

A PATIENT'S JOURNEY

The reluctant patient: Parkinson's disease

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This patient was diagnosed with Parkinson's disease 17 years ago and had surgery for the condition in 2005

Living with Mr P

I was diagnosed with Parkinson's disease in 1990. Somehow I was reluctant to admit to myself that I was ill. Therefore I had difficulties understanding, let alone accepting, people who thought I needed special treatment or consideration or, worst of all, colleagues who thought I wouldn't want or be able to do complicated work.

As my condition worsened and it became obvious to friends and colleagues that I had a neurological ailment, my opinions were sought less and less frequently. This was perhaps the most hurtful part of my illness, but I was comforted by the reaction of a few good friends with whom I had always worked and continued to work, and a few new friends who were wise enough to overlook my physical condition. They realised that nothing had changed and that my brain was not in the least affected.

Physically, the most striking aspect of my illness was the extensive tremor. I always suspected that this was the reason why some people's attitude towards me changed—they could not take me seriously any longer. Some who were not doctors confused Parkinson's with Alzheimer's disease and therefore expected to find that I had lost control not only of my body but also of my wits. It can be exasperating to prove constantly that this is not so.

I remember being deeply shocked by an acquaintance who had Parkinson's disease who, when she received her diagnosis, quit her job in order not to "be in the way." I could never dream of voluntarily getting out of the way. It was Mr P who was an intruder, and a true nuisance, who increasingly demanded time and attention but who has never become part of my identity. I have sick friends who insist on being regarded as professional patients—but that could never be my identity.

The operation

The doses of multiple drugs that I needed to remain functional began to produce intolerable side effects, primarily dyskinesia and bouts of depression. When

my condition became really intolerable, and my drug doses had reached extremely high levels, I started seeking some other form of help. Someone I knew with Parkinson's disease had had surgery (implantation of a bilateral subthalamic nucleus stimulation system) and described it as the best thing that had happened in his life. That made me decide to give it a try.

Letting someone into your brain while you are awake (so that the effect of the implanted electrodes can be controlled) feels like consenting to an invasion of your most private and innermost parts. All my hair would have to be removed, and as I had always had very long hair, this was really an infringement of my femininity.

Fortunately, the anaesthesia, which was intended to reduce fear of the surgery, did just that and also induced a sense of indifference to what was happening to me. This indifference persisted after the operation. I rather liked my bald head and toyed with the idea of keeping the new style, had it not been for the scars, which would have needed constant explanation.

Living without Mr P

What are the effects of the operation nine months later? I was and am still suspicious and expecting the worst—while hoping for the best. Physically, the tremor and especially the dyskinesia are now under control. Drug treatment is down to a very low level, and I do not need levodopa. The depression that used to accompany the tremor when it was particularly strong has vanished without trace. After 40 years of dependence on benzodiazepines for falling asleep, I find that they are no longer necessary. And I have gained some 9 kg in weight, after being excessively thin for the past decade. My handwriting is definitely worse, but my driving is back to normal. I watch myself suspiciously, expecting that the messing about inside my brain must have had some untoward effect. The insertion of foreign bodies inside my head bothers me.

Lessons learnt?

I do not yet know how people regard this "new" person. I do not regard myself as new as I never gave in to being sick in the first place. However, I notice with awe how friends and acquaintances seem overjoyed at

This is one of a series of occasional articles by patients about their experience of traumatic medical events that offer lessons to doctors. The BMJ welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

A doctor's perspective

Two years ago Elisabet Helsing was referred to our department for evaluation of deep brain stimulation, a surgical treatment for advanced Parkinson's disease. More than 15 years earlier, she had been diagnosed with Parkinson's disease after presenting with the cardinal motor symptoms of tremor, rigidity, and bradykinesia. Dopaminergic drugs had provided effective treatment for years, but as her disease progressed, the treatment was becoming increasingly difficult owing to the appearance of levodopa induced complications such as involuntary movements and motor fluctuations. Drug treatment often cannot control these disabling symptoms, and surgical treatment is then an option in selected patients.

Not every patient with parkinsonism is eligible for deep brain stimulation. A careful examination of all the patient's symptoms, including levodopa response of motor symptoms, is required before a decision is made. After we had evaluated Elisabet's motor symptoms and psychiatric and cognitive functions, as well as her general medical condition, we found that she was eligible for bilateral stimulation of the subthalamic nuclei. This is currently the most common surgical procedure for patients with advanced Parkinson's disease, and its efficacy for relieving motor symptoms is well established.

Increased neuronal activity in the subthalamic nucleus and other parts of the basal ganglia are believed to account for motor dysfunction in Parkinson's disease. Thus, subthalamic stimulation has an effect on each of the cardinal features, decreasing the severity of these symptoms to a level comparable with that when the patient was taking medication before the procedure. Levodopa and other drugs can be reduced by 50% on average, and some patients can stop taking medication

completely. Motor fluctuations are decreased, and as a result of reduced medication, there is a marked reduction or total disappearance of dyskinesias. Changes in motor function also lead to improvement in quality of life, with improvement in measurements of activities of daily living, emotional wellbeing, and physical discomfort.

Elisabet's story highlights several important effects of deep brain stimulation. Subthalamic stimulation is an effective and safe symptomatic treatment for motor symptoms and levodopa induced motor complications in selected patients with advanced Parkinson's disease. However, stimulation also has significant effects on non-motor symptoms, including neuropsychiatric symptoms, cognition, and sleep. After subthalamic stimulation either improvement or worsening of mood and anxiety may occur. This probably results from a combination of changes in dopaminergic medication, the effects of a life changing event, and stimulation related effects. Over the long term, different problems emerge, more related to natural disease progression and development of cognitive decline.

Parkinson's disease has traditionally been seen as a disorder mainly affecting movement, and non-motor symptoms have not received appropriate attention. Today the motor symptoms of the disease can often be acceptably controlled. In many patients, non-motor symptoms have a greater impact on quality of life than the motor symptoms defining the syndrome. As Elisabet says in her article, to understand all aspects of deep brain stimulation and its impacts, physicians should also pay more attention to these non-motor symptoms.

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the development. Some cannot stop looking at me.

What surprises me is the neurologists' and neurosurgeons' lack of interest in the less obvious effects of the operation. After focusing intensely on my brain around the operation time, they apparently no longer see me as an interesting case. Why not? True, my initial impression that my fingernails had suddenly grown healthier may have been quite wrong. But surely the sudden and complete relief from benzodiazepine dependence is relevant in some way? In retrospect, I can see that I had developed a habit of staying awake at night (to work in the peace and quiet) then sleeping in the morning. This is no longer the case: I now get up early and fall asleep promptly at night. And for me it is a small miracle that the episodes of depression have disappeared. None of this seems to concern my saviours.

Do neurologists and neurosurgeons perhaps feel a need to protect themselves against the growing body of grateful repaired people who by necessity come to consult them about their batteries, electrodes, and mundane matters such as exactly what voltage to apply? Or is it just that the neurosurgeons find the thrill of the operation (and its success) more attractive than the slow process of healing that is experienced by patients like me, trying to get used to living with foreign bodies in their heads? Is my thrill when I see or feel small changes in my daily life performance

inconsequential to their daily work?

The future

I hope that some of the professionals will have the strength and wisdom to overcome their resistance to the tales of their grateful patients. They could then try to learn more from these stories, picking up clues that might lead to understanding why the treatment works—and how it might be further developed.

It is quite something to have an incurable disease that is suddenly cured. A "miracle" they used to call it. And miracles may even provide lessons if we take them seriously.

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Endpiece

Humanity has but three great enemies: fever, famine, and war; of these by far the greatest, by far the most terrible, is fever.

Sir William Osler (Canadian physician, 1849-1919). In: Cushing H. *The life of Sir William Osler*. vol I, ch 14. Oxford: Clarendon, 1925

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