

Lord Bethell MEP

When Euro MP Lord Bethell found he had Parkinson's disease, he was terrified. But here he tells how illness has taught him where there's life, there's hope.

Shaky hands, insomnia, a croaky voice, stiffness of the joints, sadness in the face, bleary eyes, grumpiness, stress, depression, a shuffling gait, a lack of synchronisation in swinging the arms - these are just some of the symptoms of a disease that has been my companion and uninvited guest for the past six years.

In 1995, when I was 57, my wife Bryony noticed a tremor of my left hand and an occasional twitch of the face muscles. We put it down to stress and hoped it would go away. It became awkward and others began to notice. It was at its worst when I made a speech in the House of Lords, or in what had been my London North-West European Parliament constituency. I had lost it to Labour in the previous year's elections and was struggling to stay afloat politically.

At the outset, we thought the tremor might have been brought on by this piece of misfortune, combined with worries about the health of my baby son John, born in August 1995, and the need to build a new career.

I was asked by a relative if I might have had a slight stroke. It was time to consult my doctor and it was he who first mentioned the dreaded words 'Parkinson's disease'. It was a bolt from the blue and a dagger in the heart.

He sent me to a neurologist, who examined me and on May 9, 1996, wrote: 'When he walks he does not swing his left upper limb as fully as the right. There is a slight facial impassivity with impaired blink frequency. When he elevates his shoulders, the left does not rise as briskly as the right. I told him that I agreed with your provisional diagnosis of early, predominantly left-sided, Parkinson's disease....'

It was the beginning of a war that I will have to fight until the end of my days, or until (as is constantly predicted) medical science comes in decisively on my side and destroys the beast.

My mother Ann had been a Parkinson's sufferer for the past year. She could hardly walk. But then she was nearly 80 and had contracted many other complaints. It never occurred to me that I was in line for the same disease. Doctors speculate that it may be inherited but nobody yet knows. My first reactions were panic and despair. But I had been led astray by the myth and the stigma. I thought, like many people, that Parkinson's rots the memory and cripples the body in short order. I believed it to be a form of Alzheimer's that quickly destroys the mind before rendering the sufferer helpless and then on a slide down to a vegetable state and death, like motor neurone and other fearful brain diseases. I certainly believed that it was the end of my working life, that I had nothing to look forward to but steady deterioration.

This is why many people keep to themselves the fact that they have Parkinson's. They sense the double stigma, incurability and involvement with the brain. In fact, more than 120,000 British people have the disease - a motor disorder characterised by the onset of a rhythmic tremor, muscle rigidity, difficulty in movement and stooped posture.

Parkinson's varies greatly. It can cripple its victim quite brutally and swiftly or it can creep up gently and almost without being noticed. But with most of us it can be controlled by medication. Many are still able to work, though usually at a slower pace than before. And there is the hope of a cure in just a very few years.

In fact, the truth is that nowadays a Parkinsonian has the same life expectancy as a non sufferer. And, although the brain is damaged by a reduction in the number of its cells, the intellect is unimpaired. The symptoms are annoying, off-putting, unattractive. A speaker's authority is not enhanced by the sight of a handful of shaking papers. They bring to mind jokes about delirium tremens and memories of the 'shaking palsy' in the Bible. I learned to hold my notes in the right hand and to put the left hand, the one with the tremor, into my pocket or, like Napoleon, behind my right lapel.

I now find that medication can usually control my tremors. The classic drug to keep Parkinson's at bay is called Sinemet, the first medication they normally give you. I take six tablets every day with another known as Cabaser to boost Sinemet's effect.

There are dozen's of drugs and brand names. I expect I shall take most of them sooner or later. Every few months some new pill is discovered, though sufferers are well advised to shop around to find a neurologist who travels the world, attends conferences and is up to speed on the latest medications.

Among well-known sufferers are the Hollywood actor Michael J Fox, the international Olympics Committee president Juan-Antonio Samaranch, the former Liberal Party leader Jeremy Thorpe, the Pope and the former US Attorney General Janet Reno, as well as several senators and congressmen who have made their problem known to the public, as is the American way.

But many people in Britain keep the disease to themselves. I do not blame them. Health is a purely personal matter - in theory. In practice it is something that can seriously damage your career. Obviously, people think twice before paying a sound wage for the services of an employee who suffers from an incurable disease. In the case of Parkinson's, the mental capacity is not affected but people often do not know this. There are also its other manifestations, some of which give an impression of old age and frailty.

And so the war continues, with the sufferer's family becoming more and more part of the battle. I have to put up with the disease. My wife has to put up with me. She sees me during the bad moments, when the stress is piling up and I have already taken my day's quota of pills.

Medical science makes progress but then so does the disease. The question is, who will win the race? Who is making more progress, the destroyers of my brain, or the medical researchers who are hard at work trying to repair it? It seems likely that the puzzle of Parkinson's will soon be solved but even here the stigma persists. Work towards finding a cure depends on a type of experimentation with human cells that many religious people will not tolerate. The Catholic Church is officially against such experiments.

I am lucky enough to be one of those who can live with the disease and still keep working. When my problem first appeared, I thought hard before deciding to persevere with efforts to get back into the European Parliament. As far as I know, no overt sufferer of Parkinson's sits in the House of Commons or in Strasbourg. It is assumed that he or she will not be up to the job. The travelling, the functions, the pressure, the stress, the challenge to the intellect - they think it will all be too much.

Furthermore, the ordeal of trying to be selected for Parliament is grievous enough without the Parkinsonian shuffle as you walk on stage, the gloom of the empty Parkinsonian face or the rustle of notes as they shake in a Parkinsonian hand.

Of all the disease's many symptoms, I see the 'grumpy face' syndrome as the most annoying and destructive. It cuts the sufferer off from the rest of humanity and from the sympathy that they would naturally feel otherwise. I thought about all this as the day approached for new European elections in June 1999. My neurologist gave me the green light. I was fit to stand and fit to do the job, he said. So I went ahead and was elected as one of the four Conservative MEP's representing the London region.

Since my condition has remained stable over the past six years, I do not expect it to deteriorate. But if it does, my supporters will not be put to the inconvenience and expense of a by-election. Under the new proportional system the next Conservative on the list would simply take over. I plan to stay in Parliament as long as I can. Properly rested and medicated and nurtured by my wife, I can still make a sensible speech at a function and talk coherently to my London constituents. And as for the desk work, after 21 years in Brussels and Strasbourg and 32 years in the House of Lords, I can manage as well as others.

My main problem is those sardine-can rides in tiny aircraft. I am large and, in my pre Parkinsonian days, the seats were uncomfortable. Now they are a pain and probably a danger.

There may well be Parkinson's sufferers in the House of Commons. If there are, they just keep it a secret. Of course, this makes the problem worse. The pretence requires very exact timing in taking one's medication as well as an immense effort of will, all calculated to worsen the stress which is one of the nastiest symptoms of the disease in the first place.

It is disagreeable to feel obliged to bare one's soul, but I have to admit that, since my condition became widely known, I feel less stress. Since I no longer try to conceal it, it is much easier to keep it from showing too much. And I have been met with great kindness everywhere, including in Parliament. It is a huge relief no longer having to pretend.

I think the answer to Parkinson's will be found in a few years. Even now there is talk of a dramatic cure involving surgery. But until then 'Parkinson' is my bitter enemy, always there with some variation in the disagreeable symptoms, some painful, some merely inconvenient, like a dose of flu that never leaves. If they desist for a short time, it is always au revoir. We never say goodbye. They come back like soldiers returning to the guard house.

Lord Bethell