

Written evidence from Parkinson's UK [SWP0079]

About Parkinson's UK

1. Every hour, two people in the UK are told they have Parkinson's - a brain condition that turns lives upside down, leaving a future full of uncertainty.
2. Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.
3. We want everyone to get the best health and social care. So, we bring professionals together to drive improvements that enable people to live life to the full.

About Parkinson's

4. There are over 40 symptoms of Parkinson's and these can include freezing, tremor, painful muscle cramps, difficulties speaking and swallowing, anxiety, depression, dementia and hallucinations.
5. Currently 145,000 people in the UK are living with the condition¹. With population growth and ageing, we estimate this will increase by nearly a fifth to 172,000 by 2030. Parkinson's not only affects those with the condition but also has a significant impact on family, friends and carers.
6. While the majority of people develop symptoms after the age of 65, thousands of working age people are also affected².
7. We welcome the committee's inquiry into the impact of COVID-19 on benefit claimants. We have answered as many of the committee's questions as we're able and have sought insights from our specialist benefits staff who provide advice and support to people with the condition and their families and carers.
8. This submission contains anonymised cases of people with Parkinson's and their carers who have sought advice from our specialist benefits staff since the outbreak began to illustrate the issues our community are facing with the benefits system currently.
9. A summary of our points are:
 - o The waiting period for Universal Credit is too long, it doesn't cover mortgage costs and many people are living on their overdraft and credit cards rather than requesting an advance.
 - o Some clients are on legacy benefits such as tax credits or income related ESA and don't want to risk a move to Universal Credit (or would be worse off) so they can't access advance payments.
 - o Communication from the DWP about Universal Credit could be clearer including the support for people in the shielding group, as the guidance from different government departments and bodies hasn't been co-ordinated.
 - o Some people with Parkinson's are not entitled to the government self-employment scheme and will experience rent issues.
 - o As DWP staff have been deployed to resource these changes delays have started to develop in providing evidence for appeals. Also we know assessment companies are trying their best to establish new ways to provide their services, but we know that some people with Parkinson's who are already in the system will have their assessments delayed, leaving them in severe financial and emotional distress.
 - o The current levels are set too low and don't cover the costs people are currently facing.

¹ Parkinson's prevalence in the United Kingdom 2018 - <https://www.parkinsons.org.uk/professionals/resources/incidence-and-prevalence-parkinsons-uk-report>

² Pringsheim, Tamara, et al. "The prevalence of Parkinson's disease" *Movement Disorders* 29.13 (2014): 1583-1590.

How well is the Universal Credit system working for the unprecedented numbers of new claimants?

10. It's too early to give a comprehensive response, however people claiming will still experience a 5 week wait for payment. It is likely that many of the new people who have claimed either won't be eligible due to other income and benefit rates being so low, or will find they have been disadvantaged by legacy benefits such as tax credits stopping in the long term. Please see the example below of a person with Parkinson's who is being supported by our advisers:

- Client is self-isolating and is on sick leave. They are getting Statutory Sick Pay (SSP) at £94 per week. He is part of a couple with children and he has a current claim for child tax credits. As a couple they could claim around £200 per month Universal Credit while his income is reduced. However a claim for Universal Credit would stop the tax credits claim. When he goes back to work the Universal Credit will stop and the tax credit claim cannot then be restarted. In the longer term he will be worse off if he claims Universal Credit now.

Has there been any improvement in the significant delays that new Universal Credit claimants were experiencing in the second half of March?

11. Yes. People with Parkinson's aren't waiting for hours on hold as they had been in March. Also they seem to be getting notification that the claim has been processed in a reasonable time.

What lessons can be learned from the changes that have been made to the processes for verifying the identity of Universal Credit claimants? Are there any particular changes that should stay in place after the outbreak ends?

12. Being able to use the government gateway account for Universal Credit verification would be sensible to keep in place. However we know there have been some delays in people using verify.

How do the needs of people claiming Universal Credit for the first time now differ from the needs of groups who've claimed it in the past? How well is Universal Credit working for these new groups of people?

13. Those claiming Universal Credit at the moment have no experience of the means tested benefits system. The benefit is not helpful to anyone that needs support with mortgage costs as mortgage interest has been eroded from the benefit system. Please see the example below of a person with Parkinson's who is being supported by our advisers:

- Mr S is 65. He was diagnosed with Parkinson's in 2018. He was earning £400 per week but at the end of March his employers went into liquidation, making 100 staff redundant. He had worked for them for over 30 years. He is now waiting for an administrator to be appointed so he can claim redundancy pay, his last month's wages and notice pay from the government redundancy fund - but this could take up to 6 months. He doesn't think he will be able to find other work. He can claim contributory (new style) Employment and Support Allowance (ESA) at £74 per week. His wife works 18 hours per week and her earnings will not cover their mortgage, council tax and other bills. They have savings of around £1000. They are not entitled to any Universal Credit or council tax reduction due to her income, they cannot get a loan from Universal Credit for help with mortgage interest as she is working.

Are there any indications of how well the Universal Credit system will work for these claimants as they move into work in the short- to medium-term?

14. We believe it won't work very well for people who may be moving back into work after a long period of sickness. The example below of someone with Parkinson's who cannot get any support from Universal Credit, even though they will be living on half pay.
- Mrs J is 57 and was diagnosed with Parkinson's in 2018. She is returning to work after being off sick for several months. She has lived off her savings and now has no money left. She is going to be working from home on half pay. She is worried about paying for food and essentials until she receives her first wage in mid-end May. She receives standard rate Personal Independence Payments (PIP) for both components. Our adviser has suggested she claims Universal Credit, but she will not be eligible unless she is assessed for Limited Capability for Work Related Activity (LCWRA) which is only paid after 3 months, at the very earliest.

How well is the benefits system working for self-employed people who aren't able to access the Government's Self-employment Income Support Scheme?

15. We don't believe support for self-employed people is working well. Legacy benefits can help a couple over pension age where one is self-employed, but under Universal Credit a couple under pension age in a similar situation are not assisted:
- **Couple over pension age.** Mrs N is 75, has Parkinson's and has a reduced state pension. She is classed as self-employed and works on a part-time basis for an insurance company. Her husband is 75, cares for her and has a state pension. They both have small private pensions. Mrs N has high rate Attendance Allowance because she has day and night needs for care. Mrs N has stopped work due to coronavirus, although she hopes to return to work in a few months. She will not qualify for the government's self-employment support scheme as her retirement pension income is more than her taxable profits from her employment. They are entitled to £2 per week in savings pension credit. They can claim housing benefit and council tax reduction and this should give them around £95 per week in additional income, but their rent is £142 per week. Our adviser has encouraged them to claim a discretionary housing payment to top up their rent but this may not be available from their local authority, or only available for 3 months. Government advice is to ask their private landlord for a rent holiday, they asked if they could pay half the rent for 3 months and the landlord rejected this.
 - **Couple under pension age.** Mrs W has Parkinson's and she lost £655 per month when her Disability Living Allowance award was transferred to PIP in February 2020 and she was given 0 points. She has now been awarded PIP after a reconsideration, but this has not yet been paid. Her husband has lost his income as he is self-employed, so they are currently living on her £112 per week contributory ESA. They live with her mother who also has Parkinson's and dementia. Our adviser has encouraged them to claim Carers' Allowance and they can also claim Universal Credit and council tax reduction but they will only get one month of Universal Credit as the government's self-employed scheme kicks in at the end of June, and this will be treated as income. Finally Universal Credit will not cover the mortgage of £400 per month.

How effective have DWP's communications with the public been during this period?

16. We recognise the government are trying hard to inform the public about changes to long established systems alongside educating them on actions they need to take to keep themselves safe. However we believe the department's communications could have clearly explained that

many will be better off staying on their legacy benefits, such as tax credits, or that Universal Credit is not designed to help with mortgage and council tax bills.

How easy is it for people to understand what they're entitled to claim? - Is it clear enough how the benefits system interacts with other forms of Government support during this period, such as the Coronavirus Job Retention Scheme?

17. We don't believe the communications from the department have been clear, especially when the system is already so complex.

Is it clear enough how public health guidance interacts with the benefits system?

18. No. We recognise there has been a lot of work across government to define the various groups of people who would most at risk if they contracted coronavirus. However clarity on this has taken some time to be established and has caused confusion, anger and anxiety.
19. Our helpline and advisers had a large number of enquiries from people with Parkinson's and their carers in the first month of the outbreak, as they were being expected to go to work even though the government advice was that they should stay at home. Members of our community however could not stay at home and claim SSP or ESA as they were not showing coronavirus symptoms or self-isolating with someone who had symptoms.
20. People who are not in the 1.5 million most vulnerable group asked to shield at home, but who have serious underlying conditions, or care for someone who has a condition, are still being asked to work as key workers in a large number of roles, such as care, supermarkets, healthcare and teaching. Many of their employers have refused to furlough them or grant paid leave. They are very anxious as they are more vulnerable to a severe infection from coronavirus and would like to be better protected.

How is the assessment process for Employment Support Allowance working? Have there been any difficulties with obtaining medical evidence to support claims?

21. In our experience so far GP surgeries seem to be supplying fit notes. However people are not getting any paper based or phone assessments, so there is a backlog building up. Also people who would expect to be assessed and placed in the support group are missing out on extra income and premiums in Universal Credit.
22. The example shared in paragraph 13 demonstrates this situation. You cannot get extra money for LCWRA or work related activity in Universal Credit unless you have been assessed for LCWRA and this only happens after the first 3 months of ESA or Universal Credit, so if assessments are delayed then this process takes longer and people cannot get the extra money they are entitled to.

What impact has the outbreak had on people who were waiting for a Mandatory Reconsideration of a decision, or who were going through the appeals process?

23. The effect of large numbers of people claiming Universal Credit means that staff have been moved from other DWP departments. This has led to long delays with mandatory reconsideration and staff providing evidence for appeals are missing the tribunal deadlines.

Have people who were already claiming benefits when the outbreak began seen any changes to the support they receive from DWP?

24. As the committee is aware face-to-face assessments have been suspended for three months. Assessment providers are putting in place other solutions to assess people using paper-based evidence or through re-scheduling virtual assessments. However there is likely to be a big backlog for assessments as the providers get their services up and running, especially for those who may need alternative arrangements put in place or a companion to help with the assessment due to communication difficulties. We are currently following up one of the assessment providers who had been waiting for 3 months for a home visit to assess them from DLA to PIP, which was cancelled due to the outbreak and now is waiting for an assessment. He is getting more anxious everyday.

Are people who are claiming benefits receiving enough money to cover their basic living costs during this period?

25. No. The levels for rent costs in the benefits system (local housing allowance rates) are set so low that many people fail to qualify for any support. Please see below an example of a furloughed worker:

- Mr L aged 50, diagnosed with Parkinson's in 2017. He has been furloughed and his wage has reduced to 80% which will be £263 per week (£13676 per year). He is not entitled to any benefits on this level of income. He still has rent and council tax to pay and was struggling to manage his bills before the 20% reduction in his income. He is worried about how he will manage over the next few months.

Are there groups of people who need support but aren't able to access it through the benefits system? What should DWP be doing to support those people?

26. Yes. We think the example above illustrates those who may need support, that the current system would exclude. We believe that the DWP should raise the levels of support for rent costs to reflect actual levels of rent, not the lowest 30% of rents.

27. We also recognise that those who don't qualify for Universal Credit may still need an advance payment while waiting for their payment through the self-employed scheme. There are no crisis loans in the benefit system outside of the Universal Credit advance payments and many local authorities have no emergency grants funding - so the only offer is a food voucher, which is welcome but will not address issues with rent and utility companies.

Are support organisations and charities able to access the resources they need from DWP to support vulnerable people? What more could DWP be doing to facilitate that support?

28. The DWP have paused their home visiting service and are working on their process to support the applications of the most vulnerable people. We welcome the move announced recently that Universal Credit claimants don't have to call the DWP. However we believe the DWP could be offering more phone support to complete claims.

29. We would be happy to work with the DWP to escalate queries of the most vulnerable in the first instance to them. We think this could reduce some of the telephone calls made to the DWP and also provide a better customer experience for benefit claimants.