



Parkinson's Disease Society

- Largest patient group for people with Parkinson's in the UK
- 28,000 members across the UK
- 330 branches and support groups
- £35M invested in research since charity founded
- Major providers of information and support to people with Parkinson's, families and carers
- Leading campaigners for improved Parkinson's services at national and local levels

2007 members survey

Life with Parkinson's today – room for improvement

- **Largest ever survey of people with Parkinson's in the UK**
- **Similar survey conducted in 1997 which shows some comparison**
- **13,000 responses**



Access to specialists doctors

- 15% of all respondents with Parkinson's have never been seen by a hospital doctor with specialist knowledge of the condition

Diagnosis by GP vs specialist

- Of those who were diagnosed more than 10 years ago, 67% were diagnosed by a specialist, this had increased to 78% of those diagnosed in the last year.
- Of those diagnosed more than 10 years ago 35% were diagnosed by a GP, this has decreased to 21% of those diagnosed in the last year

Ongoing review

- Across the UK, one in 12 people with Parkinson's has their medication reviewed less than once a year
- People with Parkinson's in England are more likely to have their medication review conducted by a GP rather than by a specialist than in any other of the UK countries

Access to PDNS

- Over a quarter of people with Parkinson's in the UK have never talked to a Parkinson's Disease Nurse Specialist
- More than four out of ten (42%) people with Parkinson's have not spoken to a specialist nurse within the last 12 months
- Currently 250 PDNS posts across the UK, still representing a shortfall of 150 posts (based on case load of 300 patients per nurse)

Access to therapy services

- 46% reported they had not been assessed or had treatment by physiotherapist
- 63% reported they had not been assessed or had treatment by a speech and language therapy
- 66% reported they had not been assessed or had treatment by a occupational therapist

Patient information

- Nearly three in ten people diagnosed in the last year reported they were not given clear information about the condition and treatments at the time of their diagnosis
- 47% of people with Parkinson's surveyed felt they needed more information about the condition.

Hospital stays

- Nearly three in ten (27%) of those who had been a hospital inpatient in the last five years felt that doctors, nurses and other hospital staff did not understand Parkinson's and how it affected them at all
- Nearly three out of five patients with Parkinson's who have had a hospital stay in the last five years were not given the option to self-medicate during their most recent stay in hospital
- Of those, nearly two-thirds did not get their medication on time every time and one in four felt that not getting their medication on time prolonged their stay in hospital

Recommendations

- Increase access to specialists with knowledge and expertise in Parkinson's, to specialists nursing and therapy services
- Development of integrated, multi-disciplinary Parkinson's services
- Integration of health and social care services
- Improved end of life services
- Increase knowledge of Parkinson's in primary care
- Improved patient information at diagnosis and ongoing
- Improved inpatient care, especially medicines management, of people with Parkinson's
- Greater emphasis on implementation of national standards at a local level



Parkinson's APPG Inquiry

- To establish the extent and variation in the provision of health and social care services to people with Parkinson and their carers – as recommended by national standards such as the NICE guideline for Pd and the NSF for Long-term conditions and Fulfilling Lives, supporting communities in Wales – in different parts of the country, to identify the causes of this situation and suggest potential remedies.



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