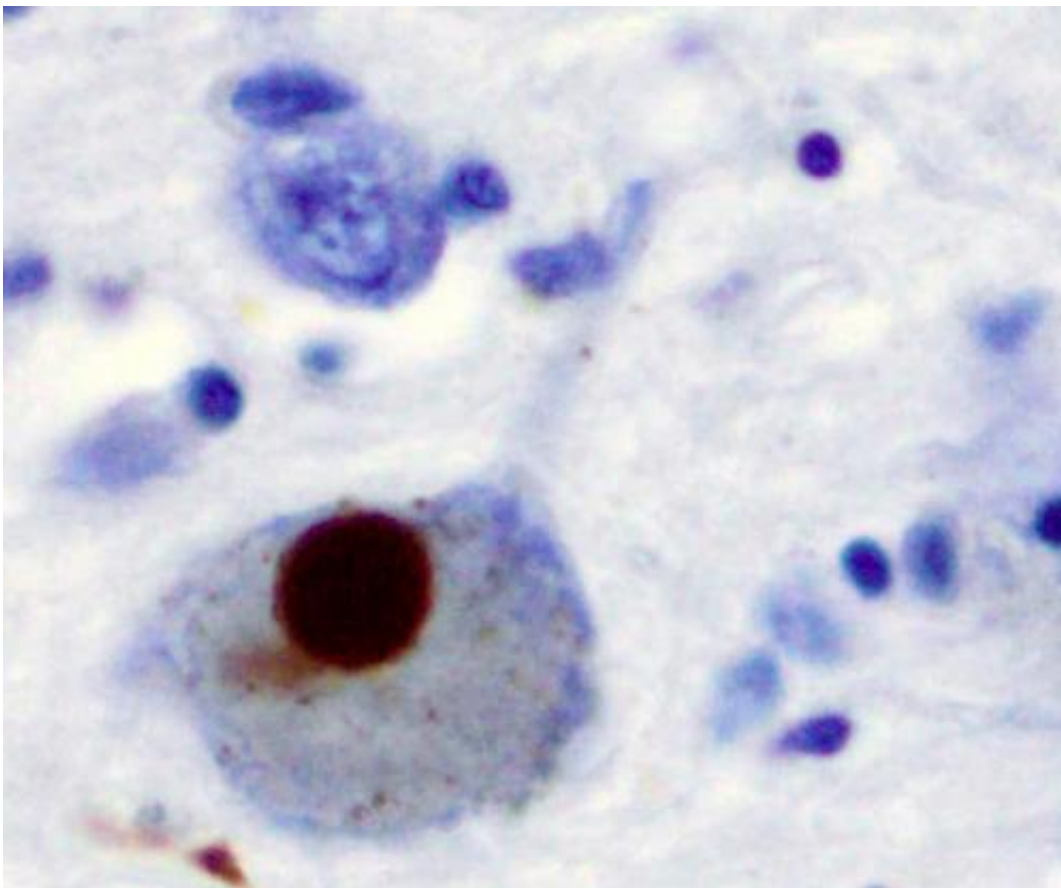


A third of people with Parkinson's have experienced increased symptoms during lockdown

July 3 2020



Immunohistochemistry for alpha-synuclein showing positive staining (brown) of an intraneural Lewy-body in the Substantia nigra in Parkinson's disease. Credit: Wikipedia

A third of people with Parkinson's have experienced increased symptoms during lockdown, according to a survey by Lancaster University and the charity Parkinson's UK.

The survey asked more than 2,000 people with Parkinson's and their family members, friends and carers about their experience of lockdown.

Responses showed that:

- more than a third experienced either more slowness of movement or stiffness or fatigue
- more than a quarter experienced increased tremor or anxiety or sleep problems

Around 10 percent also reported an increase in hallucinations, which can be caused by a number of reasons but most usually from the side-effects of Parkinson's medication, especially when not well controlled.

Parkinson's is a [neurological condition](#) causing muscle tremors, slowness of movement and muscle stiffness, and people with the condition may also experience anxiety and depression. It is known that stress can exacerbate both the movement symptoms and other difficulties, such as sleep, that can be associated with the condition

There are around 145,000 people diagnosed with the condition in the UK, with more than one million people affected as family members, friends or colleagues.

Professor Jane Simpson and Dr. Fiona Eccles from Lancaster University analysed the survey findings which also revealed that:

- Around a third (34 percent) said reduced access to exercise had a big impact on their lives

- Around a third (34 percent) had appointments with their Parkinson's Nurse or consultant cancelled and more than half were not offered a phone or online appointment
- Of those who received [social care](#) and support at home before lockdown, almost half (48 percent) received less care during restrictions

Many people with Parkinson's have an increased risk of severe illness if they get coronavirus and are in the clinically vulnerable category. While some people with Parkinson's are choosing to shield, they are not classed as extremely vulnerable and are therefore not eligible for the increased level of support.

The survey found that as well as concerns about loneliness and isolation, people reported an increase in stress levels, particularly around access to food for those with advanced symptoms if there were no neighbours or family to help, and this stress exacerbated their [physical symptoms](#).

Coronavirus has also impacted on the mental health of the respondents. Measured with a validated scale, the average mental health and wellbeing score of people with Parkinson's responding to the survey was more than 5 points lower than the average score for the general population in non-lockdown times, with many saying they needed emotional support at this time.

Beverley Lucas, 64, was diagnosed with Parkinson's in 2014. She lives alone and prior to lockdown was in the process of moving house to be closer to her children.

Beverley started to self-isolate on the 18th March. She said:

"My Parkinson's symptoms have absolutely been flaring up in lockdown. I know from past experience that stress seems to accentuate reactions in

my body, and my tremor has been much worse. The problem is, I know that Parkinson's is a degenerative condition—so, in lockdown I try to stay calm and chalk my worsening symptoms up to stress, but it's impossible to know: Is it just my Parkinson's developing? Living alone, I don't have anyone to bounce those thoughts off of, who can reassure me or say, 'Actually, you have seemed worse lately.' I don't have that second set of eyes on my condition. It's scary.

"I feel more isolated than ever. As far back as early February, I started to worry about COVID and decided to stop dancing. I stopped swimming later that month. That's been very hard, because it's a social activity as well as a physical one. When I dance, it takes me away from everything. I still love music and it's a wonderful mood booster for me. I'll have a little dance around the house, but the dancing I was doing was partner dancing—a mop or a chair just isn't the same. I'm a very social person, so that's been incredibly difficult.

"As a person with Parkinson's, I'm not on the official NHS list of high risk individuals, but I am more vulnerable. I'm so fortunate to have a lady who lives up the street who has been getting shopping in for me. It's incredibly kind and means I'm not exposing myself more than I want to.

"A big source of stress for me is what the 'new normal' will be after this, and what the risks for people with Parkinson's will be. Some people are saying COVID will become like the flu, something we all live with or get annual jabs for. But what does that mean for people with Parkinson's?"

Increased caring responsibilities for family, friends and carers also had a negative impact. 68 percent had taken on more caring responsibilities since the coronavirus restrictions started, 42 percent said the restrictions were negatively affecting their mental health and 34 percent their physical health.

Professor Jane Simpson of Lancaster University said: "We will be continuing this survey with the same questions to find out what effect the easing of lockdown restrictions has on the Parkinson's community. We are concerned that the changes people have had to make have been so severe and so disruptive of their usual, well-planned routines that it may be difficult for people to bounce back. Consequently, we are concerned about the long term effects of this period of lockdown.

"We think the increase in symptoms is a result of lots of factors—lack of access to health professionals, loss of established regimes for medication, physical exercise and other social activities and the general stress that this period is causing."

During the pandemic, Parkinson's UK has been adapting to reach their community in new ways, including moving exercise classes online, and providing up-to-date, tailored information for everyone affected by the condition.

Katherine Crawford, Director of Services at Parkinson's UK, said: "Unfortunately these results show just how hard the Parkinson's community has been hit by the Corona crisis, both physically and emotionally.

"We know that over a million people with Parkinson's, [family members](#), friends and carers have needed Parkinson's UK more than ever during the pandemic. In response, we have boosted our helpline capacity, built the online Parkinson's community and made sure people who normally receive face-to-face support continue to do so in new ways.

"As we start to move out of lockdown into a 'new normal', it is vital that we can continue to support everyone affected by Parkinson's, so together, we can move towards everyone with the condition feeling empowered to take back control of their life with Parkinson's."

Provided by Lancaster University

Citation: A third of people with Parkinson's have experienced increased symptoms during lockdown (2020, July 3) retrieved 25 April 2024 from <https://medicalxpress.com/news/2020-07-people-parkinson-experienced-symptoms-lockdown.html>

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