

All-Party Parliamentary Group on coronavirus: Government response and future preparedness

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 All-Party Parliamentary Group's (APPG) inquiry into coronavirus and the government's response and how this can inform future preparedness. We have sought insights from people with Parkinson's, their carers and families and from our specialist staff who provide advice and support to our community.
8. A summary of our points are:
 - o Impact on care and the NHS
 - i. A third of respondents to our coronavirus survey shared appointments with their consultant or Parkinson's nurse had been cancelled with the majority not being offered a telephone or online appointment. They also shared many of their Parkinson's symptoms had increased during this time. We fear that people with the condition will face a long wait for health and therapy services, due to these cancellations and the impact could be felt for years.
 - ii. Almost half of respondents to our survey who had received care before the pandemic stated they had received reduced care during this time. At the same time a significant percentage of carers took on greater caring responsibilities and this had an impact on their wellbeing.
 - iii. There was great confusion around the emergency discharge procedures and the care costs someone would have to pay.
 - iv. Concerns about paid carers being able to access Personal Protective Equipment (PPE) and being able to get tested for the virus.
 - o Support for those with protected characteristics

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.

- i. Our community was unclear and confused with the definitions around the clinically vulnerable and extremely clinically vulnerable groups. NHS data was not accurate so some people got letters at the end of the period to thank them for shielding, but didn't get anything at the start to tell them to shield. As lockdown lifts many people who have been shielding, but aren't technically in the shielding group are fearful of the risk of contracting coronavirus and some have told us they would support the introduction of the Distance Aware badge.
- ii. People with Parkinson's were anxious about catching the virus and being hospitalised, as they feared they would not get access to a ventilator as they would not be deemed a priority to access to life-saving treatment.
- iii. Many members of our community found it difficult to get support to access food and medicines in the first few months of the pandemic, especially those who don't have access to the internet.
- iv. Our charity like many others were inundated with calls and emails to clarify government advice, get more personalised guidance on the risk of infection and being unwell with coronavirus while living with Parkinson's, get access to everyday items and also employment support. At a time when businesses and charities are facing a financial black hole government support was unveiled in a piecemeal way. These packages, while welcome for smaller charities, don't address many of the challenges the sector will face, as many are consulting on redundancies, which will ultimately reduce support to our communities, which the government will need to address.

Impact on care and the NHS

Cancelled appointments

9. Parkinson's clinics and therapy services have understandably changed the way they operate due to the outbreak. Many Parkinson's professionals were also redeployed into the NHS to play their part in containing the virus. This meant appointments were cancelled. Our survey³ found that:
 - o 34% of people with Parkinson's had appointments with their Parkinson's nurse cancelled and of these, 52% were not offered a phone or online appointment.
 - o Similarly, 34% had appointments with their Parkinson's Consultant cancelled and of these, 68% were not offered a phone or online appointment.
 - o 29% of respondents had a GP appointment cancelled.
 - o Cancellation rates were also high for those accessing physiotherapy (70%), speech and language therapy (57%), occupational therapy (55%) and mental health support (50%) and phone or online alternatives were limited.
 - o 15% of respondents decided to cancel their own appointments as they were anxious about the risk of catching coronavirus if they entered a hospital.

10. We are aware that as the NHS restarts services there is anxiety from patients to attend face-to-face appointments as they may be scared about the risk of infection, they may not know what mitigations services have put in place to reduce infection risk or they may be unable to get to the appointment safely if they only have access to public transport. This report from Traverse⁴ outlines some of the concerns from patients with long-term conditions about accessing healthcare services currently.

11. We are particularly concerned about the gap in rehabilitation services and the increased need and a new approach the NHS will need to take after the outbreak has been contained, in order to meet the needs of the entire population, including those who have survived the virus and those with

³ The impact of the coronavirus restrictions on people affected by Parkinson's, Lancaster University, June 2020 - <https://www.parkinsons.org.uk/news/how-have-coronavirus-covid-19-restrictions-impacted-people-affected-parkinsons>

⁴ Knock-on effects of coronavirus on access to healthcare: lived experience, April 2020: https://traverse.ltd/application/files/3315/8823/6199/knock_on_effects_of_coronavirus_on_healthcare.pdf

long-term neurological conditions like Parkinson's⁵.

Virtual appointments

12. While some of our community have welcomed telephone or virtual appointments, many have not been offered them. Those that have had a telephone or virtual appointment are split in its effectiveness.
13. The positives included no having to travel and wait for the appointment. Some clinicians have also reported that they have had very few 'no shows', which maximised the number of patients they could see.
14. However, those who had less positive experiences included people who weren't able to raise the progression of their movement related symptoms effectively by phone, as the clinician couldn't assess that visually. The person with Parkinson's wasn't able to have their carer or family member involved to assist the consultation, the technology didn't work or the individual wasn't able to physically hold the phone for very long due to their symptoms.
15. With the NHS moving towards greater use of virtual appointments we could caution the use of these on a widespread basis, as they may not be suitable for everyone. This report from Healthwatch England, National Voices and Traverse highlights some patient feedback on virtual appointments⁶.

Impact on symptoms and wellbeing

16. Cancelled appointments were seen by many people with the condition as a contributor to deterioration of their Parkinson's and many of our community shared they were worried they were storing up future difficulties.
17. Our Lancaster survey⁷ showed that:
 - more than a third of respondents experienced either more slowness of movement or stiffness or fatigue or anxiety
 - more than a quarter experienced increased tremor or sleep problems
 - around 10 per cent also reported an increase in distressing hallucinations; and
 - around a third said reduced access to exercise had a big effect on their lives;
18. The survey also found that
 - 34% of people with Parkinson's said that reduced access to exercise had a big impact on their lives. Many were frustrated that established physical self-care routines had been disrupted and they were worried about the impact on their symptoms, and the long-term effects on their health.
 - 72% said socialising with family and friends had become more difficult during the pandemic, with the lack of social contact and loneliness being devastating for many.

Reduced care packages and impact on carers wellbeing

19. Our report found that 48% of the people with Parkinson's receiving social care and support at home received less care during the pandemic. This left people unable to manage safely in their own homes. For instance a person with Parkinson's had their care package, which helped them manage their daily medication stopped. Medication is crucial for people with the condition to control their symptoms.

⁵ HSJ, 8 April 2020: <https://www.hsj.co.uk/commissioning/we-need-a-nightingale-model-for-rehab-after-covid-19-/7027335.article>

⁶ The Dr Will Zoom You Now: getting the most out of the virtual health and care experience , July 2020: <https://www.nationalvoices.org.uk/publications/our-publications/dr-will-zoom-you-now-getting-most-out-virtual-health-and-care>

⁷ The impact of the coronavirus restrictions on people affected by Parkinson's, Lancaster University, June 2020 - <https://www.parkinsons.org.uk/news/how-have-coronavirus-covid-19-restrictions-impacted-people-affected-parkinsons>

20. Carers also shared they were worried about the risk of infection from paid carers entering the house, so they stopped care, which placed additional burden on the unpaid/informal carer.
21. The impact on family members, friends and carers, particularly spouses or partners, has been considerable. The findings of our survey showed that 68% took on more caring responsibilities, and this figure rose to 74% if you lived with the person with Parkinson's. 42% of family members of carers said the coronavirus restrictions negatively affected their mental health and 34% said it impacted their physical health.
22. We used a validated wellbeing scale to measure respondents' answers against; and it showed lower rates of mental health and wellbeing for carers of people with Parkinson's. Stress, boredom and loneliness were often reported, with some saying the situation had caused family strain.
23. This is echoed by Carers UK research⁸ about care provision during the outbreak that showed:
 - o 70% of unpaid carers in the UK are picking up even more care for older, sick or disabled relatives; on average, carers are taking on an extra 10 hours of care a week.
 - o A third (35%) of unpaid carers are providing more care because their local care and support services have been reduced or closed.
 - o More than half (55%) of unpaid carers feel overwhelmed managing their caring responsibilities during the outbreak, and are worried about burning out in the coming weeks.

Continuing healthcare confusion

24. Some of our supporters have shared their confusion around the emergency discharge funding and guidance. We are aware that some local authorities have been assessing people who have been discharged from hospital using the emergency procedures and this could jeopardise their hard fought NHS continuing healthcare funding.
25. We were pleased to see clarity on NHS continuing healthcare in a recent letter from NHS Chief Executive Sir Simon Stevens and Chief Operating Officer Amanda Pritchard on 31 July 2020⁹ about the third phase of NHS response to coronavirus. However, there will be countless families who may get a bill in the coming months for care they thought was free.

Availability of PPE and testing for care workers

26. Our supporters have shared that they have stopped care visits as their paid carers were unable to get adequate PPE to provide low risk care to their loved ones. If an individual has a personal health budget they should provide the PPE to their carer from this, but being able to get supplies when they are an individual has been largely impossible, especially when many established social care agencies and providers have struggled to get suitable equipment to cover their own staff.
27. We have also recently been made aware that private paid care staff do not have the same access to testing, which is desperately needed to provide peace of mind to carers, who need this support, so they can keep the people they care for safe.
28. The government response in the areas discussed above needs to improve for further spikes and a possible second wave. We would therefore recommend the APPG encourages the government and where appropriate the NHS to:

⁸ Carers UK, *Caring Behind Closed Doors: the forgotten families of the coronavirus outbreak*. 23 April 2020: www.carersuk.org/closeddoors

⁹ NHS, 31 July 2020: <https://www.england.nhs.uk/coronavirus/publication/third-phase-response/>

- Engage with the Neurological Alliance report and letter to Sir Simon Stevens¹⁰ on restarting neurological services safely (including mental health care) and urgently to meet patient demand.
- Provide appointments in the most suitable format to meet the individual needs of the patient.
- Raise the level of Carer's Allowance to support people who are struggling financially, while also recognising the crucial role carers are playing in the country's fight against coronavirus.
- Provide urgent clarity on funding for NHS continuing healthcare so families are not left out of pocket.
- Ensure there is adequate PPE and testing for paid carers, regardless of whether they are providing care to self-funders or those who are publicly funded.

Support for those with protected characteristics

Unclear definitions and poor data

29. Everyone with Parkinson's is different. Many people with the condition are not clinically extremely vulnerable. However, we believe that some people in the more advanced stages of the condition or those who may have respiratory issues, and some of those who have other conditions alongside their Parkinson's, would meet the clinical criteria to be classified in this way. We believe that these people should have been added to the extremely clinically vulnerable list and in many occasions weren't. They had to contact their GP or their consultant to get themselves added to the list.
30. It is clear Public Health England and NHS Digital undertook a substantial piece of work to define those who were clinically vulnerable and extremely clinically vulnerable in an extremely short time frame. However, the data the NHS holds is not entirely accurate and should as a matter of priority be reviewed to ensure that future lockdown arrangements include the correct individuals.
31. The lack of clarity on who is defined as extremely clinically vulnerable has cut across many different issues the Parkinson's community have faced - from whether someone has to shield, the support to access supermarkets and medication deliveries and now with the changed government advice from last week, it has now impacted employment.
32. Here is an example of the impact of these changes to government guidance from just one person in our community, who has faced employment issues. Mr H, 51, was diagnosed with Parkinson's in May 2019. He works full-time in a finance department. He was initially placed on furlough and then was working from home. He was asked by his employer to return to the office on 6 July but with advice from Parkinson's UK, he was able to negotiate continued home working until the end of July.

"Parkinson's makes me slow and people have been rushing past me in the street when I have gone out, not giving me space, so going back to the office is a big concern for me. I have to use public transport to get to work and even in quieter times, social distancing feels impossible. I'm also worried about shared spaces at work - the toilets are used by other organisations as well as mine, so I have no control over how safe they are.

"Luckily I have been able to negotiate working from home until the end of July with the possibility of a further extension, but I'm worried about what today's announcement means for me and whether my employer could change their mind.

"I feel like I'm only just getting back to being myself since my diagnosis, every day used to be an effort, so the thought of risking my health unnecessarily when I know I can do my job from home is really discomfoting."

Mr H, a person with Parkinson's

¹⁰ Neurological Alliance, July 2020: <https://www.neural.org.uk/wp-content/uploads/2020/07/Letter-to-Sir-Simons-Stevens-on-Restart-of-Neurology-Services-FINAL-7-July-2020-for-website.pdf>

33. This is why we're supporting the joint charity campaign that calls on the government to introduce a furlough-style scheme to protect high risk workers who may be forced back to their workplace¹¹.

Ethical treatment

34. The coronavirus outbreak has sparked concern over equality of access to medical treatment if people become unwell, and in what circumstances decisions may be taken not to provide the highest levels of care to individuals.
35. This has led to very high levels of anxiety among people with Parkinson's and their families. The UK Government has said that people with Parkinson's are at higher risk of complications if they catch coronavirus. The perception that all people with a diagnosis like Parkinson's may be prevented from accessing the life-saving treatments needed to survive coronavirus complications is extremely alarming for our community and in the early stages of the pandemic was propagated by media reports and individual conversations with health professionals.

Isolation

36. People with Parkinson's who have fewer social connections and no online access have reported feeling particularly isolated. Our local advisers have identified their most isolated clients and have made calls to these people to check-in and signpost them to support and services in their local area. Over 2,500 calls have been made by our advisers to isolated people with Parkinson's since the beginning of April¹².

Food and medication access

37. For those who are shielding, getting access to shopping and supermarkets was eased by government arrangements through the NHS Volunteer scheme and close working with charities, the Department of Environment Food and Rural Affairs (DEFRA), local authorities and supermarkets. But this took several weeks and people were left with little food while these initiatives were developed. But for those in our community who are not on the extremely vulnerable list this caused a great deal of anxiety, as they were unable to access online supermarket deliveries. Also those who don't have internet access were unable to access food and in many cases were also unable to wait in long lines to get their shopping or take advantage of quieter shopping times at the beginning of the day, or at least until their medication starts to work.
38. Medication is an important part of the regime for someone with Parkinson's to stay well, alongside exercise and physio or speech and language therapy. People with the condition work with their professional to find the best drug, dose and timing. And this may need adapting as Parkinson's symptoms change over time. It is therefore important that once a regime is established this is maintained.
39. Medication supply issues are commonplace, but have become more frequent in recent months in the lead up to Brexit. Several key Parkinson's medications have been in short supply - co-careldopa 25mg/100mg and Rasagiline 1mg- and this has led to severe anxiety across our community. Throughout the pandemic we have been in regular contact with pharmaceutical companies and the Department of Health and Social Care to understand supply issues and reassure our community, but this is an ongoing concern.

Support for charities

40. Like many other charities calls and requests for support peaked at the start of the pandemic and remained high for the first few months. However this is in contrast to our income reducing

¹¹ Age UK, July 2020: <https://www.ageuk.org.uk/our-impact/campaigning/protect-workers/>

¹² Shared Information System, Parkinson's UK. April 2020

significantly. The government has provided funds to support smaller charities and also the furlough scheme. However these packages don't address many of the challenges the sector will face and therefore communities are facing the prospect of needing assistance but being unable to get it from third sector organisations due to redundancies.

41. The government response in the areas outlined above must improve to ensure services meet the needs of the public for further spikes and a possible second wave. We would therefore recommend the APPG encourages the government and where appropriate the NHS to:
- Investment in developing more consistent and effective data to help the NHS and government identify people who may be at the greatest risk of illness if exposed to a virus. This could aid all government operations and future planning.
 - Introduce a furlough-style scheme to protect high risk workers.
 - Consistently apply guidance and principles around ethical treatment across all health settings, that enables people with Parkinson's to access critical care.
 - Develop programmes with the third sector to reach those who are socially or digitally excluded and tackle loneliness.
 - Support continued engagement activities between DEFRA, the third sector, local authorities and supermarkets to ensure that disabled people and carers continue to be able to access food and medicines to keep them healthy and well.
 - Commit to the Association of Medical Research Life Sciences-Charity Partnership Fund¹³.

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¹³ Association of Medical Research Charities, July 2020: <https://www.amrc.org.uk/Handlers/Download.ashx?IDMF=1cf57b61-5794-46ff-b3a6-0814bc6e9127>