

Deep-Brain Stimulation: Steadies the Body, But What About the Mind?

24 May 2010. With a few electrodes deftly threaded into a troubled brain, surgeons can often still the embarrassing tremors and alleviate the painful muscle cramps that come with Parkinson disease. But this deep-brain stimulation does not treat all that Parkinson's does to a person. People may still have to cope with declining cognitive abilities, speech difficulties, or poor impulse control. And although DBS can quell some symptoms, it does not halt the inexorable progression of neurodegenerative disease. Sometimes, aspects of a person's life—success at work, or in personal relationships—suffer following the huge upheaval that successful DBS surgery tends to bring with it. DBS can even break up a marriage.

Despite doctors' best efforts, some people have unrealistic expectations for their outcomes, said Elena Moro of Toronto Western Hospital in Ontario. Unfortunately, the surgery's results are not a sure thing, and people's hopes are sometimes dashed. "It's not working for me," wrote J.R. Jay, a retired woman in Mobile, Alabama, in an e-mail to ARF. "I can't tell you how I feel." Jay had DBS for essential tremor. She has now been told the malfunctioning equipment necessitates a second surgery, but is seeking a second opinion. "I'm not happy," she wrote.

Less Than a Miracle

People go through many changes following DBS, some positive, and some negative. In a [survey \[.pdf\]](#) conducted by the nonprofit [Parkinson Alliance](#), people who had DBS reported less anxiety than those whose Parkinson's was managed by medication alone. However, reports of depression were no different between the groups.

Some aspects of disease may remain the same, or even worsen, with deep-brain stimulation. For example, DBS can adversely affect speech, already a problem in people with PD—although in at least one case, DBS relieved stuttering in a person with PD ([Walker et al., 2009](#)). Impulsive behavior, such as hypersexuality or addiction to gambling, may remain after DBS or even worsen. In one instance, scientists in Amsterdam, The Netherlands, reported on a man who got hooked on slot machines after his DBS surgery. He had no history of compulsive gambling; indeed, family members described him as "stingy." Dopamine agonists can also influence impulsive behavior, so his doctors were eventually able to control the compulsion by altering his medication ([Smeding et al., 2007](#)).

Emotional responses, too, may be altered by DBS. In a recent Danish study comprising in-depth interviews with people before and after DBS, one person told the researchers, "I have become much more sensitive; I cry over nothing" ([Haahr et al., 2010](#)). Another research group found that following DBS, many people with Parkinson's are less able to recognize the emotion in other people's faces—particularly fear and sadness ([Péron et al., 2010](#)).

The potential side effects worried Greg Rice, a retired banker in Dover, Massachusetts, who had DBS for Parkinson's five years ago. Rice has had Parkinson's since 1993. Before his surgery, he had developed a late-blooming musical streak, [composing symphonies](#). He suspected that his disease, plus a divorce in the late 1990s, unleashed his creativity, and with Parkinson's keeping him from sleeping, he spent many night hours composing. He initially feared DBS would give him back mobility but take away this creativity. However, when he reached a point where he fell down 30 times a day, Rice decided the risk was worth taking.

Post-op, Rice is happy to still be composing, with the added benefit that he no longer falls down so often. Most importantly, he told ARF, the involuntary dyskinesia has stopped. "I would do it again even if I did lose the creativity, because the dyskinesia was driving me crazy," Rice said. However, the surgery did not solve everything; he still struggles to speak intelligibly and sometimes gets "frozen," crashing into things when he unfreezes. He copes with his disease by focusing on what he can do for others, working with his church, and coaching his daughter's softball team. He was careful to note that DBS is not for everyone.

New Body, New Life

Symptomatic improvement in one arena does not always translate to the rest of a person's life. For example, in a study of 23 people, researchers in Houston, Texas, found that people generally experienced greater energy levels and needed less help from a carer following DBS. But at the same time, the researchers found, some DBS recipients were unable or unwilling to apply their newfound abilities to succeed in the workplace, maintain interpersonal relationships, or to do more fun activities ([Ferrara et al., 2010](#)).

Researchers in France, who conducted pre- and post-op interviews with 29 DBS recipients, found similar results. In fact, they wrote, "Marital life and professional activity...worsened more often than they improved." Of 16 participants who were working before surgery, only nine returned to work afterward. Social lives generally improved, but some participants reported that although they now had the physical ability to go out, they had no friends to see ([Schüpbach et al., 2006](#)).

The French study included 12 couples that had no notable marital problems before the surgery. In five of those couples, conflict arose post-operatively. It turned out that surgery changed a caregiver-patient dynamic that many couples were used to. In the study, the researchers noted one woman who spoke of her husband's surgery: "When he was sick, we were a perfect couple. Now he wants to live the life of a young man, go out, meet new people; all of that is intolerable! I would rather he be like he was before, nice and docile!"

Families tend to stick together when someone is sick, said Helen Mayberg of Emory University in Atlanta, who was not involved in the study. But once a partner is physically independent, some caregivers may no longer feel obligated to stay in the relationship. Alternatively, people who previously needed care may want out of a relationship, and DBS gives them the opportunity to leave. Anthony Lang, a leading Parkinson's physician-researcher at the Toronto Western Research Institute, noted in a plenary lecture

at the 2009 AD/PD conference in Prague, Czech Republic, that response to DBS has become one of the more common reasons for divorce among PD patients. This has prompted some discussion among experts on whether the surgery should be offered at earlier stages of disease to people who are still more active and better able to make the most of their motor improvement without upending their pre-op life.

Any major surgery can cause upheaval, and for some people, the change is too much to bear. Researchers in a 55-center, global survey of more than 5,000 people who had DBS for Parkinson's found the overall rate of successful suicide was 0.45 percent, and the attempt rate was 0.90 percent. When they compared post-DBS rates to the general population suicide rates in each country in the study, they found that DBS increased the suicide risk. The increased suicide rates continued for at least four years following the operation ([Voon et al., 2008](#)). Both researchers and patients suggest that a DBS team should include not only physicians and neurologists, but also psychologists or psychiatrists to guide people through the transition.

And in most cases, it is a transition worth making. For example, retired teachers Barbara and Peter Higgs, of Workworth, Ontario, were thrilled with the results of Peter's DBS for Parkinson's. "I am not that keen on being a caretaker, to tell you the truth," Barbara Higgs said. "I was delighted to see him regain control of his life." And the French study authors noted that despite mixed results from their surgery, none of the 29 people in their study wanted to turn the device off.—Amber Dance.