

PARKINSON'S^{UK}
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Impacts of lockdown on wellbeing for people with Parkinson's

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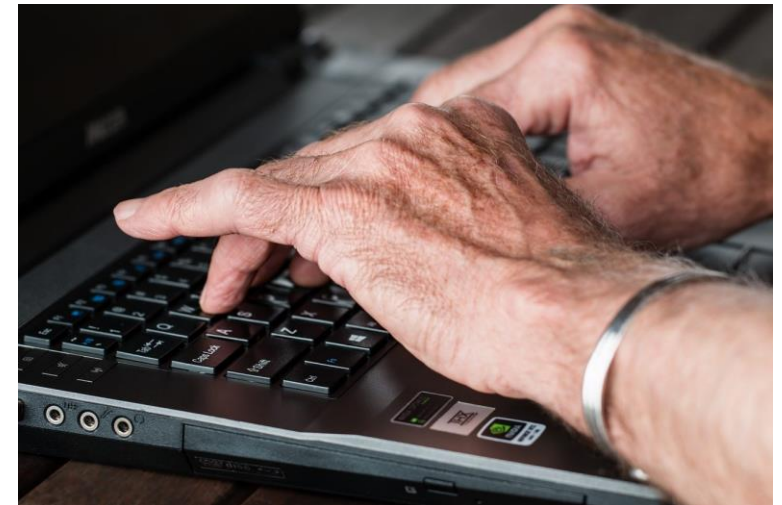
What is Parkinson's?

- Progressive neurological condition causing tremor, slowness of movement and stiffness
- Pain, fatigue, sleep, bowel & bladder, skin/sweating, swallowing/saliva, anxiety, depression, apathy, thinking & memory, hallucinations & delusions
- Age of onset typically over age of 50, but younger onset also possible
- About 145,000 people in UK (2nd most common neurodegenerative condition after Alzheimer's)



Parkinson's UK survey

- Parkinson's UK surveyed their members in April-May 2020 (during first lockdown)
- Survey available online
- Quantitative (tick box) and free text
- Data analysed jointly by Parkinson's UK and Lancaster University



Respondents: People with Parkinson's

- Completed by 1491 people with Parkinson's and 275 carers on behalf of someone with Parkinson's
- Age 32-90 (average 67 years)
- 45% female, 97% White
- 80% lived with partner, 16% alone
- 78% retired



Change in symptoms during lockdown

- Over third experienced increased slowness of movement, stiffness and fatigue
- Over quarter experienced increased tremor, anxiety and sleep problems
- Also increases in pain, other movement problems, memory problems, depression, hallucinations and delusions, eating and drinking problems

Experiences of symptoms

*“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**”*

*“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.”*

Impact on healthcare

- A third had appointments with Parkinson's nurse cancelled; over half were not offered a phone or online appointment
- A third had appointments with their Parkinson's consultant cancelled; over two-thirds were not offered a phone or online appointment
- 70% physiotherapy cancelled
- Nearly half of those previously receiving social care, received less care during lockdown

NHS appointments

“I feel abandoned really. All my NHS appointments [...] 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.”

Impact on everyday life

Nearly half did not go out (or only exercise)

Main problems

Accessing exercise or physical activity

Getting food or other essential items

Getting prescriptions from the pharmacy

Reduced socialising with family and friends

Loneliness

Lack of clear guidance



Exercise and shopping

“Taking away my regular exercise has been the worst thing. Weekly sessions with a lively, positive group and brilliant leader are what keeps me going. Trying to follow it from home is just not working. I am getting stiffer and weaker and that has an effect on my mental state too.”

*“Before the coronavirus 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?”*

Social contact

*“**Coronavirus pandemic initially felt like a bereavement, a loss to me. One day I was allowed out and the next day had to stay home. There was no time to adapt to the lock down. I have been having zoom calls but this is nothing like face to face contact.**”*

*“**[Local Parkinson’s UK Branch] have been splendid keeping everyone together with Zoom meetings as well as Zoom singing groups, Tai Chi, Camera Club, [Name of area] Group, Facebook Group and Quiz nights to name a few.**”*

Impacts for people with Parkinson's

- Increased symptoms and increased distress
- Reduced access to healthcare
- Reduced access to exercise and also food and medication
- Loss of social contact and support
- Reduced social care

Respondents: Carers/family/friends

- Completed by 540 carers/family/friends
- 74% partner/spouse, 21% family, 3% friends
- 76% lived with person with Parkinson's
- 65% retired, 20% working, 6% homemakers, 5% furloughed
- 47% said person with Parkinson's depends on them totally, 40% to some extent



Carers/family/friends

- Over two-thirds had taken on more caring responsibilities
- 42% had worsened mental health (52% when person depends on them)
- 34% physical health impacted (49% when person depends on them)
- Over two-thirds less time away from person with Parkinson's to focus on their own needs

Impact on carer wellbeing

“Feeling more of a prisoner than ever in own home - life restricted due to Parkinson’s now seems to have come to a complete halt.”

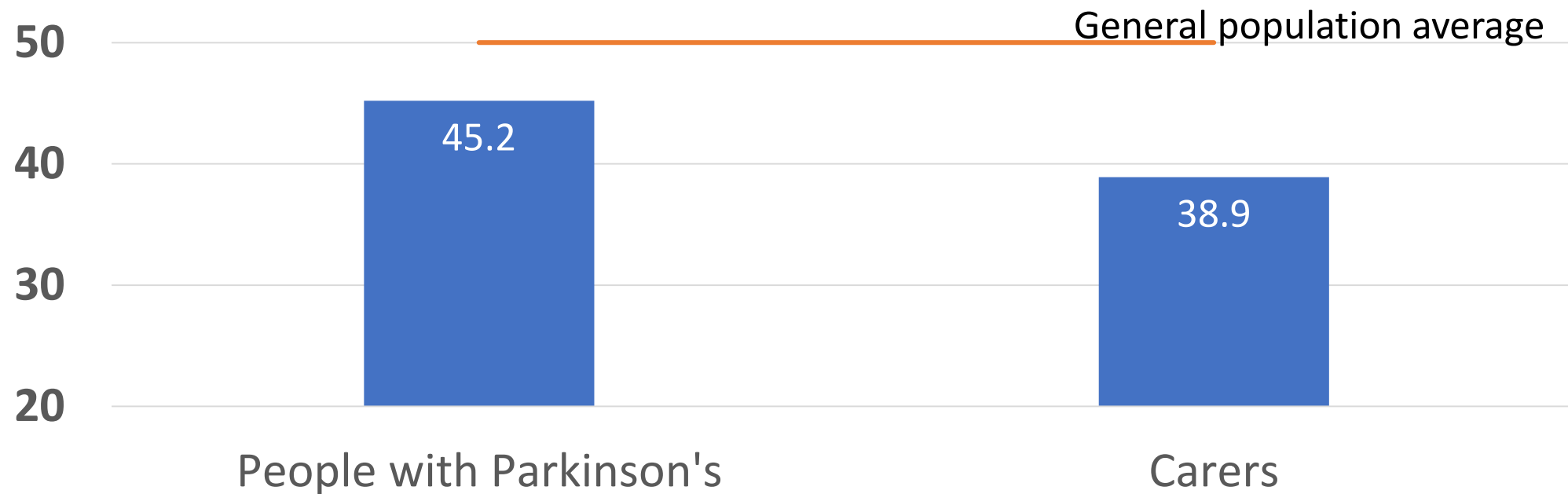
“Being at home all the time and my mum becoming more dependent on me when there isn’t anyone else to help has seriously affected my mental health and it’s difficult to manage.”

“I have lost my support networks - family, friends and support groups. Some days it is hard to keep going.”

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

Wellbeing

Average wellbeing on Warwick-Edinburgh Mental Wellbeing Scale



Good care

“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”.



More recent data

NeuroLifeNow app in March 2021 (348 respondents)

- 31% mental health needs not being met
- 57% felt anxious/hopeless
- 44% consultation by phone, 41% in person, 13% videoconference



(NeuroLifeNow Analysis Report, April 2021)

Services going forward

National Neurosciences Advisory Group (NNAG, April 2021)

- Neurology services already stretched pre-pandemic; Waiting lists have increased
- Online access has been helpful for some but not always appropriate
- Digital health inequalities mean those most vulnerable may not receive care
- Neuroscience services need to be properly resourced going forward

(NNAG, Lessons learnt from the COVID-19 pandemic. Priorities in care for people with neurological conditions, April 2021)

