

SUBMISSION FROM PARKINSON'S UK

The Committee invites views on all aspects of the Bill. Responses should address all or any of the following points in turn:

Views on the Bill as a whole

1. Are you generally in favour of the Bill and its provisions?

Parkinson's UK finds it difficult to comment on the Bill because of the lack of information available about the way in which the Bill's provisions may be used.

We recognise that - although Welfare Reform is a reserved issue - policy in this area has a very significant impact on areas of devolved responsibility including health, social care, local government and housing policy. Co-ordinated policy in these areas is essential for people with Parkinson's and their families.

We appreciate the constraints imposed as a result of the Westminster Government's timetable for implementing the Welfare Reform Act 2012, and the limitations of the information available about its proposals for further regulations. We strongly support the Bill's aim of ensuring that individuals and families in Scotland are able to access a full range of support that they are entitled to after the UK Welfare Reform Act 2012 is enacted.

In common with other organisations representing disabled people and people with long term conditions, we have significant concerns about the Welfare Reform Act.

There are about 10,000 people with Parkinson's in Scotland. 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 also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact on peoples' 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, though one in seven will be diagnosed before the age of 50 and one in twenty are diagnosed before the age of 40.

We believe that the Welfare Reform Act will have a negative impact on many people living with Parkinson's. Some of our concerns are outlined below.

General Principles Underlying the Bill

2. What are your views on this principle?

Parkinson's UK supports this principle because we believe that it is important that policy is joined up as much as is possible. There is a large degree of political consensus in Scotland about the need for Scottish Government policy to focus on preventative spending in devolved policy areas such as health, social care and housing. However, there remains an enormous tension between these policies and the nature of the reforms to welfare benefits.

In common with other organisations working with disabled people and those with long term conditions, we believe that the Welfare Reform Act removes sources of low-level early intervention and is likely to stimulate additional demand for devolved services, including unplanned and crisis interventions. For example, someone with Parkinson's may use their DLA to pay for more expensive pre-prepared food to enable them to prepare nutritious food safely. If they lose their DLA they may be at risk of accidents from kitchen equipment or malnutrition through not being able to prepare meals.

We acknowledge that this Bill is limited in its scope to address these issues, which reflects the nature of the devolution settlement and note the calls by civic organisations including SCVO and the STUC for the welfare system to be devolved to Scotland for these reasons.

Universal Credit

3. What are your views on the proposed powers in relation to Universal Credit?

We support these powers, although we have ongoing frustrations about the lack of information available at UK and Scottish level about how these powers may be used and the full implications of the introduction of Universal Credit.

4. Do you have any other comments on the introduction of Universal Credit?

Parkinson's UK is not opposed in principle to the introduction of the Universal Credit, which could simplify and streamline the process of applying for benefits. However, it will be essential to make sure that people are accurately assessed for benefits included in the Universal Credit, and particularly for contributory Employment Support Allowance (ESA). The experience of people with Parkinson's in being assessed for ESA raises serious questions about the accuracy of the Work Capability Assessment (WCA), and therefore the whole assessment process. Benefits assessors often underestimate the impact of Parkinson's on a claimant's wellbeing and care and mobility needs, and people with Parkinson's in Scotland have reported very mixed experiences of assessment for ESA.

Parkinson's UK has Information and Support Workers based in every mainland health board in Scotland (also providing cover to the islands), and it is their role to provide free, confidential one-to-one advice and emotional support to anyone affected by Parkinson's. Last year, our service reached nearly 1,000 people affected by Parkinson's, and supported people to raise well over half a million pounds in benefits.

Our Information and Support work enables us to have a good overview into how benefits changes are impacting on people living with progressive, fluctuating neurological conditions like Parkinson's.

The majority of people with Parkinson's are being allocated to the Work Related Activity Group (WRAG), but increasing numbers of ESA claims are being rejected. Claims that would have been awarded in the past are now being refused, and people with very significant Parkinson's symptoms are being allocated to the Work Related Activity Group or to Job Seekers' Allowance (JSA).

We have found significant issues around lack of disability proofing of the application / assessment process. Problems include distance to travel for assessment, difficulties with completing forms due to issues with handwriting and a lack of clarity in the information that people receive from DWP after their assessment. Our Information and Support Workers are finding that people are often unclear about the group they have been put into and the implications of this – making it harder to meet the 14 day time limit for lodging appeals where people are inappropriately classified.

The revolving door of assessment and appeal is affecting people with Parkinson's across Scotland.

Where people are being allocated to the WRAG, we are finding people who have received no contact from Jobcentre Plus or other agencies offering work related activities – they have heard nothing at all since receiving their award, making a mockery of the idea that people are being supported to find work.

In addition to financial hardship, people with Parkinson's and their carers are expressing very high levels of anxiety about the process of application, assessment and appeals. Our Information and Support Workers are frequently told that people would simply not have had the courage to submit or attend an appeal without our support.

Personal Independence Payments

5. What are your views on the proposed powers in relation to Personal Independence Payments?

Parkinson's UK recognises the Scottish Government's difficulty in specifying the form that regulations might take in relation to PIPs. We are supportive of the principle that the Scottish Government should have power to make regulations in this area, but note that the Bill is limited in its scope by the devolution settlement.

One area of particular concern is the Blue Badge scheme, which is seen as a lifeline for many people with Parkinson's and their families. We believe that PIP recipients ought to have passported eligibility to the Blue Badge scheme. However, Parkinson's UK would be concerned about any regulation that sought to limit eligibility for the Blue Badge scheme to those who qualify for PIPs. This would seriously reduce the numbers of people with Parkinson's eligible for a Blue Badge, particularly as it may

mean that most older people with Parkinson's (who receive Attendance Allowance and not DLA / PIP) would be excluded from the scheme.

6. Do you have any other comments on the introduction of Personal Independence Payments?

Parkinson's UK has significant concerns about the introduction of PIP, and in particular the Westminster Government's stated intention to reduce expenditure on this benefit by 20%. In Scotland about 1,800 people with Parkinson's receive DLA. In its consultation on the criteria for PIP and associated regulations, the Westminster Government revealed that of the 2.2 million people of working age who currently receive DLA, some 0.5 million people will not be eligible for PIP.¹

It is very hard to ascertain who will lose their DLA and be unable to access PIP under the proposed criteria. As the Westminster Welfare Reform Committee² commented:

"We are unable to ascertain, from the latest figures released by DWP in January, from which DLA rate combinations the projected PIP caseload reduction of 500,000 claimants will come and therefore which current DLA recipients are likely to have their benefit withdrawn altogether. We recommend that, in its response to this Report, DWP sets out further case studies to show how the introduction of PIP is likely to affect current working-age recipients of each rate combination of DLA."

We are therefore very concerned about the implications of the proposed eligibility criteria for PIP, and are consulting people with Parkinson's for more detail about how the changes will impact on them. Our initial thoughts are that the proposed criteria are potentially extremely problematic for people with fluctuating conditions like Parkinson's. People with Parkinson's have already experienced significant problems with the introduction of the Work Capability Assessment, and we are concerned that the PIP process will also impact negatively on them.

PIP eligibility will focus on those with "greatest need". This ignores the fact that people with "low needs" often face significant additional costs because they are not receiving help elsewhere. This preventative support averts costs to social care and the NHS, and we are concerned that demand for these services will increase markedly if benefit support is withdrawn. We are also concerned of the impact of the removal of DLA / PIP on people with Parkinson's and their families, who may find themselves requiring more intensive support sooner as a result of losing these benefits.

¹ See Personal Independence Payment thresholds and consultation (16 January 2012)
<http://www.dwp.gov.uk/docs/pip-assessment-thresholds-and-consultation.pdf>

² See Work and Pensions Committee (2012) 7th report - Government support towards the additional living costs of working-age disabled people
<http://www.publications.parliament.uk/pa/cm201012/cmselect/cmworpen/1493/149302.htm>

In addition despite the focus of PIP on those in “greatest need” we also have concerns that people with Parkinson’s who have high needs may fall foul of the new criteria. The majority of people with Parkinson’s receive the high rate of mobility DLA but it is by no means certain that they will do so under the new PIP regime.

In particular:

- The draft PIP criteria are less appropriate for assessing people with Parkinson’s than the system currently in place. The assessment will not take into account life-limiting symptoms associated with Parkinson’s such as problems with getting out of bed, moving around indoors, the risk of falls and night-time care needs, along with managing high levels of medication (the latter scores “O” points in the proposed criteria).
- Although fluctuations will be measured, the proposal is for someone to ask themselves “does this criteria apply to me at some stage of the day, and if so, does it apply for 50% of those days in a year?” The focus on cumulative scores over 12 months may make it difficult for someone to recall their condition accurately – a shorter timeframe such as a month may make it easier for people to assess their capacity. It may also be difficult to establish “proof” of the extent of disability over a year
- There is a risk that someone may be on the borderline (ie unable to perform a function for half of the time, but could score zero points because they are able to do it the other half of the time). This is particularly likely if people have a fluctuating condition like Parkinson’s
- The definitions of key words in the draft PIP criteria (like repeatedly, reliably, safely and in a timely fashion) are provided, but are ambiguous

There are a number of issues in relation to passported benefits that are reserved. The Westminster Government has clarified that both standard and enhanced rates of PIP will provide a gateway to Carer’s Allowance, and has recently published its proposals for retained links on other passported benefits including Motability³, which is welcome. Both carers’ allowances and the Motability scheme are hugely important to people with Parkinson’s and their families. However, passporting is more than just a case of retaining existing links between DLA and transferring them to PIP. When 500,000 people lose their entitlement to DLA, they will also lose these essential passported benefits.

Subordinate Legislation

³ DLA reform and Personal Independence Payment – completing the detailed design (March 2012)
<http://www.dwp.gov.uk/docs/pip-detailed-design-consultation.pdf>

7. What are your views on the proposed subordinate legislation powers in the Bill?

Parkinson's UK supports these provisions.

8. Do you have any other comments on regulations that would follow this Bill on 'passported' benefits and eligibility for them?

We welcome the Bill's provisions to make provisions relating to passported benefits that have a particular impact on people with Parkinson's in devolved areas. In particular NHS travel costs reimbursement, free NHS dental treatment and optical vouchers are of importance. People with Parkinson's sometimes need additional dental treatment and experience vision problems as a result of their condition, and require frequent attention from medical specialists. Some people will experience significant hardship if their travel costs to NHS treatment are not reimbursed.

Furthermore, the concessionary travel scheme is highly valued by many people living with Parkinson's who are still able to access public transport. The scheme can enable people to travel and remain engaged in their communities.

Once again, there is an issue of what happens to people who are deemed to be no longer eligible for benefits under the Welfare Reform Act, and who will therefore lose their passported benefits too. We would be concerned if eligibility for these schemes were to be further restricted as a result of regulations.

Financial Memorandum

9. Do you have any views on the assumptions and calculations contained in the Financial Memorandum?

The financial assumptions and calculations are currently very limited. We understand the reasons for this, but it will be important for the Parliament to scrutinise these in light of new information that comes to light as the UK Welfare Reform Act is implemented.

Effects on Equal Opportunities, Human Rights, Island Communities and Sustainable Development

10. Are you satisfied in the assessments that have taken place in regard to these matters and in the conclusions reached by the Scottish Government?

Parkinson's UK regrets that so much of the detail needed to make an accurate assessment of these issues remains unavailable to the Scottish Government and other interested parties.

We note that the Joint Committee on Human Rights, in its legislative scrutiny of the Welfare Reform Act⁴ found that the Westminster Government had failed to produce

⁴ See Joint Committee on Human Rights, Legislative Scrutiny: Welfare Reform Bill. December 2011 <http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/news/twenty-first-report/>

an analysis of the Act's compatibility with international treaties on human rights, had not demonstrated reasonable justification for the negative impact of the introduction of Personal Independence Payments on the right of disabled people to independent living and had produced inadequate assessment of the impact on carers and cumulative impacts of multiple provisions on particular groups with protected characteristics (including disabled people).

We believe that the Bill may perpetuate these these ongoing issues, and look to the Committee to seek advice on whether and how the Bill might better protect human rights of people with protected characteristics in Scotland.

I wish to give oral evidence: YES