

Parkinson's UK policy statement Mental health

"My specialist only asked about my physical symptoms. But I also had dreadful feelings of fear and panic. I was prescribed medication that improved my mobility but the anxiety continued and made my life a struggle.

"Since my medication has been adjusted, my anxiety has subsided. It is an enormous relief to know that the problem was a part of my Parkinson's and it is treatable."

Person with Parkinson's

What we believe

We believe that people with Parkinson's should have accurate diagnosis and effective treatment of mental health problems associated with Parkinson's. People with Parkinson's and their carers should be kept fully informed about mental health issues that are common in Parkinson's, including possible side effects of Parkinson's medication, such as psychosis. The mental and emotional strain that can affect carers of people with Parkinson's must also be recognised.

Why we believe this

The links between mental health and Parkinson's

Mental health problems are common for people with Parkinson's. Around 40% of people with Parkinson's experience depression,¹ up to 50% experience anxiety² and around 25% experience mild psychotic symptoms.³

There are different factors that link mental health problems and Parkinson's.

- It can be part of the condition, for example changes to the chemicals in the brain that are part of Parkinson's could also cause depression and anxiety.
- Mental health problems can be caused by the difficulties of living with Parkinson's, for example not being able to move can make people more anxious and may even cause panic attacks.⁴
- Medication can have side-effects including psychosis and compulsive behaviours.⁵
- Coming to terms with a diagnosis of Parkinson's can be difficult and there is some evidence to suggest that quality of life is more influenced by someone's psychological adjustment to the illness and disability than the severity of the condition.

¹ Reijnders J et al (2008), 'A systematic review of prevalence studies of depression in Parkinson's Disease', *Movement Disorders* (23, 2, pp 183-189)

² Prediger R et al (2012), 'Anxiety in Parkinson's disease: A critical review of experimental and clinical studies', *Neuropharmacology* (62, pp115-124)

³ Mack J et al (2012), 'Prevalence of psychotic symptoms in a community-based Parkinson disease sample', *American Journal of Geriatric Psychiatry* (20, 2, pp123-132)

⁴ Parkinson's UK. Anxiety and Parkinson's Information Sheet (2013)

⁵ Please see the Parkinson's UK position statement Impulsive and compulsive behaviours (2014)

People with Parkinson's also have a significantly increased risk of developing dementia.⁶ Recent research suggests that dementia develops in up to 80% of patients with Parkinson's,⁷ although prevalence rates vary between different studies.

Mental health of carers

Caring for someone with Parkinson's can be physically, mentally and emotionally exhausting and mental health problems, particularly depression, are common. Support for carers is often poor. Lack of respite care often means carers don't get the breaks they need to stay healthy.⁸ When people can get access to respite care or residential care, feelings of guilt are common particularly if the care is of a poor standard.

Diagnosis and treatment

There can be difficulties in getting an accurate diagnosis for mental health problems. Dementia and depression have similar symptoms and can be misdiagnosed. People may also be reluctant to talk about mental health problems, which can delay diagnosis.

Communication issues, slowness of thought and movement, and facial masking can also be misdiagnosed as indicating depression.

Access to treatment for mental health problems such as depression and anxiety, is poor. Although there have been some improvements in understanding the mental health aspects of Parkinson's, evidence to the All Party Parliamentary Group on Parkinson's inquiry into health and social care services revealed that many people with the condition are not receiving specialist mental health services.⁹ This lack of treatment could be linked to under-diagnosis or the fact that some medication for mental health problems has side-effects that make Parkinson's symptoms worse.¹⁰

People with Parkinson's do not always disclose mental health symptoms, such as hallucinations, to their medical team. It is important that health professionals create trusting relationships so that people feel safe to share their symptoms.

Getting an accurate diagnosis and effective treatment for mental health problems is reliant on having the right health professionals in place. Relatively few Parkinson's multi-disciplinary teams will have psychologists as core members, whereas most services for people with Alzheimer's will be led by clinical psychologists or neuropsychologists. It can be difficult for Parkinson's teams to make timely referrals to mental health services because of barriers within the NHS.

We believe that the services for people with Parkinson's needs to be joined up. The high prevalence of mental health problems needs to be taken into account when referring people through the pathway of services. Psychological therapies can be used to support people with Parkinson's who experience depression or anxiety, but there is variation in the availability of and access to such services.

⁶ See our policy statement on dementia for more information

⁷ Dubbelink, Kim TE Olde, et al. "Predicting dementia in Parkinson disease by combining neurophysiologic and cognitive markers." *Neurology* 82.3 (2014): 263-270.

⁸ Please see the Parkinson's UK policy position statement Carers' support (2010)

⁹ All Party Parliamentary Group on Parkinson's, *Please Mind the Gap: Parkinson's Disease services today*(2009)

¹⁰ Parkinson's UK, *Psychological services for people with Parkinson's disease* (2009)

What's the evidence?

In 2007 we surveyed 13,000 members. Their responses showed widespread experience of mental ill health and low levels of access to appropriate support. In the month before completing the survey:

- 58% of people had felt depressed
- 45% of people had felt anxious, frightened or panicky
- 37% of people difficulty concentrating or staying focussed
- 63% of people had problems with concentration

Yet only 11% of people had seen a mental health professional.

There was a similar picture for carers: 51% reported that their health had got worse as a result of caring for someone with Parkinson's. Of these, 87% reported stress or anxiety, 44% report mild depression and 6% reported severe depression.¹¹

In 2014 we carried out a further survey with 3,630 people who have either been diagnosed with Parkinson's or are family members/carers of a person with Parkinson's. In the year before the survey only 7% had received mental health support. This also had the longest waiting time for any particular therapy, with 13% of people who accessed support having to wait 3-6 months and a further 9% having to wait for over 6 months.¹²

What Parkinson's UK is doing

We campaign for better services for people with Parkinson's, including mental health services. We train health and social care professionals so they have a better understanding of the links between Parkinson's and mental health. We provide information and resources on mental health and Parkinson's.

We are also funding a large research project to get a better understanding of Parkinson's and dementia.

Acknowledgement

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

Further information

Please contact the Policy and Service Improvement team. Tel: 020 7932 1325 or email: campaigns@parkinsons.org.uk

Parkinson's UK: January 2015
Review date: January 2017

¹¹ Parkinson's UK. *Life with Parkinson's today – room for improvement* (2008)

¹² Parkinson's UK/YouGov, *Survey of people with Parkinson's and their friends, family and carers* (2014)