Parkinson’s UK policy statement
Mental health

“What 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 and their carers should have accurate diagnosis and effective treatment of mental health problems associated with Parkinson’s. People with Parkinson’s should be kept fully informed about the possible side effects of medication, including mental health side effects such as psychosis. There also needs to be recognition of the mental and emotional strains on carers of people with Parkinson’s.

Why we believe this

The links between mental health and Parkinson’s

Mental health problems are common for people with Parkinson’s. At any given time up to 40% of people with Parkinson’s will have depression. Up to 40% of people with Parkinson’s will experience anxiety and up to 50% will experience mild psychotic symptoms.¹

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.²
- Medication can have side-effects including psychosis and compulsive behaviours.³
- 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.⁴

Dementia is common and one in three people with Parkinson’s have some form of dementia and up to 80% of people with Parkinson’s may develop dementia.⁵ Parkinson’s dementia is a

¹ Parkinson’s UK. Psychological services for people with Parkinson’s disease (2009)
² Parkinson’s UK. Anxiety and Parkinson’s Information Sheet (2010)
³ Please see the Parkinson’s UK position statement Impulsive and compulsive behaviours. (2010)
⁴ Parkinson’s UK. Psychological services for people with Parkinson’s disease (2009)
⁵ NICE guidelines for Parkinson’s Disease (2006)
specific type of dementia and one that often does not get the recognition or understanding it needs.\(^6\)

**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.\(^7\) 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

Access to treatment for mental health problems, such as depression, is poor. As few as 20% of depressed people with Parkinson’s receive treatment.\(^8\) 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.

Getting an accurate diagnosis and effective treatment for mental health problems is reliant on having the right health professionals in place. Relatively few multi-disciplinary teams will have psychologists as core members, whereas most services for people with Alzheimer’s will be lead by clinical psychologists or neuropsychologists.

We believe the commissioning of 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 for depression or anxiety for some people with Parkinson’s, but there is variation in availability.

**What’s the evidence?**
In 2007 we surveyed 13,000 members.\(^9\) Their responses show how widespread the experience of mental ill health is and how poor the access is to appropriate support.

A large number of people with Parkinson’s had experienced mental ill health. 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 with Parkinson’s have seen a mental health professional. This is the lowest of any therapy.

\(^6\) The dementia strategy for England fails to mention Parkinson’s dementia in the list of different dementias

\(^7\) Please see the Parkinson’s UK policy position statement Carers’ support (2010)

\(^8\) Parkinson’s UK. *Psychological services for people with Parkinson’s disease* (2009)

\(^9\) Parkinson’s UK. *Life with Parkinson’s today – room for improvement.* (2008)
There was a similar picture for carers. 51% of carers reported that their health had got worse as a result of caring for someone with Parkinson’s. Of these, 87% of people reported stress or anxiety, 44% of people reported mild depression and 6% of people reported severe depression.

**What Parkinson’s UK is doing**

We are funding a large research project to get a better understanding of Parkinson’s dementia. 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 also provide information and resources on mental health and Parkinson’s.

**Acknowledgement**

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on carers. 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 Health Policy and Campaigns team. Tel: 020 7932 1325 or email: campaigns@parkinsons.org.uk

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