

Written evidence submitted by Parkinson's UK

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.

Delays to care and treatment caused by the pandemic

7. We welcome the committee's inquiry into NHS backlogs and waiting times. People with Parkinson's have been severely impacted by cancellations and delays to the delivery of care and treatment they need to live well with the condition.
8. Many NHS staff providing care for people with Parkinson's were redeployed, especially during the early waves of the pandemic to assist with the increased pressures placed on the NHS by COVID-19. Parkinson's UK internal monitoring of Parkinson's NHS services in England showed that in December 2020 23 Parkinson's services had staff redeployed and 40 Parkinson's services with staff partially redeployed. This left many people with Parkinson's with reduced access to the healthcare they needed to manage their condition.
9. The latest NHS waiting times data shows that there are currently 162,522 (September 2021) people waiting for a neurology appointment, up 4,932 from the previous month and a 48% increase on the same time last year.³ Of these 2,732 have been waiting more than a year, which is an increase of 11% on the previous month.
10. Some people with Parkinson's are seen under Care of the Elderly. There are also significant numbers of people waiting for treatment in this speciality – 20,912 (September 2021), up 255 on the previous month, and a 32% increase on this time last year.
11. The Neurological Alliance obtained hospital episode statistics (HES) data that compared hospital-based appointments for neurology, physiotherapy, speech and language therapy and occupational therapy and hospital admissions for people with neurological conditions for the first lockdown

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.

³ LCP insight, clarity, advice - NHS Waiting List Tracker [accessed 3/12/21] <https://nhswaitlist.lcp.uk.com/>

(March – June 2020) to the same period in 2019. The majority of people in this dataset, 58%, had a diagnosis of Parkinson's. The findings showed:

- Neurology appointments remained steady, but face-to-face appointments fell by 31%.
- Physiotherapy appointments fell nationally by 44% for people with neurological conditions.
- Speech and language therapy appointments fell by 23% overall.
- Occupational therapy appointments saw a 37% drop compared to the same period in 2019.
- Hospital admissions declined nationally by a third. Emergency admissions were reduced by 20% and planned admissions fell by 55%.

12. Parkinson's UK and Lancaster University have twice (May 2020 and August 2021) surveyed people with Parkinson's, their families, carers and friends across the UK about their experience of lockdown. Over 2000 people responded to the first survey, and over 600 responded to the latest survey⁴. From the most recent survey (The majority of respondents, 79%, were from England) we have found:

- Since March 2020 the symptoms that had worsened the most were – movement slowing 88%, fatigue 86% and stiffness 83%.
- Nearly one in five have had their appointment with their consultant cancelled, and around one in six had their Parkinson's nurse appointment cancelled in the three months prior to completing the survey.
- Strikingly 36% and 42% were not given an appointment at all with their consultant or Parkinson's nurse respectively.
- Since March 2020 46% of people with Parkinson's surveyed have had an online healthcare appointment. However, only 42% were satisfied with the outcome of their appointment and 52% described these appointments as 'worse' or 'much worse' than in-person appointments.
- 38% of people living with Parkinson's and 48% of carers were living with low mental wellbeing. Just under half of the participants living with Parkinson's felt more lonely now, compared to during lockdown.
- More than two-thirds of participants (66%) said their anxiety had worsened since March 2020, and 44% said their feelings of depression had increased.
- Since March 2020, 79% of carers had taken on more caring responsibilities. Consequently, 63% of carers felt their mental health had deteriorated.

13. Parkinson's UK conducts a quarterly survey of people who use Parkinson's UK information and support services. From the period July 2020 to April 2021 there has been a steady decline in people reporting their Parkinson's NHS service is 'good or improving' from 62% to 52%. Although there was an uptick in July 2021 of 67%, this has since fallen to 61% in October 2021.

Deconditioning

14. Parkinson's nurses and physiotherapists also reported 'deconditioning' of people with Parkinson's as a result of the pandemic. They felt this was due to having to limit their movements and their usual sources of support (e.g. access to physio or exercise classes) being closed down during the various lockdowns.

15. Results from the Lancaster University survey referenced above also saw over half of people with Parkinson's exercising less compared to pre-pandemic levels. These observations are supported by a Public Health England report which projects that 110,000 more older people will have at least one fall per year due to reduced strength and balance activities during the pandemic⁵. A Sport England

⁴ Lancaster University and Parkinson's UK (2021) 'The Impact of COVID-19 Restrictions on People Affected by Parkinson's - Findings from the Second Survey by Parkinson's UK' (unpublished)

⁵ Public Health England 2021 - 'Wider impacts of COVID-19 on physical activity, deconditioning and falls in older adults' [accessed 3/12/21]
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1010501/HEMT_Wider_Impacts_Falls.pdf

report highlighted that people with long term conditions and disabled people were among groups disproportionately impacted by a fall in physical activity levels as a result of the pandemic⁶.

16. Parkinson's UK has seen an increase in support-related calls to our helpline and local adviser staff due to the continued impact of delays to health care appointments. As demonstrated by these statistics:
 - The number of clients supported by our adviser services has increased each month from December 2020 until July 2021 where we supported 2,877 clients.
 - In September 2021 this reached a high of 2,931 clients supported in that month. In July 2021, we supported 328 more individual clients across the service than in January 2021.

Delays to deep brain stimulation

17. We are also seeing the impact of these delays on people with Parkinson's physical and mental health, as demonstrated by the following quote by a person with Parkinson's facing a delay to deep brain stimulation (DBS) surgery:

“I'm having one major attack of dystonia every day now, it lasts for 2-3 hours, I'm just switched off. I can cope with it, I can. I just want to be me.”

18. DBS can be a life-changing treatment for some people with Parkinson's, it is not a cure but it can drastically improve physical symptoms of the condition including tremors, and uncontrolled movements. Due to the pandemic, the number of new DBS procedures taking place across the UK has plummeted and it is also classified as a lower priority for the NHS to resume. HES data from 2020 shows there were 115 new DBS implants in England, compared with over 240 in 2019. And no procedures were carried out across England for the first three months of 2021.
19. Long waits for DBS could be disastrous for people with Parkinson's because even a few months delay can mean some people are no longer suitable for the surgery meaning they have to rely on medication, which becomes less effective the longer they take it. People who have DBS take on average a third less medication after their procedure and rely less on NHS services and support from carers. Therefore restarting DBS services could save the NHS precious resources.

Access to therapy services and reduction in physical activity levels

20. The following is a statement from a physiotherapist based in the East Midlands on the current state of play for people with Parkinson's in their area:

“COVID-19 has had a major impact on people with Parkinson's in our region. As a result of lockdown restrictions and self-isolation, many patients have not been able to access therapy assessment and intervention when they needed it. Staff in many services were redeployed during the height of the pandemic and most outpatient services ceased all face-to-face contact with patients. A few services managed to leave one or two members of staff to try to help patients by telephone or video. All of this has led to a backlog in the number of people with Parkinson's who need therapy services.

“As we have begun to emerge from the pandemic, we are finding that many individuals are experiencing more complex symptoms, often the result of a combination of less activity and exercise over the previous 16 months or so, and little access to services, and many therapists across the whole country have found that some individual's Parkinson's has progressed more rapidly than might have been expected.

“By and large, waiting times for follow-up appointments are lengthy, and more complex problems require longer appointments with therapists. Many services have had to reduce the number of face-to-face appointments they can offer as cleaning rooms in-between patients takes extra time, further reducing capacity.

⁶ Sport England (2021) - 'Active Lives Adult Survey November 2019/20 Report' [accessed 7/12/21]
<https://www.sportengland.org/news/impact-coronavirus-activity-levels-revealed>

“There is little or no funding for extra staffing in many services, so demand is exceeding capacity. Patients who have not been able to access Parkinson’s timely therapy services may be at increased risk of admission to hospital (for instance, due to falling), which, for patients with Parkinson’s, can lead to a longer length of stay than someone without Parkinson’s.”

21. Parkinson’s UK has heard from healthcare professionals and people living with Parkinson’s of supply issues with rehabilitation aids. In some cases people are being asked to buy their own. Leading to a widening of health inequalities and risks an increase in the incidence of falls and fall related injuries. Leading to a further increase in demand for healthcare services.
22. The Royal College of Speech and Language Therapists report ‘[Speech and language therapy during and beyond COVID-19](#)’ highlighted that 52% of adults had less therapy than before lockdown and 44% had no speech and language therapy at all. Speech and language therapy is a crucial part of the care of many people with Parkinson’s and has a significant impact on quality of life. A letter calling for the government to increase investment in speech and language therapy signed by 22 All-Party Parliamentary Group (APPG) Chairs and Co-Chairs was sent to the Prime Minister and Chancellor, unfortunately no new funding commitments were forthcoming in response.
23. We welcome NHS England and NHS Improvement’s appointment of the first director of rehabilitation and hospital discharge, Jenny Keane. We hope this will help raise the profile of rehabilitation services within the NHS at a national level. However we believe this needs to be replicated at local level and support the Community Rehab Alliance’s call for every Integrated Care Board to have a Rehabilitation Lead.

Conclusions and recommendations

24. We acknowledge that NHS staff have been working flat-out throughout the pandemic and this has caused many to have been left feeling exhausted and burnt-out. We believe the wellbeing and recovery for NHS staff should be a priority for the government to address going forward.
25. We recommend that more granular NHS data (such as referral to treatment times) be published by health condition and a greater range of specialities (for example physiotherapy) so that Integrated Care Systems, NHS Trusts and clinicians have better information on where to target finite NHS resources. As well as increasing transparency and accountability of health systems for the patient populations they serve.
26. We support the recommendations made in the National Neurosciences Advisory Group (NNAG) [report](#) – ‘Lessons learnt from the COVID-19 pandemic – Priorities in care for people with neurological conditions after the pandemic’. In the context of this inquiry we would like to encourage the committee to reflect on these short term recommendations:
 - NHS England and NHS Improvement, commissioners, healthcare professionals, professional bodies, patient groups and people affected by neurological conditions should work together to ensure the needs of people with neurological conditions are central to any decisions made about the recovery of NHS services.
 - NHS England and NHS Improvement nationally – All restoration and neurological service improvement initiatives, for example the NHS England and NHS Improvement neuroscience transformation programme and the neurology (GIRFT) programme should actively engage and support people affected by neurological conditions to be involved in the development of this work.
 - Clinicians and providers - In order to address the backlog of appointments caused by the COVID-19 pandemic waiting lists for specialist care should be risk stratified and prioritised on clinical grounds. This must be underpinned by robust digital IT systems which capture real time data to support decision making.
27. Prior to the pandemic neurological services varied in quality and were not delivering for people with neurological conditions. Results from the Neurological Alliance patient experience survey 2018/19

found 26% of respondents felt their healthcare needs were not being met at all, rising to 40% for people's mental health needs⁷. We support the Neurological Alliance's call for a National Clinical Director for Neurology and a national plan for neurology to not only recover from the pandemic but provide the leadership needed to deliver high quality care for all people living with a neurological condition.

28. Workforce shortages in the NHS were an issue prior to the pandemic, and the impact of these shortages have been brought to bear during the pandemic. A parliamentary [question](#) last year revealed that the mental health workforce fell 50% short of the 19,000 target of additional mental health staff by 2020. In 2019 a survey by the European Academy of Neurology estimated the number of neurologists per head of population in the UK to be 1 per 39,059 where as the average for Europe was 1 per 15,799⁸. We therefore recommend that the committee pushes for a national workforce plan, to ensure the NHS has the right workforce to ensure that people with Parkinson's and other neurological conditions can access the right care at the right time in order to live well.

December 2021

⁷ Neurological Alliance 2019 'Neuro patience - still waiting for improvements in treatment and care'. [accessed 7/12/21] <https://www.neural.org.uk/wp-content/uploads/2019/07/Neuro-Patience-Technical-Report.pdf>

⁸ Nitkunan A, Lawrence J, Reilly MM: 'Association of British Neurologists UK Neurology Workforce Survey', ACNR. 2020. <https://acnr.co.uk/2020/09/neurology-workforce/>