

Life with Parkinson's today - room for improvement

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

Scotland

There are approximately 10,000 people with Parkinson's living in Scotland.

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. 601 people with Parkinson's and 164 carers of people with Parkinson's living in Scotland 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

In its Patient Pathway for Parkinson's Diseases +/- Tremor Disorder, the Scottish Centre for Change and Innovation (2005) emphasised the importance of a referral to a specialist in Parkinson's for the diagnosis of the condition. It also identified the need for people with Parkinson's to have support from a multi-disciplinary Parkinson's Disease Service throughout all stages of the condition, and recommended that this team should include a Parkinson's Disease Nurse Specialist and therapists

Responses from the survey showed that:

Although we are seeing a slight trend towards more people being diagnosed by a specialist, things still need to improve with 32% of people with Parkinson's diagnosed in the last five years missing out on a diagnosis by a specialist (neurologist or care of the elderly physician)

It is an issue of great concern that people with Parkinson's in Scotland diagnosed within the last five years waited longer for the first appointment with a neurologist or care of the elderly physician than those diagnosed more than 10 years ago.

47% of those diagnosed more than 10 years ago waited less than six weeks for the first appointment with the specialist, compared to only 37% diagnosed within the last five years

Access to Parkinson's Disease Nurse Specialists is the top campaign priority for people with Parkinson's and carers living in Scotland. But still over three in ten people with Parkinson's in the Scotland have never talked to a Parkinson's Disease Nurse Specialist

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

- Over one third of people with Parkinson's in Scotland have never been assessed for or received a course of physiotherapy
- More than half of people with Parkinson's in Scotland have never been assessed for or received a course of Speech and Language Therapy
- More than half of people with Parkinson's in Scotland have never been assessed for or received a course of occupational therapy

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 local health board 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 help fund new nurse posts and can help local teams find a model of specialist nursing that works for them
- PDNSs to have caseloads of approximately 300 patients– unmanageable caseloads impact 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:

Four out of ten people with Parkinson's in Scotland were not given clear information about the condition and medication at the time they were diagnosed

41% of people with Parkinson's in Scotland 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 91% of people in Scotland using PDS publications rating them as very useful

87% of people who have talked to a Parkinson's Disease Nurse Specialist in Scotland felt they were very useful sources of information about Parkinson's. However, many people are missing out on the information they provide, with three out of ten people with Parkinson's in Scotland 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 PDS and 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:

Improving knowledge and understanding of Parkinson's among health and social care professionals is one of the top five priorities of people with Parkinson's and carers living in Scotland

Three out of ten (31%) of those who had been an in-patient 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

48% of UK members living in residential care now 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'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 work with the multi-disciplinary care team

Finance and Parkinson's

The PDS wanted to understand the way in which living with Parkinson's is affecting people financially

Responses from the survey showed that:

24% of people with Parkinson's in Scotland gave up work because they developed the condition and a further 20% retired earlier than planned due to Parkinson's.

More than one fifth of carers (22%) gave up work because they are caring for someone with Parkinson's

When people living with Parkinson's in Scotland were asked whether they have any additional spending requirements due to their condition, the reasons given were:

Heating	45%
Domestic help	44%
Mobility/Transport	31%
Laundry	22%
Aids and appliances	18%
Additional insurance	17%
Incontinence supplies	16%
Prescription charges	14%

One quarter (25%) of people with Parkinson's paying prescription charges in Scotland have not applied for a pre-payment certificate

People with Parkinson's in Scotland were asked about the benefits they are receiving:

- 43%** are receiving Attendance Allowance
- 37%** are receiving Disability living allowance
- 14%** are receiving Incapacity Benefit
- 26%** are receiving council tax benefit

What the PDS wants:

- 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
- Simple to complete benefits forms and assistance provided by local authorities to those that need it
- More support for people with Parkinson's to remain in employment

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 of carers of people with Parkinson's in Scotland are caring for more than 50 hours per week

One quarter of Scottish carers are financially worse off since becoming a carer

Only 17% of carers in Scotland are receiving the Carers allowance

Nearly three quarters of carers in Scotland do not know about their right to a local authority assessment. This is very surprising given that Carers have a right to an assessment under the Community Care and Health (Scotland) Act 2002 and Local Authorities have an obligation to offer Carers such an assessment. 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 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