If I had Parkinson’s…

‘I often say now I don’t have any choice whether or not I have Parkinson’s, but surrounding that non-choice is a million other choices that I can make.’

(Michael J. Fox, Canadian-American actor, diagnosed with Parkinson’s aged 30)

A Patient’s Perspective

Parkinson’s disease (PD) is a progressive, neurodegenerative disease, first described nearly two hundred years ago by James Parkinson in ‘An Essay on the Shaking Palsy’. The hallmark motor symptoms are bradykinesia, tremor, rigidity and postural instability. However there are also a host of non-motor symptoms associated with the disorder that have a significant impact on patients’ quality of life. Even though one in five hundred people suffer from PD in the UK, there is relatively little research into patients’ perspectives and experiences of the disorder and their expectations of treatment for PD. In this essay, I will try to put myself in the shoes of someone with PD, and consider the process of diagnosis, the impact of PD on daily living and expectations of treatment, based on personal accounts and studies of patients’ responses.

How would I know?

If I had Parkinson’s, when I would notice? About 80% of patients with PD initially present with motor symptoms, however these usually start asymmetrically and may be relatively subtle in the early stages. Would I notice my writing getting progressively smaller, a slight tremor in my right hand, or a decrease in my arm swing on one side? And even if I did, would I automatically make the connection between these signs and PD?

More than likely, I would not immediately associate my symptoms with Parkinson’s, and instead I would find an alternative explanation for my symptoms, as many Parkinson’s patients do:

‘I experienced difficulties with writing, which I noticed when writing many Christmas cards in December….I blamed increased computer use being the reason I was no longer accustomed to handwriting a lot.’

Alternatively, the initial unilateral onset of symptoms may encourage me to develop compensation strategies such as using the unaffected limb or using a home-made orthotic device:

‘My left hand started to shake in more and more situations, it was especially bad in the choir, new sheet music in my hands….I sang with a home-made brace to control my hand.’

Depending on the responses of my friends, family and GP, I may put my symptoms down to ‘getting older’ rather than PD:
‘My GP: “There is nothing wrong with you.” But where does the fatigue come from then? GP: “Well, I’m not sure. But you’re not that young anymore!”’

So what would lead me to seek a medical diagnosis for my symptoms? Perhaps the persistence or deterioration in symptoms within a set time frame, their interference with my daily life or work, or the comments of a perceptive relative or friend would eventually lead me to a diagnosis of PD²:

‘I was a production worker and noticed I had more and more trouble with my motor skills, then I went to the GP.’

If I happened to be in the 21% of patients that initially present with non-specific, non-motor symptoms, I think I would find it even more difficult to identify PD as a possible cause. These symptoms include anosmia, depression, constipation and REM sleep disorder and can precede motor symptoms by up to ten years¹:

‘I had a lot of symptoms including a frozen shoulder, no sense of smell and an arm that didn’t swing when I walked. But, because I was suffering from depression when I went to the doctors they didn’t take any notice of me....’

I would agree with the 84% of Parkinson’s patients who feel that the public are not sufficiently informed regarding this disorder¹. Also, like most patients, I would ideally like to be diagnosed as early as possible to allow myself more time to discuss treatment options and plan for the future². Therefore, increased awareness of the early motor and non-motor signs of PD amongst the general public and healthcare professionals is key to facilitating earlier diagnosis of people with PD:

‘If I had gone to the GP earlier, and the GP had known more about PD, then some things could have been detected faster. If the diagnosis was made earlier, I could have felt better about it emotionally.’

How would it affect my day-to-day life?

If I had Parkinson’s, how would my life change? Although 5% of people with Parkinson’s are diagnosed when they are less than 40 years old, most develop the disorder between the ages of 45 and 55. When I am this age, I hope to have a successful medical career and a family of my own. A diagnosis of PD would impact drastically on both of these. Sarah, aged 42 and mother of two describes how difficult having a young family can be when you also have Parkinson’s:

‘The school run is probably my worst time of the day. Getting my boys dressed when you are short of time, and you are fumbling to get their socks on, shoes laced up, blazer buttons done up is just so stressful. I hate having Parkinson's then.’

In the first few years of having PD, I think the motor symptoms would bother me the most. This is consistent with research showing that patients that have had Parkinson’s for less than six years find slowness, tremor and stiffness their most troublesome symptoms, because they interfere with even the simplest of activities such as making a cup of tea, getting dressed or spreading butter on toast³:

‘I can’t address an envelope, write a cheque or take a simple message over the telephone.’

Whilst I may be able to adapt my lifestyle to cope with these motor symptoms, the non-motor symptoms associated with PD tend to become more bothersome with time. Patients that have had
PD for more than six years find mood and sleep disturbances and drooling even more distressing than tremor and slowness:

‘I get restless at night, and worry about disturbing my wife. I go to bed around 11.30pm, wake about 4am, doze until 6am then get up and take my first tablets at 7am. The day can seem very long.’

Furthermore, long term use of levodopa is associated with the development of its own motor complications, including end dose deterioration, ‘on/off’ fluctuations and dyskinesias. In fact, if I had Parkinson’s for more than six years, I would be most likely to find fluctuating response to medication my most bothersome symptom.

What would I be hoping for from my treatment?

‘Health professionals would gain by asking one simple question to their patients: what role do you want to play in making decisions about your health?’

In the early stages of PD, my initial focus for treatment would be on improvement in motor symptoms, as these are likely to have the biggest impact on my day-to-day life. I would be particularly hoping for an improvement in walking, because slowness and gait difficulties are highly debilitating and have a significant impact on quality of life and levels of distress in patients with PD.

Later on in my Parkinson’s care, when the motor complications of levodopa are likely to become my major issue, my main goal for treatment would be a continuous level of symptom control. The ideal treatment for most patients is a once-a-day formulation that is able to keep morning akinesia, symptom fluctuations and ‘on-off’ phenomena under control for the whole day. This is now a possibility with new extended-release preparations of dopamine agonists which require once-daily oral administration.

I would also like doctors to consider my non-motor symptoms, particularly any difficulties with sleep. Early morning symptoms and sleep disturbances significantly impact on quality of life, and 77% of patients with Parkinson’s admit to wanting better quality sleep. However, this can be easily overlooked if healthcare professionals focus only on improvements in motor symptoms. A ‘patient-centred’ approach can help to reconcile any differences between the patient’s and healthcare professional’s agenda.

‘Patient-centred’ healthcare is defined by the Institute of Medicine as ‘providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions’. Research has demonstrated that PD patients who are more involved in their care show increased satisfaction with and adherence to treatment. I know that if I had Parkinson’s, I would like to play an active role in my healthcare, including participating in goal-setting, decisions about treatment and monitoring treatment effects.

Last words

Patients with Parkinson’s experience a range of motor and non-motor symptoms that can have a significant impact on their activities of daily living and quality of life. Recognition of the symptoms in the early stages of the disease can be difficult, but through increased awareness of PD amongst
doctors and the general public, earlier diagnosis may be possible for many patients. A ‘patient-centred’ healthcare approach can help identify PD patients’ priorities in terms of treatment and ultimately increase their satisfaction and adherence to treatment.

References


With special thanks to ‘Parkinson’s UK - real life stories’ for some of the patient quotes.