

THE IMPACT OF CORONAVIRUS RESTRICTIONS ON PEOPLE AFFECTED BY PARKINSON'S

The Findings from a Survey by Parkinson's UK

**PARKINSON'S<sup>UK</sup>**  
**CHANGE ATTITUDES.**  
**FIND A CURE.**  
**JOIN US.**

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## **Executive summary**

Parkinson's UK, the largest charity supporting people with Parkinson's in the UK, surveyed 2031 people affected by Parkinson's in April-May 2020 to find out the impact of the coronavirus restrictions on the Parkinson's community. This included 1491 people with the condition and 540 family members, friends and carers. 97% of respondents were White British, and 2% were from Black, Asian, other, or mixed ethnic backgrounds. 55% were male and 45% female.

The findings were analysed jointly with Lancaster University and the key findings are as follows:

### **Living arrangements during restrictions**

49% of respondents with Parkinson's were living under the same restrictions placed on everyone (still going out a limited amount for food, medicine and exercise). Around 38% of respondents were only going out for exercise and medication (not going out for food shopping or any other reason). 8.5% were in shielding households (not going out at all).

### **Guidance and advice on risk of the coronavirus**

People wanted more clarity about what the consequences of COVID-19 would be for someone with Parkinson's, and whether they needed to be concerned. Guidance and advice on shielding and the categorisation of risk were seen by many as confusing and inadequate.

### **Impact of restrictions on mental health and wellbeing**

72% said socialising with family and friends had become more difficult during restrictions. The lack of social contact and loneliness was devastating for many. Stress and anxiety were commonly reported. Measured with a validated scale, the mental health and wellbeing of people with Parkinson's responding to the survey was low. Many needed emotional support at this time.

## **Parkinson's symptoms getting worse**

Many said their Parkinson's symptoms had got worse since the restrictions began. Over a third experienced increased slowness of movement, stiffness and fatigue and over a quarter increased tremor, anxiety and sleep problems. Stress and isolation and reduced access to health care and exercise (see below) were seen as causes of deterioration.

## **Access to exercise**

34% said reduced access to exercise had a big impact on their lives. Many were frustrated that established physical self-care routines had been disrupted and worried about the impact on their symptoms currently and the long-term effects on their health.

## **Reduced health care appointments**

For those in regular contact with health services, many had appointments cancelled and alternatives had not been routinely offered via telephone or online. 34% 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 themselves to cancel appointments because they were worried about the coronavirus. Cancelled appointments were seen by many as a contributor to deterioration of the condition and some were worried they were storing up future difficulties.

## **Impact on families, friends and carers**

The impact on family members, friends and carers, particularly spouses or partners, has been considerable. 68% took on more caring responsibilities since the coronavirus

restrictions started. 42% said the restrictions were negatively affecting their mental health and 34% their physical health. The validated wellbeing scale administered showed lower rates of mental health and wellbeing than people with Parkinson's. Stress, boredom and loneliness were often reported, with some saying the situation had caused massive family strain.

### **Reduced home care and support**

Half of the people receiving social care and support at home received less care during restrictions.

### **Care homes**

The spread of the coronavirus in care homes and visiting restrictions was a worry for people whose loved ones with Parkinson's were care home residents.

### **Access to food and supplies**

Access to food and other essential supplies had not been straight-forward and was another source of stress and anxiety; when delivery slots were unavailable, queueing at supermarkets was not possible and some respondents felt that they were reliant on others.

### **Digital technology**

The use of technology was seen by many as crucial to staying in contact with family and friends and joining classes, meetings and leisure activities. Several had to learn this at the start of lockdown, while others relied on partners to be able to access this

### **Work**

Experiences of employers and work varied. Some had supportive employers who were taking Parkinson's into account and considering their needs. Others were furloughed and worried about their return to work, including whether it was safe and whether they would be allowed. Some thought that they would be pressured to return to work, when it was not safe.



## **Introduction**

The COVID-19 pandemic has caused significant impacts across the globe, both due to the disease itself and the measures taken to mitigate the spread. It has been particularly challenging for those with pre-existing health conditions for whom the consequences of catching the disease may be more serious. Furthermore, measures implemented such as lockdown can have particularly deleterious effects due to the resulting loss of formal and informal support and health and social care provision.

Parkinson's UK, the largest charity supporting people with Parkinson's in the UK, surveyed people affected by Parkinson's in April-May 2020 during the most severe part of lockdown to find out the effects of the COVID-19 situation on the Parkinson's community. Unfortunately, because of restrictions imposed by the lockdown, the survey could only be distributed online and no paper version was available. The age profile of the sample is younger than the Parkinson's population as a whole and this may therefore underestimate the difficulties of people with Parkinson's as a whole.

The survey had two parts. The first part focused on the impact of the coronavirus restrictions on the person with Parkinson's and the second part on the impact on family members, friends and carers. The first part was completed either by the people with the condition or by a family member, friend or carer on their behalf. The second part was completed only by family members, friends and carers. Finally, both people with Parkinson's and their carers completed a validated measure of wellbeing, the Warwick-Edinburgh Mental Wellbeing Scale. Data from this measure are presented in a third section of the report.

Following appropriate ethical approval, Lancaster University collaborated with Parkinson's UK to analyse the data pertaining to the people with Parkinson's and Parkinson's UK analysed the family, friend and carer data. The findings are presented here in a joint report.

## **Part 1 – People with Parkinson's**

### **Survey details**

The first part of the survey was completed by 1491 people with Parkinson's and 275 carers on behalf of someone with Parkinson's. Of these, the majority of the responses came from individuals living in England (82%), with 8.7% from Scotland, 6.6% from Wales, 1.4% from Northern Ireland, <1% from the Channel Islands and Isle of Man and the rest (1.2%) from overseas. This report will focus on the data from the participants from the four UK nations (total n=1741; England n=1148; Scotland n=153; Wales n=116; Northern Ireland n=24). Note that the small sample size for Northern Ireland means their findings will be less reliable and less generalizable.

The ages of participants ranged from 32 to 90 although overall the sample was relatively young for people with Parkinson's with mean age of 67 (means across nations were similar, although Northern Ireland was younger with a mean of 62). The sample was approximately 45% female, similar across nations (Northern Ireland slightly higher at 50%) and the sample was 97% White, again similar across nations (Northern Ireland 100%), with 1.4% from Black, Asian or mixed backgrounds.

The majority of respondents (79.9% UK wide) lived with their partner/spouse ranging from 79.4% for England to 87.5% for Northern Ireland. The rest lived on their own (15.8% UK wide) or with other family (3.2% UK wide) with only 6 participants, all from England, reporting that they lived in a care home.

The majority of respondents were retired (78% across the sample and similar across nations except Northern Ireland at 67%). However, some were working as keyworkers (UK 3.4%; England 3.2%; Scotland 4.6%; Wales 5.2%; none in Northern Ireland). Others were continuing to work in other roles (ranging from 3.3% in Scotland to 8.3% in Northern Ireland; 6.2% UK wide), were furloughed (2.6% in Wales to 8.3% in Northern Ireland; 3.3% UK wide) or were homemakers (1.1% in England; none elsewhere; 0.9% UK overall). The percentage unemployed ranged from 0% in Wales to 8.3% in Northern Ireland, with 2.0% in the UK overall.

Mean time since diagnosis ranged from 6.4 years in Wales to 9.7 years in Northern Ireland, with an overall UK mean of 7.1 years. In England 8% of the sample thought they had a diagnosis of Parkinson's dementia or dementia with Lewy bodies, compared to 5.2% in Scotland, 6.0% in Wales and 0% in Northern Ireland. The figure was 7.6% for the UK overall.

### **Living under lockdown**

Participants were asked to describe their current circumstances regarding the lockdown and whether they were still going out at all. Considering those who reported they were living under the restrictions placed on everyone, i.e. were still going out for food, medicine, exercise and (when appropriate) work, Scotland had the higher proportion (55.2%) and Wales the lowest (40.9%) with England (49.1%) and Northern Ireland (50.0%) in between (UK wide 49.1%). When considering those who were not going out, or only going out for exercise or vital medicine due to concerns about themselves or a member of the household catching the virus, Scotland had the lowest number (31.7%) and Wales the highest (48.2%) with Northern Ireland (41.7%) and England (37.7%) again in between, with the UK overall at 37.9%. Of the very high risk households, where someone required shielding, the highest proportion was in Scotland (9.0%) and lowest in Wales (5.5%) with England and Northern Ireland at 8.6% and 8.3% respectively; UK overall was 8.5%. Putting these last two groups together as those who were concerned or very concerned not to catch the virus, in Wales over half of respondents were isolating themselves as much as possible; in Northern Ireland half were doing so, in England 46% and in Scotland 41%. Thus UK wide, 46.4% were going out not at all or hardly at all.

The proportion of households self-isolating due to possible virus symptoms in their family was low and ranged from 0% in Northern Ireland to 2.8% in Scotland, with 1.9% for the UK overall. A small proportion of people were also unable to go out due to their disabilities or were in hospital (<1%) and a final 2.1% were unsure or had other arrangements.

### **Experiences at work**

The reports regarding adjustments at work from the 167 people who replied to this question were fairly positive. Across the nations (i.e. UK wide) 63 people (37.7%) had asked for adjustments and had them put in place and 86 people (51.5%) said they did not need adjustments or social distancing was already being implemented. However, 4 people in England (2.4% of the overall sample) said they had asked for adjustments and not been permitted them and 7 people (5 in England, 1 in Scotland, 1 in Wales; 4.2% of the overall sample) said they were concerned about not being able to maintain social distancing at work. The remaining 7 people were unsure.

### **Experiences in care homes**

Only 6 respondents (3 people with Parkinson's reporting directly and 3 carers on behalf of the person with Parkinson's) reported they lived in care home so little can be concluded overall about care homes, although all 6 reported negative experiences and that visits were no longer allowed. They reported that they missed going out and missed having visitors and that it was depressing and frightening. One person reported they had to stay in their room as there was a case of coronavirus in the home and they did not know what was happening and another reported they had just moved to the home for respite care and didn't know anyone and that visits by medical staff had not been allowed.

### **Experiences of paid care**

157 respondents (9.2%) said they were receiving paid care before the onset of COVID-19. 151 of these respondents answered the question about change of care and 48.3% overall said they were receiving less care. 47% said their care had not changed, 1.3% said it had increased and 3.3% were unsure. The numbers in each nation are small, so should be treated with caution, but show that less care was experienced by 44.9% in England, 50.0% in Scotland, 33.3% in Northern Ireland (1 person) but 90% in Wales (9 people).

## **Experiences of being ill with COVID-19**

The majority of respondents reported they had not had possible virus symptoms, ranging from 87.4% in England to 90.2% in Scotland (87.7% for the UK overall). A small proportion had had possible symptoms but no test (England 3.9%; Scotland 2.0%; Wales 1.7%; Northern Ireland 4.2%; UK overall 3.6%). Only 5 people in England and 1 person in Wales had definitely had COVID-19, confirmed by a test, and a further 3 people in England were waiting results. Perhaps unsurprisingly, quite a number were unsure (ranging from 7.8% in Scotland to 8.6% in Wales; 8.2% overall).

Of the 6 people who had definitely had COVID-19, 5 had been in hospital; of the 3 waiting results, 1 was in hospital; and a further person who had symptoms but no test was also in hospital. Hospital stays had varied from 11 days to 6 weeks and one person had sadly died. Two had needed oxygen (including the person who died) and one had needed a ventilator.

## **Change in Parkinson's symptoms during the COVID-19 period**

Participants were asked to indicate if particular Parkinson's symptoms had worsened since coronavirus restrictions were introduced. This was answered by 302 people<sup>1</sup>. The most common difficulties that worsened were slowness of movement (39%), stiffness (39%), fatigue (37%) and anxiety (31%). Worsening tremor (27%), sleep problems (26%) and pain (21%) were also regularly endorsed. Other worsening symptoms included muscle cramps and uncontrolled movements (18%), freezing (14%), talking problems (15%), memory problems (15%), falls and dizziness (13%), depression (13%), hallucinations and delusions (9%), eating problems (7%), dementia (3%) and drinking problems (3%).

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<sup>1</sup> The sample size is smaller than for the rest of the survey for this question on symptoms and the next one on other difficulties due to an error in the survey logic which affected those answering the survey earlier in the survey period.

## **Other difficulties during COVID-19 period**

Another question asked about other difficulties experienced during the COVID-19 period. The main difficulty experienced was reduced socialising with family and friends, which was selected by the majority of respondents (72%). Other commonly experienced problems were accessing exercise/physical activity (34%), getting food or other essential items (25%), loneliness (19%) and getting prescriptions from the pharmacy (15%). Concerns about finances (7%) and getting the prescription from a doctor or nurse (4%) were less common.

## **Coping**

95% of the sample answered the coping question. Generally, respondents reported that they were coping well; however, 11.4% overall selected the bottom two categories saying they were coping not very well or not very well at all, suggesting a significant minority were struggling. In Wales only 6.2% were not coping, compared to 12.0% in England, 11.8% in Scotland and 8.6% in Northern Ireland.

For those with a diagnosis of Parkinson's dementia or dementia with Lewy bodies the percentages were higher, with 26.7% overall reporting they were not coping well, which suggests this group in particular need more support.

## **Effect on healthcare appointments**

### *Regularity of appointments*

Respondents were asked to indicate whether their appointments with the healthcare professionals they engage with had been cancelled, become less frequent, stayed the same or become more frequent. The percentages below are for those who would typically have appointments (i.e. excluding those who do not usually have the appointments).

Cancellation of GP appointments across the UK sample was 29.7%, similar across England, Wales and Scotland with Northern Ireland lower at 21.4%. Reduced frequency of GP appointments was variable across nations ranging from 19.4% in

Scotland to 39.6% in Wales; 25.2% for the UK overall. Across the sample therefore, over half reported that their appointments had been reduced in frequency or cancelled.

Cancellation of Parkinson's Nurse appointments was quite high (33.5% UK wide), although lower in England (31.2%) than in Scotland (43.5%), Wales (48.6%) and Northern Ireland (45.5%). Reduced frequency of appointments was less common (14.4% UK wide), ranging from 9.1% in Northern Ireland to 11.1% in Scotland, 14.4% in England and 20.0% in Wales.

Cancellation of Parkinson's consultant appointments were at a similar rate than that for nurses (34.4% UK wide). Again, this was lower in England (31.4%) than in Scotland (41.9%) which in turn was lower than Northern Ireland (54.4%) and Wales (57.1%). Reduced frequency in appointments was reported by 7.0% in Scotland, 12.7% in England, 16.7% in Wales and 18.2% in Northern Ireland; 12.5% for the UK overall.

Cancellation of physiotherapy appointments was a very high rate across nations (70.4% UK wide), ranging from 69.4% in England and 69.6% in Scotland to 78.1% in Wales and 100% in Northern Ireland. Reports of reduced frequency of appointments was 11.3% for England, 8.7% for Scotland and 6.3% for Wales; 10.6% for the UK overall.

Occupational therapist appointment cancellations were also high (55.8% UK wide), and ranged from 40.9% in Scotland, to 55.1% in England and 77.8% in Wales. Reduced frequency was also reported by 12.2% for the UK overall; 13.5% in England, 9.1% in Scotland, and 5.6% in Wales. In Northern Ireland only one person has these types of appointments and they had been cancelled.

Speech and language appointment cancellations were similar (57.5% UK overall) and ranged from 56.2% in England, 60.9% in Scotland to 76.5% in Wales. Reduced frequency of appointments were reported by 12.4% in England, 4.3% in Scotland and 5.9% in Wales; 11.4% for the UK overall. Four people in Northern Ireland reported having these appointments and one said they were cancelled and one reduced in frequency.

Psychologist/counsellor appointments were also frequently cancelled (51.4% UK wide), ranging from 48.2% in England, to 60.0% in Scotland and 70.0% in Wales. Both the respondents from Northern Ireland who had these appointments also reported they were cancelled. Reductions in frequencies were reported by 15.6% in England, 15.0% in Scotland and 10.0% in Wales; 15.0% for the UK overall.

Some respondents had also chosen to cancel appointments themselves due to the risk of COVID-19 (14.8% UK wide); 15.8% of respondents said they had done so in England, 9.9% in Scotland, 7.9% in Wales and 17.4% in Northern Ireland.

### *Use of online or telephone appointments*

Respondents were also asked about their use of online or telephone appointments and asked to indicate if they had not been offered these, were offered but had not used them or had used them. Again, the numbers below exclude those for whom these appointments were not applicable.

Considering GP appointments, 37.3% in England had not been offered these types of appointments, compared with 40.6% in Scotland, 49.3% in Wales and 56.3% in Northern Ireland; 38.5% UK wide. Use of these types of appointments ranged from 31.3% in Northern Ireland, to 34.8% in Wales, 39.6% in Scotland and 48.8% in England; 47.0% for the UK overall. For those whose GP appointments had been cancelled, 37.8% had not been offered a telephone or online appointment.

It appeared that online or telephone appointments were often not available for nurses. Those saying these were not offered ranged from 46.4% in Scotland, to 53.5% in England and Wales, to 76.5% in Northern Ireland; 53.1% for the UK overall. The use of these appointments ranged from 23.5% in Northern Ireland and 27.9% for Wales to 35.4% for England and 39.3% for Scotland; 35.1% for the UK overall. For those whose nurse appointment had been cancelled, 51.9% were not offered an online or telephone appointment.

Online or telephone appointments were even less available for Parkinson's consultants and these were not offered to the majority of respondents. 68.4% in



Northern Ireland, 68.6% in England, 74.3% in Scotland and 80.0% in Wales said these had not been offered them; 69.9% for the UK overall. Use of these appointments ranged from 13.8% in Wales, 15.8% for Scotland and Northern Ireland and 24.7% in England; 23.0% for the UK overall. For those whose consultant appointment had been cancelled, 68.2% were not offered online or telephone appointments.

Online or telephone appointments were also not frequently offered for physiotherapy/occupational therapy or speech and language appointments (70.9% UK overall). 60.0% in Northern Ireland, 63.3% in Scotland, 70.4% in England and 87.2% in Wales said they had not been offered this type of appointment. 20.4% of respondents had accessed these types of appointments; 8.5% in Wales, 10% in Northern Ireland (1 person), 20.0% in Scotland and 21.7% in England.

Access to psychologists and counsellors was similarly difficult, with the majority not being offered these sorts of appointments (79.9% UK overall). 60.0% in Northern Ireland, 78.9% in England, 83.7% in Scotland and 89.3% in Wales had not been offered telephone or online appointments. 15.8% in England, 7.0% in Scotland, 3.6% (1 person) in Wales and no-one in Northern Ireland had accessed these type of appointments (13.9% UK overall).

### **Sources of helpful support<sup>2</sup>**

Respondents were asked to indicate where they had found helpful support, first selecting from a range of options and then giving a free choice response. The Parkinson's website had been a particularly helpful source of support in England, Scotland and Wales, with 45.9%, 47.7% and 51.7% rating it as helpful respectively; 29.2% rated it as helpful in Northern Ireland (but sample sizes are smaller here). Overall across the UK 46.2% rated it as helpful. Local Parkinson's UK support groups were also rated as helpful by 20.6%, 21.6%, 26.7% in England, Scotland and Wales

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<sup>2</sup> We know for this question if people found something helpful, but not if they accessed it and it was not helpful – i.e. the information about whether a resource was accessed is not included.

respectively with Northern Ireland lower at 8.3%, giving 21.0% across the UK rating this as helpful. Endorsements for other support groups was lower (7.4% UK wide) and were helpful for 7.0%, 9.2%, 9.5% and 4.2% in England, Scotland, Wales and Northern Ireland respectively.

The Parkinson's helpline was helpful for 8.2% in England, 10.5% in Scotland, 7.8% in Wales and 16.7% in Northern Ireland, giving 8.5% for the UK overall, and the percentages for the Parkinson's forum were somewhat similar at 8.1%, 4.6%, 7.8% and 12.5% for England, Scotland, Wales and Northern Ireland respectively, with 7.9% for the UK overall.

NHS websites also seemed to be generally helpful, rated so by 30.7% in England, 36.6% in Scotland, 26.7% in Wales, 20.8% in Northern Ireland and 30.8% across the UK, whereas NHS111 or equivalent were perhaps less so, deemed helpful by 4.2% in Northern Ireland, 4.3% in Wales, 6.4% in England but 11.8% in Scotland and 6.7% overall for the UK.

Social media such as Facebook or Twitter was also rated as helpful by 20.4% in England, 26.8% in Scotland, 30.2% in Wales, 29.2% in Northern Ireland and 21.7% across the UK as a whole.

When asked to state other useful forms of information or support (in addition to health and social care providers), many people indicated they accessed the news and information from the media (e.g., television, radio, newspapers and their associated websites). Respondents used trusted sources such as the BBC or named national newspapers. A few others searched the internet more broadly (e.g. using google or you tube) or sought information from scientific or other trusted sources (e.g. scientific journals or university websites, other organisations or individual blogs). Government official information was also useful for some people, whether that be the government's website, leaflets or the daily briefings. A few people indicated that their council provided helpful information and some had obtained useful information from their employer/place of work. Several other organisations were mentioned too as being helpful, including Age UK, the Michael J Fox Foundation, dementia organisations

and other local and national organisations. The Parkinson's UK Facebook group and newsletter were also specifically mentioned as helpful by a few people. Many people stated that they received support and information from family and friends. Three people noted that all the information they received was confusing or overwhelming.

In summary the most helpful form of support identified through the specific questions was the Parkinson's website with 46% of respondents overall saying this was helpful. Local Parkinson's UK support groups, NHS websites and social media were also rated as helpful by over 20% of participants. In the free text responses, national media and family and friends were also frequently mentioned.

### **Support required**

One question asked about additional support now needed. Emotional support, practical tasks and contact from Parkinson's UK were given as specific choices, as well as a free text option.

Overall, 20.2% said they would like more emotional support, ranging from 16.3% in Scotland and 19.8% in Wales to 20.6% in England and 20.8% in Northern Ireland. Similarly, 20.9% overall wanted more help with practical tasks, ranging from 20.2% in England and 20.7% in Wales to 25.0% in Northern Ireland and 26.8% in Scotland. More regular contact from Parkinson's UK was desired by 11.4% across the UK with 11.5%, 10.5%, 10.3% and 16.7% in England, Scotland, Wales and Northern Ireland respectively.

In the free text part of this question, unsurprisingly, given the large number of cancellations of appointments reported above, many people indicated that they required urgent access to their consultant or specialist nurse for help in managing symptoms and medication. Access to other (non-Parkinson's) healthcare was also a priority for non-Parkinson's healthcare needs. Some people were also struggling with personal care and with everyday tasks around the home due to cancellation of carers (noting above that receiving less care was frequently reported by those reliant on paid care) or domestic help. Others were in need of a "handyperson" to help with

maintenance. Difficulties in exercising was also frequently mentioned. Although some had managed to access online classes, others commented that they needed additional support and/or motivation to exercise and were missing their usual exercise classes.

Difficulties in obtaining groceries was also frequently mentioned, with people unable to access online delivery slots from supermarkets or struggling with queuing when they had no option but to go out. "Getting on the priority list" had been a struggle.

Respondents also frequently mentioned the lack of social contact and/or that people were struggling emotionally. While many were managing with video calls and telephone calls, others wanted help with this, while others were desperate for human contact "a hug" or to "see people in person".

Another request from several people was for more clear information to be made available about the specific effects and risks of COVID-19 for people with Parkinson's. Individuals wanted this to inform themselves, but also to inform employers, including what adjustments/protections might be needed for someone with Parkinson's.

Other comments that perhaps related to the situation more generally, included calls for increased testing, for more clarity from the government and more confidence in the government's response. There was frustration for some that others were not following lockdown rules and for others that they wanted more freedom to go out, including to perceived low risk activities such as garden centres etc.

### **Other information**

The final question in the first section of the questionnaire asked for respondents to give any other information that was relevant to their experience of COVID-19. The free text answers gave more insight into the difficulties that many people were experiencing. On the whole these replicated and expanded on the issues raised on the "help needed" free text section reported above. The main themes are briefly described below. As one person summarised:

*“Parkinson's is an emotional journey at the best of times, coronavirus adds significantly to the experience by reinforcing the feeling of lack of control, lack of influencing ability or just waiting for the inevitable. Getting out of the house and dealing with the issues of getting around was a significant distraction, now denied.”*

## **Health and statutory 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”.*

*“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.”*

*“If it hadn't been for neighbours help, we would have been forgotten. Local authority very, very slow.”*

*“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, condition deteriorated considerably. The worry surrounding virus is also not helping condition. Isolation and not being able to go out is increasing existing depression and panic attacks.”*

A few people reported good support from health and other organisations (e.g. appointments moved online, contact from the council etc). However, this experience was certainly not the norm and a considerable number felt “abandoned”, “invisible” and “ignored”; no-one (e.g. council, social care or healthcare professional) had been in touch, health appointments had been cancelled and no alternative (e.g. phone) had been offered. Social care visits had reduced or stopped, as had visits from cleaners and domestic support, as well as respite care leaving people struggling to manage on their own or relying on their partners who often were also older people, leading to concerns about burden and carers becoming overwhelmed.

In general, there was considerable anxiety about deteriorating health and need for medication reviews and no access to help. Sometimes, as in the quotation above, people were mid-way through some aspect of treatment and left in limbo with a variety of symptoms. The difficulty of phone consultations for those with low voice volume and voice tremors was also noted, with one person saying the consultation was just stopped after a short period of time due to these issues.

Other services which contributed to physical wellbeing, e.g. podiatry, had also stopped. Several people also had other conditions which needed attention which added to their worries, for example operations and other procedures were cancelled and some individuals were left in considerable pain and discomfort as a result, with increased anxiety as to when such procedures would be available again.

### **Access to exercise/physical activity**

*“Had to stop horse riding and tennis, making up with 3 hours a day dog walking. Find not being active makes me stiff and balance off.”*

*“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.”*

*“Being unable to attend physiotherapy or go outside for brief spells of exercise has made me more anxious and depressed. I feel my movement has got worse as I have been unable to practice.”*

Another difficulty highlighted by many was lack of access to the usual forms of exercise/movement whether that be physiotherapy appointments, particular forms of exercise (e.g. swimming) or particular classes that were helpful and valued. Many participants noted that this was leading to a loss of both physical and mental health, with increased movement problems, constipation, anxiety and low mood.

Some had managed to access classes online but others did not seem aware of this option, perhaps did not have access to the internet or found the technology too difficult. Lack of access to massage was also noted as problematic.

A small number said lockdown had given them more time to exercise which had improved their physical wellbeing.

### **Physical symptoms, stress and anxiety**

*“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.”*

*“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.”*

In addition to the lack of exercise exacerbating symptoms, others highlighted how anxiety, stress and low mood were also contributing factors to increasing difficulties with movement, tremors, pain, and digestion. Several people just noted that during the lockdown their symptoms had become worse. The impact of family members being cooped up together, managing work or home schooling, or couples living together in a small space was also noted, with an increase in stress which again exacerbated physical symptoms. Some who usually experienced anxiety could not access their usual support networks of family and friends, which in itself also increased anxiety.

Increasing anxiety leading to physical symptoms led to a vicious cycle, as increased physical symptoms also led to increased anxiety. In particular, having freezing episodes or falls were more worrying without access to the usual medical help and support and others worried what would happen if they deteriorated, again without access to help.

Some noticed they had “lost confidence” and become more anxious generally about their condition or now suddenly felt much more vulnerable. Others had specific fears, of catching the virus, of going into hospital both for general issues (and thus being exposed to the virus) and for COVID-19 (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.

Going out was anxiety provoking, worrying about others socially distancing. Some felt that they would be too worried about the virus to go out after lockdown was relaxed and other were fearful of how long the virus was going to be around and worried about the future. Being at home gave more time for ruminating about Parkinson’s rather than getting on with life. Others were concerned about impacts on other family members (e.g. jobs, health and finances) and some worried whether they would see their family again. Others had more general worries about the future for the country, employment and health.



Two people also noted how their Parkinson's symptoms had worsened when they believe they had had the coronavirus.

### **Accessing food, medication and other vital supplies**

*"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?"*

*"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 to 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."*

*"The arrangements for shopping were very unclear at the start, the guidance notes stated to qualify for assistance from government you needed to be a vulnerable or elderly. Parkinson's yoyoed 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."*

*"Home delivery of groceries, medicines and from garden centre have been fantastic. Also on line purchase of other requirements has helped considerably."*

One 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. 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.

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 had to go shopping but this could be hugely difficult when fatigue was an issue and queueing not possible/exhausting and there were added concerns about social distancing and bringing the virus home. Some who had been relying on online deliveries prior to the COVID-19 pandemic, suddenly could no longer access them, leaving them stranded. Many felt that Parkinson's needed to be highlighted on the priority list and that they needed help to be able to get food safely and without risks to their health.

Accessing medication had also been difficult for some, although that was less often reported in this free text section. However, any difficulties in obtaining medication obviously caused considerable anxiety, as well as concerns in going to the pharmacy.

### **Confusion about Parkinson's, COVID-19 and lockdown**

*"I am anxious that as I am not in the shielding category I will be expected to return to work when lockdown is over but as a person with Parkinson's I am still vulnerable"*

*"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."*

*"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."*

*“It was difficult at first for Dad to appreciate that coronavirus was an actual thing and not something we made up to stop him going out. Even now he still doesn’t fully appreciate the risks and consequences. Not his fault, he just doesn’t think as well as he used to.”*

There was generally confusion about the state of Parkinson’s and COVID-19 and the level of vulnerability and risk for people with Parkinson’s. People wanted more clarity about what the consequences of COVID-19 would be for someone with Parkinson’s, and whether they needed to be concerned. As noted above, this was partly for themselves so they knew whether it was safe for them to go outside. However, younger people still at work wanted clear guidance for them and their employers to know if it was safe to return to work and what support and protection would be needed. Clarity was also asked for, to inform supermarkets for instance (as above) to enable people to receive online deliveries.

There had been long waits for some to receive their “shielding letter” and others were confused why some met the criteria and others did not. This uncertainty led to increased anxiety and worry.

Lockdown itself was also a source of confusion for some, trying to work out what the rules were. Those with dementia (or those reporting on their behalf) indicated how hard it was to understand the rules and keep up with the changes. Also, information from lots of different sources was also confusing.

### **Contact with family, friends and activities**

*“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.”*

*“My mood is very low. My wife works so I spend a lot of time on my own. We live in a small 1 bedroom flat. I do have a small garden but I suffer with hay*

*fever. Time outdoors is limited. I do not have family so my wife is my only contact with the outside world."*

*"Missing all the social activities, gym, meeting friends, eating out, indoor bowls, local Parkinson meetings and activities and coffee mornings"*

*"[Name of 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."*

*"The benefits from technology have been extremely useful for keeping up to date, keeping in touch with friends and family etc. Also allows connection to local Parkinson's group and even have a choir session once a week."*

Some felt well supported by family and friends and had managed to maintain contact with them and with their usual activities via telephone and technology. Some Parkinson's local groups appeared to have been particularly proactive in that regard, in helping to keep up social and wellbeing activities. Many people mentioned staying in contact with family via technology (although often noted that it was inferior to in person meetings).

Others felt isolated, trapped or claustrophobic as not able to go out. Many were lonely with a huge yearning to see family and friends with many reporting they very much missed their children and grandchildren. People who had been very active in religious organisations and had many leisure activities suddenly felt isolated and bereft of the activities that maintained their sense of self and wellbeing and where they received social support. For those with more advanced disease, being able to go out (e.g. in the car with others) was a key activity which maintained their wellbeing and this was now denied. An increase in low mood was mentioned by several people as a consequence of the COVID-19 situation and associated restrictions. Not being able to perform rituals or attend key life events, e.g. missing the first days/weeks of the life of a grandchild or not being able to attend funerals of family and friends, also added to the sense of loss.

A small number resented their loss of freedom and queried whether it was necessary.

## **Work**

*“Because of the nature of work that I do I am currently working from home. My employers are very supportive of me and my PD. My PD symptoms are very much under control and I think probably slightly reduced doing due me not having to go/drive into work.”*

*“For me as a younger person I'm concerned about the effect a prolonged absence from work will have on my ability to do my job. I'm a self-employed cleaner so it's fairly physical and I'm finding that I'm less physically able and more easily fatigued as the weeks pass.”*

*“Stress of work has increased symptoms. Stress has increased due to economic impact affecting the work I do, led to increased symptoms”*

*“I work in a primary school and I'm quite confused as to the safety of the setting when and if I return to school in June. The Parkinson's online info advises me to stay at home but the government guidelines suggest I'm fine to return to school. This uncertainty is the only aspect I'm currently struggling with.”*

Experiences of employers and work was quite variable. Some had very supportive employers who were taking Parkinson's into account and considering their needs during the pandemic. Indeed, some found work a valuable distraction. However, others were furloughed and worried about their return to work, including whether it was safe and whether they would be allowed and some thought that they would be pressured to return to work, when it was not safe. Some worried about the impact of being away from work and whether their physical health would deteriorate as a result.

## **What helps**

Several participants mentioned strategies and approaches that had helped them during the lockdown. Use of technology was mentioned by many as being a “game changer”, with several having to learn this at the start of lockdown, particularly video

calling. This was a satisfying achievement for some, but a source of frustration for others and some had to rely on partners to be able to access this (some asked if help could be provided). Technology had enabled people to stay in contact with family and friends but also to “attend” virtually, classes, meetings, leisure activities (e.g. choir), religious services and support groups. Support from organisations including Parkinson’s UK (nationally and also locally) as well as other support groups were mentioned.

Several people mentioned attending “quizzes” either organised by friends or by organisations. Mindfulness, reading, listening to music, exercise outside or online exercise classes, being in the garden/outside, volunteering (e.g. making gowns for healthcare staff), doing online card games for one (e.g. solitaire), were all mentioned. Some suggested limiting exposure to news.

Staying with your “glass half full”, keeping yourself busy, and focusing on positives, e.g. finding something to enjoy (even something simple), were also suggested as helpful.

### **Positives from the lockdown**

*“In some ways it has been a relief to let go of some responsibilities. I am lucky to live in a retirement village with lovely grounds, so I can walk. Were it not for the sadness of friends partners dying in the attached care homes, I would actually be enjoying this bit of rest and space.”*

*“I think I am less anxious now because I am in my own little bubble and I have nothing to worry about.”*

*“Due partly to a generally optimistic outlook, I think there have been silver linings in the whole situation. People offering help more, thinking of one another more, a feeling of banding together plus more time to pursue hobbies and try new ones. At least— for us oldies!! The weather has certainly helped as well. I’m not that proficient with all this techno stuff but am getting better almost without realising it! Another bonus.”*

While it was no means universal, a small number of people spoke about the positives from the lockdown. This included learning new skills (e.g., in IT) or having more time to cook or exercise or talk to friends and family. Several people commented they had got to know their neighbours or seen more kindness and compassion in society.

Others found the reduction of responsibilities and calls on their time a relief and actually found life in lockdown less stressful than normal life, which they had perhaps been struggling with because of their Parkinson's. Others noticed not much difference (sometimes noted as a positive and for others their physical health impairments limited their life anyway and therefore there was not much change).

### **Other issues**

Other issues mentioned included anger and frustration at the government's handling of the crisis and/or the media reporting of it (including the situation in care homes which understandably was a cause for concern). People also talked about the lack of testing for COVID-19 (including some suggestions that those with Parkinson's, and similar conditions, should be a priority to be tested). Some were frustrated at others not following the lockdown rules, but others frustrated by lack of freedom.

Some expressed frustration at not being able to help others as they usually would and also that it was difficult to help people who were not on the internet/able to use computers etc.

## **Part 2 – Families, friends and carers**

### **Demographics**

The second part of the survey was completed by 540 family members, friends and carers. 74% of these were a husband, wife or partner, 21% another family member, 3% a friend and 2% reported themselves as 'other'. 76% were living with the person with Parkinson's, 18% did not and in 5% of cases the person with Parkinson's lived in a care home. 65% of respondents were retired, 20% were working, 6% were homemakers and 5% were furloughed due to coronavirus restrictions. For those working, 31% said their work situation due to COVID-19 made it more difficult to provide care for the person with Parkinson's.

47% of respondents said the person with Parkinson's depends on their support and care 'totally' and 40% 'to some extent'. 13% said the person with the condition does not depend on their support and care.

### **Illness of family, friend or carer**

9% said they were ill since coronavirus restrictions began (either due to the coronavirus or other reasons).

### **Caring for person with Parkinson's and impact on family, friends and carers**

68% of respondents say they have taken on more caring responsibilities since the coronavirus restrictions started. For people living with the person with the person with Parkinson's, this figure was 74%. 19% have not been able to provide as much care. 42% said the coronavirus restrictions were negatively affecting their mental health. Where the person with Parkinson's 'totally depends' on the care of the respondent, this figure was 52%. 68% of all respondents say they have less time away from the person with Parkinson's to focus on themselves. This figure is higher where the respondent lives with the person with Parkinson's (79%) and where the person with Parkinson's totally depends on their care (88%). 34% said the restrictions are



negatively affecting their physical health and for those providing care the person with Parkinson's 'totally depends' on, this figure is 49%.

### **How COVID-19 is affecting friends, family and carers**

Families, friends and carers were asked to describe in their own words how the coronavirus restrictions are affecting them and the following themes were identified.

Many answers focused on the impact of restrictions on the person with Parkinson's they were caring for. The themes identified in these comments echo those of respondents with Parkinson's described above.

Fear of contracting the virus was a common theme.

*"We have been mega careful, including going into self-imposed isolation about 3 weeks before we had to - felt that if my husband caught the virus and was hospitalised, assuming he recovered, he would have lost his mobility completely. Equally, if I had caught it, he wouldn't be able to look after me ...."*

Some attributed constant negative media exposure as a contributor to increased stress and fear.

*"I am completely fed up with the adversarial style of news reporting, the lack of other world news. No wonder my Partners of People with Parkinson's Facebook group is reporting high levels of stress and poor symptom control in their PwP [person with Parkinson's]."*

*"Can't help feeling the media only focus on the negative data, rarely the positives, which is unnecessary and can be depressing. But then again, the media knows fear sells!"*

Some expressed frustration at what they perceive to be 'government spin and lies'.

*"Government needs to be honest about everything and not cover up errors."*

Many expressed a frustration at the lack of clarity or confusion around guidance on the risk of the virus to their loved ones.

*"I keep being asked by work if we should be shielding because of hubb[y's] PD- I have assumed no, but then get a covid hub letter which is really confusing."*

Many are concerned the categorisation of risk for people with Parkinson's compromises the care and support available for their loved ones.

*"Because Parkinson's isn't in the highest risk category, it's hard to see how mum would be able to access the help and care she needs if we weren't here. We are very happy to be here but it's scary to know that she'd be basically treated the same as anyone over 65 when she has really challenging needs."*

*"We were surprised that people with Parkinson's are not included the government's "vulnerable group". This means we have been unable to get a delivery from any of the local supermarkets. We have had to go to the pensioners hour. After a week numbers were restricted so that only one person could go into the supermarket at a time. Going in alone is difficult for my husband as a person with Parkinson's, also for me as a medical condition means I am unable to lift heavy shopping bags."*

*"I think that the NHS has not identified the extremely vulnerable very well. I am aware that his Parkinson's only puts my husband into the "vulnerable" category. However, he also has Rheumatoid Arthritis for which, amongst other medication, he takes two immuno-suppressant drugs and he also had pneumonia 12 months ago and was on a high dependency ward for a week on oxygen ... I think that he should have been classified in the shielding category and that we should have had access to more help."*

Many families, friends and carers were concerned about a worsening of Parkinson's symptoms in their loved ones.

*“As far as I am aware my Mum has only left the house once since lockdown began. She feels 100x more vulnerable now and it's definitely affecting her Parkinson's.”*

*“Being with my husband 24/7 has made me realise how much his condition has deteriorated and this impacts both our mental health....”*

The impact on mental health of the person with the condition was a common concern.

*“Coronavirus has affected my Dad's mental health a lot. At times it seems he has forgotten he can't go out to see family and that we can't visit. He has shown anxiety about the virus and keeps asking myself and brothers when he can go out ...”*

Many said reduced access to health and social care was affecting the ability of the person with Parkinson's to manage their condition and is leading to deterioration.

*“... my relative was admitted to hospital after the first two weeks of lockdown. His admission was in relation to PD symptoms which were ignored by GP, paramedics and messages left to Parkinson's team... He had been constipated hence meds not as effective resulting in complete loss of function from neck down now has a gastric peg had swallow mechanism has not return and hasn't walked for 5 weeks. This could have been avoided if the professionals had listened and took action sooner but all resources were focused on Coronavirus and not other health issues.”*

*“...(restrictions have) impacted on my husband due to the fact that appointment to see Parkinson Nurse was cancelled ... I did say to the nurse in a telephone conference call that he really needed to be seen ... as in my mind he seems to be going downhill.”*

*“I feel totally abandoned by... Social Care. I emailed my MSP 10 days ago to highlight my situation and although I have had a reply saying my email will be sent to the body concerned, I've still had no response.”*

Some were concerned about the impact on care provision for people with Parkinson's in the future when things 'get back to normal'

*"It's also very worrying to think about accessing neurology appointments and Parkinson's Nurse time once things go back to normal - demand will be even higher and it's already 9 months between appointments. Very scary."*

There was some frustration at not being phone or online alternatives.

*"I cannot believe phone call or Skype cannot be used to have a consultation with a Parkinson's specialist. Are medical records on line?"*

Many believed that reduced access to exercise and other activities was affecting the ability of their loved ones to maintain their physical and mental health and contributed to a deterioration of the condition.

*"It is also upsetting to see the person you are for not being able to use facilities that are important to maintaining physical and mental health. I believe ground has been lost that will not easily be regained."*

*"She (mother) normally attends 2 exercise classes, laughter yoga, does shopping when she feels fit and keeps herself moving. Since coronavirus all of this has stopped and as a result it is affecting her both physically and mentally."*

*"Seeing decline in husband from his Parkinson's as he is no longer able to attend gym or do the other outside home activities he enjoys."*

*"...unable to meet exercise is very important to my husband and he appears to have lost all motivation"*

### **Impact of restrictions on family, friend and carers**

Many described how the restrictions impacted on them personally. Common themes were a growing sense of 'frustration' or 'boredom', loneliness, increasing levels of stress and in some cases despair as the restrictions continue. This, and not knowing

when restrictions will end or an inability to see 'light at the end of the tunnel' affected mental health.

*"As the weeks go by it becomes more stressful."*

*"Frustration, boredom and a wish to get back to some normality for both our sakes."*

*"We've been stuck with windows shut and no escape. Bad for our mental health, and very lonely."*

*"Been tied to the house, wife unable to leave and there is very little light at the end of the tunnel."*

*"... worried about how long before we can get out and about again"*

*"Feeling more of a prisoner than ever in own home - life restricted due to Parkinsons now seems to have come to a complete halt. "*

Some were fearful of their ability to protect the person with Parkinson's when restrictions are eased and 'normal life' resumes.

*"Now I am comfortably in the zone with shopping etc being delivered I feel safe in my bubble and won't be in any hurry to go out. I'm content now, more concerned about mix with people again in the future."*

Many said that increased care responsibilities during restrictions affected their own mental health and wellbeing.

*"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."*

*“Going to work used to give me a mental break from PD, now I don't have that. The impact on the children is massive too ... they have suddenly been confronted with how poorly dad is. That has also been hard to manage”*

Some said the increased caring responsibilities meant they have had less respite or time to focus on themselves to maintain their mental wellbeing.

*“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 ... .”*

*“I miss being able to go for a walk on my own or shopping as I don't have very much interaction with anyone except my husband.”*

Some felt the impact of restrictions is straining their relationship with the 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.”*

Family members not living with the person with Parkinson's were worried about the impact of their reduced ability to provide care.

*“I worry constantly about my mother who provides all care for my father. Whilst I can offer support from a distance, I cannot offer either hands on support. My parents miss my visits and they now feel very alone and isolated. I don't think there is any other option for them at the moment and they try to stay positive ... but I believe there will be long term consequences for both their physical and mental health if their isolation continues for very much longer.”*

*“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 hospital after I had been*

*shielding him... I can't visit. Phone calls are difficult as he is so deaf. Consultant says his injury is life changing."*

For some, this was a source of guilt.

*"Every weekend I would normally make a 1 day 180-mile round trip to spend a few hours with my Mum so she has contact with more of her family... if I'm honest deep down I resent losing that free time but what it gives Mum outweighs that by miles. Coronavirus has turned that resentment to guilt, guilt because I have time to do things for me and with my partner, guilt because I can't spend time with Mum ...."*

Visiting restrictions and the spread of the virus in care homes were also worrying.

*"Concerned about mum's emotional health. Daily visits from family are the norm and as she is in palliative care time is limited and it is so distressing for her not to have her loved ones with her."*

*"I am worried about my mam going back into the care system, she seems pretty protected at the moment, but the care homes are rife with CoVid 19 and it's a big worry and very stressful."*

*"I can't understand why people are dying in care homes when there is capacity to care for them in hospital where there is also access to skilled medical teams and medical equipment ... We have seen countless times on the news where elderly people often with underlying ailments are beating the virus when they have access to hospitals with skilled medical personnel and equipment. It's as if there is some unwritten rule that patients in care homes don't have the same human rights to life."*

Some respondents wrote about how their interests and self-directed activities have helped them cope.

*"I dropped into a new routine easily, I have increased my time with some of my hobbies, running & gardening. I have had to stop other hobbies, dancing &*

*swimming. I attend Sunday Church Service via Zoom which has become a highpoint in our week. I really miss physical contact with others especially my children & grandchildren. I can sense that I am losing interest in things however I have my run first thing in the morning which sets me up for the day."*

*"I am fortunate I live in a semi-rural area so can get out for exercise. I have a garden and have enjoyed spending extra time working on it ... I count myself very blessed."*

Some have found online activities helpful

*"I have appreciated the ... Parkinson's Group for providing a Zoom exercise class each week and keeping me informed."*

*"I really like the exercise opportunities that came through from Parkinson's UK."*

Some emphasize the importance of digital technology for dealing with isolation and staying in touch with family and friends.

*"As my husband's condition has deteriorated during the lockdown, I have had to be with him all the time ... However, I have been getting lots of support via telephone, email, WhatsApp, Zoom, Facebook, etc."*

Some saw the increased use of digital technology to help people manage their Parkinson's as something that will or should continue when restrictions are eased.

*"There will be a big rush in the older population to get smart phone and tablets. I would love to see a proper, independent, evaluation of devices designed for older people. "*

*"Coronavirus has forced organisations to come up with innovative online solutions, and this has made it obvious that very few previously tried to make events accessible for disabled and ill people ... Once the pandemic eases I hope*



*more thought will be given to this. The virus has also highlighted how important internet access and basic technology skills are for people with Parkinson's."*

### **Part 3 – Mental health and wellbeing for people with Parkinson's and their family, friends and carers**

Mental health and wellbeing were measured using the Warwick-Edinburgh mental wellbeing scale<sup>3</sup> (Tennant et al., 2007; NHS Health Scotland, University of Warwick & University of Edinburgh, 2015) for both people with Parkinson's and family, friends and carers. This scale ranges from 14 to 70 with higher scores indicating greater wellbeing. NHS direct have used a cut point of 40 and below to indicate low wellbeing (Warwick Medical School, 2020).

The overall mean of the sample with Parkinson's was 45.2 (*SD*: 10.5) with little differences between the nations (means ranged from 42.7 in Northern Ireland to 45.3 in England). These are lower than those typically reported by the general population. In previous studies means have ranged from 49.7- 50.0 for Scotland and 50.9 - 52.3 for England (NHS Health Scotland, University of Warwick & University of Edinburgh, 2015).

Those who were living under the general restrictions placed on everyone had greater wellbeing (mean 47.0) than those who were self-isolating due to fears about the virus (mean 43.7) and those who were in a shielding household (mean 41.9). This may well reflect the general health of these three groups, as well as the restrictions. Although the following groups are too small to be tested statistically, those unable to go out due to disability (mean 39.4) and those in hospital (mean 35.0) unsurprisingly had low mean scores.

For family, friends and carers the overall mean of the sample was 38.9. Where the person with Parkinson's totally depends on their care, the mean was 36.8. Where the

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<sup>3</sup> The Warwick-Edinburgh Mental Well-being Scale was funded by the Scottish Government National Programme for Improving Mental Health and Well-being, commissioned by NHS Health Scotland, developed by the University of Warwick and the University of Edinburgh, and is jointly owned by NHS Health Scotland, the University of Warwick and the University of Edinburgh

family member, friend and carer were ill during the coronavirus period, the mean was 29.3.

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