

Life with Parkinson's today - room for improvement

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

Wales

There are approximately 6,000 people with Parkinson's living in Wales.

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. 393 people with Parkinson's and 137 carers of people with Parkinson's living in Wales 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.

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 Wales, 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:

Although we are seeing a slight trend towards more people being diagnosed by a specialist, things still need to improve with one third (34%) of people diagnosed with Parkinson's within the last five years missing out on a diagnosis by a specialist (neurologist or care of the elderly physician)

Respondents from Wales diagnosed in the last five years were more likely to wait more than a year for their first appointment with a specialist than people in other areas of the UK

It is an issue of great concern that one quarter (25%) of those referred to and diagnosed by a neurologist in the last five years waited more than a year for the appointment

However, waiting times in Wales for the first appointment with a specialist (neurologist or care of the elderly physician) are getting better

37% of people with Parkinson's in Wales diagnosed more than 10 years ago waited less than 6 weeks
47% of people with Parkinson's in Wales diagnosed in the last five years waited less than 6 weeks

Access to Parkinson's Disease Nurse Specialists (PDNSs) is the top campaign priority for people with Parkinson's and carers living in Wales. Although our members in Wales were more likely than people elsewhere in the UK to have spoken to a PDNS, still one in five (20%) of them have never talked to such a nurse

Wales respondents were more likely to be able to see a therapist than in any other part of the UK. However, the majority of people with Parkinson's are still not being assessed for or receiving therapies to help them manage their condition.

- Three out of ten people with Parkinson's in Wales have never been assessed for or received a course of physiotherapy
- More than four out of ten people with Parkinson's in Wales have never been assessed for or received a course of Speech and Language Therapy
- Half of people with Parkinson's in Wales have never been assessed for or received a course of occupational therapy

Wales respondents were more likely to have attended three or more out-patient clinics in the last year (41%) and to have had more regular medication reviews

Eight survey respondents from Wales have been recommended for the operation, Deep Brain Stimulation, to be later turned down on cost grounds or because surgery is unavailable

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 – PDNSs are their number one priority
- Every Local Health Board to have PDNSs 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 PDNS 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 manageable caseloads – In its National Cost Impact report, NICE recommends an average caseload of 300 patients per specialist nurse. Many currently have double this workload
- 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
- Everybody who meets the clinical selection criteria for Deep Brain Stimulation to have the operation if they so wish. Health Commission Wales to reverse the decision it made in 2006 to suspend funding for this procedure

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 (31%) people with Parkinson's in Wales were not given clear information about the condition and medication at the time they were diagnosed

Four out of ten (41%) of people with Parkinson's and carers in Wales 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 Wales using PDS publications rating them as very useful

Respondents living in Wales were more likely than in other countries to have first learnt about the PDS through their Parkinson's Disease Nurse Specialist

Almost nine out of ten people in Wales (88%) who have talked to a Parkinson's Disease Nurse Specialist felt they were very useful sources of information about Parkinson's. However, many people are missing out on the information they provide, with one in five people (22%) with Parkinson's in Wales 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 needs 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 Wales

Almost three out of ten (29%) of those who had been an in-patient in Wales 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

Six out of ten (59%) were not given the option to self-administer during their hospital stay
Of those who weren't given the option to self-administer their medication during their hospital stay, seven out of ten (72%) didn't get their medication on time

One third of those (33%) who didn't get their medication on time as a result of not being able to self-medicate feel this resulted in an extended stay in hospital

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 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

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 Wales (64%) are caring for more than 50 hours per week

One third of Welsh carers are financially worse off since becoming a carer

Only 18% of carers in Wales are receiving the Carers allowance

Nearly two thirds of carers in Wales do not know about their right to a local authority 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 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

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

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