

Written evidence submitted by Parkinson's UK (CVD0027)

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 condition. 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 affected.
7. We welcome the committee's sub-inquiry into coronavirus and the impact on disabled people and their access to services. This submission builds on the evidence we shared with the committee in April. It has been informed by a survey we conducted of our supporters on the impact of coronavirus. We worked with Lancaster University to analyse the findings of the survey and published a report earlier this month.
8. A summary of our points are that people with Parkinson's:
 - Want greater clarity on risks around Parkinson's and COVID-19 and less confusing guidance on who is deemed clinically vulnerable or extremely clinically vulnerable. The different approach across the 4 UK countries has added extra confusion.
 - Want better and more meaningful engagement and consultation is required with patient groups to ensure government advice meets the needs of disabled people.
 - Want to ensure that definitions of vulnerability don't stop people getting access to the food and medication they need, as they did at the start of the pandemic. However engagement with the Department for Environment Food and Rural Affairs (DEFRA) was positive and has addressed many of the issues our community faced. It has also enabled us to develop ongoing work with supermarkets to ensure their services meet the needs of disabled people as lockdown restrictions ease.
 - Have faced a significant reduction in healthcare appointments, which is having an impact on their condition.
 - Have faced issues with their mental and also their families and carers mental health has been impacted by the pandemic, with many being unable to access the support systems they usually do to maintain their wellbeing.
 - Have faced a reduction in their social care support through the pandemic, which has increased the pressure on families and carers who are providing additional care every day. There is also confusion about whether emergency discharge procedures are still being used or if the NHS continuing healthcare national framework is being used to assess people and their eligibility for care.

The effectiveness and accessibility of Government communications and consultation with disabled people during the pandemic

9. People with Parkinson's who responded to our survey wanted greater clarity about what the consequences of COVID-19 would be for someone with Parkinson's, and whether they needed to be concerned. Government guidance and advice on shielding and the categorisation of risk were seen by many as confusing and inadequate. We have seen this reflected by an increase in calls to our Helpline on this issue.

"Just in the 70+ group but - apart from Parkinson's - healthy and no underlying conditions. So unsure how high my risk and how rigorous to be with self isolation."

Person with Parkinson's

"The guidelines for people with Parkinson's have been vague and changing. It was really unclear why we are not in the 12-week isolation group. To say that we are at high risk of complications if we got the virus, yet provided with no shielding, was and is a great cause of anxiety."

Person with Parkinson's

10. As a charity we support people living right across the UK, so the 4 different approaches taken by the different governments has also been confusing.
11. Parkinson's UK actively participates in a number of stakeholder foras with the Department of Health and Social Care and NHS England and NHS Improvement. However during the initial stages of the pandemic some third sector organisations were invited to participate in discussions about definitions and communications. We weren't able to influence any of these discussions as government bodies transmitted information, rather than engaged in a dialogue. In recent weeks we have worked with National Voices and other organisations to develop a statement of five principles to ensure the patient voice is heard in the next stage of the coronavirus response.

Disabled people's access to food and the effectiveness of the Government's response to reported problems

12. A common problem people with Parkinson's shared during the pandemic was being able to access food and essential items from shops, including medication.
13. People with the condition shared they had difficulties in obtaining groceries, as they were unable to access online delivery slots from supermarkets or they would struggle with queuing when they had no option but to go out.
14. A major source of stress for many with more advanced symptoms was accessing food if there was no one locally (e.g. neighbour or family) to help. Some were on the supermarkets' "priority list" and were therefore fine, or had managed to get on it after a struggle, and found home deliveries helpful and reassuring.
15. Those with family, friends without health conditions or helpful neighbours nearby relied on them and felt well-supported. However, some were relying on people they did not know well and worried for how long this could be sustained.
16. However, for others who had no-one locally to help getting an online delivery slot was a huge source of stress. For some who could not access food online, they, or another vulnerable member of the household, had gone shopping. Also there were additional concerns about social distancing and bringing the virus home. Some people with Parkinson's who had been relying on online deliveries prior to the pandemic, suddenly could no longer access them, leaving them stranded.

"Before the corona virus crisis we were shopping online, now we cannot - no free supermarkets slots. We are immobile, I am 74, my husband 79. What can we do?"

Person with Parkinson's

“I am in that bracket where I don't look disabled. My local supermarket (Asda) has used the disabled parking bays for its queueing system as it is closest to the shop door. I have no problem with that but I have to join the queue. There does not appear to be any help for disabled people. And as I do not use a walking aid, no one realises that I can't walk too far and indeed if the queue is long, by the time I get into the shop. I can hardly move. There is nowhere to sit down and rest and no one to help.”

Person with Parkinson's

“The arrangements for shopping were very unclear at the start, the guidance notes stated that to qualify for assistance from government you needed to be vulnerable or elderly. Parkinson's yo yoed from being on the vulnerable list to not on the list. Getting a delivery slot was extremely difficult and free for all, necessitating checking for slots late at night (midnight plus) or very early morning. (5.00am). Having completed the Gov form we were pleasantly surprised to receive phone calls from Sainsbury's and Asda stating we were now on the vulnerable list only for our Doctor to inform us that Parkinson's didn't qualify. We are both elderly and the shopping arrangements were confusing.”

Person with Parkinson's

17. We were therefore supportive of a joint initiative by the Alzheimer's Society and the MS Society to bring another 23 charities together to raise our concerns and urge action by DEFRA.
18. Both civil servants and the minister were responsive and for the past 3 months we have been collaborating with DEFRA on increasing offline shopping options and online delivery slots for vulnerable people that can be booked through Local Authorities (and three approved charities) across England. They have also helped to bring charities and supermarkets together to discuss how we can improve the experience of disabled people in supermarkets as lockdown arrangements change. This activity has been positive for our community.

Disabled people's access to healthcare services, including treatment for COVID 19 and access to other healthcare services

19. We have been informed that Hospital Episodes Statistics for March 2020 show around a 19% reduction in admissions for people with Parkinson's across England. It is worth noting that the virus hadn't shut health services down until later in March, so we would expect to see a greater reduction in hospital admissions in April and May 2020.
20. For those people with Parkinson's in regular contact with health services, many had their health appointments during the pandemic cancelled and no telephone or online alternatives were routinely offered. Below is a more detailed breakdown from the survey of cancelled appointments by type:
 - 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.
 - Similarly, 34% had appointments with their Parkinson's Consultant cancelled and of these, 68% were not offered a phone or online appointment.
 - 29% had a GP appointment cancelled.
 - 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.
 - 15% of respondents decided to cancel appointments as they felt unclear on what arrangements would be put in place to keep them safe.
21. Cancelled appointments were seen by many as a contributing factor in the deterioration of their condition and some people with Parkinson's shared they were worried they were storing up future difficulties.

"I feel abandoned really. All my NHS appointments (in April and May) with the neurologist, PD nurse and neurophysio, that I have waited a long time for, have been cancelled with no alternative offered. I had built up a whole programme of activities for myself (outside the house) and was feeling much better as a result. I am obviously not able to do them now. I have tried to fill the gaps with exercising at home, joining various zoom classes but I am still regressing. My meds. don't work as well and I need some professional support." Person with Parkinson's

"The situation has had a big impact on me as I was changing medication when it started. I have now been left in a situation where medication has been removed but not replaced due to lack of consultation/cancelation of appointments. Thus, the condition deteriorated considerably. The worry surrounding the virus is also not helping the condition. Isolation and not being able to go out is increasing existing depression and panic attacks." Person with Parkinson's

22. However some of our community have embraced and been content with the changes to digital delivery of their health and care services.

"I am pleased with the contact we have had with offers of help and people checking on us. Our health coach at the GP surgery has phoned, the council have phoned to check if we need food or anything else, we had a telephone consultation with our neurologist & our Parkinson's nurse will also be making a phone call. We have our carer calling once a week to do shopping and we shop online".

Person with Parkinson's

23. Parkinson's UK wants to see NHS services for people with Parkinson's restarted as quickly as it is clinically safe to do so. This is why we're supporting the Neurological Alliance's statement on restarting neurology services which was launched last week.

The mental health of disabled people, including the effects of isolation, access to mental health services and the implications for disabled people of temporary changes to the Mental Health Act;

24. Findings from our survey showed that:

- 31% of people with Parkinson's reported an increase in anxiety worsening during lockdown and 9% stated they experience an increase in hallucinations and delusions.
- 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.
- 50% of people with Parkinson's had their mental health appointment cancelled, and of these people 80% had not been offered a telephone or video appointment as an alternative.

25. Survey respondents shared that anxiety, stress and low mood were also contributing factors to increasing difficulties with other Parkinson's symptoms for instance movement, tremors, pain, and digestion. Some also noted that the impact of family members being stuck at home together, managing work or home schooling, or couples living together in a small space contributed to an increase in stress, which could exacerbate their physical Parkinson's symptoms.

26. Some who usually experienced anxiety could not access their usual support networks of family and friends, which in itself also increased anxiety.

27. Increasing anxiety led to an increase in physical symptoms, which in turn led to increased anxiety. In particular, having freezing episodes or falls were more worrying without access to the usual medical help and support.

28. Some respondents noticed they had “lost confidence” and become more anxious generally about their condition or now suddenly felt much more vulnerable.
29. Other survey respondents had specific fears, of catching the virus, of going into hospital both for general issues (and thus being exposed to the virus) and for coronavirus (and whether they would not be seen as priority for treatment) or of other vulnerable members of their family becoming ill, or of their carer becoming ill.
30. The survey also found that going out was anxiety provoking as they worried about whether others would socially distance. Many shared they felt they would be too worried about the virus to go out after lockdown was relaxed and others were fearful of how long the virus was going to be around and so were worried about the future.
31. Some survey respondents reported that being at home gave them more time for thinking about Parkinson’s, whereas others were concerned about the impact on other family members (e.g. jobs, health and finances). Some were worried about whether they would see their family again and others had more general worries about the future for the country, employment and health services.

“The last few weeks have been exhausting. I’m still working (from home), home-schooling my 3 kids and all the usual household chores. Trying to exercise also. The stress has definitely made my Parkinson’s much worse - more tremor, more anxiety, more pain.”

Person with Parkinson’s

“Since the lockdown it has been sheer hell, I am currently experiencing severe problems with extended off periods and freezing up when trying to walk. I am finding it increasingly difficult to do anything, and as a result become very anxious and frightened. The problems are particularly severe during the night.”

Person with Parkinson’s

“Living with worry of how difficult it would be to cope if my wife or, worse both of us, got even moderately ill with the virus. The worry of how it would affect me long-term if I was immobilised on a ventilator for some time, like the fear I would never walk again. The anxiety of knowing we cannot take the slightest risk with this virus, so maybe years in lockdown.”

Person with Parkinson’s

32. Parkinson’s UK wants to see the government prioritise mental health services for people with Parkinson’s, as we enter this next phase of the pandemic where NHS services are beginning to resume. We also believe that in the longer term a comprehensive plan to grow the mental health workforce is needed to meet the growing demand for services.

Social care for disabled people in their homes and in residential care settings, including the effects of easements to duties in the Care Act and the approach to monitoring and review of these changes

33. 9% of respondents to the survey stated they had received paid care before the pandemic. Of these, 48% stated they had received less care during the crisis period. This was in part due to a reduction in care being provided and also carers cancelling visits as they were concerned about the risk of paid carers bringing the virus into the house and them having adequate personal protective equipment.
34. Our survey shows that family members, friends and carers, particularly spouses or partners, have been particularly impacted by the pandemic. 68% took on more caring responsibilities, and this figure rose to 74% if you lived with the person with Parkinson’s. This is in stark contrast to Office for National Statistics figures released last week that show 48% of people in the UK said they provided help or support to someone outside of their household in the first month of lockdown in April 2020.

"For someone caring for a PwP [person with Parkinson's] with dementia, meaning she can't be left unless there's a carer present, it's little different to normal life, except that for the few hours per week when I can go out, there's nowhere to go. In particular, I can't even go to my sanity preserver, my boat, because it's not allowed, even though it's just 2 miles away ..."

Carer of a person with Parkinson's

"Caring is hard at the best of times. Doing it with no respite and no professional support has almost broken me and our marriage."

Carer of a person with Parkinson's

"Dad is 91. A Carer came in and did not dress him one morning (one of her tasks), she left him to dress himself. He fell trying to get his trousers on and broke his hip. So angry & frustrated that dad is in the hospital after I had been shielding him... I can't visit."

Carer of a person with Parkinson's

35. Our community has also shared concerns related to rapid hospital discharge and the arrangements surrounding it. And the spread of the coronavirus in care homes and visiting restrictions was also a worry for people whose loved ones with Parkinson's were care home residents. This example sums these issues up.

Mrs B's husband who has Parkinson's dementia was suddenly discharged from community hospital where he was settled, to a nursing home where he is not allowed visitors due to the virus. Mrs B is concerned for her husband, as he was in distress and due to his dementia he won't understand the arrangements that have been put in place. The Clinical Commissioning Group could not organise a package of care to allow Mr B to be discharged from hospital to his home.

36. There has also been significant confusion around NHS continuing healthcare and the emergency discharge procedures. As co-chairs of the Continuing Healthcare Alliance we have asked several questions related to these issues of NHS England and NHS Improvement and we await their responses. From our conversations with Beacon and other charities we know that many people in England are confused by which guidance is currently operating.
37. It is important to understand which has primacy as the emergency discharge procedures mean care is paid for by the NHS and there is no choice about the care that is arranged and provided. However, if the emergency discharge guidance is not operating and the individual has a primary health need then they could be eligible for NHS continuing healthcare and they must be assessed against the national framework, which gives them the ability to choose their care setting.

July 2020