The Impact of COVID-19 Restrictions on People Affected by Parkinson's

Findings from the Second Survey by Parkinson's UK and Comparison between Survey 1 and 2.

February 2022

Jane Simpson

Fiona Eccles

Craig Murray

Ian Garner

Cathal Doyle

The production of this report was facilitated by a UKRI rapid response COVID grant (ref: EP/V055968/1). We gratefully acknowledge this support for our work.

Contents

Headlines

- The deterioration of symptoms for people with Parkinson’s worsened as the pandemic continued in 2021. In particular, many more people experienced worsening of slowness of movement, fatigue, muscle cramp and sleeping.
- Feelings of anxiety and depression for people with Parkinson’s increased considerably as the pandemic continued in 2021.
- Mental health and wellbeing for people with Parkinson’s (measured using a validated scale) continued to deteriorate.
- Both people with Parkinson’s and people caring for them experienced greater feelings of loneliness compared to other communities. The survey also indicates that loneliness contributed to anxiety and depression.
- 64% of respondents caring for people with Parkinson’s took on more caring responsibilities.
- For these carers, 63% said their mental health worsened and 42% said their physical health worsened. They also had lower mental health and wellbeing scores and greater levels of social isolation than people with Parkinson’s.
- As COVID restrictions eased in late 2021, many respondents said they still had feelings of loneliness and continued anxiety about socialising.
- In the 3 months before this survey, 30% of people with Parkinson’s had an appointment with their care provider cancelled.
- 58% of respondents had a phone or online appointment with their Parkinson’s nurse and 35% with their consultant. While aspects of these were seen positively, only 40% said they were pleased with the outcome of their appointment with their consultant.
- Only 50% of respondents admitted to hospital received their medication on time.

Executive Summary

This report details the responses to an anonymous survey administered online by Parkinson's UK to people affected by Parkinson's and their informal family caregivers. It is a follow-up to an earlier survey and so includes many of the same questions but also new ones reflecting the change in time. The timeframes referred to are Survey 1 (May 2020) and Survey 2 (August 2021). This report provides a comprehensive report on Survey 2 data, with some comparisons (where possible) with Survey 1.

Symptom Change

In Survey 2 the most common symptoms that had worsened since March 2020 (the start of the first COVID-19 lockdown restrictions) were movement (with 87.8% of participants reporting that their movement had slowed); fatigue (with 85.7% of participants stating their feelings of fatigue had increased); and stiffness (with 83.0% citing feelings of stiffness had worsened).

More people reported their symptoms had worsened in Survey 2 than Survey 1. The most frequently reported symptom to have worsened was 'slowed movement' for which 39.2% of participants had reported this symptom worsened in Survey 1, and 84.5% of participants had stated this symptom worsened in Survey 2, showing a 45.3% increase. This was followed by feelings of fatigue (which showed a 44.9% increase, from 37.2% in Survey 1 to 82.1% in

Survey 2), sleeping issues (43.7% increase, from 27.0% in Survey 1 to 70.7% in Survey 2), and muscle cramp (42.6% increase from 17.2% in Survey 1 to 59.8% in Survey 2).

Feelings of Anxiety and Depression

In Survey 2, of the participants with Parkinson's who reported that they were living with feelings of anxiety and depression, 74.6% reported that their feelings of anxiety had worsened since March 2020, and 57.7% reported that feelings of depression had worsened since March 2020.

When considering all participants with Parkinson's in the analysis (including those who reported they had not experienced feelings of anxiety or depression since March 2020) the percentage of participants with Parkinson's who reported that their feelings of anxiety had worsened since March 2020 increased from 31.8% in Survey 1 to 69.3% in Survey 2. Similarly, the percentage of participants living with Parkinson's who reported that their feelings of depression had worsened since March 2020 increased from 12.8% in Survey 1 to 47.9% in Survey 2.

Loneliness

Participants living with Parkinson's felt significantly less lonely than carers of people living with Parkinson's. Findings also showed that participants with Parkinson's who reported that they had feelings of anxiety since March 2020 felt lonelier than participants who did not have feelings of anxiety. Similarly, participants who reported that they had feelings of depression since March 2020 felt lonelier than participants who did not report having feelings of depression.

Just over half (51.2%) of participants with Parkinson’s felt less lonely now (i.e., at the time of completing Survey 2) than during lockdown, with 41.5% of participants having similar feelings of loneliness compared to lockdown, and 7.3% of participants feeling lonelier now than during lockdown (i.e., since March 2020 to July 2021 – when lockdown restrictions ended).

Only 37.6% of carers felt less lonely now than during lockdown, with 50.5% stating their current feelings of loneliness were similar to during lockdown, and 11.9% of carers feeling lonelier now than during lockdown.

Social Network

Participants living with Parkinson’s had significantly greater and stronger social networks than carers of people living with Parkinson’s. Findings also showed that participants living with Parkinson’s who reported they experienced feelings of anxiety and/or depression since March 2020 also felt lonelier than participants living with Parkinson’s who reported they did not have feelings of anxiety and/or depression since March 2020.

Appointment Cancellations

Of the participants with Parkinson's who had an appointment with a healthcare professional in the three months prior to completing Survey 2, 30.7% reported that an appointment with their consultant was cancelled; 27.9% reported that an appointment with their specialist nurse was cancelled; 17.9% reported that an appointment with their physiotherapist had been cancelled; 17.7% reported that an appointment with their speech/language therapist had been cancelled; 14.0% reported that an appointment with their occupational therapist had been cancelled; and 6.4% reported that an appointment with their psychologist had been cancelled.

Use of Online and Phone Appointments

A 16.9% increase in the number of participants with Parkinson's who had a phone or online appointment with the consultant was reported (from 18.2% in Survey 1, to 35.1% in Survey 2). Furthermore, a 30.5% increase in the number of phone or online appointments with a Parkinson's nurse was reported in Survey 2 compared to Survey 1, with 27.7% of participants reporting they had a phone/online appointment in Survey 1, which increased to 58.2% in Survey 2. A 10.9% increase in the number of phone or online physiotherapy/occupational therapy/speech and/or language therapy appointments in Survey 2 was reported, with 9.0% of participants reporting they had one of these appointments in Survey 1 and 19.9% in Survey 2.

Experiences of Online and Phone Appointments

Of the participants with Parkinson's who had an online or phone appointment with their Parkinson's doctor, 69.2% felt they had the doctor's full attention, 53% of participants felt physically safe, and 76.4% of participants felt their privacy was safe during the appointment.

However, only 46.1% of participants felt the doctor could understand them well, and only 23.0% of participants felt the level of connection with their doctor was comparable to that of a face-to-face appointment. Furthermore, only 42.2% of participants were pleased with the outcome of the appointment, with 13.1% reporting that phone or online appointments were their preferred option for future appointments, and 12.2% reporting that they would recommend online or phone appointments to another person with Parkinson’s.

Experiences of Hospital Admission and Stay

Of the 96 participants with Parkinson’s who had been in hospital since March 2020, only 50 (52.6%) always received their Parkinson’s medication on time. Of the participants who did not always receive their medication on time, 11 (30.6%) participants said it had a negative impact and 13 (36.1%) participants said it had a significant negative impact on their Parkinson’s.

A total of 69 (73.4%) participants reported that they wanted to manage their own Parkinson’s medications which they brought from home. However, only 43 (63.2%) were allowed to do so.

Mental Wellbeing

The average mental wellbeing score for participants with Parkinson’s (assessed using the Warwick-Edinburgh Mental Wellbeing Scale; referred to as WEMWBS) decreased from 45.19 in Survey 1 to 43.61 in Survey 2. Furthermore, the number of participants scoring less than 40 (which is indicative of poor mental wellbeing) increased from 32.4% in Survey 1 to 38.5% in Survey 2.

Even more significantly than for participants living with Parkinson's, the average WEMWBS score for carers also decreased, from 45.51 in Survey 1 to 40.63 in Survey 2. Additionally, the number of carers who scored 40 or less increased from 30.7% in Survey 1 to 48.2% in Survey 2.

Findings showed that carers have significantly poorer mental wellbeing that participants living with Parkinson's.

Caring Responsibilities

38.5% of carers reported that the person for whom they provided care totally depended on them for support and care, with a further 53.1% reporting that the person for they provide care only relied on them to some extent for support and care. Furthermore, since March 2020, 75.4% of carers had taken on more caring responsibilities, and 64.1% of carers reporting that they had less time to focus on themselves. Additionally, 42.9% of carers reported that providing care during the COVID-19 pandemic negatively affected their physical health and 58.5% reported that it negatively affected their mental health.

Finally, in the three months prior to completing Survey 2, 22 carers (16.1%) had tried to access respite, but only 10 of those carers had been offered or taken respite.

Introduction

The COVID-19 pandemic has placed great strain on healthcare services around the world. To reduce the spread of COVID-19, most countries initiated country-wide lockdowns with all non-essential services closing and socialising restricted. Lockdowns were particularly challenging for those considered ‘high risk’ (i.e., those living with underlying health issues and/or older adults) as they were instructed to take additional precautions as contracting COVID-19 was likely to result in severe adverse effects. In ordinary circumstances this would increase dependency on services used for everyday living, however, with these services often unavailable due to lockdown restrictions, the resources available to those ‘shielding’ to manage during the lockdown period(s) were diminished.

Parkinson’s UK, the largest charity supporting people with Parkinson’s in the UK, surveyed 1741 people affected by Parkinson’s during the first lockdown period (April-May 2020), when restrictions were most severe (Survey 1), to discover the effects of the COVID-19 pandemic on the Parkinson’s community (Simpson, Eccles, & Doyle, 2020). The data were analysed by Lancaster University and highlighted significant impacts on people with Parkinson’s including worsening of movement, stiffness, and feelings of fatigue. Other findings showed many participants (both those living with Parkinson’s and those who provide care) had poor mental wellbeing.

Given the ongoing impacts of the pandemic, Parkinson’s UK surveyed their members a second time (August-September 2021) to understand better the circumstances of people living with Parkinson’s as society reopened. Again, Lancaster University analysed the data, and the findings are presented in the current report.

This second survey had two components. The first part focused on the current situation of those living with Parkinson's following the easing of restrictions (this component was completed by either people living with Parkinson's, or by a family member/friend/carer on their behalf), and the second half was completed by carers wishing to discuss their experiences. All participants were given the opportunity to complete a validated measure of wellbeing, the Warwick-Edinburgh Mental Wellbeing Scale (Tennant *et al.*, 2007), as well as the UCLA 3-item Loneliness Scale (Hughes, Waite, Hawkley, & Cacioppo, 2004) and the Lubben Social Network scale (Lubben *et al.*, 2006).

This report provides key findings from the second survey and, where possible, describes changes identified between Survey 1 and Survey 2.

Survey Details

The survey was completed by a total of 722 participants. Of these, 533 respondents were people living with Parkinson’s, 81 respondents were a family member/friend/carer and were completing the survey on behalf of someone living with Parkinson’s (totalling 614 participants who provided data on people living with Parkinson’s), and the remaining 108 were carers of people living with Parkinson’s who were sharing their own experiences only. The demographic information for participants living with Parkinson’s is presented below in Table 1.

Table 1: *Demographic Information of Participants living with Parkinson’s from Survey 2.*

Total Participants	614
Average Age	67.9
Age Breakdown	
≤40	4 (0.7%)
41-50	20 (3.3%)
51-60	109 (17.8%)
61-70	203 (33.1%)
71-80	225 (36.6%)
81-90	45 (7.3%)
>90	1 (0.1%)
Missing	7 (1.1%)
Avg. Years living with Parkinson’s	7.39
Years Living with Parkinson’s Breakdown	
0-3	145 (23.6%)
4-6	176 (28.7%)
7-9	96 (15.6%)
10-12	93 (15.1%)
13-15	46 (7.5%)
>15	40 (6.5%)
Missing	18 (2.9%)

Possibly/Definitely ill with COVID-19 (%)	6.5%
Gender	
Male	283 (46.1%)
Female	329 (53.6%)
Missing	2 (0.3%)
Living Status	
Live with partner/spouse	486 (79.2%)
Live with family/friend	14 (2.3%)
Live on their own	107 (17.4%)
Live in a care home	4 (0.7%)
Region of Residence	
England	486 (79.2%)
Scotland	58 (9.4%)
Wales	48 (7.8%)
N. Ireland	16 (2.6%)
Missing	6 (1.0%)
Working Status	
Retired	481 (78.3%)
Key worker	35 (5.7%)
Not a key worker	46 (7.5%)
Unemployed	9 (1.5%)
Other	29 (4.7%)
Missing	14 (2.3%)

Of the carers who completed the survey to share their own experiences only, 54.6% reported that the person with Parkinson’s for whom they provided care was their husband/wife/partner, 41.7% another family member, 2.8% a friend, and 0.9% preferred not to say. Most carers (63.9%) lived with the person for whom they provided care. Additionally, 38.5% of carers reported that the person with Parkinson’s for whom they provided care ‘totally depends on their support and care’, 53.1% reported that the person with Parkinson’s ‘depends to some extent on their support and care’, and 8.4% reported that the person with

Parkinson's 'does not depend on their support and care'. Finally, 10.8% of carers believed that they had either 'possibly been ill' or 'definitely been ill' with COVID-19 at any time, and 89.2% reported they had not been ill with COVID-19.

Participant demographic data for Survey 1 participants was reported by Simpson, Eccles, and Doyle (2020), and can be found at https://www.parkinsons.org.uk/sites/default/files/2020-07/Parkinson%27s%20UK%20Covid-19%20full%20report%20final.pdf

Symptom Change

Participants with Parkinson's were asked about how 16 Parkinson's symptoms had changed for them since March 2020. Participants were given the option to report that they did not have the symptom, that they had the symptom and it had not worsened, or that the symptom had worsened (and were given three options: 'a little', 'quite a lot', 'a lot', to describe the extent to which the symptom had worsened). Findings are presented below in Table 2.

Table 2: *Symptom Change since March 2020*

	I don't have this symptom	No worse	A little worse	Quite a lot worse	A lot worse
Tremors	9.8%	24.0%	41.9%	19.5%	4.8%
Stiffness	3.7%	16.3%	45.3%	25.9%	8.8%
Slowed Movement	2.7%	11.7%	46.2%	28.8%	10.7%
Falls/ Dizziness	14.3%	38.9%	27.4%	12.6%	6.9%
Freezing	20.3%	40.7%	19.0%	13.6%	6.4%
Muscle Cramps	11.8%	28.5%	36.1%	15.6%	8.0%
Pain	12.5%	27.6%	33.7%	17.5%	8.7%
Fatigue	4.2%	13.5%	36.5%	31.5%	14.3%
Sleep	5.3%	24.3%	34.4%	23.5%	12.6%
Eating	14.0%	48.5%	23.8%	9.2%	4.5%
Drinking	15.8%	58.2%	18.6%	4.7%	2.8%
Talking	11.5%	33.0%	36.5%	12.8%	6.2%
Memory	11.4%	32.9%	39.8%	11.5%	4.4%
Dementia	32.3%	59.2%	5.0%	1.6%	1.9%
Hallucinations	29.4%	51.5%	13.6%	2.8%	2.8%
Other	20.7%	57.2%	12.7%	7.2%	2.2%

When focusing on participants who reported that they lived with the symptom(s) (i.e., excluding participants who did not have the symptom), it was found that movement had worsened the most (with 87.8% of participants stating their movements had slowed), followed by feelings of fatigue (with 85.7% of participants stating their feelings of fatigue had worsened) and stiffness (with 83% of participants stating feelings of stiffness worsened).

To allow for comparison between Survey 1 and Survey 2, analysis focused only on participants who reported that their symptom had worsened since March 2020 (excluding participants who either did not live with the symptom or lived with the symptom and it had not worsened). The table below (Table 3) shows the percentage of participants who stated that their Parkinson’s symptom(s) had worsened since March 2020 from Survey 1 and Survey 2, and the difference between the two surveys.

Table 3: *Change in % of Participants reporting Symptom Worsened from Survey 1 to Survey 2.*

	Survey 1	Survey 2	Change (from S1 to S2)
Slowed Movement	39.2%	84.5%	+45.3%
Fatigue	37.2%	82.1%	+44.9%
Sleeping	27.0%	70.7%	+43.7%
Muscle Cramp	17.2%	59.8%	+42.6%
Stiffness	39.5%	79.9%	+40.4%
Talking	15.2%	55.6%	+40.4%
Memory	15.5%	55.7%	+40.2%
Tremors	27.4%	66.0%	+38.6%
Pain	21.3%	59.7%	+38.4%
Falls/Dizziness	12.8%	46.8%	+34.0%
Eating	6.8%	37.3%	+30.5%
Freezing	14.5%	39.0%	+24.5%
Drinking	3.0%	25.9%	+22.9%
Other Symptoms	8.4%	22.2%	+13.8%
Hallucinations	9.1%	19.0%	+9.9%
Dementia	2.7%	8.6%	+5.9%

Comparisons between the two surveys show that all participants’ Parkinson’s symptoms worsened from Survey 1 to Survey 2, with slowed movement (+45.3%), feelings of fatigue (+44.9%), sleeping issues (+43.6%), and muscle cramp (42.6%) most frequently reported to have worsened. However, as there is a ~15-month gap between the completion of Survey 1 and Survey 2, we cannot quantitatively differentiate between natural symptom progression and the effects of the COVID-19 pandemic on symptom progression. Nonetheless this degree of change would not be expected.

Exercise

When the UK lockdown was initiated, exercise was restricted to one session per day, excluding dog walks. As lockdown had ended when Survey 2 was completed, participants were asked to reflect on how much they currently exercised after lockdown was initially implemented (i.e., after March 2020) against their pre-pandemic exercise levels (i.e., before March 2020), and compare their exercise levels over the past 3 months against their pre-pandemic exercise levels.

Just over half (54.4%) of participants reported that they had exercised less after restrictions were implemented in March 2020 than pre-pandemic. Furthermore, 55.9% of participants reported that their exercise levels over the past 3 months were lower compared to their pre-pandemic exercise levels.

Feelings of Anxiety and Depression

Given the uncertainty still surrounding COVID-19, participants living with Parkinson’s were asked if they had experienced feelings of anxiety and depression since March 2020.

Participants were given the option to report that they had not experienced feelings of anxiety or depression; that they had experienced feelings of anxiety or depression, but they had not increased; or that they had feelings of anxiety and depression and those feelings had increased (and were given three options: ‘a little’, ‘quite a lot’, ‘a lot’, to describe the extent to which the symptom had worsened).

11.6% of participants reported that their feelings of anxiety had increased ‘a lot’, with 20% reporting that their feelings of anxiety increased ‘quite a lot’, and a further 34.9% reporting that their feelings of anxiety increased ‘a little’. Of the remaining participants, 25.4% reported that they had feelings of anxiety, but they did not increase, and the remaining 6.8% reported that they did not have feelings of anxiety.

In relation to feelings of depression, 5.9% of participants reporting their feelings of depression increased ‘a lot’, with 11.9% reporting they increased ‘quite a lot’, and 26.5% ‘a little’. Of the remaining participants, 32.4% reported that they had feelings of depression since March 2020, but they had not increased, and 15.8% reporting they have not had feelings of depression.

For comparisons between Survey 1 and Survey 2 regarding change in feelings of anxiety and depression, analyses focused on participants who stated that they had feelings of anxiety and depression and that they had worsened, excluding participants who either had not experienced feelings of anxiety or depression since March 2020, or had but those feelings had not increased over time. Analyses showed that from Survey 1 to Survey 2, the number of participants who reported that they had experienced feelings of anxiety increased by 37.5% (rising from 31.8% in Survey 1 to 69.3% in Survey 2). The number of participants who reported that they had experienced feelings of depression since March 2020 increased by 35.1% (rising from 12.8% in Survey 1 to 47.9% in Survey 2).

Loneliness

In March 2020, when the UK lockdown was initiated, face-to-face social contact was prohibited, and was therefore likely to impact on feelings of loneliness. To consider feelings of loneliness participants with Parkinson's and carers completed the UCLA 3-item Loneliness Scale (Hughes *et al.*, 2004). Participants are asked three items and the scores are totalled (ranging from 3 to 9), with higher scores indicating greater feelings of loneliness.

The average score for participants living with Parkinson's was 4.97, whereas the carer average loneliness score was 6.04 There is a statistically significant difference of 1.07 (17.95%) between the two scores, indicating that carers felt significantly lonelier than participants living with Parkinson's. Moreover, scores for both participants living with Parkinson's and carers were higher than findings from other studies (indicating greater feelings of loneliness). For instance, Liu *et al* (2020) found that, during COVID-19, older adults in Chinese communities scored, on average, 3.9 on the UCLA Loneliness scale and Mays *et al* (2021) found that, during COVID-19, older adults in a small London-based community had a loneliness score of 4.82. These findings suggest both participants living with Parkinson's and carers expressed greater feelings of loneliness than reported by other communities.

Differences in feelings of loneliness were also considered based on if participants living with Parkinson's had experienced feelings of depression and/or anxiety since March 2020. Findings showed that the average loneliness score for participants who reported with feelings of anxiety was 5.03, which was significantly higher than participants who did not report feelings of anxiety, who scored 4.14. Similarly, findings showed that the average loneliness score for participants who had reported feelings of depression since March 2020 was 5.12, which was significantly higher than participants who did not report feelings of depression since March 2020, who scored 4.22. These findings show that participants who reported feelings of anxiety and/or depression felt significantly lonelier than participants who did not.

Participants were also asked how their current (post-lockdown) levels of loneliness compared to their feelings of loneliness during lockdown. A minority (7.3%) of participants living with Parkinson’s reported that they felt lonelier at the time of Survey 2 than they did during lockdown, with 41.5% reporting they feel similar levels of loneliness compared to during lockdown, and 51.2% reporting they feel less lonely compared during lockdown. 11.9% of carers reported that they felt lonelier at the time of Survey 2 than they did during lockdown, with 50.5% reporting their feelings of loneliness were similar to during lockdown, and 37.6% reporting they felt less lonely than during lockdown.

Social Network

Similar to loneliness, strength and effectiveness of social networks were likely impacted by the national lockdown implemented in March 2020. Participants with Parkinson’s and carers completed an assessment (Lubben Social Network Scale; Lubben *et al.*, 2006). This scale is comprised of six items. Scores are totalled at the end (ranging from 6 to 30), with higher scores indicative of greater social networks.

Participants with Parkinson’s average score was 14.99, and the carers’ average score was 12.69. This difference of 2.30 was found to be statistically significant, which means that carers had significantly poorer social networks than participants living with Parkinson’s. Moreover, social network scores for both participants with Parkinson’s and carers were, on average, lower (indicative of smaller social networks) than scores found in other studies. For example, prior to their intervention, Kim *et al* (2021) found that, during COVID-19, older adults' Social Network Score was 15.6 and Victor *et al* (2020) found that, prior to COVID-19, in a study examining predictors of loneliness of caregivers of people with dementia, caregivers scored, on average, 17.6 on the Lubben Social Network Scale. This score is 38.7% higher than scores derived from carers of people living with Parkinson's.

Similar to assessing factors associated with differences in loneliness, differences in social network were considered based on if participants living with Parkinson's had reported that they had feelings of anxiety and/or depression since March 2020. Analyses show that participants who reported they had feelings of anxiety since March 2020 scored, on average, 14.84 on the social network scale, and participants who reported that they had not had feelings of anxiety since March 2020 scored, on average, 16.75. The difference of 1.91 was found to be statistically significant, meaning that participants living with Parkinson's who reported they had feelings of anxiety since March 2020 had significantly weaker social networks than participants with Parkinson's who reported they did not have feelings of anxiety. Participants living with Parkinson's who reported that they had experienced feelings of depression since March 2020 scored, on average, 14.54, whereas participants who reported they have not had feelings of depression since March 2020 scored, on average, 16.79. This difference of 2.25 was found to be statistically significant, meaning that participants living with Parkinson's who reported feelings of depression had significantly weaker social networks than participants living with Parkinson's who did not report having feelings of depression since March 2020.

Appointment Cancellations

When the national lockdown was implemented, face-to-face appointments were regularly cancelled. With the nation having exited lockdown, it is important to consider whether appointment cancellations have returned to pre-pandemic levels. Therefore, participants living with Parkinson's were asked if they had an appointment with their specialist nurse, consultant, physiotherapist, occupational therapist, speech/language therapist, or psychologist cancelled in the last three months, and if their appointment was cancelled or not. Participants who did not have an appointment with any healthcare professional in the last three months were excluded from analyses. In Table 4 (see below) the number of participants who had an appointment with the respective healthcare specialists is presented (n) and the number of participants who reported their appointment was cancelled or not cancelled.

Table 4: *Participant Appointment Cancellations in the last 3 months.*

	Specialist Nurse	**Consultant**	**Physio-therapist**	**Occupational Therapist**	**Speech/ Language Therapist**	**Psychologist**
n	315	348	195	129	141	110
Not Cancelled	227 (72.1%)	241 (69.3%)	160 (82.1%)	111 (86.0%)	116 (82.3%)	103 (93.6%)
Cancelled	88 (27.9%)	107 (30.7%)	35 (17.9%)	18 (14.0%)	25 (17.7%)	7 (6.4%)

Analyses show that the most common appointment for participants living with Parkinson's in the past three months was with the consultant, which was also the most cancelled appointment. This was followed by the specialist nurse for both number of appointments and appointments cancelled.

Online and Phone Appointments with the Parkinson’s Doctor and Appointment Reflections

Since COVID-19 emerged the use of phone and/or online video appointments with healthcare professionals has dramatically increased. To understand better the quality and effectiveness of this new format of appointment, participants living with Parkinson’s were asked if they had a phone or online video appointment with the doctor providing their care since March 2020.

Of the participants who had an appointment with the doctor providing their Parkinson’s care (excluding those who did not have an appointment with the doctor providing their Parkinson’s care), 58.9% reported that they had a phone appointment, 13.5% had an online appointment, 42.9% had an in-person appointment, and 0.8% were unsure as to the type of appointment they had.

Most participants (64.3%) were not given a choice as to the type of appointment they would have preferred, with 19.2% sometimes given a choice, and 16.5% always given a choice.

Participants living with Parkinson’s who had either an online or phone appointment with the doctor providing their Parkinson’s care were given a series of statements about their appointment(s) and asked how much they agreed or disagreed with the statements. Findings are presented below in Table 5.

Table 5: *Participant Reflections on Phone/Online Appointment with Parkinson's Doctor.*

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I felt I had the doctor's full attention during the phone/ online appointment.	26.7%	42.5%	20.4%	6.3%	4.1%
I felt my doctor could see and hear me well.	14.0%	32.1%	24.8%	21.3%	7.9%
I felt physically safe during the phone/online examination.	20.0%	33.0%	39.7%	3.8%	3.5%
I felt my privacy was safe during the phone/online appointment.	24.9%	50.5%	19.6%	1.9%	2.2%
I was pleased with the outcome of my phone or online appointment.	8.8%	33.4%	31.5%	17.7%	8.5%
If given the option I would like my future appointments by phone or online appointment with my doctor whenever feasible.	5.1%	8.0%	16.9%	34.7%	35.4%

Most participants reported that they felt they had the doctor's full attention (69.2%), that they felt physically safe during the examination (53.0%), and that they felt the privacy was safe (75.4%). However, only 42.2% of participants were satisfied with the outcome of their appointment, and only 13.1% would prefer future appointments to be via phone or online whenever feasible.

Additional reflections show that only 23.0% of participants established a personal connection with the doctor providing their Parkinson’s care that was to the same level as the personal connection established in an in-person appointment, with 44.3% establishing a personal connection inferior to that established in an in-person appointment, and 32.7% unable to establish a personal connection at all. Furthermore, only 12.2% reported they would ‘very likely’ or ‘likely recommend phone/online appointments to another person living with Parkinson’s, with 57.6% ‘very unlikely’ or ‘unlikely’ to do so.

Appointment Type with Healthcare Professionals

To expand on how the type of appointments provided to participants living with Parkinson’s had changed since March 2020, participants living with Parkinson’s were asked about the type of appointments (i.e., in-person, phone, online, or multiple types of appointment) they had with healthcare professionals (i.e., Parkinson’s doctor, specialist nurse, physiotherapist, occupational therapist, speech/language therapist, and psychologist). Findings are presented below in Table 6.

Table 6: *Participants with Parkinson's type of (App)ointment(s) with Healthcare Professionals.*

	Not Sure	No App.	Phone App.	Online App.	In-Person App.	Multiple Types
Parkinson's Doctor	0.7%	21.7%	30.4%	4.7%	17.1%	25.4%
Specialist Nurse	0.2%	29.7%	34.7%	3.3%	11.9%	20.2%
Physio-therapist	0.0%	70.7%	3.7%	3.3%	18.0%	4.3%
Occupational Therapist	0.2%	87.6%	2.3%	1.0%	7.6%	1.2%
Speech/ Language Therapist	0.2%	84.0%	3.1%	6.1%	4.7%	1.8%
Psychologist	1.0%	90.5%	3.5%	2.3%	2.1%	0.6%

*** 'Multiple Types' refers to participants who had at least two different types of appointment.*

Findings show that the most common appointment type offered with the Parkinson's doctor and specialist nurse was a phone appointment. The most common appointment type offered to participants with the physiotherapist was 'in-person'. Most participants did not have an appointment with the occupational therapist, speech/language therapist, or psychologist.

Further analyses were completed to assess for changes in the use of phone and/or online appointments between Survey 1 and Survey 2. For this to be feasible, appointments with the physiotherapist, occupational therapist, and speech/language therapist were merged into a single variable (to match the method of data collection from Survey 1). Findings are shown below in Table 7.

Table 7: *Change in Number of Participants who had a Phone/Online Appointment*

	Survey 1	Survey 2	Change (from S1 to S2)
Parkinson’s Nurse	27.7%	58.2%	+30.5%
Parkinson’s Doctor/Consultant	18.2%	35.1%	+16.9%
Physio/Occ/Speech/Lang Therapist	9.0%	19.9%	+10.9%
Psychologist/ Counsellor	4.2%	6.4%	+2.4%

Findings show an increase in the use of phone/online appointments for all healthcare professionals from Survey 1 to Survey 2. The largest increase in use of phone/online appointments was with the Parkinson’s nurse (showing a 30.5% increase, from 27.7% in Survey 1 to 58.2% in Survey 2), followed by appointments with the Parkinson’s doctor/consultant.

Experiences of Hospital Admission & Stay

In response to COVID-19, hospitals amended their policy for patient care. To consider how this impacted on participants living with Parkinson’s stays in a hospital setting, participants who had been hospitalised since March 2020 were asked about their experiences of managing their Parkinson’s during their time in hospital.

A total of 96 participants living with Parkinson’s had been hospitalised at least once since March 2020. Of the 96 participants, only five were admitted to hospital for COVID-19 reasons. Only 50 (52.6%) participants reported that they always received their Parkinson’s medication on time. Of the 46 participants who did not always receive their medication on time, 24 (66.7%) reported that it had either a ‘significant negative effect’ or ‘negative effect’ on their Parkinson’s.

Of the 96 participants who were hospitalised, 69 (73.4%) reported that they wanted to manage and take their own Parkinson's medications which they brought from home. However, only 43 (63.2%) participants were allowed to do so.

Treatments

Given the expected backlog of treatments due to COVID-19, participants were asked about any outstanding treatment(s) for which they were waiting. A small number of participants (2.5%) were waiting for deep brain stimulation (DBS) treatment, with 0.2% waiting for Duadopa treatment, and 0.8% waiting for Apomorphine treatment.

Mental Wellbeing

All participants' mental wellbeing was assessed using the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Warwick Medical School WEMWBS website, 2020). The scale is comprised of 14 items, which are added together to provide a total score. Higher scores indicate greater wellbeing, and scores below 40 indicate poor mental wellbeing (Warwick Medical School WEMWBS website, 2020).

The average WEMWBS score for participants living with Parkinson's was 43.61, whereas the average score for carers of people living with Parkinson's was 40.63. This difference of 2.98 was found to be statistically significant, meaning that carers of people living with Parkinson's have significantly poorer mental wellbeing compared to participants living with Parkinson's. This point is emphasised as 38.4% of participants living with Parkinson's scored 40 or lower on the WEMWBS, whereas 48.1% of carers scored 40 or lower on the WEMWBS. Both scores are either below, or near the bottom of, WEMWBS scores typically reported from pre-COVID-19 times for the general population (NHS Health Scotland, University of Warwick & University of Edinburgh, 2015) and are lower than those reported for older adults at risk of severe illness from COVID-19, who scored 44.9 on the WEMWBS (Flint *et al.*, 2020).

The average scores for both participants living with Parkinson's and carers of people living with Parkinson's than the Turkish general population who scored, on average, 52.95 on the WEMWBS during the COVID-19 pandemic (Gül, & Yeşiltaş, 2021); however, UK students average WEMWBS scores during the pandemic were 42.2 (Savage *et al.*, 2021). These comparisons show that participants living with Parkinson's display better mental wellbeing than some cohorts, but not others, whereas carers of people living with Parkinson's appear to have poorer mental wellbeing compared to a variety of cohorts.

In Survey 1, the WEMWBS scores represented participant wellbeing scores during the lockdown period, whereas Survey 2 was completed shortly after lockdown ended, and therefore provided a post-lockdown assessment of wellbeing. WEMWBS scores between the two surveys showed that for participants living with Parkinson's, their average mental wellbeing score decreased by 1.58 (from 45.19 in Survey 1 to 43.61 in Survey 2), with the number of participants scoring 40 or less increasing by 6.0% (from 32.4% in Survey 1 to 38.4% in Survey 2). Additionally, the average carer WEMWBS score decreased by 4.88 (from 45.51 in Survey 1 to 40.63 in Survey 2), with the number of carers scoring 40 or less increasing by 17.5% (from 30.7% in Survey 1 to 48.2% in Survey 2). These decreases in mental wellbeing scores, despite lockdown ending, suggest that managing during lockdown has had a lasting negative effect on participants, and that the negative impact was more severe on carers of people living with Parkinson's than participants living with Parkinson's.

Caring Responsibilities

When lockdown was initiated, many non-essential services were closed and non-COVID resources were refocused towards COVID-19-related care. With the loss of organisational support, it is unsurprising that 78.6% of carers who completed Survey 2 reported that they took on more caring responsibilities, and that 64.1% of carers had less time to focus on themselves. It is also unsurprising that 62.7% of carers reported that their mental health had worsened while providing care, with 41.7% reporting that their physical health had worsened while providing care. Furthermore, over the last three months before Survey 2, 22 (16.1%) of carers had tried to access respite, but only nine (40.9%) had been offered respite.

People with Parkinson’s Describing Mental Health: Open-ended question

All participants were asked to describe their mental health in its current form and were given the opportunity to provide examples if they felt comfortable talking about factors affecting their mental health. The free-text answers allowed participants to express their experiences and feelings in greater depth.

Post-Lockdown Feelings of Loneliness coupled with Anxiety Regarding Socialising

Some participants reported that they felt lonely despite the ending of lockdown, and that they missed social activities and seeing other people. For instance, participants wrote about feeling lonely in their own homes and not being able to see family for nearly 2 years. Meanwhile, other participants felt lonely despite living with their family, suggesting that participants also needed to see friends to feel less lonely.

However, there remained an unease or even a fear about socialising with friends and family and going to areas where there might be others, with one participant, as an example, reporting that they no longer went to shops, and that they experienced anxiety and panic attacks when in public spaces. Alternately, another participant reported that they missed exercising and attending their social activities but lacked the confidence to re-join these classes

> *"I feel very lonely and being in the house a lot of the time with my husband and daughter is difficult. I feel anxious when I go out. If I go for an appointment with a doctor or go to a new place, I can have a panic attack."*

> *"I suffer from anxiety and panic attacks especially when I go out. Not been supermarket shopping since lockdown. You can't ask for help when you're out."*

> *"Isolation had an effect on me especially when my immediate family had to isolate from me. I didn't see my son who lives in X or my daughter and granddaughters who live in the Y for nearly 2 years. I have really missed my keep fit, boxing and tai chi classes which meant I wasn't socialising. I still don't feel confident enough yet to re-join the classes."*

> *"I am very anxious and seem to be frightened to do things like go out, if I do go out it has to be with my husband or close friends. I get frustrated with PD and cry when I can't do the things I want, I hate the fact I am starting to have to ask for help, this*

> *really depresses me. I suppose as PD gets worst I don't know how I will cope? I've already made so many changes in my life."*

Loneliness could be particularly acute in care homes, where one participant noted the lack of visits from professionals added to a sense of isolation.

> *"I feel quite lonely & unheard due to being in a care home where visiting is still very restricted. The lack of visits into the home by Parkinson's Nurse, Parkinson's specialists & GPs has impacted on my feelings of being unheard. My daughter & the care home do their best, but the lack of outside contacts has taken its toll. My family doesn't live nearby & sadly local friends have given up visiting due to fear of dealing with care home restrictions & not being able to hear my voice"*

These findings seemed to represent an internal conflict in some participants, that despite their feelings of loneliness and that they have been fully vaccinated against COVID-19, there remained a trepidation towards returning to social activities despite the mental and physical benefits they offered participants.

Difficulties were not experienced by all and some of those who experienced good support were doing well. The end of restrictions had led to some feeling more positive, with hopes of re-joining activities.

> *"My mental health is generally good as I have a good support network around me (family and friends). I also exercise daily which helps with my mood."*

"My mental health is fine. I make an effort to stay active and interested in things. I also have the company of my wife and other family members and enjoy running a successful business."

"I am feeling well. It is good to meet with our friends who live further away. It has given me a boost"

"Since lockdown has been eased or changed more facilities are open and able to meet up with friends and sing in church, I feel more positive about life. Before I felt trapped inside my house, children, and grandchildren not able to visit. The main thing that I missed most of all was exercise. Usually, I play tennis, badminton, exercise class and walking. I also helped at coffee mornings for mothers and toddler. This kept my Parkinson's under control. It is recognised that exercise is as important as medication Now I have restarted my exercise routine it will take a while to feel the benefit again. I feel more positive."

Lack of Health and Medical Appointments and Support

The importance of health appointments is apparent; participants cited the lack of appointments as one of the main factors in the deterioration of their mental wellbeing, with several participants saying they felt 'abandoned' by the health services due to their lack of contact. In addition, telephone appointments were often seen as an inadequate replacement with one participant describing how they had to wait an unacceptable amount of time for an appointment for it to ‘then be by phone’. Another participant described the telephone appointment as ‘stressful’, another described ‘feeling left out’ of the conversation, and that the time provided on the appointments was ‘insufficient’.

> *“I feel abandoned by the health service. No meaningful contact with GP service and first and only contact with PD consultant was on phone. This increased further my anxiety levels and sense of isolation.”*

> *“I feel abandoned by the NHS as I can’t get to see my neuro consultant for 5 months and we have no dedicated specialist nurse to go to for advice. I worry that my deterioration is very speedy now and it frightens me. The worry affects me in lack of sleep and then depression.”*

> *“I feel as though I am not achieving anything, I lack motivation. I am anxious about the future (my future as well as that of the planet). I cry a lot. I feel abandoned by the health service.”*

> *“Periods of anxiety concerning symptoms, sometimes depressed. Frustration at appointment schedules, not enough time in telephone consultations, feeling left out as consultants talk to partner so no contact with me.”*

> *“Lockdown has made me more anxious, Not being able to see our families, our grandchildren and friends. Trying to contact Parkinson‘s nurse’s proved to be very*

> *difficult as they were redeployed to Covid 19 wards. Face-to-face appointments were all cancelled, consultations on the Telephone which were very stressful."*

These findings emphasise the importance of appointments to people living with Parkinson's, how they provide a substantial amount of support, and also how phone appointments do not provide the amount of support required by people living with Parkinson's.

Carers Describing Mental Health: Open-ended question

All participants were asked to describe their mental health in its current form and were given the opportunity to provide examples if they felt comfortable talking about the factors affecting their mental health. The free-text answers allowed participants to express their experiences and feelings in greater depth.

Lack of Respite

Participants' comments on mental health showed how they were placing the needs of the people they provided care for above their own but doing so was having a negative effect on their mental wellbeing, with carers unable to access respite. For instance, one participant described how they could not plan vacations whereas another described her need to relax and partake in everyday activities and how she was unable to because of her caring responsibilities. Indeed, one participant described her situation as if she felt 'trapped', whereas others frequently cited how they felt 'helpless', 'powerless', or 'useless' within these situations too. Unsurprisingly, this environment and lack of support also impacted on the carer’s physical and mental health.

> *“My inability to go away for a break has affected me enormously. The boredom is excruciating. My partner is awaiting DBS surgery so forward planning is not an option.”*

> *“I feel helpless and am struggling with not having any time to myself or to see my partner whom I have seen twice (4 days in October 2020 and 20 days in May 2021). I'm not willing to put my mother at risk, as she doesn't do well in hospitals and I have to be there with her and am worried that they will not let me stay with her.”*

> *“Extremely stressed. Husband’s PD got much worse during CV but it was impossible to access help or even ask a friend if they thought the deterioration was as bad as you did. Feelings of powerlessness.”*

> *“I'm anxious about everything in my life and frightened too. I can't see how it will all resolve. It seems as if organisations and service providers are hiding behind the excuse of the pandemic for not being available and not offering the service and support that we should be able to access. Can't get to see a doctor for my own illness let alone my relative for her problems.*

Other participants who were able to partake in some activities such as seeing friends and who had had respite show the beneficial impact it provided despite their caring difficulties.

> *"My mental health has improved since restrictions easing as I can see my friends. My husband had severe anxiety and being with someone indoors most of the time was very difficult and worrying. His anxiety has improved greatly as well now he can see other people and we can do more things.*

> *"Good ATM. We have had some holiday time away and productive meeting with PD consultant."*

> *"Since lockdown restrictions had started to ease, my mental health had vastly improved."*

These findings emphasise the importance of providing carers with the necessary support to provide respite for their mental wellbeing and how adequate support for people with Parkinson's benefited carers and vice versa.

Appointments and Medical Support

Similar to the issues faced by participants living with Parkinson's, carers also highlighted the struggle to access medical services which could also help with their caring responsibilities. They talked about the inability to book appointments, with the appointments they did get not meeting their needs or providing any support. This lack of support also placed participants in frightening scenarios where they had to make decisions regarding care that they would not normally make and carers were fearful of making mistakes which could impact the health of the individual living with Parkinson's.

> *"There is no support whatsoever. My husband has not been seen by a doctor for nearly two years. The Parkinson's nurse has cancelled his appointment twice. Physiotherapy is cancelled. The GP surgery is incommunicado. All groups have transferred to Zoom, which is not appropriate for someone with Parkinson's. I feel fed up and angry, as my husband has deteriorated because of COVID although neither of us has had it."*

> *"Getting better, frustrated that the consultant only does telephone appointments as the PD nurses not available when needed. GPs add to stress as they are not doing anything to help. Have to sort out things ourselves."*

> *"Constant concern for my husband's worsening PD symptoms, combined with an acute awareness than in-person appointments with any health professional is not an option any time soon. Fully aware than extremely rare phone appointments are better than nothing, but that they depend utterly on good verbal communication and accurate descriptions, and that many visual signs that a professional would spot may be unnoticed by me. A growing sense of isolation and inadequacy, as we need help with a variety of problems but do not know where to find that help: my husband's consultant works in a different PCT from our GP and our PD Nurse. Also, said*

> *consultant is on long term sick leave and heads an already overstretched department."*

> *"It's ok. Continually trying to keep ahead of my wife's needs can be stressful (Especially when I make a mistake)! If she has a good day, so do I. similarly a bad day makes me feel frustrated and incompetent."*

The answers provided by participants emphasised the precariousness of their situation. Carers showed considerable anxiety and concern about having to make decisions regarding the care they provided, and steps taken to manage during COVID-19. Yet, the lack of support (described frequently as 'non-existent') and direction provided by professionals made carers feel that they had no option but to make these important decisions themselves while being fearful of the potential repercussions of doing things incorrectly and the impact that may have had on the people for whom they cared.

References

Flint, S. W., Brown, A., Tahrani, A. A., Piotrkowicz, A., & Joseph, A. C. (2020). Cross-sectional analysis to explore the awareness, attitudes and actions of UK adults at high risk of severe illness from COVID-19. *BMJ open*, *10*(12), e045309.

Gül, İ., & Yeşiltaş, A. (2021). Mental wellbeing and perception of health in the era of COVID-19 pandemic: A cross-sectional study in the general population. *Perspectives in Psychiatric Care*.

Hughes, M. E., Waite, L. J., Hawkley, L. C., & Cacioppo, J. T. (2004). A short scale for measuring loneliness in large surveys: Results from two population-based studies. *Research on Aging, 26*(6), 655-672,

Kim, J., Gray, J. A., Ciesla, J. R., & Yao, P. (2021). The Impact of an Internet Use Promotion Programme on Communication, Internet Use, and the Extent of Social Networks among Low-Income Older Adults. *Ageing International*, 1-24.

Liu, T., Lu, S., Leung, D. K., Sze, L. C., Kwok, W. W., Tang, J. Y., ... & Wong, G. H. (2020). Adapting the UCLA 3-item loneliness scale for community-based depressive symptoms screening interview among older Chinese: a cross-sectional study. *BMJ open*, *10*(12), e041921.

Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., von Renteln Kruse, W., Beck, J. C., & Stuck, A. E. (2006). Performance of an abbreviated version of the Lubben Social Network Scale among three European community-dwelling older adult populations. *The Gerontologist*, *46*(4), 503-513.

Mays, A. M., Kim, S., Rosales, K., Au, T., & Rosen, S. (2021). The Leveraging Exercise to Age in Place (LEAP) study: Engaging older adults in community-based exercise classes to impact loneliness and social isolation. *The American Journal of Geriatric Psychiatry*, *29*(8), 777-788.

NHS Health Scotland, University of Warwick & University of Edinburgh. Warwick-Edinburgh Mental Well-being Scale. User guide. Edinburgh: NHS Health Scotland; 2015.

Savage, M. J., Hennis, P. J., Magistro, D., Donaldson, J., Healy, L. C., & James, R. M. (2021). Nine months into the CoViD-19 pandemic: a longitudinal study showing mental health and movement behaviours are impaired in UK students. *International journal of environmental research and public health*, *18*(6), 2930.

Simpson, J., Eccles, F., & Doyle, C. (2020). The impact of coronavirus restrictions on people affected by Parkinson’s. Retrieved from: https://www.parkinsons.org.uk/sites/default/files/2020-07/Parkinson%27s%20UK%20Covid-19%20full%20report%20final.pdf

Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S., ... & Stewart-Brown, S. (2007). The Warwick-Edinburgh mental well-being scale (WEMWBS): development and UK validation. *Health and Quality of life Outcomes*, *5*(1), 1-13.

Victor, C. R., Rippon, I., Quinn, C., Nelis, S. M., Martyr, A., Hart, N., ... & Clare, L. (2021). The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme. *Aging & mental health*, *25*(7), 1232-1238.

Warwick Medical School WEMWBS website (2020), accessed 30 May 2020. https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/using/howto