

Life with Parkinson's today - room for improvement

The UK's largest ever survey of people with Parkinson's and carers

England

There are more than 100,000 people with Parkinson's living in England.

Parkinson's is a progressive neurological disorder for which there is currently no cure. It results from the loss of the chemical messenger dopamine within the brain and affects learned voluntary movements such as walking, talking, writing and swallowing. As the condition progresses it impacts on all aspects of the person's life and the lives of those around them.

In 2007, the Parkinson's Disease Society conducted the largest ever survey in the UK of people with Parkinson's and carers of people living with the condition. Over 13,000 people completed the survey from across the UK. 8963 people with Parkinson's and 2868 carers of people with Parkinson's living in England completed the survey.

What they told us provides a significant insight into all aspects of life with Parkinson's. It includes information about the experiences of diagnosis, health and social care services and support from the Parkinson's Disease Society (PDS) as well as demographic data.

Healthcare services from diagnosis onwards

Parkinson's is a complex progressive condition and people require regular input from specialists in the condition from diagnosis onwards to ensure that their symptoms are managed effectively and their quality of life is maintained.

The National Institute for Health and Clinical Excellence (NICE) Guideline on Parkinson's disease recommends diagnosis by a specialist, regular reviews, access to a Parkinson's Disease Nurse Specialist and access to therapies, such as physiotherapy, speech and language therapy and occupational therapy.

Responses from the survey showed that:

We are seeing a trend towards more people being diagnosed by a specialist. Eight out of ten (79%) people with Parkinson's diagnosed in England in the last year were diagnosed by a specialist (either a neurologist or care of the elderly physician). This compares to 67% of people with Parkinson's in England diagnosed more than 10 years ago. Despite this improvement, too many people are still missing out on a specialist diagnosis

The NICE Guideline recommends referral within 6 weeks. However, 54% of those referred to a neurologist and 41% of those referred to a care of the elderly physician in England within the last year waited more than 6 weeks for a first appointment

16% of people with Parkinson's in England have never been seen by a hospital doctor with specialist knowledge of the condition



Access to Parkinson's Disease Nurse Specialists is the top campaign priority for people with Parkinson's and carers living in England. But more than a quarter (28%) of people with Parkinson's in England have never talked to a Parkinson's Disease Nurse Specialist

As Parkinson's is a complex progressive condition, it is vitally important that people's medication regimes are regularly reviewed. People in England have their Parkinson's medication reviewed more frequently than in Northern Ireland and Scotland with 91% having a medication review at least once a year compared to 79% in Northern Ireland, 89% in Scotland and 94% in Wales

Although access to therapies is improving, the majority of people with Parkinson's in England are still not being assessed for or receiving therapies to help them manage their condition:

- Nearly half (48%) have never been assessed for or received a course of physiotherapy
- Two thirds (66%) have never been assessed for or received a course of Speech and Language Therapy
- More than two thirds (68%) have never been assessed for or received a course of occupational therapy

There are inequalities in access between people with Parkinson's living in each country of the UK, with access for all types of therapy significantly lower in England

What the PDS wants:

- Every person with suspected Parkinson's to be referred within six weeks to a specialist for diagnosis before treatment is initiated
- A continued reduction in waiting times for the first appointment with a specialist
- Commissioners of Parkinson's services to listen to what people with Parkinson's are saying – Parkinson's Disease Nurse Specialists are their number one priority
- Every area to have Parkinson's Disease Nurse Specialists as part of their commissioned services for Parkinson's to help keep specialists' waiting lists down
- All people with Parkinson's to have their medication reviewed every 6-12 months by a specialist in Parkinson's (for example, a neurologist, care of the elderly physician or specialist Parkinson's nurse)
- Any changes to a Parkinson's medication regime to be made by a Parkinson's specialist. This responsibility usually falls to the patient's neurologist, care of the elderly physician or specialist nurse
- Local health organisations to engage with the PDS when redesigning their Parkinson's services or introducing Parkinson's Disease Nurse Specialist posts – we can pump-prime new nurse posts and can help local teams find a model of specialist nursing that works for them

- PDNSs to have manageable caseloads – unmanageable caseloads impacts upon the quality of care they can offer their patients
- Commissioners of Parkinson's services to ensure that a multi-disciplinary service is in place
- All people with Parkinson's to be offered and have access to all of the therapies they need when they need them
- More therapists with an in-depth understanding of Parkinson's working within Parkinson's services

Information needs of people with Parkinson's

Good information about symptoms, treatment options and what help is available to people living with the condition is vital to help them live independent lives, make informed choices and better manage the condition for themselves

Responses from the survey showed that:

The information provided at diagnosis is improving. Nearly a quarter (24%) of people with Parkinson's diagnosed more than 10 years ago in England were not given a clear explanation of the condition or treatments, or given no explanation at all. This compares to 15% of those diagnosed in England in the last year.

More than four out of ten (42%) of those surveyed in England feel they need more information about the condition

86% of the Parkinson's Disease Society's members joined the PDS to get advice or information



The Parkinson's Disease Society's publications were rated as the most useful sources of information on Parkinson's and how to cope with the condition, with 93% of people in England using PDS publications rating them as very useful

91% of people who have talked to a Parkinson's Disease Nurse Specialist in England felt they were very useful sources of information about Parkinson's. However, many people are missing out on the information they provide, with more than a quarter (28%) of people with Parkinson's in England having never talked to a Parkinson's Disease Nurse Specialist

What the PDS wants:

- Every person with Parkinson's to have their information needs addressed throughout the course of their condition
- Specialists to spend more time explaining the condition to their patients at the time of diagnosis and checking that the information has been understood
- Improved signposting at diagnosis and throughout the course of the condition to sources of support and information such as the other agencies
- Every person with Parkinson's to have access to a specialist nurse – they are an excellent source of information
- All health professionals involved in the management of the condition, including GPs, to use the information resources produced by the PDS

Education of professionals

Parkinson's is a complex, individual and fluctuating condition and a large number of health and social care professionals are involved in helping people manage their condition. Solid understanding of the nature and complexity of Parkinson's is key to these professionals making effective health or social care interventions

Responses from the survey showed that:

A quarter (26%) of people with Parkinson's who have been an in-patient in England during the last five years

felt that doctors, nurses and other hospital staff did not understand Parkinson's and how it affected them at all

More than half (57%) were not given the option to self-administer during their hospital stay. 63% of those who weren't given the option to self-administer their medication didn't get their medication on time.

48% of UK members currently living in residential care feel that staff do not fully understand Parkinson's and how it affects them

What the PDS wants:

- All staff working in hospitals to have a better understanding of the fluctuating and individual nature of Parkinson's and why the timing of drugs is so crucial
- Hospital staff to listen to people with Parkinson's, their carers and families
- People with Parkinson's to have the option to self-medicate if they are able to do so
- Hospitals to urgently address the medicines management processes they have in place and to make use of PDS 'Get it on time' materials, training resources and information
- Care home staff to increase their understanding of the physical and behavioural symptoms of Parkinson's by attending an education seminar run by one of the PDS education and training officers
- Care home staff to involve the person with Parkinson's and their close family in the care planning process
- Staff working in care homes to give people with Parkinson's time to carry out their activities of living and only provide help when requested
- Care home staff to work with the multi-disciplinary care team

The impact of Parkinson's upon carers

Carers who responded to our survey are people who look after a family member, partner or friend who is in need of help with their Parkinson's. The care they provide is unpaid. Carers who provide unpaid support to people with Parkinson's are hugely important and we wanted to understand more about the experiences of those caring for people with Parkinson's



Responses from the survey showed that:

Nearly two-thirds (63%) of carers of people with Parkinson's in England are caring for more than 50 hours per week

More than a quarter (27%) of those caring for people with Parkinson's in England are financially worse off since becoming a carer

Seven out of ten (70%) carers in England do not know about their right to a local authority assessment

The health of over half of carers (51%) of people with Parkinson's in England has deteriorated since living with or caring for a person with Parkinson's

What the PDS wants:

- Adequate financial support for carers
- Information to ensure carers are informed about their rights to services and benefits under current legislation
- Emergency planning, including availability of emergency respite care, for when carers are unable to care due to accidents or illness
- Improved access to respite breaks and other support from social services

The Parkinson's Disease Society (PDS) is the leading authority in the UK on the condition and a world leader in research. We campaign for a better quality of life for people with Parkinson's wherever they live in the UK. We provide expert information on all aspects of Parkinson's and a local support network for people with Parkinson's, their carers, families and friends. We are the UK's leading non-commercial funder of research into the cause, prevention and improved management of Parkinson's and are confident that our work will help lead to a cure. Our work is almost entirely funded by charitable donations and we are heavily reliant on legacies in people's wills.

Our freephone Helpline, which provides help and advice to all people affected by Parkinson's, can be reached by calling 0808 800 0303 Monday–Friday 9:30am–9pm and Saturday 9:30am–5:30pm

We are a membership organisation but support all people affected by Parkinson's. Members benefit from a quarterly magazine covering all aspects of living with the condition, the opportunity to share experiences with and contact other people affected by Parkinson's.

For more information, visit: www.parkinsons.org.uk