A new “pacemaker for the brain” is giving Parkinson’s patients their lives back.

By Gord Bagley and Wendy Glauser

Photography by Roth and Ramberg
It was an odd feeling. Not a feeling at all, really. Just a steady grinding sound from the stainless-steel hand drill going through bone. How long it went on, Mike Reitsma couldn’t really say. He was undergoing brain surgery fully awake, with only the skin over his skull frozen with local anesthetic. He only knew that when the grinding sound stopped, the drill had punched through his skull, giving Dr. Zelma Kiss direct access to the surface of his brain. For the next six hours, all he could do was stare up into the cold white glare of the operating room lights, draw courage from his faith in God, family and his surgeons, and respond as best he could to the questions and directions Kiss gave him as she piloted a surgical wire thinner than a human hair – just 1/100th of a millimetre at a time – toward a destination she couldn’t see.

If the surgery was successful, the tiny electrode would send a current to a minuscule part of Mike’s brain that was partly responsible for motor control. This deep brain stimulation (DBS) surgery was Mike’s one last stab at reducing the symptoms of Parkinson’s disease, a disorder he personifies as a stealthy “thief” – an entity intent on taking away everything he had and everything he ever wanted to be.

It took 18 years for Mike to reach this place, a journey he had not embarked upon willingly. In 1986 Mike was a Christian Reformed minister in Calgary with a congregation that loved his imaginative sermons. He was happily married to Ruth, the love of his life, and was the proud father of four young children. He had also been running seriously for seven years.

After completing his fourth marathon, Mike, then only 42, was unusually exhausted. He wondered, as many people with early-stage Parkinson’s do, if it was just his age catching up with him. He kept up his training in hopes of qualifying for the Boston Marathon, but over the next few years his running times got worse, not better. He noticed strange movements, too, especially when he was exhausted. For example, when he wrote, his letters would sometimes “float up” from the lines as if his hand had a mind of its own. One foot sometimes dragged behind the other when he walked, and his right arm sometimes stopped moving in sync with his stride unless he consciously willed it to keep up. These symptoms came on so gradually that Mike can’t pinpoint exactly when they began. It wasn’t until 1991 – the same year Mike had to give up running altogether because it had become too strenuous – that he sought an expert opinion.

Mike’s doctor suspected Parkinson’s and referred him to a specialist. There isn’t a clear-cut test, blood or otherwise, that can detect Parkinson’s, so diagnosis is based on the interpretation of a patient’s movements. The specialist asked Mike to pretend to screw in a lightbulb and clench his fist, as well as a variety of other motions. A few days later, on a cold, grey day in March 1992, the 48-year-old father of four and senior pastor of the First Christian Reformed Church heard the words he had dreaded: “You have Parkinson’s disease.”

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THE PROGRESS OF PARKINSON’S

Parkinson’s disease develops when the cells that produce dopamine, a brain chemical that channels messages from one nerve cell to the next, start to die. Lowered dopamine levels mean brain messages get jumbled, causing patients to gradually lose control of their movements. The disorder affects one per cent of Canadian adults. Doctors aren’t exactly sure why Parkinson’s patients produce less dopamine, but they know that there’s a genetic link and they think that exposure to toxic agricultural and industrial chemicals may play a role.

There’s no cure for Parkinson’s. However, there are medications that curb the hallmark symptoms – slowed movements, tremors and muscle stiffness. For the first 18 months following Mike’s diagnosis, his symptoms weren’t severe enough to require drugs. But in 1993 they had worsened to the point that his doctor prescribed levodopa, a drug that mimics dopamine. He also started taking other medications – one to control dyskinesia (sporadic, involuntary jerking or twisting movements), a major side-effect of levodopa, and another to slow the death of dopamine-producing cells. For some people, these medications can work for at least a decade, but Parkinson’s disease almost always progresses to the point at which drugs can’t adequately control symptoms.

THE DBS DECISION

In the fall of 2003, Mike was at his lowest point. He had gradually given up his ministry over 18 months, from January 2002 to June 2003, as speaking and standing for long periods became too difficult. He could barely walk up stairs. He was taking 900 milligrams of levodopa a day – a heavy dose – as well as other drugs, and the side-effects made him too tired to play with his grandchildren (he has 10). His “on” time – time during which he was mobile enough to shower, shave, feed himself and stand relatively still – had dwindled to only a few precious hours a day.

His battle didn’t stop at night, either: he was lucky to get four hours of sleep, as his muscles would stiffen and force him awake. The last straw was when conversations more than 20 minutes long became impossible – he found it difficult to focus when talking to someone, likely another side-effect of...
levodopa, which, in high doses, causes confusion. Members of his close-knit family were always there to help him, but he hated feeling so helpless.

“Mr. Parkinson’s,” as Mike refers to his disease, is a nasty enemy. “He comes at will and wastes you and then steals something you cherish and runs away with it,” says Mike. “Then he comes back and steals another part of your life and makes off with that, too. He’s not just after the physical, the athletic ability. He gets around to the joy of living, the hope for a future, the ability to think and speak clearly – the attack on my mental focus has been worse for me than any of the physical aspects of the disease.”

Enter DBS, a relatively new technology that, though risky, has the potential to give patients with advanced Parkinson’s disease a new lease on life. “Deep brain stimulation is the biggest advance for Parkinson’s since levodopa,” says Kiss, the neurosurgeon who treated Mike.

In spring 2003 Mike’s doctor told him the disease had progressed to the point at which he was eligible for DBS. There’s no evidence that DBS is beneficial to Parkinson’s patients in early stages, and because of the risks, neurosurgeons won’t perform DBS until all other treatment options are exhausted. Mike had reached that critical juncture.

Mike’s doctor told him that DBS could set his Parkinson’s disease symptoms back significantly, at least for a while, making his “off” time much less devastating and giving him back much of his “on” time. Most patients who undergo the surgery, he learned, can function normally for about 70 per cent of their day.
Only eight years old in Canada at the time, the surgery already had an encouraging track record around the world. A 2001 study published in *The New England Journal of Medicine* followed 96 patients with advanced Parkinson’s disease who had undergone subthalamic nucleus stimulation; the average motor control improvement was 43 per cent. Currently, there are 150 surgeries performed every year in nine centres across Canada. DBS was allowing Parkinson’s patients, some of whom had been on the verge of living in a wheelchair, to walk with relative ease, enjoy sports again and even work out at the gym. The procedure was controlling symptoms so well that patients were drastically cutting their levodopa doses – a good thing, because of levodopa’s sometimes troubling side-effects. Besides dyskinesia, it can cause insomnia, depression and, in extremely high doses, hallucinations and psychosis.

Mike discussed the risks and potential benefits with Ruth and his children (his three daughters and son are all now in their 20s and 30s). One of their concerns was the five per cent risk of a stroke on the operating table. At first, Ruth didn’t want her husband to take that chance. “You’re still here. I’ve still got a husband,” she told him. But she could see how hard life had become for him, and she told him she would support his decision either way. He made up his mind to go for it. “We prayed about it,” he says, and so did his children and his former congregation.

Several months later, Mike was lying on the operating table. He was conscious because Kiss, his neurosurgeon, needed to monitor his behaviour. As she penetrated deep into the grey matter of his brain, Mike’s responses to her questions were the loudest warning bell she had. If he started saying gibberish or acting inappropriately, she’d know that something was wrong, perhaps that she’d punctured an artery in the brain, causing hemorrhaging and, possibly, a stroke.

Mike had made peace with the possibility that he might not make it through the operation, even though he badly wanted to watch his grandchildren grow up. But Mike, a man of deep faith, was not afraid of losing this battle.

Mike’s brain surgery was an “out of world” experience. He could see the doctor’s white coat as she fed the electrode through the nickel-size hole in his skull. He could hear the sound of the surgeons murmuring and the electronic beeping of the signals in his brain. It was disconcerting to know that Kiss was moving a foreign object inside his head. “What if she goes too deep?” Mike wondered, trying to push this thought out of his mind and concentrate on answering the doctor’s questions and following her directions.

Kiss moved the electrode slowly trying to pick up the neuronal signals in Mike’s brain as he attempted to carry out the tasks the doctors asked of him, such as counting to 10 or making a fist. These signals served as guideposts as Kiss navigated through his brain. “Each structure we pass through has different firing patterns,” explains Dr. Bin Hu, a professor of neurosciences and scientific director for the Movement Disorder and Therapeutic Brain Stimulation Program at the University of Calgary, who assisted in this surgery.

Because Mike’s symptoms were worse on his left side, Kiss headed for the right subthalamic nucleus, a piece of the basal ganglia that’s smaller than a raisin and controls movement on the left side of the body. When the signal patterns in Mike’s brain indicated that Kiss had arrived at this target, she made sure by stimulating it with an electric current: “We ask the patient to, for example, pretend he’s screwing in a lightbulb,” Kiss says. “A Parkinson’s patient will gradually make the movement smaller and do it slowly. So if they look normal doing the movement, we know the electrode is in the right place at the right voltage.”

It took five hours for Kiss to reach her target. She left the charged end of the 40-centimetre-long electrode dangling at the subthalamic nucleus and secured the uncharged end to the outside of the skull using bone cement (the electrode...
moves with the brain as it shifts and floats in cerebral fluid like fruit suspended in a gelatin salad). Then Kiss’s work was done for the day.

Two weeks later the doctors implanted another electrode, this time in Mike’s left subthalamic nucleus, to control tremors and involuntary movements on the right side of his body. Both electrodes were successfully implanted without any apparent complications. Everyone was relieved, but they still didn’t know how the stimulation would affect Mike’s symptoms or behaviour. Mike and his family had to wait until the electrodes were hooked up to the stimulator to know for sure if it worked.

The stimulator, or “pacemaker,” about seven centimetres long by five centimetres wide, was inserted under the skin just below Mike’s collarbone. When it’s on, the stimulator sends constant electrical impulses through the electrodes to even out erratic signals in the brain, just as a cardiac pacemaker evens out heartbeats. The stimulator runs on batteries, which usually need replacing every five years, although the electrodes themselves are supposed to last forever (there is a four to five per cent risk of a technical problem with the electrodes).

DBS is meant to control physical symptoms, but one of the first things that Mike’s family noticed when he came home from the hospital were the psychological changes. “My kids noticed immediately that I had a glimmer in my eye, a light that had been turned off by the medication,” Mike says. “I had my vitality and sense of humour back.”

And what about the tremors? Six months after the surgery, they’re all but gone. Mike now sleeps without pain and fills his days with the hobbies he found too difficult to do before – golfing, fishing and hunting. He goes to the gym every other day and lifts weights for an hour, a feat that would have been unimaginable just a year ago.

“He’s doing all sorts of things he could never do before,” says Mike’s son, Chris, a pitcher for the Atlanta Braves baseball team. “He’s spending more time with the grandkids. Before, he didn’t have the energy to play with them.” Mike also volunteers for his church, encouraging and praying for others battling sickness and mentoring young pastors. He’s also eager to tell his story and hopes to help others suffering with Parkinson’s disease.

Mike no longer needs any drugs – a phenomenon he attributes mainly to DBS. He has escaped the slurred speech and cognitive damage that may be associated with the surgery, and has more focus and creativity than he’s had in years. Just this past March, Mike was flying back from visiting his son at spring training in Sarasota, Fla., when he was inspired to write about his encounter with Mr. Parkinson’s. “I asked Ruth for a pencil and paper,” he says, “and I just started writing. It was like a garage door was opening and letting all this light in. It keeps getting bigger and brighter all the time.”

The idea that doctors could interfere with brain signals in the basal ganglia to help control the hallmark tremors of Parkinson’s disease was first proved by New York neurosurgeon Dr. Irving Cooper in the 1960s. Cooper ripped an artery in the brain of a Parkinson’s patient during an operation, an accident that caused a stroke in the basal ganglia area of the patient’s brain, and to Cooper’s astonishment, cured the patient’s tremor. The stroke shut down abnormal firings between brain cells in the basal ganglia that were causing Parkinson’s symptoms. Researchers continued to create deliberate minute lesions or injuries in the basal ganglia as a treatment for Parkinson’s disease until 1967, when the drug levodopa was discovered to be a more effective treatment for Parkinson’s disease. Surgical experimentation reemerged in the 1980s, however, as doctors tried to pinpoint the structure of the basal ganglia most responsible for the erratic signals in Parkinson’s patients. They finally zeroed in on the tiny subthalamic nucleus, performing the first human deep brain stimulation (DBS) in this area of the brain in France in 1993. The first Canadian DBS of the subthalamic nucleus was performed in Toronto in December 1994. Although data are only available for the last 11 years, DBS on the subthalamic nucleus has so far proven to be the most effective surgical method of relieving Parkinson’s symptoms.

Funding problems and lack of access to operating rooms means the procedure is less accessible in Canada than it is in other countries. However, there are nine centres across the country (in Halifax; Montreal; Toronto; London, Ont.; Winnipeg; Regina; Edmonton; Calgary; and Vancouver) that perform the operation. The cost of the procedure is up to $20,000 per patient, but it is covered by provincial health insurance in the provinces where the procedure is performed.

— Wendy Glauser