prompted to say, was that he only does so with his wife and literally clings on to a trolley during the whole process so he doesn't fall."

The purpose of ESA is to provide a benefit where it is unreasonable to expect the claimant to work because of mental or physical conditions. **That the discussion with the professional does not focus on the process of preparing for work, getting to and from work, and undertaking meaningful employment is a major omission.**

Someone's description of living in a home environment, often assisted by friends and family, and having significant control over the activities undertaken can bear no relation to the ability to endure a working day and perform to the time and task limitations of a work environment. For example, people with a condition like Parkinson's will have "coping mechanisms" that help them pace their activities, have rest breaks, all with the aim of keeping as independent as possible. Moreover, LiMA does not appear to record how long it would take someone to undertake the activities listed, which could again lead to false assumptions.

Reliably, repeatedly, safely

LiMA also only records ability to undertake activities reliably and repeatedly, and only via an overall screen at the end, which considers tasks collectively. There appears to be no consideration of undertaking activities safely within LiMA. We have been told by ministers that reliability, repeatability and safety should be considered for each activity but this is clearly not the case. LiMA must be changed so that the assessor is prompted at each activity or task to discuss these factors with the claimant.

Predefined options

The system encourages HCP's to use predefined options and simple sentence

building. By limiting the scope of the environments to be considered by the history taking, and by providing generic phrases, which provide very positive and clear statements, the system is unlikely to record accurate details. For example the sentence building has the word “despite” hard coded into it. The claimant is then described as being able to do something despite their condition, which implies they are fully capable. Again, this is why claimants are failing to recognise their reports, as they appear to describe someone fully capable despite the condition they are living with.

Anne gave us an example for the consultation, based on her two experiences that were heavily influenced by the output from LiMA:

“The (second) report was fairer than the previous one, but not surprisingly LIMA had still churned out under Functional Problems “I advise that a return to work could be considered within 12 months” and the Reason for the Opinion Given, “Her condition appears to have worsened; it is possible she could still stabilise”. If only ... ! These comments are computer generated and I have noticed that other people get the same comments as me. So I presume everyone gets called back every six to twelve months because LIMA always spews out a time span for a return to work, like Christmas cracker jokes – there is a range of four jokes in a box of twelve crackers. My second medical report says it took just 5 minutes to complete; not much time for it to be individually tailored for me.”

Medical and other evidence

It was unclear how medical history and evidence, versus this typical day information is weighted in LiMA in order to recommend a descriptor of choice. It is also unclear how assessors might be prompted by LiMA to enquire more around certain issues pertinent to less known conditions, for example, many people with Parkinson’s report problems with sleeping, as well as fatigue.

Question 8

Is there a need to present and explain the face-to-face assessment in a different way, making it very clear to claimants what it will involve and how a functional assessment relates to work capability?

- A. Urgent need to present and explain the face-to-face assessment in a different way**
- B. A need to present and explain the face-to-face assessment in a different way
- C. Not sure whether there’s a need to present and explain the face-to-face assessment in a different way

- D. No need to present and explain the face-to-face assessment in a different way
- E. Definitely no need to present and explain the face-to-face assessment in a different way

Answer

A B C D E (delete as appropriate) and provide any written comments ...

In our experience there still continues to be a lack of clarity from JobCentre Plus at the outset at what people can expect from the WCA process, their rights and the way the process can be adapted to suit individual needs.

For instance some people with Parkinson's have said that they remain unaware of the facility to request an assessment to take place at home if they would find it difficult to attend (for example, if they have fatigue, mobility problems or anxiety symptoms), or that they can ask someone to accompany them to the assessment. They continue to depend on our advisory officers to guide them through the process and inform them of these opportunities.

Even the initial letter and prospect of a phone call can be very daunting for a person with Parkinson's.

This was a recent response from Mrs P, whose husband has Parkinson's, to the consultation:

"The dreaded letter has arrived. I can "feed back" that it certainly makes me VERY angry that people like my husband have to go through this stress. He, and many others already have enough to cope with!! The letter says that "we will telephone you soon".....as you are probably aware.....phone calls can be very stressful and difficult for PwP. I think i shall have to answer ALL calls just in case it is them!!!!"

Moving on the ESA 50 form there is also concern that the descriptors in this form do not accurately reflect the descriptors used in the rest of the assessment process. For example ESA 50 asks whether someone can mobilise over 50m or 200m, and not over 100m as per the full set of descriptors.

Then when it comes to the assessment the questions then centre around a "typical day" rather than the impact that a working day may have for the person.

All this is very confusing for applicants as to what the assessment is actually seeking.

Question 9

What one thing would you change about the WCA to make it operate more fairly and effectively?

Answer

Please provide any written comments ...

It is very difficult to pinpoint one thing.

As the review team will know the work of the fluctuating conditions group took a comprehensive look at the WCA and made 12 key recommendations ¹ and many more suggestions for improvement of the WCA in its report *Making it work for fluctuating conditions*.

We hope that our suggested improvements in the descriptors of the WCA and the prospective "real world" test will lead to a more nuanced, fairer WCA but this may not be until 2013.

Therefore, if there is one immediate aim we have it is to achieve a situation where people with Parkinson's are not encountering a WCA where they feel as if their condition is treated as irrelevant.

We are not saying that a diagnosis of Parkinson's is the end of someone's life in work, nor are we arguing that the diagnosis means someone is not employable. Far from it. However it must be accepted by policymakers that people with Parkinson's will need support either i) back to work, or ii) because they cannot work.

Yet the two ESA groups have the bar set so high that we suspect many of those who fall in the former category (i) are being told they are "fit to work" and get JSA and no support, while the many of the latter group (ii) who cannot realistically work are being told they "can return to work with support" and are put in the WRAG.

Someone with Parkinson's in this situation (ii) then finds the WRAG subjects them to repeated reassessments and work focussed interviews, which is both wasteful and damaging to their health.

Anne, who is in the WRAG following one appeal, and a further assessment, and is now due another assessment later this year, sums up the injustice that is being felt:

"Claiming ESA over the past two years has made me very bitter. First I apply in good faith to be confronted with a process that amounts to a scam. I am dragged through the most awful procedure in order to get the support I paid in for throughout my working life. Then I have to go through it all again, and again. It feels like continual harrassment. The government has taken the money off me as a matter of course, but now I am ill and need support I have apparently made a life-style choice to live on benefits and have to be punished."

We would like to see the following changes:

Work Related Activity Group

People with Parkinson's who currently feel able to undertake work or **certain types of work** are allocated to the Work Related Activity Group when they apply for ESA.

This is because the WRAG properly acknowledges that people with Parkinson's not in employment will need support into work, because it is a condition that is unpredictable and progressive. In spite of disability equality law, the reality is that the condition puts people at a disadvantage with employers and indeed employers may actively discriminate against employing someone with Parkinson's.

At present the bar for entry to the WRAG is set so high that many applicants are falling at the first hurdle, on the basis that they are not obviously, or entirely, *unfit* to work. This is a wrongful application of the initial assessment.

People with Parkinson's whose ability to work rests on their ability to receive the right support and understanding from employers should not be turned down for ESA. As one father (a retired doctor) put it when he heard his son was declared fit to work despite his Parkinson's, *"he has been left to rot on JSA"*

In addition there should be flexibility about the need for 6 monthly repeated WCA assessments for the WRAG. The 6 months usually has no bearing to how long the person may need for support into work. The timespan should be based around the needs of the individual rather than fixed at what is for many people, too short a time to be able to be supported back into work.

Support Group

People with Parkinson's who feel too ill to work and where work will in fact make their condition much worse, **putting their health at risk**, should be put in the Support Group.

Unlike Incapacity Benefit where there were exemptions for people with severe and progressive neurological diseases, there is no distinction made for those with progressive and degenerative conditions in the WCA.

To save seriously ill people with Parkinson's being found fit to work and the cost of unnecessary appeals, the range of exemptions from the WCA should be extended to explicitly cover these conditions and be considered at the outset. This would be on the basis of medical advice.

This would allow the decision maker to exempt from the face to face assessment

those who are clearly unwell and unlikely to regain capability to work and endure a working day. That is not to say someone with Parkinson's could not choose to engage in work related activity or work but this would be optional and not forced.

In addition, the WCA already has "non-functional" descriptors that describe circumstances in which someone may be found to have limited capability for work or for work-related activity for a medical reason not picked up in the descriptors. Therefore it is not impossible for these to be used in the case of Parkinson's.

These non-functional descriptors exist for good reason, but do not seem to be used at an appropriate point in the system - before the decision. Up to May 2010, 5% of ESA claims were awarded based on the non-functional descriptors (classed under the heading 'medical reasons'), compared to 24% awarded after appeal or reconsideration.

Much more use should be made of these provisions by using the medical evidence available.

Appendix A

Disability Benefits Consortium survey (DBC) September 2011

We note that the feedback shows that the majority of DBC survey respondents considered that since the beginning of 2011:

- Support offered by Jobcentre Plus had not improved, nor had written communications to ESA applicants.
- Customers did not feel better informed for example, on the need to gather evidence from their nominated healthcare professional
- The free text box on the ESA form was not being given sufficient weight
- The accuracy of ATOS reports had not improved
- The customer charter had not made any difference to the behaviour of ATOS assessors
- Jobcentre Plus decision makers were not taking a more central role in decision making, or giving greater weighting to healthcare professional/medical evidence.
- There was low awareness of the existence of mental, cognitive and intellectual champions at ATOS
- There was no noticeable increase in the use of a reconsideration process.

Benefits advisors had also noted the obvious impact of the change to the descriptors from the government's internal review of the WCA. The reduction from 21 to 17 descriptors led 92% of advisors to conclude that the process had become less fair and accurate.

Appendix B

Recommendations of *Making it work for fluctuating conditions* (2011) a report by 5 charities representing people with fluctuating conditions including Parkinson's UK.

1. At the start of every WCA, claimants should be invited to comment on how their condition affects them, whether it is relatively stable, improving, deteriorating or fluctuating. If it is fluctuating, they should be asked how frequent and severe fluctuations are, and what factors may cause or exacerbate them.
2. We strongly encourage the DWP to develop a definition of 'work' for the purposes of the Work Capability Assessment, based on the Australian system's definition (see Section 3b).
3. Further research should be done with employers to develop a better understanding of 'capability for work' (see Section 4).
4. Descriptors should be multi-dimensional – they should take into account both severity and frequency of the symptom or symptoms. Where possible and appropriate, a time dimension should therefore be brought onto the face of all descriptors. We recommend that this be done by assessing the percentage of time that someone is affected by the relevant symptom or symptoms in a three to six month period.
5. To more accurately assess the impact of multiple symptoms or conditions, and to recognise their cumulative impact, the WCA should include descriptors worth 3 and 6 points (see Section 4b).
6. All descriptors should expressly assess whether someone can perform an activity 'reliably, repeatedly and safely' and, as appropriate, 'within a reasonable amount of time', without significant discomfort, breathlessness or fatigue.
7. The descriptors cannot be dealt with in isolation – we make a number of supporting recommendations regarding the implementation of the descriptors as part of the assessment process as a whole in Section 5b, including guidance and training for assessors and decision-makers, the general approach to the assessment, timing of assessments, and gathering additional medical evidence.
8. The descriptors need to be amended to reflect more accurately working activities. More research needs to be done, particularly with employers, to establish what these activities are.
9. Further work should be undertaken with impairment-specific groups to develop exact wording and scoring of descriptors, and consideration must be given to re-establishing a descriptor regarding moving between standing and sitting.
10. The recommendations of the group regarding mental, cognitive and intellectual function should be seriously considered and implemented. In particular, a descriptor which covers this sort of cognitive dysfunction in both physical and mental conditions is a crucial addition which should be made to

the WCA. It is extremely important that the time taken to complete activities is taken into account.

11. An additional descriptor should be added which addresses the impact of generalised fatigue and/or pain.

12. The 'non functional descriptor' should be used more actively and consistently. It should be included on the face of the WCA alongside the functional descriptors to encourage this.