PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

Financial health during the coronavirus pandemic

What we believe

The coronavirus pandemic has affected the population's finances. The UK government has announced a series of measures to assist people who are facing an uncertain financial future, with devolved governments also announcing some additional financial support measures. However, we are concerned that the pandemic could impact the financial health of people with Parkinson's and their carers.

We believe that people with Parkinson's should be:

- supported to continue to work where possible, with the necessary safeguards implemented by their employer
- able to easily access information and support about their employment rights to ensure they are supported during this time
- able to get their prescriptions for free (in England, which is the only UK country where people still have to pay for prescriptions) during this crisis to maintain their wellbeing and reduce the need to go into hospital
- able to get their prescriptions delivered for free if they are unable to leave the house due to the government shielding advice
- able to get shopping delivered from supermarkets and, for the duration of the crisis, all supermarkets should cap their delivery charges at £5 for those who are on low incomes, the vulnerable or the elderly
- supported to access the benefits they need to live independently in a timely fashion and in a way that suits them.

We also believe all governments of the UK need to do more to support the self-employed, including those who are carers or are service providers, as current government provisions don't adequately address the financial issues they may face.

We also believe that local authorities across the UK should bring forward their 2-month payment holiday for council tax to May and June, rather than have it at the end of the financial year. This could help to ease the population's financial health.

In Wales, as of 6 April, a long-planned increase¹ in the maximum weekly charge (applicable in non-residential settings) for care and support came into effect. This took the charge from £90 to ± 100 per week at a time when some people are not getting their full package of support for a range of reasons related to the coronavirus emergency. We believe that Welsh Government should halt the increase in charge until such a time that the pandemic is over.

¹ Social Services and Well-being (Wales) Act 2014

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It is also important that governments across the UK do more to support charities who are, on average, facing a 30-40% drop in income, at a time when many are struggling to meet the increased needs of their community

Why we believe it

Call volumes to our helpline and visits to our website have increased as the coronavirus pandemic has progressed.² We have been monitoring the subject of calls and queries and have produced information³ to reassure our community and also ensure our advice is meeting their needs.

Sheffield Hallam University's research on the cost of Parkinson's showed that an average household in the UK where someone has Parkinson's is £16,582 out of pocket each year.⁴ Households where someone has Parkinson's experience:

- higher health costs (£2,229) as they have to pay for items to help them live on a daily basis. These include things like pill timers, prescriptions (in England only) and mobility aids
- higher social care costs (£3,622) as they pay towards changes to their homes, assistance with daily tasks such as cleaning and shopping, and for equipment to help them stay independent, thereby avoiding additional hospital admissions
- **loss of income** due to early retirement or reduced working hours (£10,731) because of the progression of the condition.

In 2019, we had 2,633 completed enquiries to our advisory services – helpline, local advisers and Benefit and Employment Advisers. 78% of these enquiries were around benefits. Of those, 19% were employment enquiries. Our advisory services were successful in getting £454,767 from appeals and reconsiderations for people with Parkinson's, demonstrating that the benefits system is not working for people with the condition, but that our services are successful in their advocacy. $_{5}$

What we are doing

The Policy Panel suggested there are also things that Parkinson's UK could do to provide reassurance and information to our community at this time too. They included:

- tailoring government advice to the condition and promoting it to our community
- providing support around funerals both financial support to arrange the funeral and emotional support to prepare people to attend it.

We have already taken action based on feedback from our community on many of the suggestions above. These include the following:

• Producing <u>regularly updated information on coronavirus and Parkinson's</u> and signposting, where relevant, to Department for Work and Pensions (DWP) information.

² Parkinson's UK shared information system, April 2020

 ³ Parkinson's UK website, April 2020: <u>https://www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons</u>
⁴ Sheffield Hallam University, June 2017:

https://www.shu.ac.uk/research/specialisms/health-and-social-care-research/reports/economic-social-and-financial-cos t-of-parkinsons-on-individuals-carers-and-their-families

⁵ Parkinson's UK shared information system, January 2020

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- Increasing the capacity of our <u>helpline</u> to answer queries and maintaining our local adviser and specialist Benefit and Employment Adviser service.
- Engaging with the DWP and assessment providers to ensure the concerns of people with Parkinson's are highlighted and that any alternative services meet their needs.
- Advocating for our community.
- Supporting work that the National Council of Voluntary Organisations and the Association of Medical Research Charities is doing to lobby the government for more funding to safeguard charities.
- Supporting members of the Parkinson's community who feel strongly about the issue of funding to safeguard charities in writing to their elected representatives.
- Furloughing staff as part of the government's Job Retention Scheme to ensure the future of the charity.
- Gathering evidence on the impact of the coronavirus pandemic on people with Parkinson's and their carers so we can use this in our future campaigning and lobbying.
- An small emergency grant programme to financially support those in our community who need it most.

Acknowledgement

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on financial health during the coronavirus outbreak. The Policy Panel consists of people with experience of Parkinson's who meet on a regular basis to help guide the charity's position on a range of policy issues.

Further information

Please contact the Policy and Campaigns team. Tel: 020 7963 9349 or email: campaigns@parkinsons.org.uk

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