

## **Of little benefit and not working: People with Parkinson's experience of Employment and Support Allowance**

(My husband) “has all the usual symptoms of Parkinson’s: freezing, slow and quiet speech, difficulty with swallowing, shuffling, poor balance, dribbling (mouth), accidents when he can't reach the toilet on time, he has difficulty getting in and out of bed, nightmares, needs help with personal hygiene, and assistance with getting dressed... (he also) suffers from prostate problems which means that he has to go to the toilet around 4-6 times a night. (He) was given NO POINTS in his medical assessment and advised to join JobSeeker’s Allowance at Jobcentre Plus.”

**Case study – Carer of person with Parkinson’s**

**October 2009**

**Parkinson’s Disease Society**

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## **About this report**

This report describes people with Parkinson's experience of claiming Employment and Support Allowance (ESA), which was introduced in the Welfare Reform Act 2007 and replaced Incapacity Benefit (IB) for new claimants from 27 October 2008.

ESA is paid to people whose ability to work is limited by ill health or disability. A minority of claimants are judged to have a limited capacity for work related activity and are placed in the Support Group. The remaining successful applicants are placed in the Work Related Activity group and required to undertake work related activity and attend a series of compulsory work-focused interviews. Those failing to attend the interviews or meet the activity agreed in their 'action plan' face sanctions (benefit cuts).

ESA was introduced in October 2008, so only a small number of people with Parkinson's will have been through the claims process. However, the government plans to move all existing Incapacity Benefit claimants onto ESA by 2013, an additional 2.6 million claimants.

The PDS members survey<sup>1</sup> found that one in ten of all people with Parkinson's were in receipt of IB, the benefit which preceded Employment and Support Allowance (ESA), and nearly half of those people of working age were on IB. If these figures are representative of the general population, this would mean that there are 12,000 people with Parkinson's in receipt of Incapacity Benefit or ESA in the UK today.

Initial feedback from people with Parkinson's claiming the new benefit, leaves many people who have considerable physical and mental disabilities being placed in the Work Related Activity Group, and in many cases denied ESA altogether and forced to claim Job Seekers Allowance.

One in five respondents (22%) had been placed in the Support Group and thus spared the requirement to carry back to work activity. One in five (22%) were placed in the Work Related Activity group, and required to attend a series of work-focused interviews at JobCentre Plus. Four out of ten people were told that they didn't qualify for ESA and were either awaiting for an appeal of their decision, or claiming JobSeeker's Allowance. 93% of those not placed in the Support Group believed that this was the wrong decisions.

This report is based on a survey of 40 people with Parkinson's carried out between January and May 2009, and followed-up during September and October 2009.

The responses highlight a number of problems with the new system, problems that need to be addressed before existing Incapacity Benefit claimants are required to undertake the new process.

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*Life with Parkinson's today – room for improvement*, Parkinson's Disease Society, 2008

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

### **ESA - What's the problem?**

- Medical assessments for ESA do not allow sufficient time for consideration of complex conditions like Parkinson's
- Mental health symptoms of Parkinson's are being overlooked
- The fluctuating nature of Parkinson's is not being taken into proper consideration
- Medical assessors do not have sufficient understanding of Parkinson's to make accurate judgements
- Medical assessors are not taking proper account of patients' medical records and the judgement of neurologists and other experts

### **PDS Recommendations**

- More time needs to be allocated for medical assessments for complex conditions such as Parkinson's.
- Medical assessors should be trained to understand Parkinson's, which has a range of symptoms, including both mental health and physical, which fluctuate in intensity.
- Apparent regional variations in ESA decisions should be investigated to ensure consistency of decision making process across the UK.
- ESA decisions should reflect the claimant's full medical record, not just the result of a brief medical assessment, and mechanisms must be introduced to ensure that medical notes and evidence from specialists are properly taken into account
- powers for claimants to ask for their action plan to be reconsidered where they feel that they have not received appropriate support
- There needs to be an independent review of the Work Capability Assessment to ensure that it is effective in identifying those people with a limited capacity for work.

## People with Parkinson's experience of claiming ESA

### Back to work interviews

One new feature of ESA is the requirement on those placed in the Work-Related-Activity-Group to attend a series of compulsory work-related interviews, from which they are expected to agree an 'action plan' setting out steps the claimant must take towards returning to work. Those failing to attend interviews or fulfil their action plan face sanctions (benefit cuts).

Advisers have the flexibility to defer attendance at interviews at their discretion. People with Parkinson's report a generally favourable experience of work-focused interviews, including several cases where the assessor has agreed to defer their interview indefinitely, because it is obvious that, contrary to the outcome of the medical assessment process, they are unable to return to work. In one instance the assessor helped the claimant initiate an appeals process to be placed in the Support Group, which would exempt them from further work related activity.

#### **Case study - Person with Parkinson's**

The (JobCentre Plus) staff were supportive and gave the impression that they did not agree with the way their department turned down so many applications for benefits.

However, although it is reassuring that Job-Centre Plus (JCP) staff are sympathetic to the needs of people with Parkinson's, less than one in five people felt that the Pathways to Work process would help them find work. Resources are being wasted on forcing people through the back to work process even when the personal advisor admits there is no realistic chance of the person returning to work.

Several people with Parkinson's have reported problems attending the Pathway to Work interviews. The fluctuating nature of the condition means that many people have 'off days' where their mobility is severely impaired and they may be unable to leave the house. Many people report that they found the interview process very stressful and needed support to help them attend their series of back-to-work interviews.

In several cases an Information and Support Worker (ISW) from the PDS attended the interviews with the claimant. However, not all claimants have had this support, and 41% of people reported problems attending interviews and just a third of these felt that JCP staff were understanding about their problems, with two thirds facing sanctions (loss of some benefit) as a result. It is essential that account is taken of the difficulty people with Parkinson's can have attending interviews and that sanctions are not applied to people whose condition can prevent them attending interviews at JobCentre Plus.

As part of the ESA process, 'action plans' should be agreed between the claimant and their personal adviser, but two thirds of those who had an action plan as a result of their assessment thought that this was 'unrealistic'. Genuine agreement must be sought from the claimant before their 'action

plan' is 'agreed'. We would like to see claimants given powers to ask for their action plan to be reconsidered where they feel that they have not received appropriate support.

**Case study - PDS Information and Support Worker**, describing the support she had to provide to an ESA claimant with Parkinson's who was placed in the Work Related Activity Group. The ISW drove the claimant all but one of the interviews: the one day she was unable to help there was bad weather resulting in the cancellation of buses, and the claimant was late for her interview. The claimant also fell over on the way to the interview.

"I have attended all but one of her Pathway to Work interviews with her, and also her initial Jobcentre Plus interview. The reason I attended was that she would have found it difficult to get there under her own steam as she gets so tired. Each person that she has dealt with has been very understanding of her condition but have felt that their hands have been tied due to the system they are having to follow: we have to fit in the five interviews in a specified time frame and with doctors appointments, clinics etc this can be a problem."

### **People with Parkinson's experience of Medical Assessments**

The Work Capability Assessment undertaken by claimants, is made up of three elements:

- The limited capability for work assessment – which decides whether you have a limited capability for work – if you do you qualify for ESA.
- The limited capability for work-related activity assessment – determines whether you should be in the Work Related Activity group or the Support Group.
- The Work-focused health-related assessment – looks at the support a person needs to be able to return to work

Medical assessments are currently undertaken by a private company, Atos Healthcare on behalf of the Department for Work and Pensions.

People with Parkinson's report a very negative experience of medical assessments and say that medical assessors lack training in and understanding of the condition. Just 10% of respondents felt that the professional assessing them had a good understanding of Parkinson's.

In order to qualify for Employment and Support Allowance you need to score at least 15 points in the limited capability for work test, part of the Work Capability Assessment, which is based on a series of 'descriptors'. Feedback from people with Parkinson's highlights that these descriptors are failing to identify serious disability that would make any return to work unrealistic, with descriptors failing to take into account factors such as the time taking to perform a task and fatigue, a common symptom of Parkinson's.

Though the government has undertaken a review of the 'descriptors' used in the WCA, this review had a stated aim of reducing the number of successful claimants and did little to address problems with existing descriptors. We would like to see an independent review of the Work Capability Assessment and the descriptors used in the assessment, to ensure that fair and accurate decisions are made.

**Case study - Person with Parkinson's**

"(I was) placed in the Work Related Activity Group and was told with suitable training and rehabilitation and medication will be fit for work in 6 months, although I have trouble walking, and I am starting to become very forgetful, and find it very difficult to finish tasks/jobs (and my) neurologist has mentioned possible Parkinson's related dementia."

**Case study - Person with Parkinson's**

"I highlighted difficulties in writing, balance, simple tasks taking much more time e.g. putting letters in envelopes, using paper fasteners, aspects of dressing, stress, stiffness causing some difficulty in walking, getting up from kneeling, Difficulty in locating objects from pockets. Voice at times is croaky and I have become more softly spoken. I do not sleep well and I do get very tired at times. I was told I needed 15 points to qualify and I was given none."

**Lack of time for medical assessments**

Claimants tells us that the medical assessor did not allow them time to properly answer the questions, in more than one case putting their hand up to stop the claimant talking. 85% of people report that they did not have a chance to discuss all of the relevant health problems. Claimants report that their medical took as little as 20 minutes, far from sufficient to cover all of the likely symptoms of Parkinson's.

Rushed assessments are likely to have a disproportionately negative impact on people with complex and fluctuating conditions such as Parkinson's, who are likely to need more time to discuss the wide range of symptoms and the fluctuations in those symptoms. This problem is exacerbated by a general poor understanding of the condition, which means that the assessor does not understand the combined impact those symptoms are likely to have on the person's ability to work.

**Case study – Carer of person with Parkinson's**

"I would have liked the opportunity to have explained all of this to the assessor, however, he would not allow me to clarify or explain what X was trying to say as he put his hand up to me to stop me helping/talking."

**Case study - Person with Parkinson's**

"I was not given the opportunity to elaborate any of the answers. i.e. all questions asked were yes/no answers If, I tried to elaborate the Doctor raised hand in a dismissive manner, did not seem interested."

Those people who were placed in the Support Group as a result of their medical stated that they felt they had time to discuss their condition and that the medical assessor seemed to understand the condition. This suggests that correct decisions are being made when time is taken to carry out a comprehensive assessment.

Allocating more time for assessments of complex conditions will lead to less mistakes, meaning that severely disabled people are not mistakenly required to seek work. This will also reduce the number, and related cost of, avoidable appeals.

### **Medical notes and reports from specialists are not properly taken into account**

Feedback from ESA claimants with Parkinson's suggests that decisions are being made based on how the person presents during the medical examination, with scant regard to their medical notes and the opinion of specialist consultants involved in their care. This means that people with fluctuating conditions such as Parkinson's are often wrongly assessed.

#### **Case study - Person with Parkinson's**

"Both interviews I had with Atos employees were of the same ilk, I was not even allowed to give them letters from my neurologist, cardiologist or my GP, stating that in their opinion I would be unlikely to return to work with my disabilities and illnesses."

Atos Doctors making the assessments lack expertise in Parkinson's, yet in some cases, they appear to be over-ruling the expert opinion of a neurologist, based on a 20 minute examination and without taking account of years' of medical evidence.

#### **Case study - Person with Parkinson's**

"My consultant rates my condition now as severe, whereas the Atos adviser rated my Parkinson's as "mild". I am also on a high dose of Sinemet, the Atos adviser said I was on a "moderate" dose."

### **Fluctuations in symptoms are not understood or taken into account**

Parkinson's symptoms fluctuate during the course of a day, depending upon when the person's medication was taken. Symptoms can also fluctuate from day to day, meaning that someone who is mobile one day can have great difficulty moving and many other complications the next day. It is essential that proper consideration is given to the medical notes so that these fluctuations can be properly taken into account.

**Case Study - Information and Support Worker** describing the experience of a claimant with Parkinson's

"He felt reasonably well at the time that his Work Capability Assessment (WCA) meeting started. However, he says that if it had started at a different time of the same day, the results/points would have been quite different, and his entitlement to ESA would not be at risk."

**The mental health elements of Parkinson's are frequently overlooked.**

People with Parkinson's tell us that their mental health symptoms are being overlooked during their ESA medical assessment. Non motor symptoms such as depression and fatigue are common in Parkinson's, but claimants tell us that they are not being given an opportunity to describe these problems. In one instance, symptoms of dementia appear to have been overlooked completely.

It is unclear whether these problems are due to poor understanding of the condition, or the time pressures discussed above, which prevent detailed discussion of both mental and physical symptoms, though both are likely to be factors. Whatever the reason, the impact is that people with severe physical disability plus mental illnesses such as dementia or depression are being told that they are fit for work.

**Case study - Person with Parkinson's**

"If I'd been under the heading of mental illness I'd have probably been awarded ESA, but because I'm classed as neurological I didn't qualify."

Additional time must be allocated for medical assessments of people with conditions that have both a physical and mental health element to ensure that the assessment is accurate and reflects all relevant symptoms.

Improved training of medical assessors is also needed to ensure that they are aware that mental health symptoms are common in Parkinson's.

**Automated computer systems do not allow medical assessors to give an accurate picture of people with a complex and fluctuating condition**

Several people report being forced to give yes or no answers to questions about complex and fluctuating symptoms and report that the medical assessor have stated that they are unable to take into account the time taken to undertake the activity.

The PDS has not seen the computer systems in question, but have had consistent reports that assessors are unable to enter the detail of an individual's condition because it doesn't fit the tickboxes used by the computer system. We would like to see the computer system reviewed to ensure that assessors are able to give an accurate picture of the medical condition of the person they are assessing.

**Case study - Person with Parkinson's**

It seems that you are judged based on computer generated questions and answers which must "fit" the appropriate box on screen.

**Case study - Person with Parkinson's**

(The Doctor) would only accept yes/no answers, that to me seemed loaded questions that you could only say "Yes" to. When asked if I could get out of bed in the morning I said, "Yes, but I have a...", the interviewer stopped me and said he only wanted a simple yes or no. So I was not given the opportunity to tell him about the rail I have to help me on bad days, or the fact that I have to stay in bed for up to an hour, while my drugs kick in.

**Apparent regional inconsistencies in decision making**

Initial feedback from our network of Information and Support Workers (ISWs), suggests that there are variations in how Employment and Support Allowance is applied across the country. One ISW has supported three people to claim the benefit, all were unsuccessful, despite serious disabilities in all three cases. Recent media reports<sup>2</sup> have stated that 90% of ESA claimants were turned down in some areas, which suggests that there are major regional inconsistencies in how ESA is applied, although the DWP have yet to make public the data behind these reports.

**Appeals**

People who fail the Work Capability Assessment are able to appeal and, until their appeal is heard, can continue to receive ESA at the basic level. Respondents with Parkinson's who have appealed their initial decision report poor communication about the decision, the appeal process and the details of the interim payment.

One claimant reported receiving conflicting letters and phone calls, including two letters on the same day – one saying that he had been awarded ESA and one saying that he was unsuccessful. He finally received a (backdated) payment for ESA, only to find out weeks later that this was a temporary payment until his appeal was heard, this was not made clear to him.

Another claimant was not told that he was entitled to continue to receive payments whilst waiting for his appeal and needed the support of his local Parkinson's Disease Society Information and Support Worker to ensure that his payments were made.

It is important that claimants are clearly informed about the appeals process, including clarity about decisions made and pending and any interim payments being made.

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<sup>2</sup> Financial Times, 12 July 2009

**Case study - Family member of person with Parkinson's**

"We have had to repeatedly request that ESA continue to be paid whilst the appeal is heard. My brother is signed off by his GP and therefore cannot claim JSA so falls through the gaps in the system. Without the support of family and the PDS I dread to think what would happen... My brother has found the whole process stressful and degrading and this has had a detrimental impact on his health."

**Case study - Person with Parkinson's**

"I am trying to contact JobCentre Plus to get confirmation of my situation in writing so that I can begin to understand what my exact situation is. Furthermore for them to explain how they worked out the sums of money they have paid."

**People deterred from applying for ESA**

There is also some evidence that People with Parkinson's are being put off from applying for ESA by the anticipated stress of the assessment process and series of back to work interviews. Stress can make the symptoms of Parkinson's worse and it is understandable that people would wish to avoid a stressful series of back to work interviews where returning to work is not a realistic option.

**Case Study – Person with Parkinson's**

"I have tried filling out an online trial form for ESA, only to discover that I would not be in the Support Group, which means going to all those work-related activities... I would perhaps have applied if I knew they would take notice of where I am at the moment."

In this context it is disturbing that the initial figures published by the DWP show that 38% of claimants closed their claim before the assessment was complete. Our concern is that this may include people with Parkinson's who were put off from completing their claim by the stress of the claims process and we would like to see the DWP survey a random sample of these people to ensure that those with serious disability are not dropping out of the ESA claims process.

**Case study – Relative of person with Parkinson's**

"Four days after the assessment my husband was rushed to A&E with severe chest pains. All of this has been a nightmare for us, it has caused so much stress and upset and I feel that the assessment could have been handled in a much better, kinder manner. As you know stress is not good for Parkinson's patients."

## **Degenerative conditions**

Because ESA is a relatively new benefit, it is unclear how well the system will work in identifying deterioration in people's condition or illness.

The underlying assumption of ESA is that the majority of disabled people will be able to return to work over time, if they are offered the correct support. Little attention has been given as to how people with degenerative conditions like Parkinson's will fare under ESA as their condition deteriorates. It is essential that where their condition has deteriorated that this results in reassessment that facilitate an easy transition from the WRAG to the Support Group.

## **Conclusion and recommendations**

The government has stated that they wish to reduce the number of people claiming incapacity benefits by one million, hence the introduction of a stricter Work Capability Assessment, which aims to support people with low levels of disability to return to work.

However, feedback from people with Parkinson's suggests that the impact of the new system is hitting people with high levels of disability, with no realistic prospect of ever returning to work, and who face unnecessary, and potential harmful stress as a result. This is both damaging to individuals and poor use of resources that should be directed to those better able to return to work.

The PDS would like the government to take action to ensure that the problems identified in this report are addressed.

- More time needs to be allocated for medical assessments for complex conditions such as Parkinson's.
- Medical assessors should be trained to understand Parkinson's, which has a range of symptoms, including both mental health and physical, which fluctuate in intensity.
- Apparent regional variations in ESA decisions should be investigated to ensure consistency of decision making process across the UK.
- ESA decisions should reflect the claimant's full medical record, not just the result of a brief medical assessment, and mechanisms must be introduced to ensure that medical notes and evidence from specialists are properly taken into account
- powers for claimants to ask for their action plan to be reconsidered where they feel that they have not received appropriate support
- There needs to be an independent review of the Work Capability Assessment to ensure that it is effective in identifying those people with a limited capacity for work.

## Further case studies

### **Case study – person with Parkinson's and dementia**

Both interviews I had with Atos employees were of the same ilk, I was not even allowed to give them letters from my Neurologist, Cardiologist or my GP, stating in their opinion I would be unlikely to return to work with my disabilities and illnesses. I think I was briefly given the opportunity to tell the second interviewer of any aids I needed, to which he replied, from what you have told me, you would only require say a raised toilet seat in your work place.

In the second interview, the medical assessor said that he appreciated I had no transport, if they could arrange transport, would I be willing to "go to Coventry" (65 miles away) to find work. I will not put what my wife said to that, needless to say she was very upset, and told the interviewer that only a couple of weeks earlier I had wandered off, that most of my family were out looking for me, that when found I was in no fit state to look after myself, and had no idea where I was. If I could not tell where I was in my own area, what would happen if it happened in Coventry?

The interviews I have had so far with staff from JocCentre Plus (JCP) have been better. First I had an interview with a guy who was very friendly and told me what they would be doing in the coming months. He said that they were there to help, not force me back into work. When I told him about the medical interviews, he seemed genuinely shocked about how the interviews had been held and told me that he would pass on my concerns.

Then a few weeks later I was called for my second interview at the local JCP office, this time I saw a young lady who was very helpful indeed. As I walked to the interview cubicle that she was in she noted my slow movements, and the way I walked, so as soon as we sat down she started to ask what, when I interrupted with "Parkinson's".

This young lady went away to talk to a supervisor, but returned rather quickly and said she would defer me for six months. Then at that time I would not have to come in, as she would ring me and ask if I was the same, to which I would reply "Yes", and she would defer me for another six months. I said to her how long can you do that, she grinned and said forever. So stop worrying, you will not be forced into work that you cannot do, and after a year or 18 months of deferrals they would possibly be able to put me into the Support bracket automatically. I have to admit I cried at this point, as I had been very frightened at the thought of having to try and cope with work again.

I feel very strongly that medical assessments are missing the problems that people with Parkinson's have to deal with on a daily basis. It does not seem to even touch on the grounds of memory, or communication skills or the ability to carry out a task when you are coming into your 'off period'. When I told the medical assessor about the off period, which in my case starts an hour before medication, his reply was, "I am sorry but I don't know much about Parkinson's".....I think that sum's it up for me.

### **Case study 2 – Person with Parkinson’s**

X (58) has a form of Parkinson’s, called Multiple System Atrophy (MSA). It’s a much rarer form of Parkinson’s that does not respond well, if at all, to medication. MSA also progresses more rapidly than typical Parkinson’s, and he says he has been told by his consultant the outlook for his condition is “not good.”

He was rejected for ESA, having been awarded zero points in his medical assessment, and has been waiting the decision of his appeal for over four months. It has now been 10 months since he first submitted his application for ESA.

Like the more common form of Parkinson’s, his symptoms include a slowness of movement, stiffness, freezing, and his speech is also affected. When the medication does work, and wears off, he becomes stiff, like a statue. Parkinsons’ and MSA both fluctuate in the severity of the symptoms, meaning people can be capable one minute, but severely disabled the next.

“The assessment was more like a computer tick-box system and the questions they ask you bear no resemblance to the condition you’ve got. Then there was a medical, for about 20 minutes, and it seems that if you can move your arms and your legs, you’re fit enough to work.

“I was a heavy goods driver. I do have problems with my movement, and I don’t see how there’s anything I can really do– I can’t operate machinery for safety, and my symptoms mean I can’t write. What I really should have done is not take my medication that day - then they wouldn’t have been seeing me at my best.

Yesterday, I had my six-monthly appointment with my Consultant Neurologist. He confirmed that he is certain I have Atypical Parkinsonism called Multiple System Atrophy (MSA). This is a much rarer form of Parkinson’s that does not respond well (if at all) to medication. The outlook for this condition is not good he told me, and that the progression is a lot faster than in normal Parkinson’s. He rates my condition now as severe, whereas the Atos medical assessor rated my Parkinson’s as "mild". I am also on a high dose of Sinemet, the Atos adviser said I was on a "moderate" dose and stated I could return to work within six months.

My medical assessment took only 20 minutes and did not ask enough questions on my condition, I thought the procedure very unprofessional, the Doctor just asking questions and ticking the boxes on his computer. I feel with Parkinson’s, the patient’s consultant should be the person making this report as to the abilities and disabilities of his condition.”

## **About the Parkinson's Disease Society**

Parkinson's Disease Society (PDS) was established in 1969 and now has 30,000 members and over 330 local branches and support groups throughout the UK. It provides support, advice and information to people with Parkinson's, their carers, families and friends. It also provides information and professional development opportunities to health and social services professionals involved in their management and care.

This year, the Society is expected to spend £4 million on research into Parkinson's Disease. The Society also develops models of good practice in service provision, such as Parkinson's Disease Nurse Specialists, community support, and campaigns for changes that will improve the lives of people affected by Parkinson's.