

How I Beat Parkinson's Disease  
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I tried placing this article with a major weekly news magazine, but they showed no interest. I now publish it here and encourage its free widespread dissemination provided it is not changed at all and that clear attribution to the author's web site (from which it may be freely downloaded) is provided [www.MathAndSuch.com] as was just done.

This is my story of how I beat Parkinson's disease with surgery. If you have Parkinson's or essential tremor it just might become your story, too.

I was first diagnosed with Parkinson's disease in 2007 when I was 56 years old. My neurologist at that time told me I was young to have acquired the disease, Michael J. Fox notwithstanding, and prescribed the standard medicine levodopa for the tremors. My neurologist also mentioned that the incidence of Parkinson's disease is increasing, expressing the opinion that a Nobel prize awaits whoever discovers why.

Levodopa worked wonders for me, and I continued to work, drive, shop, hike and in general live a full life unaffected by the tremors. I had little dyskinesia although my understanding is that this, too, can be helped by surgery.

Tremors are what everyone thinks they are, uncoordinated shaking of part of the body. Dyskinesia is an other-than-willful, coordinated motion of part of the body. Perhaps a shoulder and arm move forward together and then back. Mr. Fox visibly suffers from dyskinesia.

My full life was not to last. Six months after I retired at the age of 66, the tremors got worse, much worse, over a period of only six weeks. At times I could not even walk

using a walker. My son had to fly to meet me and escort me to a relative's house who would care for me because I certainly could not travel on my own.

The next fifteen months were not fun. I existed rather than lived. At times I had to be fed my meals like an infant. I needed help dressing. As a matter of what little dignity I had left at least I could handle the toilet, just barely. I had trouble speaking clearly as I could not control the muscles in charge of my larynx as well as I once did.

It wasn't 100% bad. For some reason, levodopa was effective for 2-3 hours each morning before losing all effectiveness. In those hours I was active with a project – writing a book (no, not about Parkinson's). What is relevant from this period is that levodopa still had some effect.

My local neurologist in the Denver area where I now lived said I was a candidate for a surgical procedure called DBS or Deep Brain Stimulation which, despite its name, is considered minimally invasive. My previous neurologist where I had previously lived near Portland, Oregon had said the same, but the very idea of brain surgery terrified me. Now it seemed I had little choice. It was DBS or nothing.

All I knew about DBS is that it involved sticking electrodes into the brain and turning them on with a tiny electrical current. Not what I wanted at all. Fortunately, my older son was a medical student and now researched DBS for me. His report to me is copied below verbatim.



*Two bumps on my head over the leads*

## My Son's Report

I've done some reading from a trusted medical resource meant for doctors. I will continue to do more but figured I should give you what I have so far. I will summarize the important points.

Overall, deep brain stimulation (DBS) looks like an option for you based on your history of Parkinson's that is/has been responsive to levodopa. It does no good for Parkinson's patients who never had any improvement on levodopa. In a study comparing medical treatment against DBS, patients with DBS had an additional 4.5 hours of good time every day on average. The good period is reported to be as good as the patient's best response to levodopa. This is good news for you since your best response is near symptom free. It was unclear if the DBS patients were still taking levodopa, but that will be addressed as needed. Patients who receive the DBS surgery get quote, "beneficial antiparkinsonian effect for at least three to five years after electrode implantation".

There are two exceptions to this extended good period provided by DBS. First, patients tend to still experience some mild unsteadiness while initially walking. This means you may need to keep a cane handy but are still otherwise able to move around just fine. This does not reflect the presence of other lingering Parkinson's symptoms. Patients otherwise felt like they were at their best with levodopa. I suspect it's more a side effect of the stimulation and not a leftover of the disease.

Second, a few of the patients in the study had slower speech formation with DBS on long term follow up. It is difficult for the studies like this to differentiate between DBS-caused side effects and natural disease progression. Therefore, normal symptoms

often get lumped into the category of side effects. The take-away for you on this is that it may not help with your speech much. However, you should remember that this was only a fraction of the study participants. I'm just including it to be thorough and so you won't be surprised when your neurologist brings it up.

The surgery itself is preceded by an MRI to map your brain. They have a special MRI setup and brace to facilitate getting a clear picture despite tremor. You will be fully awake during the operation. Anesthesia will be local to the skin. There are no pain receptors under the skin, so you won't feel anything. The surgeon will be able to ask you questions about symptoms as he goes to ensure proper placement. The wires will be routed out of the skull but remain under the skin and put down into the skin in your chest. This is where the device will be located. You will be able to turn it on or off or adjust the settings from there. Your neurologist will help you turn it on several weeks after the operation and assist you in finding the proper settings for you.

Placement of the device and wires is straight forward and does not cause problems. The risks come from having brain surgery in general. 40% of patients experience some sort of complication, but the vast majority of these are mild to moderate headaches that resolve after a couple weeks, or problems that are resolved with proper adjustment of the stimulator. Only a few percent of patients experience serious side effects, which are mostly infection related and can be handled with antibiotics. In a large study of several hundred patients, there were only 2 deaths and one of those was from unrelated lung cancer. (They have to include all deaths.)

You will need to undergo periodic (once a year I'm guessing) imaging to ensure the

leads are still properly placed. Occasionally leads must be readjusted, which may or may not require another surgery. This occurs at some point in about 6 percent of cases.

#### Summary:

From everything I can find, you are a candidate for this operation. It works well in almost everyone who tries it. It's obviously not perfect, but it will likely give you an additional 4 to 5 hours a day (giving you 5 to 7 hours total) for 3 to 7 years. The complications are what you might expect from brain surgery. However, this is now a fairly common procedure and complications are less than even I expected. This will involve a fair number of visits to the doctor for various evaluations, and the adjustment period after the procedure may take a couple months. You will be able to enjoy your life more after this operation. Medicare does cover the operation for Parkinson's disease not responding well to medication. (That includes you.)

I think you should try this. You should try it sooner rather than later as the window of benefit may shrink with time. Best case, you have several years of great function and time with family. Worst case, nothing happens and you waste time in a hospital. I feel I may have focused mostly on the negative things in this email. Really consider the benefits I talked about in the beginning.

On the off chance they tell you this might not be for you (I have no reason to think they would), you go get a second opinion. Doctors are not trained the same way in all parts of the country and I've run into several examples of therapies many doctors swear by that others won't touch.

End of my son's report

This was all encouraging. Neurologists are not neurosurgeons and my then current neurologist told me their neurology group always sent people to one neurosurgeon, Dr. David VanSickle, also in the Denver area. I include his name because without him in particular I would never be writing this article. I was lucky to have been sent to him and hope others will be able to delay their own surgery until finding a neurosurgeon who emulates Dr. VanSickle. But I must not jump ahead.

In the lead up to the surgery, the doctor's PA (physician's assistant) who assists in every surgery held a class for those of us soon to undergo it. The class' goal was to educate us as to what to do and not do, what to expect and not expect.

The class was invaluable to me because I had expected the surgery to be straightforward (for some reason I expected this of brain surgery) and it was not to be. Contrary to my son's report, there were to be two surgeries not one and I was to be under general anesthesia for each. I was also to be knocked out for the special DBS MRI the day before, for a total of three occasions of general anesthesia, something that frightened me.

Obviously, I made it through each time, but the reason for two surgeries and for being knocked out for them is all important. DBS involves the insertion of two electrodes not one. Each half of the brain controls movement of the other half of the body, hence two electrodes. The region into which an electrode must be placed is roughly a sphere three millimeters in diameter. Neurosurgeons historically have inserted multiple electrical leads and, in conjunction with the conscious patient have selected the one most accurately placed for electrical activation. But even with this, the best lead



*Front of a charger*



*Back of a charger*

is too often sufficiently misplaced that results are far from optimal.

Dr. VanSickle was not always a neurosurgeon. In a previous career he was an engineer who pondered how this surgery might be done better. One part of the answer is the use of a medical robot to assist in placing the leads. Now do not get the

impression that a medical robot inserts the leads into the brain because the surgery is still done 100% by the surgeon. He explains that the feel and the resistance of pushing the lead into the brain is an important part of the procedure. The robot's task, and it is a small robot less than a foot across, is to initially place the lead outside the brain with precision previously unheard of. This is the purpose of the DBS MRI done the day before or even the day of the surgery. It provides an up to date map of the brain and shows precisely where the leads must go.

Being a mathematician, I attest from followup conversations that Dr. VanSickle does understand the relevant mathematics of his surgery. Yes, I really did write the words Mathematics of His Surgery. He considered all sources of error that were going into DBS surgeries, all of which contributed to errors in lead placement.

All systems, both mechanical and human, have small errors that can be characterized by an average and what is called a standard deviation. Averages are statistical quantities that we all use but they are of limited use in medicine. An old medical joke says that the average human has one breast and one testicle, which is true, but there is not a single average human on earth.

Standard deviations are the mathematical way of resolving this. But while doctors in general and neurosurgeons in particular know about standard deviation as a statistical concept, most go blank when considering it as a measure of physical distance in the brain.

Errors in lead placement can occur in all three spatial directions, errors of over a millimeter in each using the old DBS techniques. How these errors combine is a matter of understanding standard deviation,



*Charging station that charges the charger*

not typically emphasized to neurosurgeons in training.

Other neurosurgeons from around the country visit Dr. VanSickle to observe and learn from him. When I asked how many of them understand the mathematical concepts, he didn't say 50% or 25% or even 10%. He said 3. Only 3 other neurosurgeons out of a countless number over a period of years. Can we blame them? Not really. As a mathematician I try to educate people to the relevance of mathematics to life (that is partly what my book is about), but not even I expected it to intrude into neurosurgery and certainly not in such a personal way.

Having long ago worked in the field of industrial robotics I know there are two distinct concepts in this field: accuracy and repeatability. If you tell a robot to insert a screw at a certain point and instead it goes one inch left of that point, its accuracy is off by one inch. If you tell it again and it exactly



*Charger in charging station*

repeats itself, its repeatability is perfect even though its accuracy is not. Repeatability is often more important, and this is also relevant to the error analysis of lead placement.

It turns out Dr. VanSickle derived the mathematics of surgical error sources from first principles. Later he found that the same mathematics had been derived in the 1960s for other purposes than surgery and with the same result.

Returning to my own two surgeries, surgery one was to place the leads. I was unconscious because there was no reason to be conscious. Dr. VanSickle used his medical robot for accurate placement and only inserted one lead in each side of my brain. There was no need to insert several leads on each side and ask a conscious me which lead seemed best. I was then kept in the ICU for three days of observation, a standard procedure after neurosurgery.

Surgery two, the more difficult one to recover from because of the pain and temporary (three months) movement restrictions, took place two weeks later as outpatient surgery. Here the surgeon implanted two pulse generators under the pectoral muscles and connected them via wires to the brain leads inserted earlier.

After three more weeks it was time to turn on the generators. As explained to me in the advance class, this is a process not an event. Each brain lead has eight electrical contacts that can be independently turned on. Each contact can be pulsed at a different rate and each pulse duration is adjustable. There are so many knobs to turn that it isn't just a matter of flicking a switch.

Because there are two implanted generators, each side can be set independently. For me this is beneficial as the two sides require quite different settings, possibly because of slight (sub-millimeter) variations in lead placement. Several companies make this medical equipment and I don't know enough to compare them. My surgeon implanted what the original programming neurologist specified from Boston Scientific and it has worked superbly for me. Perhaps another company's product would be better for you.



*Counterweight (left) and charger (right)*

Complicating matters even more, once any settings are determined, the brain adjusts to it a little bit, requiring the setting to be slightly changed to get the same effect. From a human perspective there is also a complication: the neurosurgeon is not the

neurologist who does the adjustments. Beyond that, most neurologists have never worked with these implanted generators. I now have a neurologist who has spent twenty years programming implants from each of the manufacturers making them. She is highly experienced and once astonished me with the following.

On one side of my brain she had previously turned on contacts 6 and 7, having determined through trial and error (not all of it pleasant due to spurious sensations such as unpleasant tingling) that they were the ones best situated. The next time she told me she would turn on contact 1, causing me to wonder what the heck? First explaining why this made sense, she turned it on and all remaining tremors suddenly vanished and it really was like flicking a switch. For other reasons she had to turn contact 1 off again, but I have never since wondered about her judgment.

Eventually she found the perfect settings. I now live life again instead of existing. I drive, bicycle, work as I desire, visit family and friends, and basically do whatever I want. I have a prescription for levodopa to take up to 10 a day, but the lead settings work so well that I take perhaps 3 a week as needed. I won't bother refilling it.

I do my current neurologist a disservice by not acknowledging her by name, but the key magic is in the skill of my neurosurgeon and the surgical techniques that he developed and now demonstrates to others. Dr. VanSickle says that only about 10% of people who could benefit from DBS get it. At the least those 10% should benefit from the modern version of this surgery.

If you have Parkinson's disease and want to see if you are eligible for DBS, consult with your neurologist not a neurosurgeon. There are several preliminary, non-surgical steps that are necessary before a neurosurgeon

consultation. If you get that far, ask the neurosurgeon if the patient is awake or asleep during the surgery. If the answer is awake, go elsewhere, as I was lucky enough not to have to do.

I live with permanent bumps on my head and the prospect of having surgery to replace the pulse generators' batteries after 15 years because after such time they cannot be recharged any more. I must recharge those batteries at least every two weeks but do so every two to three days. I still have a little trouble speaking and I do not use airport scanners, opting for a pat down instead. Aside from these considerations I don't even think about Parkinson's anymore.

For anyone concerned about artificial electric currents in the brain, the one generator that puts out the larger current puts out only 4.1 milliampères. I feel nothing from this whatsoever, save the "feel" of the absence of tremors throughout my body. Secondary symptoms such as freezing are completely gone.

I am living a miracle.



*Charging one of the generators*

The last few words Dr. VanSickle and I exchanged when I last traveled to see him (I now live in Saginaw, Texas) involved how I could help, and he said I can spread the word. Please help me do this by copying this article freely (in its entirety) in as many venues and to as many individuals as you can!

One final note: DBS is the name given to two different surgeries in two different parts of the brain. One is for Parkinson's while the other is psychiatric. I cannot help but wonder if the same name is being used to tap into the growing success and credence of Parkinson's DBS. I am aware of at least one doctor who is both a neurologist and a psychiatrist, so be sure you get the Parkinson's surgery.

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