

UK PARKINSON'S

Excellence
Network



Improving
management
of mental health
in people affected
by Parkinson's





Professionals involved in the UK Parkinson's Excellence Network came together to discuss how to improve management of mental health in people affected by Parkinson's.

Mental health problems, such as anxiety, depression and psychosis, are common in Parkinson's. They can be due to the condition itself, or caused by the difficulties of living with Parkinson's or medication side effects.¹

Despite this, access to treatment is low. As few as 20% of people with Parkinson's experiencing depression receive treatment.¹

Here are some suggestions from fellow professionals for how you might improve the management of mental health for your patients with Parkinson's.

“I recognised the depression myself around the time I was diagnosed with Parkinson's. I had previously been depressed and I could feel myself slipping towards it again. I found myself walking around the house crying – my face would be wet and I would wonder what it was.”



Accessing psychological services

People with Parkinson's who have mental health needs require prompt access to professional support, via efficient referral processes. Knowing what support is available and identifying the symptoms of mental health problems early on can speed up this process and improve the management of mental health for people living with the condition.



Among those on dopaminergic treatment, 15–25% experience psychotic symptoms.¹

These are some ways in which you could improve access to psychological services for people with Parkinson's:

- Identify mental health services available in your local area so you can refer appropriately. NHS Choices provide details of services offering treatment through the NHS Improving Access to Psychological Therapies programme (www.nhs.uk/Service-Search).
- Contact a Parkinson's UK local adviser who can also provide confidential, one-to-one information about Parkinson's and local services. They liaise with health, social care and other local professionals to help people with Parkinson's access the support they need. They may be able to offer information about support available from mental health NHS services and charities, such as MIND. Find out more by calling **0808 800 0303** or visiting parkinsons.org.uk/supportnetworks
- Liaise with local mental health services to clarify referral processes. Ensure that all team members are aware of the range of services that exist so they can refer appropriately.
- Ensure that mental health is considered at the initial assessment and regularly after this to ensure early identification and intervention for signs of mental health problems. Treating psychological symptoms early can prevent them from worsening and interfering with a person's everyday life.


Standardised tools for routine assessment of mental health

- Several self-report measures to screen for depression have been validated for use in Parkinson's, including the Beck Depression Inventory, Hospital Anxiety and Depression Scale, and the Geriatric Depression Scale.² Valid clinician-rated scales include the Hamilton Depression Rating Scale and Montgomery and Asberg Depression Rating Scale. Some scales specific to Parkinson's are available but have not been sufficiently evaluated to support their use at this time.
- For anxiety there are fewer options available, but self-report scales include the Hospital Anxiety and Depression Scale, and The Spielberger State-Trait Anxiety Inventory.³ The Hamilton Anxiety Rating Scale can be also be used
- Two short scales, the PHQ-9 (depression) and GAD-7 (anxiety) are widely used in primary care and can be used as part of the assessment for access to psychological services.

NB Please note any permissions necessary for use of these scales in clinical practice via the links.

Access to information

People with Parkinson's need access to accurate and relevant information to help them manage their condition, including mental health symptoms.



“I feel there is not enough information or advice available for the mental problems caused by Parkinson's – people seem to be wary of these.”



These are some ways in which you could improve access to information for people with Parkinson's:

- Provide people with **appropriate written information** to take away with them. This can support what you have communicated verbally during the appointment.
- Ensure people have **information about local mental health services** and what to expect. Provide information about how they can access and contact psychological services when they need them. Some voluntary and Improving Access to Psychological Therapies services may have a self-referral process.
- **Signpost** them to a range of support available from Parkinson's UK. In particular, our information sheets *Anxiety and Parkinson's*, *Depression and Parkinson's* and *Parkinson's dementia* may be helpful. They may also find it useful to monitor their symptoms using the *Non-motor symptoms questionnaire*.
- The Royal College of Psychiatrists website also provides some useful information: www.rcpsych.ac.uk/expertadvice.aspx

“I went to the GP and I told her about what was happening. She agreed that I was depressed and referred me straight away to the Archway Centre where there are counsellors. I was very lucky. I was told there was a three month waiting list but there was a cancellation, so I was seen within eight weeks.”

Forming links with local mental health support providers

It is important to build good working relationships with local mental health teams. Contacting and developing relationships with local teams can enable you to develop ways of integrating the services you offer, to better manage the psychological symptoms of people with Parkinson's.

These are some ways in which you can form links with local mental health services:

- Arrange to meet with local mental health team leaders. Provide information about the number of referrals they currently receive from you to highlight the level of need among people with Parkinson's.
- Liaise with staff from psychological services, and meet regularly to develop and maintain relationships. Invite them to participate or speak at networking meetings, events or steering group meetings. You could also invite local mental health professionals to take part in your local UK Parkinson's Excellence Network regional working group's activities.
- Clarify within your service's pathway what can be appropriately handled by the Parkinson's service and when a referral to specialist mental health teams is needed.
- Arrange to meet with your local commissioners. Individual funding approval may be needed for referrals to specialist services.
- Make links to local services providing care for patients with other long-term conditions, such as MS, diabetes and rheumatology, that may have already established effective ways to identify psychological problems and developed care pathways.



“Depression is the worst symptom. I can deal with the tremor, tiredness and pain, but depression is a growing, hidden factor.”



At least 75% of people with Parkinson's who survive for more than 10 years will develop dementia.⁴

Working together

Managing the mental health of people with Parkinson's will require a number of different professionals and multidisciplinary teams to work together. Working collaboratively will allow professionals to share their expertise and make sure patients receive high-quality care from the appropriate healthcare service. Integrating services can also provide better continuity of care.

Of newly-diagnosed people with Parkinson's, 36% have one or more areas of cognitive impairment, including problems in executive function (planning, judgement and decision making), attention or memory.¹

These are some ways in which you can work together with mental health teams to manage the mental health of people with Parkinson's:

- If possible, have a mental health professional as part of the multidisciplinary team. For example, a clinical psychologist, psychiatrist or community psychiatric nurse could provide valuable input to care planning for people with mental health needs alongside their Parkinson's. Also, having an in house psychology team could make it easier to form links with local mental health services and improve referral processes.
- Consider employing staff with previous experience of mental health, for example a Parkinson's nurse with a background in mental health.
- Arrange joint clinics with mental health teams to discuss the care of patients. It might also be possible to arrange joint home visits with Parkinson's nurses and community mental health teams.
- When working with mental health professionals, share patient records appropriately and ensure all involved professionals as well as the patient are copied into correspondence.
- Where possible, identify a local Parkinson's champion within mental health services.
- Consider setting up a support group for people with Parkinson's and their carers, with input from the local mental health team or get them involved in the established Parkinson's UK local group network.

“People muddle on. The right questions need to be asked in the first place. I think the hospital consultation needs overhauling to make efficient use of limited time.”

Sharing expertise, education and training

Use your specialist knowledge to provide training for local mental health teams who lack experience with Parkinson's. In return, you could invite staff from mental health teams to share their expertise through training and education.

These are some ways in which you can share expertise with mental health teams to improve management of mental health of people with Parkinson's:

- Engage in outreach to local mental health services. Use your connections to educate mental health professionals about the mental health needs of people with Parkinson's.
- Meet with your local mental health services to discuss ways in which you can work together to support people with Parkinson's experiencing mental health problems. Suggest an exchange of skills.
- Identify skills gaps in your own team, and invite mental health experts to provide education and training. Encourage specialist mental health input into the training and development of staff.

Depression affects between 30–40% of people with Parkinson's, but as few as 20% receive treatment for this.¹

Find out more: Read [Parkinson's UK policy statement: Mental health](#).



“We identified that the current set-up of mental health services meant that many of our patients were waiting too long to be seen. So we connected with a psychiatrist who had shown an interest in Parkinson's. He will now see any of our patients with complex mental health needs on a rapid basis, if needed, including if they are admitted to hospital. In addition, he's now hoping to join our multidisciplinary clinic at least once a month so that patients can be seen jointly.” Sally Jones, Consultant

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