



All-Party Parliamentary Group (APPG) on Parkinson's inquiry: Terms of reference

Mental health matters too: improving support for people with Parkinson's

About the APPG

The APPG on Parkinson's is a cross-party group of MPs and Peers with an interest in Parkinson's. The group aims to raise awareness of the condition among parliamentarians and to influence legislation and policy makers to improve the lives of people living with or affected by the condition.

Parkinson's UK provides the secretariat to the APPG. The charity drives better care, treatments and quality of life to bring forward the day when no one fears Parkinson's.

Introduction and background to the inquiry

Mental health problems are common in people with Parkinson's and can have a huge impact on their quality of life. At any given time up to 40% of people with Parkinson's will have depression¹ and up to 40% of people with Parkinson's will experience anxiety². People may experience these mental health conditions at any time in the course of Parkinson's and even before diagnosis.

Currently mental health is often an under-recognised and overlooked part of Parkinson's, with treatment and support focusing on the physical symptoms of the condition. Good care for people with Parkinson's requires addressing a range of different needs, including mental health. Without mental health support people may struggle to take control of their condition, which will impact on all aspects of their life.

When facing a diagnosis of Parkinson's, it's understandable to feel anxious or depressed. But anxiety and depression can be a clinical symptom of Parkinson's, just as tremor or slowness of movement are due to changes to chemicals in the brain. Mental health problems can be also caused by the difficulties of living with Parkinson's or coming to terms with a diagnosis.

¹ Aarsland, D. et al. Depression in Parkinson's disease – epidemiology, mechanisms and management. *Nat. Rev. Neurol.* 8, 35–47, 2012.

² Broen, M. P. G., Narayan, N. E., Kuijf, M. L., et al. Prevalence of anxiety in Parkinson's disease: A systematic review and meta-analysis. *Mov. Disord.*, 31: 1125–1133. 2016.

The NHS Constitution includes a commitment to achieving ‘parity of esteem’ to ensure that the system can “improve, prevent, diagnose and treat both physical and mental health problems with equal regard”³. To date there has been no consideration of how ‘parity of esteem’ applies to people with Parkinson’s.

The purpose of the APPG inquiry is to establish the current provision of mental health support for people with Parkinson’s experiencing anxiety and/or depression, and to make recommendations to improve the system for people living with the condition.

The inquiry will take evidence from those with expertise in, or experience of, Parkinson’s – including people with or affected by the condition, clinicians, professional bodies and others.

Scope of the inquiry

While the APPG is a cross-UK group, health services are devolved to each of the nations and structures are not necessarily comparable. The inquiry will therefore focus on England. However, the APPG is keen to learn from examples of good practice in Scotland, Wales and Northern Ireland and therefore encourages representatives in the devolved nations to contribute to the inquiry.

Structure of the inquiry

Written evidence

The APPG will issue a call for written evidence from organisations and individuals with expertise in, or experience of, Parkinson’s, including people with the condition, carers, clinicians, professional bodies and others. This is open **22 June – 25 August 2017**.

Oral evidence

The APPG is planning to hold a number of oral evidence sessions in autumn 2017 with a variety of people being invited, including those living with the condition and professionals, to inform the final report.

Report

A report, based on the written and oral evidence, will be produced which will make clear recommendations for the government and health decision makers, such as NHS England, to improve access to mental health support for people with Parkinson’s.

Terms of reference

To determine the current provision of mental health support for people with Parkinson’s experiencing anxiety and/or depression.

³ NHS Constitution for England, Department of Health,
<https://www.gov.uk/government/publications/the-nhs-constitution-for-england>

Please note while we understand that people with Parkinson's can experience a number of different mental health problems, please answer the questions below in relation to **anxiety** and **depression**.

Questions for professionals, professional bodies, commissioners and other organisations

The APPG welcomes written submissions from a range of stakeholders on these questions and any others which fall within the scope of the inquiry.

1. Please describe from your perspective the current situation, issues and any concerns regarding the following:
 - The specific needs of people with Parkinson's with anxiety and/or depression and the types of interventions and treatments that are appropriate.
 - The current state of mental health support for people with Parkinson's including service provision, access and availability, funding and commissioning, and quality of service.
 - The identification and diagnosis of anxiety and/or depression for people with Parkinson's.
 - Mental health professionals' involvement in multidisciplinary teams.
 - Referrals from Parkinson's services to mental health services.
 - Integration between mental health services and neurology services.
2. How difficult or easy do you perceive it to be for people with Parkinson's experiencing anxiety and/or depression to access mental health services?
 - Very difficult
 - Difficult
 - Somewhat difficult
 - Moderate
 - Easy
 - Very easy
3. What are the barriers to accessing mental health support for people with Parkinson's (including barriers in attitudes, resources and structure of the NHS)?
 - What is needed to overcome these barriers and achieve parity of esteem between the mental and physical aspects of Parkinson's?
4. How do you think mental health support for people with Parkinson's could be improved?
 - Are there certain organisations and individuals, at local and national level, that are best placed to lead this work?
5. What factors, if any, do you think stop people with Parkinson's seeking early help and intervention to address any mental health problems?
 - How can these factors be overcome?

6. What, if any, are the most promising developments for mental health support for people with Parkinson's?
 - Can you outline any areas of best practice in the management of anxiety and depression in people with Parkinson's?
 - Are there examples of cost-effective services where mental health is integrated with Parkinson's services?
7. How should progress be measured on access to mental health support for people with Parkinson's?
 - What data should be collected?
8. What are the top three priorities to focus attention and investment on to deliver timely access to quality mental health support for people with Parkinson's over the next 12 months?

Questions for people affected by Parkinson's

Here are some further questions that people affected by Parkinson's, including carers, friends and family may wish to consider in relation to their personal experience.

1. Have you experienced depression and/or anxiety alongside Parkinson's?
 - Depression
 - Anxiety
 - Both
 - Don't know
 - No
2. Have you accessed mental health support?
 - If yes, what has been your experience of accessing support? How quickly did you access it and what type of support did you receive?
 - If no, how did the lack of support affect you?
3. Have there been any aspects of mental health support that have been particularly good or disappointing, and how did this affect you?
4. How would you describe the current services available to meet your mental health needs?
 - Excellent
 - Good
 - Average
 - Below average
 - Poor

5. Do you feel that the mental health symptoms of Parkinson's are addressed as effectively as the physical symptoms?
- a. Yes
 - b. No
 - c. Don't know
6. How do you think mental health support for people with Parkinson's could be improved?

Submission guidelines

Please follow these guidelines when submitting your evidence:

- The deadline for submitting evidence is **25 August 2017**.
- Evidence can be submitted in Word format, either attached to an email or sent by post. The word limit is 3,000 words.
- Alternatively evidence can be submitted through the following online surveys:
 - People affected by Parkinson's – **surveys.parkinsons.org.uk/s/appginquiry**
 - Professionals, professional bodies and other organisations – **surveys.parkinsons.org.uk/s/appginquiryprofessionals**
- State clearly who the submission is from, and whether it is sent in a personal capacity or on behalf of an organisation.
- Only answer the questions you feel are relevant to you, you don't have to answer them all.
- Where applicable, please state each question heading in your response.

Submitting your evidence

All submissions by email to **appginquiry@parkinsons.org.uk** or by Freepost to:

Freepost RLUB-RSHA-KSET
APPG on Parkinson's Inquiry
C/O Policy and Campaigns Team
215 Vauxhall Bridge Road
London SW1V 1EJ

Evidence can also be submitted through the online survey,

- People affected by Parkinson's – **surveys.parkinsons.org.uk/s/appginquiry**
- Professionals, professional bodies and other organisations – **surveys.parkinsons.org.uk/s/appginquiryprofessionals**

If you have any questions then please do not hesitate to contact our secretariat, Parkinson's UK, at the email address above or on **020 7963 9349**.

We may publish the written evidence that we receive or make reference to it in the final report. If you do not wish your evidence to be made public, then please say so in your submission.