

Life with Parkinson's today - room for improvement

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

United Kingdom

There are approximately 120,000 people with Parkinson's in the UK.

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.

The survey was completed by more than 13,000 people with Parkinson's and carers living in the UK. 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.

Access to healthcare services

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, which covers England, Wales and Northern Ireland, 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:

15% of people with Parkinson's have never been seen by a hospital doctor with specialist knowledge of the condition. This is extremely worrying as Parkinson's is a complex condition requiring specialist input

Although we are seeing a trend towards more people being diagnosed by a specialist, things still need to improve. One in five people with Parkinson's diagnosed in the last year was diagnosed by their GP

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

Although access to therapies such as physiotherapy, occupational therapy and speech language therapy is improving, the majority of people with Parkinson's are still not being assessed for or receiving therapies to help them manage their condition

What the PDS wants:

- Local health organisations to urgently review the ongoing training of GPs to ensure that GPs are able to recognise Parkinson's symptoms more quickly and refer their patients immediately to a specialist
- Every person with suspected Parkinson's to be referred within six weeks to a specialist for diagnosis (usually a neurologist or care of the elderly physician) before treatment is initiated. This is a key recommendation in the NICE Guideline
- An increase in the number of neurologists and care of the elderly physicians who have expertise in Parkinson's or movement disorders
- 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)
- All professionals involved in the management of Parkinson's to look out for side effects, especially changes in the behaviour of their patients with Parkinson's
- Commissioners of Parkinson's services to listen to what people with Parkinson's are saying – Parkinson's Disease Nurse Specialists are the number one priority

- Local health organisation to engage with the PDS when redesigning their Parkinson's services or introducing Parkinson's Disease Nurse Specialist posts – we can help fund new nurse posts and can help local teams find a model of specialist nursing that works for them
- All people with Parkinson's to be offered and have access to all the therapies they need when they need them
- 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 the support and information available from the PDS and other agencies
- Every person with Parkinson's to have access to a specialist nurse – they are an excellent source of information

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:

Three out of ten people diagnosed with Parkinson's in the last 12 months were not given clear information about the condition and medication at the time they were diagnosed

47% of people with Parkinson's feel they need more information about the condition

86% of members joined the PDS to get advice or information

The PDS's publications were rated as the most useful sources of information on Parkinson's and how to cope with the condition

Nine out of ten people who have talked to a Parkinson's Disease Nurse Specialist felt they were very useful sources of information about Parkinson's. Many people are missing out on the information a specialist nurse provides, with more than one in four people with Parkinson's having never talked to a Parkinson's Disease Nurse Specialist

What the PDS wants:

- All health and social care professionals involved in the management of the condition, including GPs, to use the information resources produced by the PDS
- All health and social care professionals involved in the management of Parkinson's to signpost their patients to the PDS
- All staff involved in the management of Parkinson's to improve their knowledge and understanding of the condition
- 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

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:

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 half of those 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 involved in the management of Parkinson's to improve their knowledge and understanding of the condition
- 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's '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's 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 always be included in the multi-disciplinary care team
- One in eight people with Parkinson's feel that their home is not suitable for them
- Two out of five people with Parkinson's find buses and trains difficult or impossible to use
- 17% of people with Parkinson's gave up work because they developed Parkinson's
- Over half of people with Parkinson's have additional spending requirements due to the condition
- One-third of people with Parkinson's under 65 are just getting by financially and 5% are getting into difficulties
- The financial situation of 28% of carers has worsened – increasing to 45% of carers under 65
- Nearly half of people with Parkinson's wanted to do activities outside of their home such as socialising, visiting relatives or pursuing hobbies, but could not in the three months before being surveyed. Common reasons why not were feeling too unwell, feeling too tired, lack of public toilets, problems getting around the streets, difficulties with transport, problems with access to buildings

Support for living day to day with Parkinson's

As Parkinson's progresses, people become increasingly reliant on others. Having access to the care and support they need both from people around them and professionals is vitally important to them being able to live at home independently.

- Assistance from family or friends to manage everyday tasks is needed by a significant proportion of people with Parkinson's
- The two most common everyday activities people with Parkinson's usually rely on professionals for are housework and bathing
- Nearly one in ten people with Parkinson's need professional help and advice with housing adaptations but have not received it
- One in ten people with Parkinson's are not receiving but need home help (help with shopping or housework)
- All people with Parkinson's to get the health and social care support they require when they need it so they can live in their own homes for as long as possible
- Better promotion of professional services provided by local authorities to help people live day to day with Parkinson's and easier methods of assessment for these services
- All people with Parkinson's to have regular assessments of their needs resulting in appropriate and meaningful support by local authorities. Equipment such as hoists, wheelchairs, handrails and grab bars to be provided where appropriate to help people with Parkinson's maintain independence

What the PDS wants:

- Aids and equipment to be provided promptly. Delays can have a significant negative impact on people with Parkinson's mobility, comfort and ability to live socially active, independent lives
- Transport to be affordable and accessible to ensure that people with Parkinson's are less isolated
- Greater use of the Access to Work Grant to pay for aids and adaptations and travel to work to enable people to remain in employment
- Steps taken to increase awareness of the Blue Badge Scheme
- Better public toilets and more accessible public buildings
- Better information and advice about benefits and support available, to ensure that all people with Parkinson's are able to access the benefits to which they are entitled
- More support for people with Parkinson's to remain in employment
- Exemption from prescription charges for people with Parkinson's in Northern Ireland and England. Prescription charges have already been abolished in Wales, and Scotland is set to abolish them in the lifetime of this parliament
- Doctors and health professionals responsible for decisions about sickness benefits to have appropriate training about Parkinson's and understand the interactions between the condition and medication

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:

- 93% of carers of people with Parkinson's are living in the same house as the person living with the condition
- Most are full-time carers, spending 50 hours a week or more caring for the person with Parkinson's
- Carers are spending more hours caring than in 1997 and are getting less support
- More than half (55%) of those who gave up work to care for somebody with Parkinson's are financially worse off
- The vast majority of carers are still unaware of their rights to an assessment of their own needs despite this right existing since 1996
- 37% of carers receiving the Carer's Allowance are financially worse off since becoming a carer
- The health of over half of carers of people with Parkinson's 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 an assessment, 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
- Better recognition of carers as a group at risk of poor health with appropriate support in place, such as access to respite breaks and annual health checks

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