

**Feedback given to  
Healthwatch  
Gloucestershire about  
people's experiences of  
being diagnosed and living  
with Parkinson's**

March 2025

**The following stories represent feedback that we have received from patients and carers through our feedback and signposting service, and attendance at events and community groups around the county. We have identified several themes that are consistent across the range of people and groups that we have spoken to.**

These themes are:

- 1. People have told us that there is a lack of information being provided to people at the point of being diagnosed, as well as at follow-up appointments.**

Gerry told us that “there is information out there, if you know where to look and you are proactive.”

However, this can be incredibly difficult for people as Beverly’s experience highlights, and which represents much of the feedback we received. “With a Parkinson’s diagnosis it is easy to lose track of time and feel overwhelmed with everything, which is not conducive to being proactive.”

Other people told us about feeling in ‘limbo’.



**“I had no idea what to expect from my condition and what I could expect in the future”**



Julie was diagnosed with Parkinson’s quite young, in her early 50’s, which brings different kinds of challenges for her to overcome. She believes there needs to be more age-appropriate information and advice, and opportunities for social support – this is currently lacking, and therefore she doesn’t feel recognised. As a result, she set up her own informal group in her local area to offer peer support and share knowledge, experience and guidance. Members of Julie’s group reported that their experience of 15-minute appointment lengths is insufficient to discuss the often-long list of symptoms people experience. This is not enough time to go through their concerns in enough detail and feel heard.

**“It would be useful if they offered you some information at diagnosis on the Parkinson’s UK website – information on local groups, diet, exercise and so on ... but nothing is offered.”**

Representatives of Parkinson's UK told us that they have created a lot of information resources, but it's about ensuring people are being given it immediately on receiving a diagnosis. There is a concern that if people do not have this information straight away, the alternative is to search the internet which can be overwhelming and yield frightening results.

## **2. People have concerns about access and the frequency of appointments, particularly with the Neurologist.**

The people we have spoken understand they should see the Neurologist once a year and then the nurse in between, meaning they see someone every six months. However, for a lot of people the reality is very different, with many saying they have not seen a Neurologist for over two years. This also means that a lot of people have not had their medication reviewed for more than two years.

Mary told us that she was diagnosed in August 2023, but hasn't seen anyone since, nor received any information.

Danielle said that she was referred to a neurologist in around January 2021 with a tremor.

### **Danielle**



"I saw a neurologist in March 2022 received a diagnosis of likely Parkinson's disease - follow up in 6 to 9 months. No information was given about Parkinson's other than to notify DVLA and insurance company. My family and I researched and found Parkinson's UK helpline which was very good and a local group, which I started attending. My next appointment with a neurologist was in March 2023. This time he asked a Parkinson's nurse to make an appointment with me and said he would see me again in 9 to 12 months. After several changes of appointment, I finally had a telephone appointment with a Parkinson's nurse in June 2023. She asked me a number of questions and asked if all was ok. She told me the neurologist I had been seeing had left and I would need to be assigned a new one. She would see me in person for my next appointment. In April 2024 I had a telephone appointment with a Parkinson's nurse, same questions asked as last time, said as I didn't have a neurologist she would see me in person in 3 months' time.



Then changed her mind and said she would ask for me to be assigned a neurologist as I would need this for the DVLA when my license is due for review.”

We also heard from people who live in the North Cotswolds who seem to have very different experiences, despite living very close to one another. One of them explained how they see the same Neurologist every four months at Moreton-in-Marsh Community Hospital. Another person said they have contact from the Parkinson’s Nurse every 8 months but have not seen a Neurologist in three years. Someone else said they go to Swindon to see a Neurologist because when they were diagnosed 12 years ago, there was no one for them to see in the County. They said that they have been very happy with their experience to date.

### **3. People feel that there is a lack of coordinated and holistic care which affects their overall experience and outcomes.**

There doesn’t appear to be a clear pathway to follow for either staff or patients – do patients need to book appointments or wait to hear from the hospital? Some people appreciated that there have been staff shortages which impact this process.

Stephen said “I had a letter offering an appointment in July 2023 prior to being diagnosed. I arrived for the appointment feeling anxious and concerned about what to expect, only to be advised once I had signed in and waited, that the Consultant was actually on holiday. The appointment had not been cancelled or re-arranged, and it appeared even the people on the desk were unaware of the Consultant not being there. Finally, two nurses appeared and eventually after a few hours, I was able to see a Registrar who, after a few further tests, confirmed the diagnosis was Parkinson’s. Within a few weeks of this appointment, I also received a letter advising me that I had missed an appointment which I had been completely unaware of as no letter or call had been received. I was last seen in December 2023 by a nurse but haven’t seen anyone since. I am going to ring the Booking Office to try to arrange an appointment for next year.”

Sally was given two separate appointments in one week. “The first was with the nurse and a couple of days later I was due to see the Neurologist. When I went to the appointment with the nurse, she asked why I had arranged both appointments within the same week! I said this was not my doing and this is what they had been offered but came away feeling the nurse thought it was my fault.”

“There should be more onus on the relevant professionals to make regular contact with the patients and not the other way around. A text/letter or call to keep in touch is more beneficial and information on appointments

should include who I am going to see and what it is about and be shared with carers too.”

Martin told us that “Every professional person you see gives you new medications and asks you to “try this”. There needs to be a feedback service after a month to see if it is working, otherwise it is another 6 months before you can talk to anyone about this.”

Dorothy explained the impact her husband’s experience of living with Parkinson’s has had on her as his wife and carer. “Isolation, fear, anxiety, lack of hope, feeling of being totally overwhelmed by the situation, tears and great distress. Difficulty in trying to support Tom to keep staying positive and proactive in fighting this terrible illness. Blue badges should be compulsory to all Parkinson’s patients, and we need more help to get funding such as PIP, Carers Allowance and Attendance allowance its time consuming, distressing and near on impossible at times to provide the physical evidence they require.”

### **What worked well**

- Many people spoke about the benefit of the VCSE sector in establishing social support through local groups and having someone they could approach informally with any concerns for advice and guidance. However, not everyone is made aware of these.

### **What could be done differently to improve care for everyone**

- Patients and their carers need to be signposted at the earliest opportunity to appropriate information and advice about what to expect following a diagnosis of Parkinson’s. For example, providing a leaflet on ‘What is Parkinson’s’ and what support groups are in their area, as well as practical things like the importance of diet and exercise. People could also be signposted to verified and trusted websites/ resources so they can research things for themselves.
- Many people also felt that having a simple leaflet listing contact details for Statutory and VCSE professionals and organisations supporting people with Parkinson’s would be beneficial as knowing who to go to and when is confusing. This should also include support with completing benefits applications.
- Booking appointment systems need to be more streamlined and communication through letters or phone calls should include more information to clarify the purpose of the appointment and who the patient is going to see.
- People need to be informed about who they can contact, and provided with contact details, if they have concerns or need to speak to someone in-between appointments.



# healthwatch Gloucestershire

Healthwatch Gloucestershire  
The Vassall Centre  
Gill Avenue  
Fishponds  
Bristol  
BS16 2QQ

[www.healthwatchgloucestershire.co.uk](http://www.healthwatchgloucestershire.co.uk)  
t: 0800 652 5193  
e: [info@healthwatchgloucestershire.co.uk](mailto:info@healthwatchgloucestershire.co.uk)  
X @HealthwatchGlos  
Facebook.com/HealthwatchGloucestershire