



Improving the diagnosis
experience for people
with Parkinson's

“I’ve recently been diagnosed with Parkinson’s and I don’t know what’s in front of me or what the future looks like.”

“I saw a consultant for a second opinion. He confirmed it was Parkinson’s, but was helpful and sympathetic. I felt really supported and have gone on fairly positively from there.”

“We saw a consultant who wouldn’t answer any of my mother’s questions and kept slamming his hand down on the table to make her stop talking.”

Improving the diagnosis experience for people with Parkinson’s

As part of the UK Parkinson’s Excellence Network, professionals came together and discussed how to improve the diagnosis experience for people with Parkinson’s.

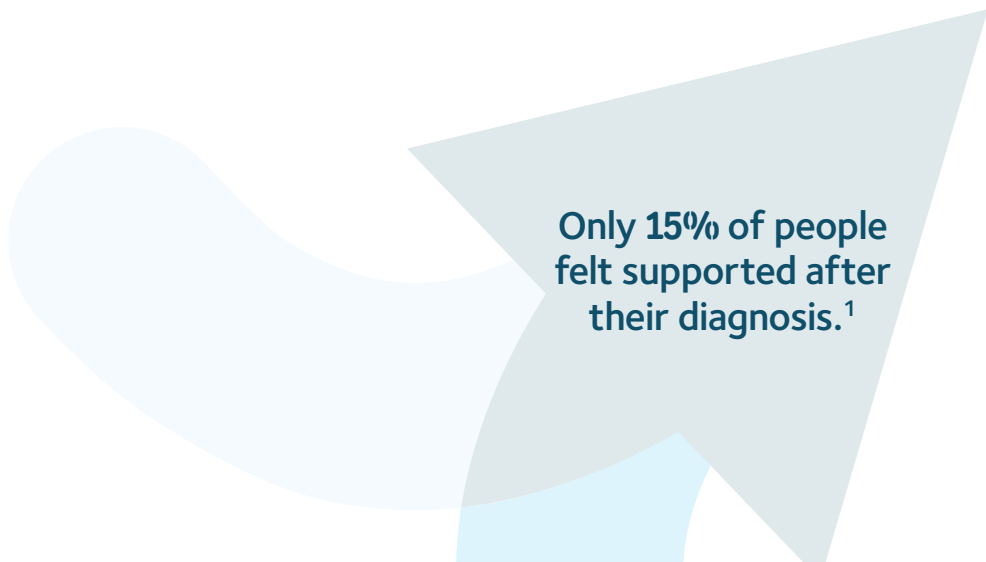
Receiving a Parkinson’s diagnosis can leave a person feeling scared, confused, or unsure about what the condition actually is and may mean. Evidence shows the importance of the diagnosis experience for the way people approach the condition.

Being positive about how people can live with Parkinson’s and emphasising to a person that they will be supported to manage their condition can enable them to take control and lead the life they wish to lead.

Here’s some suggestions for how you might make the diagnosis experience more positive for the people you diagnose.

“I feel like I’ve been diagnosed and just left to get on with it.”

“There were no reassuring words at all. It was the attitude of ‘well, there’s nothing more I can do for you’.”



Only 15% of people felt supported after their diagnosis.¹

“The Parkinson’s nurse was very, very informative about extra therapies, medication, home life, social life – any need at all that we had.”

“The clinic is like a support group with lots of information available and people to talk to.”

“I was told I would be seen every six months by a neurologist, but it’s been a chapter of disasters. I had one appointment in January. The next one was arranged for October and then cancelled without reason.”

Structure of the clinic

- Create and foster an environment conducive to support, time and listening for people. Involve people with Parkinson’s in reviewing how your clinic is run and how the patient experience could be improved.
- During the appointment, try and ensure the person has someone with them for support. This may be a friend, family member or a Parkinson’s nurse.
- Ensure patients are given adequate consultation time when they are receiving a diagnosis. This allows you to explain the condition properly and provides the opportunity for patients to ask questions they may have.
- Offer an early follow-up appointment with the Parkinson’s nurse, ideally within two weeks of the initial diagnosis.
- Make sure people are booked in for a follow-up appointment with you before they leave the clinic. This should be within six months of being diagnosed.
- Ensure access to the multidisciplinary team from the point of diagnosis.
- Consider what scope there is to integrate Parkinson’s UK advisors in your clinic.

“The consultant phoned me personally twice during the fortnight after my initial diagnosis to see how I was.”

43% of people felt scared after being told they had Parkinson’s.¹

“My consultant was absolutely fantastic and was really, really caring and understanding in the way he told me.”

“My consultant gave me time to absorb the information and was positive about treatment options.”

“My consultant was laughing and joking with a colleague on the phone and when he finished the call, he asked, ‘Did you hear that?’ I said no, so he told me I had Parkinson’s and pushed a box of tissues towards me. Because he had been laughing and joking I had been lulled into a false sense of security. It was very clumsy and extremely insensitive.”

Approach and communication

- Treat every person you see as an individual and adjust how you deliver a diagnosis accordingly.
- Remember you are breaking life changing news to a person and their family. Make appropriate eye contact with someone and deliver the diagnosis sensitively, compassionately and with empathy.
- Use simple language without medical jargon or acronyms.
- Answer questions honestly. People need to understand what you suspect, even if you are not certain at this stage.
- Be positive and emphasise to people they will be supported to manage their condition and live life to the full. Talk to the person about their options and ways they can take control.
- Develop your skills in how to deliver a diagnosis as part of your continuing professional development. Look at organised communication courses running in your area or hold more informal learning sessions with your peers.

“Just as I thought the appointment could not get any worse the neurologist opened the consulting room door and asked me to walk down the corridor towards the waiting room. I have no memory of how many people were waiting or watching me but I felt embarrassed and humiliated.”

24% of people felt they weren't given enough time to talk about their diagnosis at their appointment.¹

“We were given leaflets and asked if we knew about Parkinson’s UK. Giving the carer support as well as the patient means you don’t feel isolated or on your own.”

“It has taken me a long time to come to terms with my diagnosis and I mostly blame the initial contact. It would have been helpful to have spoken to someone at that point to hear something more positive. I think being pointed towards the charity would have helped.”

Access to information


- Provide people with appropriate written information to take away with them. This can support what you have communicated verbally during the appointment.
- Ensure people have information about your Parkinson’s service and what to expect. Provide the person with information about how to access and contact the multidisciplinary team.
- Signpost them to a range of support available from Parkinson’s UK.

For people who are newly diagnosed, Parkinson’s UK offers:

- a website (**parkinsons.org.uk**)
- Parkinson’s UK helpline, including a peer support service (**0808 800 0303**)
- a range of evidence-based, user-tested information resources
- local information and support staff
- self-management programme
- local groups

For more information, please see **parkinsons.org.uk/support**

“It would be helpful to be given some information during the diagnosis appointment – nothing too detailed, but something to help when a doctor breaks the news.”



Only a **THIRD** of people were given written information to take away with them at the time of diagnosis.¹

Thank you

Thank you for very much to everyone who reviewed this resource:

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Thanks also to all the professionals who contributed to the development of this resource as part of the UK Parkinson's Excellence Network.

¹'Survey of people with Parkinson's and their friends, family and carers' (YouGov and Parkinson's UK, 2014). The survey was completed by a sample of 3,630 people, aged 16 or over who have either been diagnosed with Parkinson's or are family members or carers of a person with Parkinson's.

The UK Parkinson's Excellence Network is the driving force for improving Parkinson's care, connecting and equipping professionals to provide the services people affected by the condition want to see.

The tools, education and data it provides are crucial for better services and professional development.

The Network links key professionals and people affected by Parkinson's, bringing new opportunities to learn from each other and work together for change.

Visit [**parkinsons.org.uk/excellencenetwork**](https://parkinsons.org.uk/excellencenetwork)