

Michael Holman

The following article, written by Michael Holman, outlining his experiences of undergoing Deep Brain Stimulation surgery, was originally published in the Financial Times Weekend, March 31st, 2001.

Listening to my Brain

After suffering the debilitating affects of Parkinson's disease, FT journalist Michael Holman was earlier this year offered the chance of an amazing life changing operation, which has freed him from most of the symptoms. Here he describes the 11-hour operation, during which he had to remain conscious.

I am watching from my hospital room as the sun rises over the snow-covered Alps surrounding Grenoble. It is the first day of the rest of my life, and I want to extract the essence of every moment.

I feel liberated from a ghastly prison in which I have lived for 16 years. It had become almost as claustrophobic as the steel cage within which my conscious head was screwed into place for the 11 hours it took a team of neuro-surgeons at Grenoble's university hospital to work what seems little short of a miracle.

It was in 1986, while I was writing a postcard on the veranda of my beach front hotel on the island of Mauritius, that I realised that what had been called a "benign essential tremor" in my right hand was really something very nasty. Not only was my writing becoming cramped and tiny, I found it hard to complete a sentence, as if my fingers were operated by a battery that was fast running out of power.

A few weeks later, in August that year, not long after turning 40, I was told I had Parkinson's Disease, a degenerative condition of the nervous system that affects more than 120,000 people in Britain, caused by the brain's failing capacity to make dopamine, the chemical that helps control movement.

The discovery of levadopa in the 1960s was a breakthrough in the treatment of a condition that cripples. But it does not halt the progress of the disease. And as the deterioration continues and the dosage is increased, the side effects of treatment become crippling in themselves - notably the involuntary twisting and squirming movements known as dyskinesia.

Sixteen years after diagnosis, daily tasks - cleaning my teeth, buttoning my shirt, answering the phone - had become ordeals. Dyskinesia had become more pronounced. As my legs swung wildly, I regularly kicked unsuspecting colleagues. I began turning down invitations for lunch, attended fewer press conferences, and travelled increasingly rarely. Retirement from my job as Africa editor at the Financial Times seemed imminent.

Then came the phone call that was to change my life.

Although there is a long history of brain surgery to ameliorate the impact of Parkinson's, the benefits have been modest. The best known is a pallidotomy, in which cells are destroyed by laser. But, once done, there is no going back - a crucial consideration should research into the regeneration of dopamine-producing cells lead to a new form of treatment.

But in the late 1980s, Professors Alim-Louis Benabid and Pierre Pollak of Grenoble's university hospital pioneered a new technique that produced remarkable results and is reversible. It is called subthalamic stimulation, and involves implanting two electrodes deep in the brain, one on the right, the other on the left.

A wire connecting the electrodes is buried just under the skin, and linked to a pacemaker device inserted below the collarbone, which is programmed to the patient's condition. Sending a low-voltage current into the subthalamus has the same effect as a dose of levadopa, but without the side effects. Nobody could adequately explain this. What mattered was that, quite undeniably, it worked.

But why choose Grenoble, where I will be the first patient from Britain to undergo the operation? After all, 10 years on, the operation is now done in Oxford, Bristol, Dundee and London. Compared with Grenoble, however, where more than 150 operations have been performed, the experience of the procedure at these centres is modest which is hardly surprising.

Unlike France, it is not available on the National Health Service on the grounds that the operation ameliorates but does not cure, a view shared by most private healthcare schemes.

Encouraged by my London specialist, Andrew Lees, I arranged for consultations, first with Benabid and then with Pollak. I was lucky. I discovered that only 10-15 per cent of Parkinson's sufferers are suitable for the operations, and I was one of the fortunate ones.

But there was a second hurdle. There was a formidable waiting list of 200 people, some of whom had been on it for more than three years. I would have to join it.

Every time the phone in my office rang, I could hardly bear to pick it up as Christmas approached last year. The shakes - my term for the tremor - were bad. Conducting a conversation would be very demanding, and probably the call was no more than an invitation to pre-Christmas drinks.

Then once when I answered, I heard: "This is Professor Benabid. Could you make an operation on February 27?"

Eight weeks later I set off from London's Victoria station with my mother and Michela Wrong, friend, companion and FT colleague. For the third time in my life I was embarking on a journey which, whatever the outcome, I knew would change everything.

My small-town horizons had been broadened when, as a 17-year-old, I made the journey from Gwelo in what was then Rhodesia, to the US, to spend a year living with a family in Klamath Falls, Oregon.

The second journey had followed a similar route, but this time it was a landmark in my clash with white minority rule. Confined to Gwelo as a troublesome student by the Smith government, I was freed from "restriction" on condition that I left the country to take up a postgraduate place at Edinburgh University.

My most recent life-changing journey began this year on:

Thursday February 15

I check into the hospital, where I am greeted by a huge bunch of flowers from the FT. Never have the good wishes of friends and colleagues been so welcoming, so sustaining. "When are you going to blub?" Michela asks.

Friday 16

I must start the day without medication. I dread going without my eight-times-a-day dose of dopamine, like a junkie missing a fix. When the first dose of the day kicks in, I experience a wonderful relief as my muscles relax. But dyskinesia soon follows.

Saturday 17

The day begins with a session with Pollak. I am off medication again, and I shake and shuffle as I accompany him to a sparsely furnished room equipped with a television monitor, a tripod and a video camera.

I sit on a chair facing him and Michela, and go through a series of tests that have long become familiar: I touch the tip of my nose with my finger, raise and lower my foot as rapidly as possible, manipulate my hands and feet.

Then come a series of questions: Do I dribble? Am I incontinent? Do I get depressed? Has my memory deteriorated?

Monday 18

We go to meet the psychologist and after introductions and pleasantries, formal evaluation gets under way. "Who is the prime minister of Britain? What is today's date?" I pass with flying colours.

This is followed by far more subtle tests. I don't enjoy the experience. I can cope up to a point with the physical demands of Parkinson's, but I cannot bear the thought of a deterioration in my mental faculties.

Tuesday 19

Another round of tests, once more without medication. I have managed to wash my hair and get dressed, and regard this as a triumph. A young PhD student comes to my room at 9:15am. He sees me shaking, and - looking at Michela - asks her if I need a wheelchair. It is not the first time this has happened - the assumption that physical frailty goes hand in hand with some sort of mental infirmity, that the person who might need the wheelchair cannot speak for himself.

Michela looks on sceptically as I struggle with seemingly simple tasks. He wants a control, so later on Michela takes my place. I'm delighted to see that she starts to feel some of the tension.

One of the tests involves tracing the letter "e" on a mat connected to a monitor screen. Michela traces the letter several times clean, firm replicas, they appear on the screen without a trace of tremor.

"I love your 'e's," I tell her, and we both collapse in giggles.

Friday 23

The first of three operations: four holes are drilled in my head and titanium bolts inserted. When the main operation takes place, my head will be screwed into a frame, ensuring its immobility while the surgeons use a robot to guide the electrodes into place.

Thursday 27

The day of my renaissance. I am wheeled into the theatre feeling terrified, but not of the operation itself.

The day before, I had my first experience of the head cage. Before the brain scan, my head had been screwed into the device, which in turn was secured to the bed-like tunnel into which I was inserted. Within minutes I was gripped by the worst pain I had ever experienced, as my shoulder muscles cramped. I ended the 60-minute scan exhausted and apprehensive: if the cramp came back I doubted I would be able to endure an operation I had been warned could last at least 12 hours.

Today, there are about 20 people attending the operation which, at my request is being filmed by Michela and Peter Chappell, a documentary film maker, and his soundman, Andre. Neuro-surgeons from Portugal, Italy and the US are also present.

I have to remain conscious so I can respond when the electrodes reach the correct part of the subthalamus. When they hit the right spot, the tremor will stop.

The noise of the drill as the surgeon cuts an access hole in my skull is disconcertingly loud, but there is no pain. Cauterising the hole is painful, but almost refreshingly so. It keeps me in touch with reality.

Best of all, the feared cramp does not materialise, thanks to the skills of an attendant physiotherapist.

The highlight is listening to my brain as the electrodes were plunging deep into the subthalamus. It is an ocean of sound, a huge river in full flow, awesome and inspiring, the essence of me but it also seems to be the sound of mankind, as close to a religious experience as I have ever experienced.

Half-way through, the team breaks for lunch, leaving me still screwed into my head cage, but with the physiotherapist keeping me company. I cannot make out the doctors' conversation, but I recognise the tone: it is like the positive noises one hears during the interval on the first night of a play that is going well. How long have I been in the theatre, I ask. Six hours another six and I should be out.

Towards the end of the operation, the surgeon begins to wind down by talking to me in French which I barely understand about the shortcomings of Britain's agricultural policy, the merits of the Common Agricultural Policy, and his regret at the erosion of the traditional divide between the left and right in French politics. How do I say "the third way" in French?

The moment comes when I am freed from the cage. I feel euphoric, and, as the bolts are withdrawn, I make sure the camera is running. I want to have this

moment on record: "The men and women who have imprisoned me for 11 hours have now set me free." It's corny, I know, but it's the best I can do.

Friday 28

It is 5am, less than 12 hours after the operation ended, and I watch the Alps take shape as the day dawns. Four hours later, I have a farewell cup of coffee with Peter and Andre, and then decide to surprise my mother and make the 15-minute walk to her hotel. When I get back, I'm in deep disgrace. For the next four days I'm confined to the hospital.

I have become a Francophone and a Europhile during my four-week stay, but my conversion is another story. It included a visit to Grenoble's museum of the French Resistance, the quality of the French health service and the fact that no one has called me Michael during my stay. It is always "M'sieur Holman", in contrast to the spurious matey-ness of Britain where everyone from nurses to cold-calling insurance sellers use first names on first encounters.

I am asked how I will celebrate. Will I take a holiday? I'll certainly go on holiday, but the celebrations began that first day, when ordeals became ordinary. In particular, I celebrate the end of my drug regime, which saw me taking more than 30 pills a day. It is down to eight, but that does not give the whole picture.

I no longer take dopamine, or Comtess, a drug which enhances my capacity to absorb dopamine and turned my urine an alarming colour. My dyskinesia has disappeared, my joints no longer ache, and for the first time in 10 years I am sleeping through the night.

But I am not cured. I still have Parkinson's Disease. My head still feels tender, and I am tired, although I am told that is to be expected as one recuperates from brain surgery. And I still have a tremor, which I hope will be reduced if not removed when I visit Grenoble in mid-May for fine-tuning of my pacemaker.

And while all who undergo the Grenoble operation will benefit, it will not necessarily be to the extent I have experienced. I am - comparatively speaking - young and fit.

I am warned by the Grenoble team about the dangers of depression. After years of being the centre of attention daily visits from family members, for example the resumption of a near-normal lifestyle can be demanding. It does not surprise me. Parkinson's can become a crutch: an excuse for not completing an FT leader, or an excuse for declining a dinner one would have wanted to duck out of anyway.

I'll face that if and when it comes. In the meantime, I want to make the operation better known, and cheaper. At £20,000 it is beyond the reach of most of us, unless you have a generous and compassionate employer like the FT.

But it can be cost-effective: the reduction in my medication saves Britain's NHS £3,500 a year. Keeping me on my feet and self-sufficient saves the social services at least £5,000 a year. Keeping me at work gives the state another several thousand pounds a year in tax.

"So where is the catch?" I ask a friend who rings from Edinburgh, after I have reviewed my good fortune.

"Michael, there is no catch" he replies firmly. "At our age (we are both in our mid-50s) we are used to passing on bad news about friends with cancer. Yours is a good news story let's just enjoy it."

Michael Holman

The following article, written by Michael Holman (journalist for the FT), describes his life 12 months after undergoing Deep Brain Stimulation surgery, and was originally published in the Financial Times Saturday April 6th, 2002.

A body liberated from Parkinson's

Michael Holman returns to Grenoble for a check-up, 12 months after brain surgery

My new life began disastrously well. As I made my way from Grenoble's university hospital to the hostel where I was staying, my limbs took on a life of their own. With a power that made me grunt, my left leg would suddenly extend to the near horizontal, my left arm would shoot up, and the muscle spasms spun me round in my tracks.

But between the grunts and groans, I laughed aloud with relief. It was further confirmation that the brain surgery I had undergone to alleviate the symptoms of Parkinson's Disease had been a success.

Three months earlier, in February 2001, I had arrived in Grenoble worn out by 16 years of the neurological condition that leaves sufferers shaking uncontrollably, frozen-faced and freezing mid-stride.

The operation, pioneered at the city's teaching hospital by professors Alim-Louis Benabid and Pierre Pollak, was my last hope.

After spending 11 hours conscious on the operating table - a couple of hours less than it usually takes - I had emerged euphoric.

I left the operating theatre feeling reborn.

The dyskinesias - an involuntary, squirming movement that had become a disabling side-effect of dopamine, the chemical I had been taking in drug form - had gone. The tremor had been all but eliminated. I slept through the night for the first time in a decade, and my muscles no longer ached.

The final stage of the procedure - implanting a battery-powered device under my collarbone, which was then linked by a wire running under my skin to two tiny electrodes inserted deep in my brain - took place soon after.

The first check-up came three months later, in May. Pollak and Dr Mendes, his colleague from Portugal who was on a six-month attachment, put me through my paces.

The voltage to the electrodes was increased, but by too much. The effect was akin to an overdose of dopamine. Severe dyskinesias set in and in mid-afternoon I returned to the hospital for an unscheduled visit to have the voltage reduced.

Mendes beamed with satisfaction: "It is a good sign," he kept repeating.

I started travelling widely, and returned to my job as the FT's Africa editor. But there was one further check to come, one I increasingly felt was necessary.

The tremor in my right hand had resurfaced, albeit not severely, particularly when under stress. And the lassitude I associated with Parkinson's was returning, albeit comparatively mildly, at the start of the day. And so last month, a year after the surgery, I returned to the city where my renaissance had taken place.

I recalled vividly the taste of the chocolate I was given, just after returning to the ward from the operation, and the quality of the coffee, the taste of the yoghurt, served in the hospital cafe. I remembered the compassion and skill of the staff, the comfort and encouragement of friends, and the thrill of "listening" to my brain.

Above all, I remembered the glorious sense of liberation when, after the day-long procedure, my head was withdrawn from the "cage" into which it had been bolted.

Now, the euphoria, induced partly by the benefits of stimulating the brain, has subsided. The dyskinesias is eliminated. The muscle aches and pains are a thing of the past. I continue to sleep well at night. The lassitude has also gone, and the remaining tremor is so mild that it does not interfere with my typing.

My dosage of Requip - the only drug I now take - has been increased to six tablets a day, compared with nearly 36 tablets and capsules of five different drugs before the operation; and the voltage has been slightly increased.

The operation is not a cure for Parkinson's Disease. I reckon I am at 85 per cent of the capacity of a "normal" man in his mid-50s. Some days are better than others. But if I needed a reminder of what my health was like before the operation, one event in my first-year check-up provided it.

It could not have been simpler or starker. At the touch of a button, the battery-operated stimulator implanted in my chest was turned off by the doctor in charge of my assessment. My tremor returned within seconds, steadily gathering force. In a couple of minutes I was shuddering and flopping hopelessly.

Another touch of the button, and I was restored to my tremor-free state.

Although not all sufferers from Parkinson's are suitable for the procedure, for those that are, the benefits are substantial and indisputable. About 200 such operations have been performed at Grenoble, the first taking place 10 years ago, and the benefits for the patients continue.

It is not only successful, but cost-effective: the operation might be expensive, but in my case that outlay will be recouped in two or three years. The drugs I no longer take were costing the UK's National Health Service more than £2,000 a year, and the operation means I remain a taxpayer instead of a costly drain on the state.

Yet the operation, although performed at several centres in the UK, is not readily available on the NHS. The result is that Britain lags behind the rest of Europe. One in five of the 120,000 sufferers from Parkinson's Disease are suitable for the operation: but of those that it would benefit, fewer than one in 20 have undergone deep brain stimulation - compared with one in three in Switzerland.

The figures are an indictment of a British medical establishment that has allowed caution to become inertia, and of the Parkinson's Disease Society, which has belatedly come to recognise the dramatic benefits of the operation.

This may be about to change, however. Fund-raising is under way, with a target of £3.5m, of which £1.5m has already been committed. The fund is supporting a team of experts, led by Professor Marwan Hariz of Umea, Sweden, and the first operation is scheduled for October. The unit is based at London's National Hospital for Neurology and Neurosurgery at Queen Square.