

WELFARE REFORM COMMITTEE

THE FUTURE DELIVERY OF SOCIAL SECURITY IN SCOTLAND

WRITTEN SUBMISSION FROM PARKINSON'S UK

Introduction and context

Parkinson's UK believes that the devolution of welfare benefits provides a major opportunity to support disabled people, older people and carers in Scotland in a fairer, more positive way.

Our response is informed by our work with some of the 10,000 people in Scotland who have Parkinson's and their unpaid carers, families and friends. Our team of Information and Support Workers covers the whole of Scotland, and provides free, confidential support and advice to anyone affected by Parkinson's. A significant amount of their time is spent supporting people affected by Parkinson's to understand and claim the financial benefits to which they are entitled.

Parkinson's UK believes that the Scottish Parliament's priority must be to ensure that any new benefits arrangements are used to improve the lives of disabled people and those with long term conditions such as Parkinson's, and their carers and families.

In common with SCVO, Parkinson's UK is very concerned about the problems that may arise if the UK Parliament passes the Welfare Reform Bill into law before the Scotland Bill completes its legislative journey.

Just as disabled people claiming multiple benefits have been hard hit by previous cuts to welfare benefits,¹ they will be a key group affected by the interaction of two benefits systems. Many people affected by Parkinson's who receive disability or carers' benefits are also eligible for other benefits, including ESA and tax credits, that will remain reserved to Westminster under Universal Credit. We want to ensure that people with Parkinson's, their families and carers are not disadvantaged by the interactions between two separately administered systems. For example, if the replacement for Personal Independence Payment (PIP) in Scotland were to be awarded at a higher rate than in the rest of the UK, that this increase is not clawed back through reduced Universal Credit payments.

Parkinson's UK has long argued that devolved welfare powers should be full powers of decision making, not merely powers to administer systems agreed in Westminster. In Northern Ireland, the principle of parity severely constrains the ability of the Executive to adopt different welfare policies from Westminster. We note with concern that the Scotland Bill appears to limit the ability of the Scottish Parliament to create new benefits and make decisions about redesigning the Welfare system in Scotland.

There must be a straightforward transition to a new system so that existing and new claimants are not disadvantaged. People must be able to access the benefits they need as quickly and simply as possible.

a) Personal Independence Payments, Disability Living Allowance, Attendance Allowance and Carer's Allowance

Disability and carers' benefits, including Attendance Allowance, should be given as income to assist people to meet the additional costs associated with being disabled and caring respectively, and must not be appropriated by Scottish Government or local authorities to pay for care.

CoSLA has argued that the devolution of disability benefits provides an opportunity to align benefits for carers, disabled people and those with long term health conditions with integrated health and social care via "a single gateway, administered by local authorities".²

Parkinson's UK strongly opposes this approach. Integrating disability benefits with local health and social care arrangements implies that people who receive disability benefits are, or ought to be, receiving social care services. In fact, many disability benefits recipients do not use social care. Disability benefits have an important role in promoting independence and enabling people to live without social care support. There is a real danger that this approach would result in people outwith the social care network missing out on essential benefits. Local delivery could also lead to a postcode lottery in terms of access to disability benefits.

People with Parkinson's strongly support the retention of Attendance Allowance in its current form. When surveyed about plans to abolish Attendance Allowance and integrate the money into an improved system of social care, 62% of people with Parkinson's stated that Attendance Allowance should not be abolished under any circumstances.³

PIP and DLA

Parkinson's UK has longstanding concerns about the impact of the changeover from DLA to PIP. Those with physical difficulties walking, including people with Parkinson's, are expected to bear the greatest burden of cuts to the benefit, with 548,000 due to lose the high rate payment in reassessment across the UK,⁴ 56,000 of them in Scotland.⁵ The full impact of the changeover to PIP will not be seen until 2018.

Most people with Parkinson's were awarded the high rate of mobility on DLA and most received indefinite or lifetime awards because Parkinson's is progressive and incurable. Some people with Parkinson's in Scotland have lost their mobility award when they were reassessed. As this passports to the Motability car scheme, losing this benefit has severe implications for people's independence and ability to participate in their community.

Parkinson's UK believes that the Scottish Parliament should use delegated powers to create a replacement benefit that more fairly reflects the needs of disabled people including those with long term conditions. Specifically:

- **Paper assessments** for people with incurable, degenerative conditions like Parkinson's. DWP guidance section 2.5.10⁶ states that - with sufficient medical evidence - people with Parkinson's should be assessed for PIP on paper. Despite this, our Information and Support Workers report that most clients are invited to face-to-face assessments and that local DWP staff are not aware of the guidance
- **Long-term or indefinite awards** for people whose condition is incurable and degenerative. People with Parkinson's will become more disabled over time. It is a waste of resources to reassess people with a diagnosis like Parkinson's.
- **Information and application processes** must be simplified and disability-proofed. The two-stage application process for PIP is confusing and acts a major barrier to applications. It involves a phone call to request a form (which can be very challenging for people with Parkinson's because their speech is commonly affected) and completing a hard copy of a form (most people with Parkinson's struggle with handwriting from very early in their condition). Given that disability benefits are substantially underclaimed, the emphasis should be on facilitating disabled people to apply, rather than making it difficult and confusing to do so.
- **Mobility criteria** – the arbitrary 20m rule must be dropped. Parkinson's UK would support a return to the 50m specified under DLA.
- **Fluctuating conditions** - any new benefit must take into account the experience of people with fluctuating conditions such as Parkinson's, where symptoms can vary considerably from day to day, and even hour to hour. Assessments must not be based on a snapshot of how well someone functions on a single day.
- **Medical evidence** – some applicants for disability benefits are let down by health professionals who refuse to provide medical evidence, or charge applicants high fees for doing so, although we are not aware that this has been a particular issue for people with Parkinson's. Parkinson's UK would strongly support introducing reimbursement or other mechanisms into the benefits system to encourage GPs, consultants, nurses and others to provide the medical evidence that claimants need to make a claim before cases reach Tribunal.

Some health professionals have a very limited understanding about the benefits system, so evidence may be framed in an unhelpful way. For example, someone with significant Parkinson's symptoms may be described as having "mild" Parkinson's, because the professional is comparing someone at an early stage in their Parkinson's journey with those with very advanced Parkinson's, rather

than with a person without the condition. This may suggest that someone is minimally affected by their Parkinson's when in fact they are being compared with people who are extremely unwell – typically those with most advanced Parkinson's would be largely immobile, unable to speak or swallow, and have dementia.

Other professionals may encourage their patients to consider their condition in a positive way, focussing on what they can do, rather than what they can't. Unfortunately, continuing this approach in a medical report may underrepresent the impact of the condition, when a full picture - including the "bad days" - is needed.

Parkinson's UK would support clearer instructions for health professionals to help them to understand what is required.

- **Customer care** – one of the major opportunities could be to address the culture of DWP and its contractors.

People with Parkinson's have told us about medical assessors who have been rude, dismissive and sometimes dangerously misinformed about Parkinson's. We are currently dealing with a case where an applicant and his wife were left in tears at a PIP Tribunal because of the overbearing and unpleasant behaviour of a DWP Presenting Officer. We would hope that this kind of behaviour would have no place in a new benefits system.

We'd like to see the assessment based on a meaningful assessment of what people need to be able to lead active lives, rather than focussing on how their condition disables them. Forms must be freely available in multiple formats to enable people to apply.

- **24 hour care needs** – PIP does not account for night-time needs. This is important for people with Parkinson's because insomnia, night terrors, and sleep disorders are a very common and debilitating aspect of the condition. Many people need assistance to enable them to turn over or go to the toilet in the night. Any new benefit must account for night time needs.

Attendance Allowance

The experiences of people with Parkinson's who apply for Attendance Allowance (AA) are generally positive, and it is worth comparing their experiences those who are applying for PIP.

The paper-based assessment process means that most applicants with Parkinson's receive the benefit without the stress of a face-to-face assessment. People are able to apply using either an online form or a hard copy, unlike the rigid hard-copy only approach adopted for PIP. It is rare for people with Parkinson's to have to reapply for Attendance Allowance unless their situation changes.

We have some suggestions for improvements:

- **Complex forms** - the application form for this benefit is long, and some people with Parkinson's find it too daunting to complete. An explanation of why certain questions are being asked could help applicants to understand the information that they need to provide.
- **Mobility component** – AA should introduce an assessment of moving around, both indoors and outside.

The lack of a mobility component also means that AA recipients have no access to the Motability scheme, which can make all the difference in enabling people to maintain independence and remain active in their communities. Nowadays, it is very unusual to give up driving in your 60s, and it seems that AA has not kept pace with the expectation that older people will continue to drive, or will wish to be driven by a carer, and that an adapted vehicle may be the most suitable mode of transport.

The lack of a mobility component also means that there is no passport to the Blue Badge parking scheme, which people affected by Parkinson's often describe as a lifeline. The long application form is a barrier for many older people.

Parkinson's UK believes that AA recipients with mobility issues should be able to passport to both Motability and Blue Badges.

Carer's Allowance

It is estimated that informal carers provide up to 80% of the costs of care for people living with Parkinson's. Carers typically have very high levels of involvement over many years, as the needs of the person they care for increase over time. In a recent survey, nearly two thirds of carers of people with Parkinson's in Scotland were providing care for more than 50 hours a week, yet fewer than one in five people who care for someone with Parkinson's in the UK say they receive Carer's Allowance.

Carer's Allowance should be reformed to deliver a fair income and help if carers wish to work or be in full time study. The earnings limit for Carer's Allowance should be raised, as the limit prevents many carers from returning to work; those in full time education should be able to claim; and the overlapping benefit rule that prevents those in receipt of a pension from receiving Carer's Allowance should be removed.

b) Universal Credit (housing element and administrative arrangements) and Discretionary Housing Payments

Payments to tenants - Parkinson's UK is concerned housing payments being made directly to tenants as part of a monthly lump sum. We believe that the option to pay the landlord directly should be retained. Disabled people typically have much higher living

costs than non-disabled people, and it is common for people to struggle to apportion their spending when budgets are tight.

Although many people with Parkinson's are as able to budget and plan as people without the condition, some people with Parkinson's are at particularly high risk of budgeting problems. This is because mental health, cognitive and behavioural issues are common in Parkinson's. All of these can have a very significant negative impact on people's ability to budget and plan, and could lead to arrears. Having a poor credit rating as a result of rent arrears could drive vulnerable people into dangerous levels of additional debt.

Bedroom tax – Parkinson's UK welcomes the current use of Discretionary Housing Payments to ameliorate the effects of the bedroom tax. However, this scheme is complicated to administer, and for tenants to claim. We hope that the Scottish Parliament will take this opportunity to abolish the bedroom tax altogether.

About Parkinson's

About 10,000 people in Scotland 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. There are also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact. 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'. There is no cure.

¹ Scottish Parliament Welfare Reform Committee(2015) 1st Report, 2015 (Session 4): The Cumulative Impact of Welfare Reform on Households in Scotland

<http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/87136.aspx>

² CoSLA (2015) Welfare Reform, Risks and Opportunities
www.cosla.gov.uk/system/files/private/rc150611item06.pdf

³ Parkinson's UK survey and response to the Big Care Debate (Parkinson's UK 2009)
<http://www.parkinsons.org.uk/default.aspx?page=9848>

⁴ UK Government (2015) response to the PIP moving around activity consultation – October 2013. Table 4 and paragraph 6.10

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/251631/pip-mobility-consultation-government-response.pdf

⁵ Scottish Government (2015) Annual Report on the Impact of Welfare Reform.

<http://www.gov.scot/Publications/2015/06/6720/10>

⁶ DWP(2015)Guidance for PIP Assessors

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/368122/pip-assessment-guide.pdf