

# Parkinson's and government definitions of vulnerability

Should people with Parkinson's be defined as "moderately vulnerable" or "clinically extremely vulnerable", and what support do people with Parkinson's need during the coronavirus pandemic?

## Background

We acknowledge that people with Parkinson's do not currently fall into the government's clinically extremely vulnerable category of those who should be shielded during this time. The people in the clinically extremely vulnerable category (also known as the shielded group) were defined as those who had specific health conditions placing them at risk of severe illness if they caught coronavirus.

The conditions defined in this category include a weakened immune system, severe respiratory issues, or those who have had an organ transplant. Parkinson's was not included.

## What we think

Everyone with Parkinson's is different. Many people with Parkinson's are not clinically extremely vulnerable. However, we believe that some people in the more advanced stages of the condition, and some of those who have other conditions alongside their Parkinson's, would meet the clinical criteria to be classified in this way. We believe that these people should be added to the extremely clinically vulnerable list.

Looking at the overall population of people with Parkinson's and guidance from medical professional bodies, we have identified common risk factors that could put some people with Parkinson's at additional risk of serious illness from coronavirus in combination with having Parkinson's. Some people with Parkinson's will be included in several of these categories:

- **Swallowing difficulties:** A small proportion of people who have had Parkinson's<sup>1 2</sup> for a long time develop swallowing problems that can result in food or saliva going down "the wrong way" meaning that they cough or splutter frequently while eating. This gives a risk of aspiration pneumonia.

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<sup>1</sup> Suttrup I et al (2017) 'Esophageal dysfunction in different stages of Parkinson's disease' *Neurogastroenterol Motil*. DOI: 10.1111/nmo.12915.

<sup>2</sup> Umemoto G, Furuya H (2020) 'Management of Dysphagia in Patients with Parkinson's Disease and Related Disorders' *Intern Med*. DOI:10.2169/internalmedicine.2373-18

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- **Breathing issues:** These particularly affect those with more advanced Parkinson's.<sup>3 4</sup>
- **Age:** Around 74% of people with Parkinson's are aged over 70 and about 36% are aged over 80.<sup>5</sup>
- **Living in a care home:** Around 10-15% of people with Parkinson's live in care homes.<sup>6</sup>
- **Having another serious long-term condition:** 31% of people with Parkinson's have more than five other long-term conditions, and only 7% have Parkinson's alone.<sup>7</sup>
- **Dementia:** Some patients with advanced Parkinson's develop memory impairment and may find it more difficult to follow social distancing guidance and hygiene instructions.
- **Pregnancy:** Women with Parkinson's who are pregnant need a specific risk assessment, for example, in relation to work.

We believe that Parkinson's specialists and GPs should identify where people with Parkinson's have one or more of these factors, and make a clinical judgement about how these combined factors would increase the risk to individuals if they develop coronavirus. We recommend that those at very high risk should be added to the shielded list.

If someone is not on the extremely clinically vulnerable shielded list, but believes that they should be included, they should contact their Parkinson's specialist or GP and ask them to consider whether they meet the criteria to be added to the clinically extremely vulnerable shielded list.

### **Guidance and support for people with conditions on the “moderately vulnerable” list**

UK governments initially identified Parkinson's as one of the conditions which places people at higher risk of complications if they develop coronavirus. The moderately vulnerable category is much bigger than the shielded list, totalling millions of people in the UK. We believe that this risk category is appropriate for most people with less advanced Parkinson's who do not have other serious conditions or risk factors.

We also believe that there is a need for the government to provide separate and clearer guidance on how those in the “moderately” vulnerable category should keep themselves safe during the pandemic, and how guidance for them differs from that for the general population.

In addition to social distancing measures, this should include:

- clearer advice for employers to support home-working or alternative solutions for people in the moderately vulnerable group, and unpaid carers who need to protect them
- what support is available to this group to help with their day-to-day needs such as access to food and medicines

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<sup>3</sup> Baille G et al (2019) 'Dyspnea: An underestimated symptom in Parkinson's disease' *Parkinsonism Relat Disord*. DOI:10.1016/j.parkreldis.2018.09.001

<sup>4</sup> Baille G et al (2019) 'Dyspnea Is a Specific Symptom in Parkinson's Disease' *J Parkinsons Dis*. DOI:10.3233/JPD-191713. <https://www.ncbi.nlm.nih.gov/pubmed/31476170>

<sup>5</sup> Parkinson's UK 2017, The incidence and prevalence of Parkinson's in the UK:

<https://www.parkinsons.org.uk/professionals/resources/incidence-and-prevalence-parkinsons-uk-report>

<sup>6</sup> Hand A et al (2018) 'The role and profile of the informal carer in meeting the needs of people with advancing Parkinson's disease' *Aging & Mental Health*; DOI: 10.1080/13607863.2017.1421612

<sup>7</sup> McLean G et al (2017) 'Co-morbidity and polypharmacy in Parkinson's disease: insights from a large Scottish primary care database' *BMC Neurol*. DOI:10.1186/s12883-017-0904-4

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- suitable arrangements once the lockdown period has ended, for example, addressing whether this group will need to continue strict social distancing when people at low risk are able to increase their contact.

For many people with Parkinson's, physical disability, mental health and cognitive symptoms may make it more complicated to access support than for those who do not face these additional challenges.

We believe that in addition to separate and clearer guidance, there should also be a defined package of support for those in for people in the "moderately vulnerable" category. There must also be a comprehensive communications strategy to make people aware of the support they are entitled to, and how they can access it.

Schemes have been set up to support people with Parkinson's who are unable to obtain food and medicine themselves or through friends, family or the voluntary sector.

### **England**

People with Parkinson's can use the [NHS volunteer responder](#) scheme to get help with food and medication deliveries.

### **Northern Ireland**

Priority delivery slots have been opened up for those who have been advised to shield by their GPs. Complete the [form on NI Direct](#) and retailers will get in touch directly to book a delivery.

### **Scotland**

In Scotland, a [free national helpline](#) was launched on 14 April for those in the wider vulnerable category who do not have other forms of support, linking them to local authority assistance hubs.

## **Why we think this**

People in the "clinically extremely vulnerable" group are the estimated 1.8 million people in the UK who are being issued with a letter instructing them to follow [very strict guidelines](#). This includes self-isolating at home until at least until the end of June, and avoiding all face-to-face contact with people outside their household.

This group is being prioritised for support from statutory organisations, charities and retailers. They can use their NHS letter to register for a package of assistance so that they can access food and medicine without leaving their home. The letter can also be used as evidence of vulnerability to support individuals and unpaid carers who are asking their employers to work from home.

Throughout the UK, GPs and specialist doctors are being asked to identify additional patients who should be added to the shielded category because they are at extremely high risk.

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In March, UK governments said that people with Parkinson's are "moderately vulnerable" and are at higher risk of developing serious illness if they contract coronavirus. Governments are advising them to practice "strict social distancing" but other information and practical support has been limited. People with Parkinson's and their families are following government advice to stay at home and have no social contact with people outside their household.

At the same time, some people with Parkinson's have found it challenging to be defined as "vulnerable". Some people, often those who are younger or who do not perceive their symptoms to be severe, do not consider that their Parkinson's affects their health enough for them to be classified in this way. We have already worked with professionals to explain why most people with Parkinson's, excluding those that may have the risk factors identified above (severe swallowing difficulties, breathing issues, live in a care home, have dementia or another long-term condition or are pregnant) are included in the moderately vulnerable group.<sup>8</sup>

Others are concerned that having Parkinson's or being identified as vulnerable may mean that they will not receive best medical treatment if they develop coronavirus symptoms. We have produced another policy position on ethical treatment to address these concerns.

The Association of British Neurologists (ABN) has identified that people with Parkinson's whose swallowing and breathing are affected are at higher risk, as are people who live in care homes, and that having a number of risk factors together will increase the risk of complications.<sup>9</sup>

The British Geriatrics Society (BGS) has summarised the risks of having more than one long-term condition in older people as follows<sup>10</sup>:

*"Older people with frailty, multimorbidity and physical dependency are particularly vulnerable to COVID-19 and are less likely to benefit from intensive medical treatment if they become unwell. Moreover, the immune system, and response to infection, changes with age – and this may explain why older people are at risk for more severe complications."<sup>11</sup>*

## What we are doing

When it became clear that the pandemic was going to have a significant impact on our community, we focussed on delivering critical support including the following:

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<sup>8</sup> Parkinson's UK, March 2020: <https://www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons>

<sup>9</sup> Association of British Neurologists, March 2020: 'Guidance on COVID-19 for people with neurological conditions, their doctors and carers' - [https://cdn.ymaws.com/www.theabn.org/resource/collection/65C334C7-30FA-45DB-93AA-74B3A3A20293/ABN\\_Neurology\\_COVID-19\\_Guidance\\_v6\\_9.4.20\\_FP.pdf](https://cdn.ymaws.com/www.theabn.org/resource/collection/65C334C7-30FA-45DB-93AA-74B3A3A20293/ABN_Neurology_COVID-19_Guidance_v6_9.4.20_FP.pdf)

<sup>10</sup> British Geriatrics Society, March 2020: 'COVID-19: BGS statement on research for older people during the COVID-19 pandemic' - <https://www.bgs.org.uk/resources/covid-19-bgs-statement-on-research-for-older-people-during-the-covid-19-pandemic>

<sup>11</sup> Ibid

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- Producing [regularly updated information on coronavirus and Parkinson's](#).
- Managing a [Facebook group](#) so members of the community can provide mutual support to each other.
- Listening to our community, raising their concerns and lobbying governments and relevant bodies across the UK to get clearer guidance, as well engaging with service providers including supermarkets, to improve access.
- Strengthening capacity on our helpline and local advisers to meet demand for information, emotional support, and signposting.
- Supporting people to find practical help locally through our helpline.
- Providing updates to our community on our website and through social media and other communications.

We plan to continue our work in this area to ensure the needs of our community are met by doing the following:

- Communicating our activity with our community and what measures they can take to get access to the support they need.
- Developing clear messages for people with Parkinson's – if they haven't had a letter and meet the criteria above they should contact their GP or specialist and ask them to consider adding them to the list.
- Facilitating a joint letter/statement from the Association of British Neurologists and British Geriatric Society to the Royal College of General Practitioners.
- Gathering experiences and insights from our community to enable us to raise concerns and influence changes.

## Acknowledgement

We are grateful for the advice and guidance of the Clinical Leads of the UK Parkinson's Excellence Network in shaping this position paper on government definitions of vulnerability.

## Further information

Please contact the Policy and Campaigns team. Tel: 020 7963 9349 or email: [campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)

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