

Chapter Three

Making the Decision to Be Evaluated for Surgery

To my mind, making the decision to investigate whether you are eligible for DBS has two stages: the internal discussion that you have with yourself, and the external discussion that you have with friends and family.

First, you decide that you are physically and emotionally ready to be evaluated. Finding this point might be likened to “hitting rock bottom” for someone with an addiction; each of us has our own level of misery that we can tolerate before we initiate change. I am convinced that this must be your own decision, not one you make for a loved one or to keep a job. Jobs and relationships end; Parkinson’s doesn’t, and DBS is meant to be a long-term solution.

I have met many other people living with PD who have said they had been too afraid to undergo the procedure or felt that their symptoms weren’t “bad enough” yet. Unlike the motor symptoms of PD, which can be measured using standard procedures, an individual’s fear of the surgery or willingness to tolerate symptoms cannot be measured.

I decided to do a survey, just to get a snapshot of how other people who have had DBS made their decisions to have surgery. I received fifty-eight responses, mostly from people with PD, although there were a few with ET or dystonia. It was not intended to be scientific in any way, but it does provide some interesting insights into the lives of fifty-eight people who have undergone deep brain stimulation surgery.

Here are some of the survey results that I find most compelling. (The entire survey is available in Appendix B.)

- Nearly 53 percent of respondents have had PD for more than twelve years.
- Nearly 42 percent were diagnosed with Parkinson’s disease between the ages of 40 and 49. It is estimated that 15 percent of PD cases are diagnosed before age 40.

- Almost 33 percent pondered the decision to have DBS for one to three years before going through with the surgery.
- More than 18 percent of survey participants stated that they did not receive adequate information about DBS prior to undergoing the procedure.
- At least 65 percent of people surveyed said that they underwent DBS for themselves. Nearly 39 percent said that their doctors had recommended it. (Note that some people had more than one answer.)
- Sixty-three percent went to the surgeon or facility recommended by their doctors. More than 13 percent chose the surgeon/facility based on their own research.
- When it came to the question of surgery-related pain, slightly more than half of respondents said that they had experienced pain (5.7 percent during surgery; 47.2 percent post-operatively).
- More than 73 percent of respondents said that they had no complications (infection, hemorrhage, etc.) with the surgery. At least 10 percent reportedly suffered infections.
- Most (87 percent) experienced at least one side effect. The most common side effect reported was a softer voice (58.9 percent), followed by slurred or garbled speech (38.9 percent), and decrease in balance abilities (37 percent).

When the surgery first became an option, researchers thought it was best to postpone it until all medication options had been tried and optimized. Now, there is an emerging school of thought that it might be more effective to do the surgery before symptoms are severe. In fact, clinical trials are enrolling participants to have DBS who have had PD for just a few years. Their disease progression will be tracked and compared to a similar group that receives medication only.

Meet with your neurologist to discuss the merits of being evaluated for the surgery now versus later.

If you are not currently seeing a **movement disorder specialist** or a neurologist who specializes in your condition, please do consult one. Professionals who treat your health problem on a frequent basis are much more likely to be aware of the most current research on DBS and other options. They are also more likely to have personal contacts with neurosurgeons that perform DBS.

The following is the first of several excerpts from my blog, titled “More Holes in My Head? My Journey toward Deep Brain Stimulation.” (The blog is no longer available on-line.)

Deciding to have “the surgery”

Never say “Never”

Friday, December 23, 2005

Many of you know that DBS is something that I swore I would never ever do. For more than three years, I have endured well-meaning comments and letters—often from complete strangers!—asking if I had “heard about ‘the surgery.’” I would thank them as politely as possible and think about the people I’ve known who have had DBS who have had a stroke or who had to be on intravenous antibiotics because of infections, or who had a surgeon who, when asked why the pacemakers were so close to the patient’s collarbone, could not recall performing the operation! And I would think about folks whose speech had become slurred after the surgery. (The effects that PD has already had on my speech—making it softer and sometimes very halting, with little or no expression—are some of the symptoms that bothers me the most.)

But as I was doing research for my book and talked with more people who’ve had the operation, I found that even most of the people who’ve had what I would consider some major complications are still glad that they did it. That seemed like a pretty good testimonial.

Then there’s the fact that I am taking a lot of medication around eight Sinemet^{1***} [levodopa] 25/100 tablets; plus a

1 *** Most of the people I know who have Parkinson’s disease refer to the levodopa medication by its brand name, Sinemet, even if they take a generic version of the drug. I happen to have to take the brand name because the generics I have tried are not nearly as effective. For both of those reasons, I will use “Sinemet” throughout the book to refer to levodopa unless I am quoting another publication.

Sinemet CR; 100 mg of amantadine; 1–2 mg of Mirapex, an antidepressant; Ativan for anxiety and restless legs; and meds for my Crohn's disease) every day. I've been wondering what the long-term effects on my body might be from that extensive pharmacopeia.

And if the damn things worked consistently, I might not mind anyway, but lately, I have had considerable fluctuations in my “on” (meds working) time. The “off” time has gone from having my muscles decide that they will do their job very slowly, to a full-fledged sit-down strike. I have tried to express my willingness to negotiate a new “contract,” but they are having none of it. So DBS will be sort of like “binding arbitration” for my brain.

Here are some of the reasons that others have undergone DBS surgery:

I did it so that I could play with my grandchildren.

~ Dawn, diagnosed with PD at age 42, DBS at age 54

I did it so as not to be a burden to my husband so soon.

~ Paulette, diagnosed with PD at age 45, DBS at age 61

I was young, in decent health, and wanted quality of life earlier rather than later.

~ Sean, diagnosed with PD in his 40s, DBS at 57

Some of my father's doctors really pushed for DBS (especially the ones with a financial benefit from performing DBS), while others said that because he was only 64 and doing fairly well, there was no rush to DBS but that it was certainly an option for future treatment. My father's medicines had been terribly mismanaged by his original Parkinson's doctor, who really preferred to handle MS patients. My father switched doctors and spent many months getting his medications back on track, to some measure of success. However, he still had a significant wearing-off effect and was taking pills (Sinemet, primarily) every two hours. Because of this, he/we began to seriously investigate DBS.

~ Anonymous caregiver

Once you have decided that *you* are ready, it is a good idea to talk with your care partner (if you have one), family, and friends about your decision. You will need their help and emotional support if you have the surgery, and

you will need it if you are turned down for the procedure.

It really helped our family to sit down together and watch Medtronic's DVD, which explains the procedures. We discussed my younger son's concerns about the risks of surgery and about long-term complications. We also talked about the fact that the status quo clearly was not working and that was why I wanted to be evaluated for DBS.

Next, talk about expectations. You can avoid relationship "train wrecks" if you discuss everyone's expectations before you have the surgery. If possible, bring your neurologist or neurosurgeon into this discussion. He or she will let you know whether your expectations are realistic.

Paulette, 61, agreed that being "on the same page" as your family is important. She said, "Make sure that your family understands that it is not a cure. ... My relatives just plain don't get it. My own mother (81 years old—may have something to do with it) thinks I can do anything, anytime."