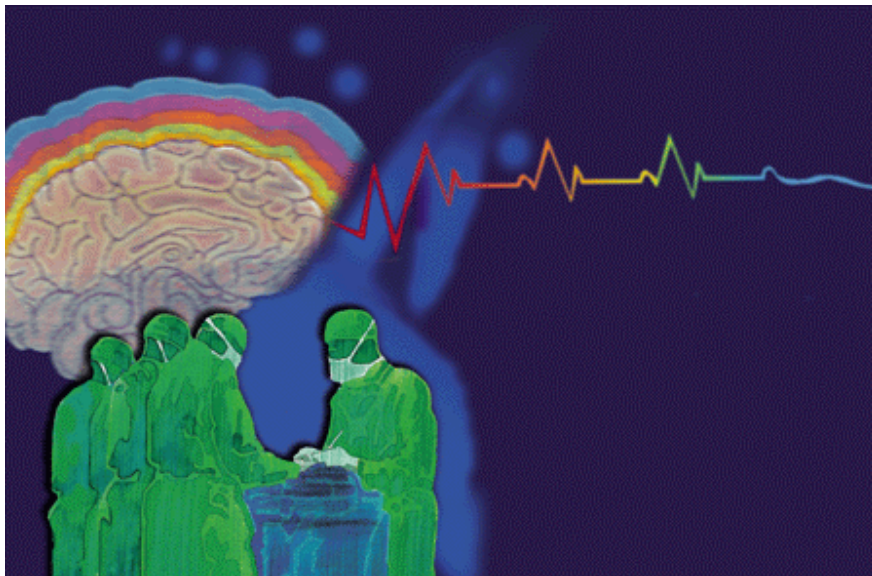


My Brain

I Helped Operate on

By Jacob John* with Kalpana Deuskar By Jacob John* with Kalpana Deuskar



Drill, please,” says the bespectacled figure from behind his green mask, and I know my moment of truth has come. Neurosurgeon Paresh Doshi is about to cut into my skull and jolt my brain in a last-ditch attempt to give me back my life again. The hush of the operating room shatters as the drill starts grinding near my right temple. Bone dust spews into the air but, thanks to local anaesthesia, all I feel is some vibration. So, as Dr Doshi drills on, I suck a lozenge and try to make myself comfortable.

As he quietly sipped tea at Mumbai’s Cricket Club of India one evening last July, 55-year-old Jacob John didn’t look sick. But when the tall, soberly-dressed chartered accountant began leaving the club, it quickly became obvious that all was not well with him. He shuffled towards the exit, then suddenly broke into an uncontrolled run, dodging pillars and narrowly missing an elderly man with a cane. Slamming into a sofa, he spun around and crash-landed hard on a glass table, luckily on his seat.

As other club members glared, Jacob, his face burning, muttered an apology and stumbled out of the CCI. He knew that everyone thought he was drunk. But actually he was a victim of an unpredictable and insidious malady known as Parkinson’s Disease.



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The walls of the neurosurgical theatre are lined with glass cupboards crammed with gadgets. There's a lot of equipment around my operation table too, including an X-ray machine and a laptop computer. Black cables snake across the floor. A junior doctor is even filming the operation with a video camera.

Around 500,000 Indians suffer from Parkinson's Disease (PD). Indeed, the incidence of PD amongst Mumbai's Parsis is the highest for any community.

What causes PD is still not clear—the possibilities range from faulty genes to environmental toxins. The disease, which usually afflicts people who are past 60—though young people get it too—gradually destroys brain cells that produce dopamine, a chemical that transmits the brain's messages to nerves and muscles. As the brain cells die, and the amount of dopamine goes down, the messages become garbled and normal body movements become slow and deliberate. The most common symptoms include total muscular rigidity—when the patient becomes like a log of wood—a shuffling walk, and tremors. However, symptoms vary a great deal, and PD is often called the “designer's disease” since no two patients have exactly the same symptoms. There is no cure, but medication helps, especially for the first five to ten years. Although it doesn't kill, Parkinson's Disease can make life a living hell.

To make sure that my head, shaved and painted with light-yellow disinfectant, doesn't move during surgery, it has been screwed into a rigid metal frame bolted on to the operation table. In any case, I am not likely to get frisky—my medication was stopped 12 hours before the operation, and Parkinson's has me in its own iron grip. With my feet locked together crookedly and my stiff torso, I probably look like a corpse laid out in a morgue.

Jacob contracted PD relatively young, while in his mid-40s. The first symptom was innocuous: His face often didn't register emotion, so much so that his boss told him he resembled the Buddha. Neither man realized that this supposed serenity was in fact another of PD's symptoms, known as the “Parkinson's Mask.”

Then in June 1993, Jacob was massaging the shoulders of a doctor friend when she remarked that his left hand seemed weaker than his right. Jacob told her that his left leg dragged slightly too, and that he also suffered from lower back pain. His friend asked him to immediately consult a neurologist—who confirmed that Jacob had Parkinson's Disease.

For four years, medication kept Jacob's symptoms under control. But as the disease advanced, getting through the day became increasingly difficult. His condition fluctuated wildly every few hours—sometimes he was as rigid as a board; at other times, his limbs wouldn't stop flailing.

He had to take more and stronger drugs, but their side-effects—depression, mood swings, involuntary running—were worse than the disease. By the year 2000, he was taking around 20 tablets a day, but functioning normally for less than five hours.

Obsessed by keeping his ailment secret, Jacob had confided only in his boss, and his colleagues were mystified by his odd behaviour: once a friendly and cheerful man, he now avoided everyone, rarely leaving his cabin; he swayed and lurched while making business presentations; he kept inventing excuses for not travelling. Finally, in September 2001, he took early retirement.

Jacob's morale hit rock bottom two months later, while visiting his mother in Kerala. She found him in the bathroom early one morning, collapsed awkwardly across the toilet seat. He had been frozen in that position for four hours. His frail 85-year-old mother had to haul down the 5-foot-10-inch Jacob and drag him across the floor to his room.



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Overcome with despair, Jacob recalled a newspaper article about an innovative procedure in France to treat advanced PD. It involved implanting electrodes in the patient's brain and sending a continuous low-voltage current to the malfunctioning cells from a battery buried near his collarbone. Though why this worked wasn't fully understood, the current blocked the garbled messages sent by the malfunctioning cells. Called Deep Brain Stimulation (DBS), it wasn't a cure for PD, but it greatly reduced the severity of symptoms and allowed the patient to take less medication. However, it cost around Rs16 lakhs, and Jacob had put it out of his mind. But now he decided that he didn't want to live if he continued like this, and that somehow he'd raise the money.

So he began checking into DBS, and to his delight discovered that the very same procedure was being done at Mumbai's Jaslok Hospital and Research Centre**.

The drill stops. From videos shown to me before the surgery, I know that my grey-coloured brain, tightly covered by a membrane, is visible. Doshi's next step is to cut a hole about the size of a coat button through this membrane.

The DBS procedure at Jaslok, Jacob learnt, was conducted by a two-man team—neurosurgeon Paresh Doshi and neurophysician Mohit Bhatt. The two doctors explained to Jacob that they had to plant two electrodes—one for each side of the body—in a tiny area of the brain called the nucleus of the subthalamus. MRI scans of Jacob's head would map his brain and help the surgeon locate the baby's-thumb-nail-sized nucleus, but Jacob's active participation was needed to guide them to the exact spot. So he'd have to remain conscious throughout the operation.

DBS is the kind of complicated procedure that tests to the limit the precision and delicacy of a neurosurgeon. If something went wrong, Jacob's mental faculties could be impaired or he could even be left partially paralyzed. But he was undeterred, and surgery was fixed for July 31, 2002, his 56th birthday.

Hunched over my head, Dr Doshi takes four long exploratory probes—they look like knitting needles—and pushes them one by one into my brain. Each of these probes encases a filament twenty times thinner than a human hair. The filaments will pick up electrical signals emitted by my brain cells and relay them to the laptop near me. It won't be long now before my role in the operation begins.

"Call dr bhatt," Dr Doshi tells an assistant, and a little later the neurophysician arrives and greets me cheerfully. I greet him back, the four probes sticking out of my skull.

"Are you catching anything?"

Dr Doshi asks his assistant manning the laptop.

Before he can answer, the theatre fills with snapping sounds, like rows of small firecrackers going off. Evidence of my brain cells at work! I can't see the signals, but I know that they're leaping across the computer screen in sparkling zigzags, with each cell having its own unique "signature."

Some signals flicker weakly, others are bright and loud. Suddenly a wave of bright light shoots across the screen, crackling sharply like a shorted live wire. The nucleus has just signed in with a grand flourish.

"Okay, Jacob, your job begins now!" says Dr Bhatt. He asks me if I've had a good breakfast. Before I can answer, Dr Doshi grumbles that nobody ever asks him if he's eaten. Dr Bhatt offers him an intravenous feed, and laughter ripples around me.

Dr Bhatt massages my left arm and leg, then tells me to turn my wrist and snap my fingers.

I pretend to turn a door-knob, but my hand barely moves. My middle finger brushes my thumb weakly.

"Pretend you're cycling with your left leg," Dr Bhatt tells me. But my leg feels so wooden, I can barely lift it off the table.

"Let's have the current," Dr Bhatt says. Now electricity will jolt the brain cells in the target area into action. I again try turning my wrist and cycling. Is it my imagination, or does it seem a little easier now?

"Hmmm. Twenty five percent improvement in tone and speed,"

Dr Bhatt says. "But movement is still fragmented."

As Dr Bhatt asks for different current levels, I continue my finger-snapping and cycling. But after a few minutes, I'm tired and my back hurts. I protest.

"We've got to give you smooth, strong movement," Dr Bhatt says. "C'mon Jacob. Snap those fingers! You'll need them to ring up your girlfriends when you are better!"

I try to oblige.

"Good, but not perfect. Fifty percent improvement in speed. Slap my hand, Jacob. Harder! Let's see some power!"

I'm exhausted. Then, suddenly, my leg is cycling higher, faster. The wrist-turning is smooth and easy. My fingers snap loudly, and I slap Dr Bhatt's hand with resounding whacks!

"Perfect! We've got it!" announces Dr Bhatt. I see many eyes smiling at me over the surgical masks.

I'm elated. Even with medicines, it's been years since I've experienced such free movements. Dr Doshi now fixes the permanent electrode that will be left in my brain. "You can relax now Jacob," he says. "After a while we'll do the same thing for your right side." Oh no! My back cannot survive another such session. Mercifully, the anaesthetist, offers me a sedative and I sink into a restful snooze.

Later that afternoon, the second electrode is implanted. And the next day, a battery, about the size of a cigarette lighter and linked to the electrodes by wires running under my skin, is implanted near my collarbone. I'm also given a remote control which adjusts the current coursing to my brain and enables me to do all those things—from getting out of bed to buttoning clothes—that the rest of the world takes for granted.

It's been a year now since the operation. That awful rigidity has almost gone, I take less medication, I sleep soundly, and my moods are more even. My walking, though, has improved less than I'd like. However, my doctors have assured me that with time, it will get better. So while I may not have entirely left the dark valley of Parkinson's, I'm well on my way out.

For more information on PD, visit: parkinsonsdiseasesurgery.net.

*Jacob John is a pseudonym.

**The cost at Jaslok varies according to the financial situation of the patient and ranges between Rs3.5 lakhs and Rs8 lakhs.