



Health, Social Care and Sport Committee - The Impact of the Covid-19 outbreak, and its management, on health and social care in Wales.

About Parkinson's UK Cymru

1. Every hour, two people in the UK are told they have Parkinson's - a brain condition that turns lives upside down, leaving a future full of uncertainty.
2. Parkinson's UK Cymru is here to make sure people have whatever they need to take back control – from information to inspiration.
3. We want everyone to get the best health and social care. So, we bring professionals together to drive improvements that enable people to live life to the full.

About Parkinson's

4. There are over 40 symptoms of Parkinson's and these can include freezing, tremor, painful muscle cramps, difficulties speaking and swallowing, anxiety, depression, dementia and hallucinations.
5. Currently 145,000 people in the UK are living with the condition, almost 8,000 of these in Wales¹. With population growth and ageing, we estimate this will increase by nearly a fifth to 172,000 by 2030. Parkinson's not only affects those with the condition but also has a significant impact on family, friends and carers.
6. While the majority of people develop symptoms after the age of 65, thousands of working age people are also affected².
7. We welcome the committee's inquiry into the impact of the Covid-19 outbreak, and its management, on health and social care in Wales.
8. A summary of our points are:
 - It's crucial for people with Parkinson's to continue accessing specialist services during the outbreak and beyond to maintain their wellbeing including therapists.
 - When people with Parkinson's are inpatients in hospital their medication needs to be carefully managed to maintain their wellbeing.
 - Mental health services must adapt to meet the needs of people living with the condition.
 - We believe that access to therapeutic interventions and greater support by and for GPs to provide care in the community, along with ensuring care services meet the

¹ Parkinson's prevalence in the United Kingdom 2018 -

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

² Pringsheim, Tamara, et al. "The prevalence of Parkinson's disease" *Movement Disorders* 29.13 (2014): 1583-1590.

- needs of the local community are what will need to be addressed after rapid discharge.
- On providing care to those shielding we believe it is imperative there is clarity of definitions and of the support that will be offered.

How to achieve an appropriate balance between coronavirus and 'ordinary' health and care demand

9. We recognise the health and care system across the UK is facing one of the biggest challenges in its history. We are in awe of how staff across the NHS have worked together to continue providing support for each other and patients.
10. We have been working with specialist Parkinson's services in Wales to understand the impact of any changes on our community so we can help to reassure them. We know that Parkinson's services across Wales have stopped delivering face-to-face services in light of government guidance. Many of these services have become virtual, offering video or telephone consultations. While we understand the need to provide services without contact, being able to visually assess someone with Parkinson's is an important part of the clinical consultation, to pick up on gait and how people move and also facial expressions, which can be difficult to assess on the phone and on video calls.
11. During this period of social distancing and self-isolation, we believe it is vital that people living with Parkinson's, their carers and families, have access to, and support from, their specialist services. Particularly from Parkinson's nurse specialists. It helps to avoid increased distress for people with the condition and also helps mitigate increased strain on other parts of our health system, in both the short and long-term.
12. 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. This will lower their risk of being exposed to coronavirus in the community and through hospital or care home admissions.
13. With the right care and support, people with Parkinson's can maintain a good quality of life for some time. Regular reviews of symptoms and medication are needed to stay as well as possible. As Parkinson's progresses, people with the condition are at very high risk of preventable hospital and care home admissions, and ongoing care from Parkinson's services is essential.
14. Without expert support, there is a risk that people with Parkinson's will deteriorate more rapidly. In some cases these changes will be irreversible. Not having access to expert support during the pandemic may also lead to an increased workload for the health and care services working with people affected by the condition, just as they start recovering from the fallout of the coronavirus pandemic.

Multidisciplinary care

15. Multidisciplinary input from physiotherapists, speech and language therapists and occupational therapists has stopped. But this support is often critical to a person with Parkinson's remaining well. The impact of missing several regular sessions to support physical movement, communication, swallowing or everyday tasks will reverse any progress, and could lead to more rapid deterioration in their condition. We believe that these services should be reinstated as soon as possible.
16. People with Parkinson's are telling us that they are missing face-to-face exercise sessions. We estimate that around 2,000 Parkinson's exercise sessions have been cancelled

because of coronavirus across the UK. We have worked with Parkinson's physiotherapists and Theatr Clwyd in North Wales³ to develop online information and classes⁴ to keep people with the condition active during the lockdown.

"I have not been able to see any of my community patients since we locked down although keep in contact via email/zoom. There will be a huge waiting list as a result of COVID for people to be seen, so I foresee the challenges of people with Parkinson's may actually get bigger the longer this goes on for."

Parkinson's physiotherapist

17. Similarly, in light of the cancellation of our volunteer led Live Loud! communication sessions, which support people to improve their volume and tone and increase their confidence in communicating, we have worked rapidly and flexibly with volunteers to adapt and deliver sessions online. However, by definition, online outreach is not a service for people who are not digitally connected who potentially remain isolated.

Medication management

18. If people with Parkinson's receive inpatient care at any point, they must receive their medication on time. As otherwise it can seriously impact their health, as they may not be able to move, get out of bed, swallow or talk. Some people may never recover and may permanently lose their ability to walk, talk or worse. It also costs the NHS in Wales extra money, as the person may need to be in hospital longer. In the last few weeks we have received several reports of poor medication management for people with Parkinson's in hospital, which at this time is adding unnecessary pressure on the system.

Meeting the wave of pent-up demand for health and care services that have been delayed due to the coronavirus outbreak

19. We believe there needs to be increased access to and promotion of free learning resources and opportunities for staff across the NHS in Wales. Particularly in areas where less specialised health and care staff may be required to provide additional support to specialist staff (e.g. Parkinson's nurses) who have particularly high caseloads and will face increased demand following their redeployment. Our website provides an excellent online learning resource section for health and social care professionals.
20. As clinics have reduced or stopped diagnosis of the condition has slowed. Beyond the lockdown, diagnosis risks being further delayed by increased demand from existing patients requiring face-to-face reviews that have been postponed or cancelled during the outbreak. This means uncontrolled Parkinson's symptoms could get worse. There may also be a negative impact on mental health for those awaiting diagnosis.
21. Through the work of the UK Parkinson's Excellence Network⁵ diagnosis experiences for individuals have on the whole improved, but we still hear of people being diagnosed by letter and offered no support to live with a life-changing, progressive condition. In fact in the latest UK Parkinson's Audit of services only 61% of people stated they received enough information about the condition at diagnosis⁶.

³ <https://www.theatrclwyd.com/event/dance-for-parkinsons-live>

⁴ Parkinson's UK, March 2020:

<https://www.parkinsons.org.uk/information-and-support/your-magazine/experts/staying-active-home-when-you-have-parkinsons>

⁵ UK Parkinson's Excellence Network, 2015:

https://www.parkinsons.org.uk/sites/default/files/2017-12/improving_patient_diagnosis_experience_1.pdf

⁶ UK Parkinson's Excellence Network, 2019 UK Parkinson's Audit summary report. January 2020:

<https://www.parkinsons.org.uk/sites/default/files/2020-04/CS3524%20Parkinson%27s%20UK%20Audit%20-%20Summary%20Report%202019.pdf>

22. We want people diagnosed with the condition to be signposted to our services so they can receive support from day one. This is why we are developing a new service called Parkinson's Connect.⁷ We are piloting it in 3 NHS locations across the UK to provide more holistic support to people with Parkinson's and their families, friends and carers. We believe this could help the NHS in Wales to triage and re-establish services to people living with the condition and would welcome the committee's support in encouraging the NHS in Wales to collaborate with us.

Therapist support

23. As evidenced in paragraphs 15, 16 and 17 above, therapist support for people with Parkinson's is crucial to managing their symptoms. Following the outbreak there will be a need to re-establish these services to people with the condition, however there will also be an increased need for those who have survived COVID to receive therapeutic intervention. We believe that it is therefore important adequate staff numbers are in place to meet patient demand.

Advanced therapies

24. As Parkinson's progresses medication becomes less effective, so non oral advanced therapies may be needed to control symptoms. There is a very small window of opportunity for these therapies to be effective. The consequence of not being able to commence advanced therapies at the desired time will not only negatively impact the quality of life of the person with Parkinson's but will lead to a greater ongoing burden to health and social care services. Due to changes in services no-one has started on advanced therapies during this period and we believe these services should be reinstated as soon as possible.

Continuing healthcare

25. We know that continuing healthcare assessments have stopped, and envisage that existing appeals will be delayed for long periods. We are concerned about the serious repercussions this will have for continuing healthcare and we would encourage the committee to seek further clarification on how this will be managed moving forward.

Meeting care needs

26. While the Coronavirus Act has measures that effectively reduce the care and support provided to people, it is not clear how many or which local authorities have not turned on the Social Services and Well-being (Wales) Act 2014 easements and is therefore difficult to assess the impact this is having. We would encourage the committee to seek clarity on what is happening where across Wales and for this information to be readily available.

27. We are hearing from some carers that they're worried about the risk of infection from paid carers entering the house, so they've stopped care, which places additional burden (including on their mental health) on the unpaid carer.

28. Recent Carers UK research⁸ about care provision during the outbreak showed that:

- 70% of unpaid carers in the UK are picking up even more care for older, sick or disabled relatives; on average, carers are taking on an extra 10 hours of care a week.
- A third (35%) of unpaid carers are providing more care because their local care and support services have been reduced or closed.

⁷ Parkinson's UK, February 2020: <https://www.parkinsons.org.uk/news/parkinsons-connect-our-new-support-service>

⁸ Carers UK, *Caring Behind Closed Doors: the forgotten families of the coronavirus outbreak*. 23 April 2020: www.carersuk.org/closeddoors

- More than half (55%) of unpaid carers feel overwhelmed managing their caring responsibilities during the outbreak, and are worried about burning out in the coming weeks.

29. This supports research that shows the carers of people with Parkinson's have a high burden and there is a significant relationship between stage of the condition and the level of carer strain. This research found that the mean age of carers of people with Parkinson's was 70.7 years with 66.1% of carers being female. They also cared for a median of 16 hours per day⁹. However in the current climate this is likely to be higher and carer burnout is a concern we are likely to face in the coming weeks and months.

Meeting extra demand for mental health services as a result of the societal and economic impacts of lockdown

30. While the physical symptoms of Parkinson's such as tremor, slowness of movement and rigidity are familiar, less attention has been paid to care and treatment of associated mental health and cognitive symptoms such as psychosis, impulsive and compulsive behaviours, hallucinations, mild cognitive impairment, dementia, anxiety and depression. Up to 40% of people with Parkinson's will have depression¹⁰ and up to 31% of people with Parkinson's will experience anxiety¹¹.

*"Anxiety is the single worst thing that I suffer and exacerbates all other symptoms exponentially."*¹² Person with Parkinson's

31. Prior to the coronavirus outbreak mental health services were not meeting the needs of people with Parkinson's experiencing anxiety and depression. A report by the All-Party Parliamentary Group on Parkinson's¹³ into mental health services for people with Parkinson's, which took evidence from across the UK, found:

- a disconnect between mental and physical health services
- long delays in accessing mental health support
- complex referral processes
- communication barriers between health services
- treatment not being tailored to the needs of people with Parkinson's.

32. Since the outbreak began we have been gathering insights from people with Parkinson's through our helpline, local advisers, online forum and Facebook groups on how the lockdown has been affecting them. Changes to life under the pandemic and isolation from friends, family and carers have heightened anxiety and negatively impacted the mood of many people living with Parkinson's.

33. To help respond to this growing need around mental health we have tailored our support to help our community during this time by:

- Regularly updating information on coronavirus and Parkinson's on our website including advice on [managing your mental health whilst staying at home](#).
- Providing information on how people can get hold of the medicines they need and advice if people go into hospital.

⁹ 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

¹⁰ Aarsland D et al (2012) 'Depression in Parkinson's disease – epidemiology, mechanisms and management' *Nature Reviews Neurology*; 8: 35–47

¹¹ Broen MPG et al (2016) 'Prevalence of anxiety in Parkinson's disease: a systematic review and metaanalysis' *Movement Disorders*; 31: 1125–1133

¹² All Party Parliamentary Group on Parkinson's (2018) 'Mental health matters too - Improving mental health services for people with Parkinson's who experience anxiety and depression' (www.parkinsons.org.uk/mentalhealthreport)

¹³ All Party Parliamentary Group on Parkinson's (2018) 'Mental health matters too - Improving mental health services for people with Parkinson's who experience anxiety and depression' (www.parkinsons.org.uk/mentalhealthreport)

- Increasing the capacity on our helpline.
- Conducting check-in calls with the most vulnerable in our community and signposting them to support.
- Starting a new Facebook community group, so the community can provide peer support.
- Completing online Q&As on dealing with coronavirus and mental health.
- Developing and sending printed information about keeping well, managing your mental health and medicine supply issues to people with Parkinson's who are offline.

34. We are aware that mental health services are offering people support by telephone or video in place of face-to-face services, which have been suspended due to the pandemic. We welcome the efforts that have been made to adapt, that will enable people with Parkinson's to continue accessing mental health services during this time.

35. However this will not meet the needs of every person with Parkinson's who require psychological or psychiatric support. People with the condition can experience difficulties with speech, as a result of their Parkinson's which leads them to have a quieter voice, and therefore tele counselling services may not be appropriate. People with Parkinson's who don't have access to the internet or equipment needed for video calls will also face difficulties accessing this support.

36. It is therefore inevitable that this will lead to increased demand for mental health services when this crisis comes to an end. This will magnify the pre-crisis issues outlined above. This will increase the urgency for the Welsh Government to act on physical and mental health service integration, ensuring there is the right workforce and funding to ensure people with Parkinson's can access the high quality mental health services they so desperately need.

Meeting the needs of rapidly discharged hospital patients with a higher level of complexity

37. Media reports¹⁴ have shown that people who have survived COVID-19 will need therapeutic interventions to return to their normal life. Before the crisis the latest UK Parkinson's Audit demonstrated that not all people with Parkinson's were getting access to therapy services¹⁵. Many of these services are already overstretched and post-crisis they will be under further pressure as they provide COVID-19 patients with rehabilitation support. We believe it is crucial that the Welsh Government promotes learning and research outcomes from professional bodies on rehabilitation needs of complex cohorts, for instance the Royal College of Speech and Language Therapists, Royal College of Occupational Therapists and the Chartered Society of Physiotherapy.

38. We believe other areas the Welsh Government and NHS Wales will need to focus on to meet the needs of rapidly discharged hospital patients with more complex needs are:

- Ensuring there is adequate support provided to GPs to enable them to manage people in the community. This is especially important for people with Parkinson's who need multidisciplinary care to maintain their wellbeing.
- Around ensuring care packages are increased and meet not just the medical but social needs of those who have been discharged.

¹⁴ BBC news, 30 April 2020: <https://www.bbc.co.uk/news/uk-wales-52475139>

¹⁵ UK Parkinson's Excellence Network, 2019 UK Parkinson's Audit summary report. January 2020: <https://www.parkinsons.org.uk/sites/default/files/2020-04/CS3524%20Parkinson%27s%20UK%20Audit%20-%20Summary%20Report%202019.pdf>

39. Carers have reported that people are being discharged from hospital without adequate support in place. This is increasing emotional and physical pressures on unpaid carers. The closure of day centres and other support services are having an impact on unpaid carers significantly limiting their ability to access much needed respite and short breaks. In many circumstances, alternative provisions are not being offered¹⁶.

Providing healthcare to vulnerable groups who are shielding

40. Everyone with Parkinson's is different. Many people with the condition are not clinically extremely vulnerable. However, 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. There has been confusion and anxiety from the Parkinson's community about the vulnerable and extremely vulnerable categories and the support that's being offered to these individuals. We would encourage the Welsh Government and NHS Wales to be clear about support that's being provided to those being shielded.
41. Our community has shared that getting to and from hospital or the GP can be a challenge for individuals living with Parkinson's and many people will require the support of a carer, family member or unpaid carer to attend face to face appointment. These people are already under increasing pressure, so we believe the Welsh Government and NHS Wales should be planning on a longer-term basis to help those shielding to access healthcare.
42. It is crucial that clear guidance on attending face-to-face appointments with appropriate informal support for those who need it will be essential to reduce anxiety and ensure people who need to, can attend appointments.

How to ensure that positive changes that have taken place in health and social care as a result of the pandemic are not lost as services normalise.

43. Health and social care services across Wales should be encouraged to audit the use of video and telephone consultations and identify patient groups where these will remain beneficial and increase efficiencies, for instance follow-ups where someone is technically able, as this could cut waiting times. However, people with Parkinson's may not benefit from telephone calls as there will be no visual cues to help the professional identify developing or deteriorating symptoms. Therefore, this specialist knowledge will be key in ensuring the efficacy of online / remote assessments, consultations and support.
44. All healthcare bodies should be encouraged to share good practice in a coordinated way and we believe NHS Wales and Welsh Government must invest in ways to systematically collect this information.
45. We believe that the above activities will enable the NHS in Wales to develop clear guidance on minimum standards for innovations to ensure high quality health and care services are provided.

Parkinson's UK Cymru, 22 May 2020.

¹⁶ Wales Carers Alliance letter to Welsh Government, 16 April 2020