

Health services during the coronavirus pandemic

What we believe

We recognise that the scale and seriousness of the coronavirus pandemic has meant the NHS has needed to prioritise containing and treating the virus.

However, we believe it is vital that people with Parkinson's, their families, friends and carers, have access to, and support from, their specialist services, including Parkinson's nurses. This includes telephone or video consultations.

In the short-term, it is crucial that people with Parkinson's are supported to self-manage symptoms and to strictly follow social-distancing guidance.

All services should communicate any changes clearly to their patients, and should signpost to other local and national sources of support, including Parkinson's UK.

The Policy Panel discussed what the minimum reasonable expectations should be and agreed on the following:

- Services should be offered to help people manage their anxiety, stress and depression, when these happen as a result of their Parkinson's
- Telephone support is adequate, but support provided must be accurate and provided in a timely fashion, including on medication advice – a same day response would be appreciated.
- Text messaging could be explored to provide responses to urgent questions.
- Palliative care services should continue to be offered.
- Contact with deep brain stimulation nurses should continue during this time.
- Allied Health Professionals, where able, should continue to provide support and advice during this time.
- People with Parkinson's should not be using public or hospital transport at this time.
- We welcome the NHS volunteer roles in England, but there needs to be clear roles, safeguarding procedures and complaints processes in place to protect vulnerable people. Also, any volunteers should have the appropriate identification, including their name, and this should be displayed clearly.
- The needs of carers and those living alone should also be considered, especially those who may be working or are not online. Where possible, hard copy resources should be provided.

Why we believe it

Call volumes to our helpline and visits to our website have increased as the coronavirus pandemic has progressed.¹ We have been monitoring the subject of calls and queries and have produced information² to reassure our community and promote the activities they need to undertake based on this.

Concerns from our community include:

- Prolonged and consistent anxiety is having an immediate impact on people's physical and mental health.
- People with Parkinson's and their families are increasingly worried about how they will access shopping and medication.
- People are experiencing a degradation in healthcare provision in their local areas which is causing them worry
- People are concerned about what will happen if their carer is taken ill.
- The lack of care support available is increasing the responsibility on family and friends and this will have an impact on their own mental health.
- There is a decrease in the number of therapy services for people with Parkinson's to manage their balance, flexibility and pain levels.

We have also seen the organisation of Parkinson's services change in the last four weeks. In early April, we heard back from around 100 nurses and services across the UK. The vast majority are now operating a reduced service with telephone contact only.³ They added that plans are in place to support patients during this time and they are also signposting to the Parkinsons UK helpline.

We have also discussed the long-term consequences of reducing Parkinson's-specific services with the Parkinson's Disease Nurse Specialist Association (PDNSA) and the Alliance of Scottish Parkinson's Nurse Disease Specialists (ASPNS). We agreed that reducing services could result in a loss of quality of life for people with the condition, their families, friends and carers, and could also lead to an increased workload for the health and care services after the pandemic has been contained.⁴

The latest data from the Audit of Parkinson's services⁵ demonstrates the need for improvements to meet the needs of the Parkinson's population. It even highlighted areas for improvement across the UK. Work to take forward these system improvements has been halted during this crisis, but it will be an important resource post-pandemic to focus our attention on rebuilding services.

¹ Parkinson's UK shared information system, April 2020

² Parkinson's UK website, April 2020: <https://www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons>

³ UK Parkinson's Excellence Network, April 2020

⁴ Joint statement, UK Parkinson's Excellence Network, April 2020:

<https://www.parkinsons.org.uk/professionals/news/supporting-continued-access-parkinsons-nurses-through-covid-19-pandemic>

⁵ UK Parkinson's Excellence Network, January 2020

<https://www.parkinsons.org.uk/professionals/uk-parkinsons-audit-transforming-car>

What we are doing

The Policy Panel suggested there are also things that Parkinson's UK could do to provide reassurance and information to our community at this time too. They included the following:

- Tailoring government advice to the condition and promoting it to our community.
- Sharing how to get support and information through technology that can help people to stay connected, active and well.
- Developing information on exercise and physical activity to ensure that people with the condition remain active during the pandemic. This could include online information and exercise classes, but also sending information out to those who are not online. We should also explore producing DVDs on these tips.
- Sharing information about speech exercises and promoting apps and devices that can help people to use this technology at home.
- Keeping in contact with the most vulnerable members of our community, through welfare calls. We are trying to keep in touch with people using a variety of ways as we recognise that not every person has digital technology available, which can make them more isolated.

We have already taken action based on feedback from our community on many of the suggestions above. These include the following:

- Producing [regularly updated information on coronavirus and Parkinson's](#) including signposting to [guidance on anxiety](#), [managing your mental health](#) and [going into hospital](#).
- Tracking Parkinson's services to understand the picture across the UK.
- Producing [a statement on Parkinson's services](#) with the PDNSA and ASPNS and also sharing a template letter nurses can use to inform their patients about changes to their services.
- [Signposting professionals to relevant resources](#).
- Increasing the capacity of our [helpline](#) to answer queries.
- Identifying the most vulnerable in our community and tasking our local advisers with calling them.
- Producing [physical activity resources](#), and online classes with Parkinson's physios.
- Setting up a [new Facebook group](#) so members of the community can provide mutual support to each other.
- Organising a series of [Q&A sessions](#) with Parkinson's professionals to answer questions from our community.
- Joining with other charities to demand urgent action from the government to ensure that vulnerable people not on the government shielding list have access to supermarkets to enable them to stay healthy and well.

Acknowledgement

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on health services during the coronavirus pandemic. The Policy Panel consists of people with experience of Parkinson's who meet on a regular basis to help guide the charity's range of policy issues.

PARKINSON'S^{UK}
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Further information

Please contact the Policy and Campaigns team. Tel: 020 7963 9349 or email:
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