

Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about The Michael J. Fox Foundation's work and how you can help speed a cure at [michaeljfox.org](http://michaeljfox.org).

Speaker 1: Welcome to a recap of our latest third Thursday webinar. Hear directly from expert panelists as they discuss Parkinson's research and answer your questions about living with the disease. Join us live next time by registering for an upcoming webinar at [michaeljfox.org](http://michaeljfox.org).

Donna Rajkovic: Thank you all for joining us today. My name is Donna Rajkovic. I am the founder of Team Fox Detroit. We are a peer-to-peer fundraising group for The Michael J. Fox Foundation. I was diagnosed with Parkinson's disease in 2012. I had my first deep brain stimulation surgery in 2020, and it revised in 2023. It's great to be here with you and our panelists. Today we are going to be talking about the deep brain stimulation journey, the decision making around whether or not and when to get it, the procedure, the recovery, and the life with the device. So we have a lot to discuss, so let's get started. Let me first introduce our panelists. First we have Ned Neuhaus. Ned was diagnosed with Parkinson's in 2013. He had deep brain stimulation, or DBS, in 2022. You can read more about Ned's journey in his blog [challengingparkinsonsdisease.com](http://challengingparkinsonsdisease.com). Welcome, Ned.

Ned Neuhaus: Donna Thank you.

Rajkovic: We also have Evonne Simoff. Evonne was diagnosed with Parkinson's in 2014 and is scheduled for DBS surgery later this year. Thank you for being here, Evonne.

Evonne Simoff: Donna Thanks.

Rajkovic: Finally, we have Neil Kanta Shetty. He is a movement disorder specialist and DBS expert at Northwestern Medical Group. He's also an assistant professor of neurology at the Feinberg School of Medicine. Neil is also a class of 2021 Edmond J. Safra fellow. To build networks of movement disorder clinicians and researchers across the globe, The Michael J. Fox Foundation in partnership with the Edmond J. Safra Foundation, developed the Edmond J. Safra Fellowship in Movement Disorders. Welcome, Neil.

Neil Kanta Shetty, MD: Thank you, Donna.

Donna Rajkovic: Deep brain stimulation, or DBS, is a surgical procedure that treats Parkinson's motor issues. Like many parts of life with Parkinson's, the journey and the decision making around DBS is personal and unique. It can be an emotionally and complex path. So before we get to deep into each of our stories, Neil, I'd like to start with you by asking you to level set for our audience what is DBS and how does it work?

Neil Kanta Shetty, MD: So as Donna started to mention, DBS, or deep brain stimulation is implantation of wires, very thin wires or electrodes into deep parts of the brain relevant to some of the physical or motor symptoms of Parkinson's disease. So these are

things like tremors, slowness and stiffness, and we will get into this in more detail. But the stimulators are connected to wires or extension cables that connect. This is all internally to a battery that sits under the skin typically in the chest. And that powers consistently the deep brain stimulator to provide continuous electrical energy to these deep parts of the brain and to allow improvement in the symptoms that we mentioned. So I would say the primary types of symptoms that we're talking about, again, are tremors and slowness and stiffness of movements to the extent that they respond to medications. So there may be some limitations to the ability of meds to control those symptoms, but response in some regard is important to dictate how well DBS improves those symptoms as well.

Donna Rajkovic: Thank you. Thinking about getting DBS can be a long and involved process involving you, your medical team and your community. Ned, can you share with us about the beginning of your DBS journey? What were your symptoms like and what made you consider DBS?

Ned Neuhaus: Well, if I really didn't think about it, the journey started really about 10 years ago. I went to see a movement doctor to get a second opinion of my Parkinson's diagnosis, and during that appointment he told me that he thought I displayed the type of symptoms that would respond well to DBS some time in the future. So for the next six to eight years or so, I was on a pretty normal path, steadily increasing the dosage and the timing of my medication to control my symptoms. And then about three years ago, I started to have debilitating symptoms where I couldn't walk for the first hour of every day due to very intense foot dystonia. And that really caused me to think, "Here I am, I'm in my mid-50s, I probably could live in another 30 years. What's that path look like on just medication?" I couldn't come up with a path that looked good to me. So I began to investigate deep brain stimulation as a treatment mechanism.

Donna Rajkovic: Yeah, it sounds very familiar. That's very similar to my story, because back in 2012 my doctor had a conversation about deep brain stimulation every time I saw him. So he was priming me up I guess to think about it, and I wasn't really ready to think about it until I started freezing frequently. I had severe dyskinesia and dystonia, and that was the beginning of my conversation. Evonne, I know through our conversations you were hesitant about the surgery. What made you decide that now was the right time?

Evonne Simoff: Well, same as the two of you. I was good for nine years on my medication. In fact, I didn't change my dosage or my timing for the first nine years, and then it just all of a sudden, slower, stiffness. My coordination was really bad. Just walking, my swinging of my arms was off. My meds were not really working. I tried increasing the medication and decreasing the time between pills and all I got was terrible dyskinesia. I'm really close with my sisters, and they're both very athletic and watching how much I was falling behind them was a big thing for me. I'm 57. I was diagnosed at 47, and I have a long way to go, and I'm athletic. I love to golf and hike. Both of those are becoming hard for me now, and I want my life back, and I'm going to fight for it. We all have a little bit of anxiety. It comes with Parkinson's, and I've just decided not to let that rule my life. I'm going to take back control.

Donna Rajkovic: Good. Neil, we are getting a lot of questions from the audience about when someone should get DBS. Can you discuss what are the medical considerations around eligibility and timing of DBS as well as the evaluation process?

Neil Kanta Shetty, MD: Yeah, for sure. Actually, let me throw in up front just a little bit about how it works, how we think it works to inform the rest of the discussion. This is a very complex topic and as I said, we know actually quite a bit and a lot more than we have in past years, but there are still some gaps in that knowledge. But very briefly and simply put, in Parkinson's disease, there is degeneration or loss of some of these brain cells that produce dopamine. Dopamine is one of these chemicals that helps the brain cells communicate, and those cells that are lost feed into motor circuits. So parts of the brain that communicate and control movement, again, this is a part of Parkinson's disease, but an important part and a major one that informs the rest of this DBS discussion. So when you take medications like the mainstay medication levodopa, it's essentially supplementing or mimicking the effects of what would be the typical release of that dopamine from the brain but that there's a shortage of in people with Parkinson's disease.

By doing that, you can improve how well the movement circuits are communicating, those parts of the brain are communicating with each other. So how does DBS and electrical treatment stimulation mimic this chemical, the dopamine? So when you have less of this dopamine into that movement circuit, those areas of the brain are not communicating as well, and the way that they communicate is actually all through electricity. So what actually happens in that circuit is that the different parts of this movement circuit, they become too synchronized that they're firing together when they shouldn't, and they're not communicating in a normal way. So medication, levodopa, just like the normal brain chemistry can improve and normalize some of that communication. And DBS, which is an electrical therapy, it essentially gives this high frequency of activity that stops that abnormal activity from going from one place to another. It settles it down and allows some of that normal communication in the brain to take place again.

So we can see that it is a symptom treatment. The electrical stimulation isn't protecting the brain cells, it isn't slowing down the progression of the disease. But similar to medication, it's a treatment for symptoms, but it's a powerful tool and there's some applications when the meds can fall short. And so coming into what are some of the medical indications for this, so tremor is a big one. So tremor is one of these that can respond to deep brain stimulation even when the meds don't help. So whether or not the medication helps tremor, tremor tends to be very responsive to deep brain stimulation. The other types of symptoms that respond do require some amount of levodopa response as well. And you'll see that all of these are physical or motor symptoms, so that's an important concept too. So stiffness, slowness of movements of the arms and the legs, if they respond, even if it's for a short period of time, you take your medication in the last just an hour or less, that can predict how much those movements, that stiffness responds to DBS as well.

But because DBS is a continuous electrical stimulation, you can get more even response. So whereas you take a medication, that dose peaks up and it wears off and same thing happens again and again or it's somewhat erratic the way it's absorbed. With deep brain stimulation, you have this continuous amount of electrical stimulation, so it can smooth out some of that off time or some of that wearing off, and it can allow you to reduce meds to some degree. So it can prevent some of these highs for the meds are getting too high causing dyskinesia. So tremor, whether or not it responds to meds, the people that have these wearing off effects of their motor symptoms, those are called fluctuations or motor fluctuations, and then dyskinesias, which is essentially in most cases when there's too much meds and that can be difficult. That balance of enough versus too much can be difficult.

So DBS can help open that window up a little bit more and provide more flexibility. And offshoot of that last one may be someone may not have dyskinesias, but they may have some other side effects of meds that limit how much we can use and optimize for their symptoms. So those are the primary reasons to go into it, when you're thinking about this, the different factors that are important to or someone's general health, you have to be healthy enough to undergo a surgery and anesthesia, obviously your team will help decide with you about some of those risks and benefits. Age is not a strict cutoff. In the past when DBS was first taking hold, age 70 used to be considered that cutoff and studied it more and have had much more experience with it, and that certainly is not the cutoff now.

I would say very generally speaking, as someone is approaching 80 or getting past 80, at least the risks go up. So it's still not a hard cutoff, but the age is a factor there. And then the last big thing to think about too is with cognition, thinking and memory. If someone has a fair amount of cognitive difficulties, this can put the risk of the surgery a little bit higher too. So some difficulties may not be a reason why we can't do it. And as more time goes on with Parkinson's, it's common to have at least some of these issues. But a significant or severe amount of the cognitive issues may put a little higher risk. So when all of those factors align and somebody is being bothered by their tremors or these motor fluctuations or dyskinesias, attempts have been made to optimize the meds, but we're falling short, this may be a time where DBS might apply.

Donna Rajkovic: Thank you. Yeah. So we talked a little bit about that. So your symptoms that Ned, you went and presented to your doctor and you decided, "It's time for me to have the DBS conversation," what was the evaluation process like for you?

Ned Neuhaus: The evaluation process, I'd been having conversations for a couple of years. Then once I had decided it was time and my doctor agreed, I went through what I call the on-off test. So you go into your doctor's office off medication, and they make you do this and that and all the things we all know and love, and they go through and evaluate you on the UPDRS scale and then administer levodopa and wait for it to turn on. So it's a great opportunity to talk to your doctor about more specifics of the surgery. And then once you're on, you go through the same evaluation again, and so that was one major part of it. I remember being very anxious about

going to that appointment to manage to get into the doctor's office completely off medication.

It wasn't as bad as I had made it out to be. The second to determine if there's been significant cognitive loss or not, you go through a probably three to four-hour cognition exam referred to as a neuropsych exam. Being in my mid to late 50s, I was anxious about that test. The one thing I will say is nobody gets 100% on it, so it's not a grade like we're used to in school. It's just identifying where there may be slowness in cognition or actual cognition issues that need to be discussed before they go ahead and start drilling holes in your head. And then the last thing is a MRI, and the MRI serves two purposes. One, it determines that there's a pathway to put the leads and secondly, it provides one of the maps they use during the surgery to place the leads.

Neil Kanta Shetty, MD: Donna, I think you asked me too about the evaluation process, and I neglected the answer. Ned spelled it out great I think the big steps. I would supplement, as you mentioned, a very important part is that the meeting with your movement disorder specialist, whether or not it's somebody you've been following with who is also doing the evaluation or somebody new you're meeting who specializes in DBS, but they should really very much ensure and confirm the diagnosis that this is Parkinson's disease. Atypical Parkinsonisms or cousin disorders of Parkinson's disease don't respond well to DBS. So that's essential to get to know you and your symptoms with Parkinson's and what's bothering you most, rank list of things that are important to you, how meds are working for you, what you've tried, make sure things that have been they could be tried have been, and that they're optimized.

Then they counsel you about it, the risk benefits, and really the individualization, which I think is huge is that what we'll talk about are a lot of generalities about DBS and with the help of the whole panel here, a lot of specifics to everybody's story, but everybody is different. So a key is to understand the unique features that someone who's going through this process is bringing in and their goals for the surgery and then getting from your specialist what they think will actually improve for you and what the risks look like for you. So that part is super important, and then I think Ned mentioned the big things with the rest of the steps. I would add that typically, you'd go meet the neurosurgeon as well during the process to also provide more information about what the surgery looks like and an additional chance for counseling.

Donna Rajkovic: Great. Yeah, when I went through my evaluation, I went through it twice for my first surgery and then my second surgery. So the second surgery was a whole different gamma questions. They were wondering where are the leads? Were they placed in the right place? Were they moving forward? If we move the leads, is it going to help the symptoms, not help the symptoms? So having those, gone through it twice, you have different sets of questions. But yeah, that was very interesting. So Evonne, have you gone through this evaluation? Where are you in this process?

Evonne Simoff: I did. I've gone through the entire evaluation and really for me, the worst part was the MRI. I don't know anybody out there if you're listening, loud noises like

going football games really caused me to tremor [inaudible 00:19:08]. In that MRI, they want you to sit still and then tick, tick, tick, tick in your ears, I couldn't sit still. And if I can do it, anybody else can do it. I'm really happy to say October 9th is my surgery date, and I passed everything. I was worried also, Ned, was I going to pass the psychological part, but it wasn't actually that bad. You just take it step by step and anybody can do it.

Donna Rajkovic: So going to you, Ned, how did you choose your medical team?

Ned Neuhaus: Well, I started out actually looking across the country to try and determine where good specialists were experienced teams. But as I was researching that, I was also researching the implications for my insurance. And it became quickly apparent that I needed to narrow my scope because if I was out of network for my personal plan, it meant that there was no cap on what my financial liability could be. So that forced me to look a little more locally, but I found a great team with great experience within my network.

Donna Rajkovic: Evonne, how did you select your medical team?

Evonne Simoff: Well, I have a little different situation. My good friend is chief of neurosurgery at the hospital. I was getting treated at Henry Ford in Detroit, and she was not comfortable operating on me, so she helped me find a team. I was willing to go anywhere in the United States, and I am very fortunate because our insurance allows that for me. So I'm going to University of California, San Francisco, UCSF, to have my surgery done, and that just happens to be Dr. Ayers, that was her mentor. So this is how we picked my location.

Donna Rajkovic: Okay. Yeah. Initially with my first surgery, I was with my movement disorder specialist for eight years, and I was very comfortable with the team that he put together. My surgery was during COVID, so I don't know if there wasn't much that I could have done to really be there to ask the questions or anything like that. So it wasn't until my second go around I actually did more research and decided where to go to have my redo, so that was my journey. So that was very challenging a little bit. So Neil, some people are asking questions about their doctors before moving forward with DBS. What are some of the questions that they would like to ask, should ask?

Neil Kanta Shetty, MD: I think the individualization is really, I think, the big key. So obviously, you want to learn about the basics and the general principles of DBS. But those are, if you're looking in the right places and purposes of programs like this, they're available. There's a lot you can learn in research on your own. What you can't get is how it specifically impacts you. So I think obviously you want to learn about the basics, but I think a good question to ask is when you're bringing to the doctor what bothers you most, how those symptoms, and will they respond or not to DBS? Will they improve or not with DBS? And making sure you have an understanding of that.

In a similar vein, were the risks beyond the typical or average risks, are there any parts about my health and my condition to put me at greater risk? And then about alternatives, as Ned was speaking to too, at least thinking through, if I were to not

proceed with DBS or put it off for now, what are the alternatives that we would go through? What are the other options? What does that look like? What would the timeframe be before we might reassess if we want to reconsider DBS? So individualizing those very simple things, benefits, risks and then what alternatives look like.

Donna Rajkovic: There's been many disparities about access to DBS and one of them is access to a medical team that does DBS. What are some of the other barriers that people face in having DBS?

Neil Kanta Shetty, MD: So unfortunately, a lot of the same disparities that exist throughout a lot of healthcare and access to resources are the case as well with access to DBS. So under-engaged populations, certain ethnic cultural, racial groups, rural communities, women, all of these populations tend to be diagnosed a little later with Parkinson's disease compared to the rest of the folks with Parkinson's disease. They tend to be referred to and offered DBS less and when offered often tend to utilize it less, and there's a lot that goes into that. And we talked about insurance issues, which regardless of socioeconomic status can play a role, but certainly in lower socioeconomic status folks it can be even more limiting. And there's issues with implicit or sometimes overt biases throughout the healthcare system, throughout the medical system and throughout our society that play a role in a lot of barriers with this care.

So there's a lot of research going on to try to identify, describe all that's going on so we know how to best address it. And there's a lot of work going on for outreach and informing people and making sure that the information is reaching people so that they can make the best decisions. And also to incorporate these different people that may be less engaged traditionally in DBS and Parkinson's research to get them into trials and have them represented with the data that we have throughout Parkinson's research and get them in on the medical end of things so that folks on our end that are counseling people and referring people look like our patients, and there's that trust, confidence and ability to break some of those barriers better. So a lot of work to be done, a lot of work that is being done, but certainly there are barriers to access. I think you guys mentioned some of very common ones related to things like simple geography and insurance networks, they come up very commonly.

Donna Rajkovic: I'd like to move on now to surgery. Neil, can you walk us through the surgery process?

Neil Kanta Shetty, MD: For sure. So there is obviously going to be some nuances that are different depending on the center you're going to and their preferences and also individualized to you. But some of the commonalities, so the morning of surgery, you'll come in off of medications. One of the first steps that's taken is affixing or attaching what's called a frame, which is a metal device that helps with keeping the head still once you're in the operating room and on the bed, and it also is a reference for the different coordinates with the actual surgery. They can work off of that frame with the imaging that has been done before to make sure we're going where we want to go. So fixing that frame, there's local numbing medication that's given. The frame is affixed to the head, and there's pins that are

involved there as well. You guys can speak to that process being on the other end of it. After the frame is affixed, you're given sedation, and it's not typically a full or general anesthesia, at least for awake cases, but heavy enough sedation where you're fully asleep.

During this time is when the holes are drilled, which are called burr holes. So these are quarter to nickel-sized holes roughly about there in the skull. Again, you're asleep for this part of the process. You're awakened and sedation is lifted afterwards for the awake cases. The purpose of this and being awake for the cases that are performed this way is to get some additional information so when someone is awake during surgery, we can listen to some signals from the brain that give us an additional check besides the imaging that we had that we're going where we want to go. And the stimulator can be turned on as well in the operating room to look for some benefits and some side effects in real time. So those are additional checks that we can get when someone is awake. Being awake is obviously thinking about it even as a nerve wracking experience. People tend to tolerate it surprisingly well in the operating room, and you guys can speak to the experience there.

There are cases that are done asleep too, which is a relatively newer method of doing this that we can talk about in which case the entire surgery is performed when someone is asleep, and the imaging that is used during the procedure is an MRI like one that you had before surgery. They use some of that guidance which has a little more specificity than the CT, but they don't have some of the information that you get while you're awake. Coming back to, let's say, our awake procedure. After the electrode is placed and it's tested, you're allowed to go back to sleep. And then if you're going to have the battery placed the same day, which sometimes is the case, sometimes not, that will be done while you're asleep. The battery is essentially connected. This is all internally. The wire is tunneled internally under the skin and an incision is made if the battery's placed on the chest, battery is suited under the skin in the chest connected to the wire there. Then you wake up in the recovery room, and typically it's an overnight stay in the hospital for observation before you go home.

Donna Rajkovic:

Great, thank you. I know that I've had two surgeries and people there, we have a couple of questions about my revision. When I was getting programmed for my DBS, it was very challenging for my doctor, so I realized then that something was off. And so when I had another visit with the surgeons that redid my surgery, they saw through the MRI that my lead was two four millimeters posterior on one of the leads. So how common is it to miss the target? They missed the target for me, so I had to have it redone. Is that pretty common or...

Neil Kanta Shetty, MD:

It's not common, and questions in general about outcomes for DBS, you'll get a sense for why it's hard to give specific rates because of all the differences in even how different centers perform things and record them. But generally speaking, to give a broad idea about it, meeting revision, it's certainly under 5% and probably closer to 1% or 1 to 3%. If we talk generally about success rates, that's quoted anywhere from 70 to 90% success rates of DBS. But the variables here, how you study it, how you define what successful is in addition to these very technical things like the lead being in the right place. So there are things that go into that,



as we were referring to earlier about there may be somebody who on paper is a great DBS candidate, they have a lot of tremor, doesn't respond to medications.

They undergo a DBS, the tremor is better, but let's say the thing on the top of their list was that bothered them most with speech and we would've known that that's not going to respond. Patient wasn't told or didn't have that understanding and their speech is the same or maybe even a little worse after surgery, they're going to view it as a failure. So that is super important too for the success rates that everybody has that understanding. But just from a purely technical perspective about it being placed in the right location, there's going to be some differences from center to center about what the rates of revision are, but it is quite low. It's a relatively uncommon occurrence.

Donna Rajkovic: All right. Thank you. So we talked about going through the surgery, both awake and asleep. Ned, can you share a little bit about how your surgery, did you choose being awake or asleep?

Ned Neuhaus: I was awake, but the important thing to know is you're asleep for all the scary parts. I woke up in the OR just aware of a lot of activity around me, no pain, no pain from having the burr holes made or anything. But I think it's important also to note that when they placed my first lead, I was having difficulty speaking and they weren't getting a whole lot of good results from the test. So they repositioned my lead during that surgery, and I remember very vividly one of the people in the OR saying, "Oh, look, his foot just relaxed." And everybody looked at each other and everybody's got masks on, but you could see the smile in everybody's face of the success of the placement. So that was a huge relief laying there on the operating table to see everybody excited, and this was my first surgery ever. First time I'd ever stayed overnight in the hospital. And I think Evonne said earlier, if she can do it, anybody can do it.

Evonne Simoff: So true.

Donna Rajkovic: Yeah. Well, you chose a real doozy for a first surgery, Ned, "I'll just dive right into having brain surgery." I eased into that one a little bit. Evonne, what's some of the things that are on your mind when you're preparing for your surgery? I know you're going to be out of state.

Evonne Simoff: That's not bothering me. It's shaving my head. I've already cut six inches of my hair off. Even before I told anybody else I was planning to do the surgery, I have been cutting it little by little. Next week I'm cutting two more inches off. If you don't know, Donna and I are very good friends, and she was super great in sharing every little detail with me including and shaving her head. I've just decided that, and it's a hard thing, don't get me wrong, but shaving my head, I can find myself a wig if I really need one or a cute little hat, which I wear a lot of them. But cutting my hair off is, I don't know why, that's the worst part for me. And you keep telling me, Donna, "Don't worry, you can do it."

Donna Rajkovic: You'll do it. You can do it. Yes, of course.

Ned Neuhaus: It's the shortest my hair had ever been as well, so...

Donna Rajkovic: Yeah, I started up with hair here and then it was here and then here and then here. And then at one point, it was completely platinum blonde for a short time and they shaved it off, so that's good. So let's talk about the role of care partners around the surgery. Ned, can you share a little bit about who was with you and how they helped you?

Ned Neuhaus: Yeah, my wife was really the close support. She is there day in and day out. She was the one that drove me home for the three-hour drive. In fact, she referred to it as driving Humpty Dumpty home because I had bandages on, and it's all so much easier when you've got a partner that you're going through it with. And she attends all my doctor's appointments with me. She was there on the day of the surgery and obviously the next day to be that support.

Donna Rajkovic: Yeah, support is really important. Let's circle back to Dr. Neil here. Let's talk about recovery. How is the recovery for someone after DBS? I know for me the first time when I had my surgery I was asleep, and when I woke up I woke up in the hospital during COVID, of course, and nobody was around me. So it was a little scary and lonely at that time. But what is the recovery like after you have DBS?

Neil Kanta Shetty, MD: Yeah, so the typical recovery, as we said, it's an overnight stay in the hospital, and when you go home you certainly want to plan to take things easy a week, a couple of weeks, and don't fill your schedule up. Don't have obligations, plan to take it easy. You may need a few days and be feeling okay even after that, but I think it's better to plan for some difficulties and then be happy when things go smoothly. But during that time, in the typical scenarios, you may be feeling groggy, a little bit foggy. Undergoing surgery, even if it isn't brain surgery, with Parkinson's, the recovery is a little slower, so your mobility and some of your Parkinson's symptoms may be a little worse during that time. There is a portion of people who get some transient benefit just from the surgery itself, just placing the electrode, which sometimes we refer to as this honeymoon effect. If you don't get it's not a bad sign. If you do get it, though, it tells us a little bit of information that's maybe a further confirmation that it's in the right place.

But again, not everybody gets it, and that's not a red flag, but if you have that, you actually may be feeling a little bit better right after surgery. Tremors may be better or stiffness, slowness. Potentially, if you have that, you may even have a little bit worsening of dyskinesia, though, and so there maybe need to be some reduction of meds. If you don't have the honeymoon effect, typically, we're staying on the same meds during that time and just giving yourself a little bit of time to work through things. There will be some restrictions on you related to the battery if you had the battery placed at that first surgery, lifting restrictions. And that'll be for a few weeks, usually at least four to six weeks about just how much you can do, the weight you can lift on that side to make sure the incision heals. And you'll have some guidance about wound care for the scalp during that time as well.

Donna Rajkovic: Great. Well, that leads me to ask my next question. Once all this is done and everything is healed, what about programming? What should some of the things people know about programming your DBS? 'Cause I know when I walked into my very first appointment, I didn't realize it was going to be a two-hour program. I didn't realize they were going to check all the leads and then I was going to be a puppet for a while. So can you talk a little bit about the programming sessions for-

Neil Kanta Shetty, MD: Yeah, for sure. And then obviously it'd be great to hear people's experience with that first session. So it is a long visit. We have, again, which is not an easy ask, but we have people coming off of medications. That's how we get the most information for the programming session. It is a long visit, depends on who you're seeing, but two hours is not unusual, and essentially you come in off of medications. We turn the stimulator on, and just as Donna said, we look at all of the different areas on the electrode and some different configurations of programs, and we get information about where you seem to be getting the most benefit from. If there are any stimulation-related side effects that people have, we try to find out that information too so we know what our limits are and where to avoid.

So you're typically looking at one side of the body at a time and testing the stimulation at different places, figuring out what seems to be the best, and then you shift to the other side of the body and do the same thing. Then ultimately you have at least an initial idea of what this ideal programming setting should be. It sometimes can be somewhat dramatic of a visit where people can come in with a lot of tremor or a lot of difficulties with their mobility. And when that programming is coming to completion at the end of the visit, they feel significantly better in their movement. It's a taxing visit, so you may feel quite fatigued after all of that, but that they're moving better.

But a key here is that you can't just turn the stimulation all the way up from the get-go. So you find a lot of that information out and then you have to bring it back down to a reasonable place for the person to leave the visit. The 'cause brain needs some time to get used to the stimulation and because there's a balancing act in the subsequent months about meds and stimulation. So as we said, the stimulation allows us to reduce meds to some degree, and over the next few months you're solely coming up on the stimulation, down on meds and finding out where that is. So that's another reason why you can't just turn it up because we can't just drop the meds significantly all at once. It has to be titrated.

Donna Rajkovic: Yeah, I think I was a little bit naive when we did the programming. Initially, I thought you would get programmed in the beginning and then you would be fine. It's like a little bit of a confusion. So for me, it took about two years the first time, and they couldn't program me at all. Then the second go around, I'm still in the programming process, which will be a year this October. And I'm still taking medication because the dopamine is not being produced in my brain, so that's just really... Then, Ned, talk about you're not on any medication.

Ned Neuhaus: I'm very fortunate, and the combination of my symptoms, placement of the leads and the programming has worked very, very well for me. We weaned me off of

medication between November and March, so it wasn't like I just walked home the first day and didn't take meds anymore. But that's just like an added bonus for me because I never expected to be off meds as long. As I got better control of my symptoms, any medication reduction was a bonus to me.

Donna Rajkovic: So Ned, you've had the surgery, what, you're a year or so out? Tell me about, would you consider doing DBS again? Tell us a little bit about what life is like for you now.

Ned Neuhaus: Life is wonderful because I'm no longer living by the clock of my medication or my off times. I feel the same when I wake up in the morning as I do when I go to bed at night and there's no rollercoaster during the day. Again, I'm very lucky, but by the same token, it's not a cure. I still have symptoms. I still have side effects. I have a little more difficulty moving in certain ways. I've worked through that a lot over the past year. It's improving, but I wouldn't trade it for anything right now. It's just I think it's important to understand that you will still have Parkinson's after you have DBS.

Donna Rajkovic: Yeah. Evonne?

Evonne Simoff: Ned, what's the best thing that's happened to you from DBS, if you say the number one thing?

Ned Neuhaus: The number one thing, I have not had a single episode of foot dystonia since November 2, 2022-

Evonne Simoff: That's what I have.

Ned Neuhaus: ... and it was daily. It was debilitating before.

Neil Kanta Shetty, MD: As Ned was alluding to, there's a lot of uncertainty and there's so many individual differences, and a really important thing is the expectations off the bat. Because even in the best-case scenarios, as Ned said, it's not a cure and being able to wean off of meds is actually pretty uncommon, weaning off altogether. On average, we can reduce them, but weaning off is uncommon. So it's a process, and during that process there'll be some ups and downs. The general trend is that there should be some improvement and the programming period on average is somewhere like six months or nine months.

Maybe you're coming into the office every couple months or so, every three months and making some tweaks. And you will actually have the ability, if that's what's the instruction of your team, to make some increases or small tweaks in between visits with your stimulation. But there are cases if things are more challenging, the response is not as good where it can be more prolonged, as Donna is speaking to, as people are trying to make more changes as time goes on. But even in the average best-case scenarios, it's not one-and-done type of programming. There's a bit of a process there.

Donna Rajkovic: Yeah. So can we talk a little bit about limitations? You have this device and you have now to change your whole purse size to carry a little transmitter and communicator and all that. Talk a little bit about any restrictions or activities that someone might have. Having DBS, I, for one, am not an adventurous person, so I'm not going to do any crazy sports or anything. So I'm very calm and comfortable with the limited of exercises that I do. But are there any limitations that someone needs to worry about with the DBS?

Neil Kanta Shetty, MD: Yes. So as you mentioned, contact sports would be one that you want to be careful with. Essentially, impact on the battery, the head or any rapid movements that the head and neck are things that we want to avoid, so contact sports, but also things like roller coasters or if you're bungee jumping or extreme sorts of activities. The more day-to-day things that tend to come up too are massage, that we have to avoid direct pressure on where the wires are and those components of the battery. For medical procedures, it's something you have to keep in mind now that you have the device. And so these days you can undergo most procedures still without any major issues, but the teams all need to be aware, and there may be some special precautions that have to be taken because of your battery. Same goes with MRI imaging.

Currently, with all of the current devices, there is ability to have MRIs in the typical scenarios, but precautions need to be taken with MRIs. And then travel and going through security and at a concert or metal detectors, you have hardware that has metal components, so going through metal detectors, it would set them off. So that's something you need to be aware of to inform people that you have a device through airport security that they do in manual pat down and check as opposed to the scanners and the wands. So there are things that for a lot of people may not come up every day or all that often, but depending on your lifestyle it may be more or less.

Donna Rajkovic: Thank you. The Michael J. Fox Foundation has recently updated its Deep Brain Stimulation Guide, including the commentary from many people who have considered or undergone DBS as well as several experts in the field and care partners. To download the free copy expanded guide, its full of answers to many of your questions, and you may have and also contain several checklists of things you might think about as you consider whether or not to do DBS.

Neil Kanta Shetty, MD: Donna?

Donna Rajkovic: Yes.

Neil Kanta Shetty, MD: Can I very quickly talk about risks? I feel like-

Donna Rajkovic: Oh,

Neil Kanta Shetty, MD: ... I'd be remiss-

Donna Rajkovic: Yes.

Neil Kanta Shetty, MD: ... if we didn't mention this as well.

Donna Rajkovic: Okay.

Neil Kanta Shetty, MD: And I'm sure there may be some questions about it too.

Donna Rajkovic: I'm sure there are, yeah.

Neil Kanta Shetty, MD: So we talked about some of the basic ideas of benefits, what kinds of things can improve with DBS, but the risks are obviously very important to know also. So the primary risks of undergoing the surgery are bleeding from implanting the electrodes. So this is bleeding in or on the brain, which is a 1% risk. So it's not huge, but it's not tiny. It's a real accepted risk of doing the neurosurgery. In cases where that bleeding may cause symptoms like weakness or speech problems, that is essentially akin to having a small stroke as a result of the procedure, so that's a serious risk. So that 1% risk of bleeding and then infection risk because you're implanting hardware in the body, and that's anywhere between 3 to 5%. Sometimes that means you're on an antibiotic for just a period of time or we change the wound care that's needed. But if it's more serious or persistent and not healing, that may require that the system comes out to let everything heal and the infection clear.

And potentially there would be an opportunity to get it replaced if that was opted for afterwards. Those are the big two surgical risks, bleeding and infection, but important things too. I like to think about these as middle of the body symptoms. So these are also things that don't tend to improve as much with either levodopa or DBS. And as time goes on with Parkinson's disease, these are also features that people may have more difficulties with, so middle of the body, meaning thinking and memory, speech and then certain types of balance issues or freezing. So not only are these aspects that the DBS tends not to improve so much, but there's a little bit of a risk of worsening the types of issues from implanting the electrodes.

There's a lot of ranges about how often these are quoted and it's hard to study to separate, is it just the disease? Is it the surgery? Is it the programming? Generally, we think this may be about 5% or 5 to 10 on high estimates for that whole group that people may have issues with some worsening of their cognition, speech or their balance after the surgery from the surgery itself. The neuropsych testing that we mentioned, that helps stratify some of that risk to see if it's higher or lower for an individual's cognition of getting worse from the surgery. If you're going into the surgery with a lot of speech issues or a lot of balance problems already, that may also mean you're at the higher end of that estimate for it potentially getting worse from the surgery. So the gait and the balance, and we can talk about more with the Q&A, but that's a tricky one. Again, there's some risk that everybody faces of it potentially getting worse from the surgery.

Donna Rajkovic: Thank you. Opening up to the question, we have one question that came in about building a support team, especially if you don't have a dedicated care partner. Any thoughts on that? I'll open that up to Ned. You can [inaudible 00:52:26] that?

Ned Neuhaus: I'm not in the best place because I have a dedicated care partner, but I did rely on people like you, Donna. We talked before I had my surgery 'cause you had gone through it. People through the Team Fox, Michael J. Fox Foundation, there is the Buddy Network within Team Fox to reach out. So you can build some people to be part of your support network, they just probably won't be there with you on the day of the surgery.

Donna Rajkovic: Yeah, the Buddy Network is amazing. People have reached out to me through the Buddy Network and through Team Fox Detroit, so it's good to network that way and help each other. I'm sorry, Evonne.

Evonne Simoff: Through Team Fox Detroit, we have about five or six women who are young onset Parkinson's and we talk regularly. We have a group chat. We try to get together for lunch every now and then just to meet to talk out some of these problems that sometimes it's just nice. We have care partners, sometimes you don't want to wear them out with these questions. Sometimes it's just nice to talk to somebody else. I know Donna and I have talked to... how many people have we talked to, strangers that we... People have given our phone numbers out and they call and just say, "I just need to talk to somebody," just somebody who knows what we're going through. So if there is a Buddy Network or if even a local support buddy there, but keep trying to find somebody.

Donna Rajkovic: Yeah. There's still a lot of questions around the medication after surgery. Can you talk a little bit more about that, Neil?

Neil Kanta Shetty, MD: Yeah. So I will say on average we're typically able to reduce meds by about half. There's a lot of variation on that, but that's the average. Again, it's not necessarily right off the bat with that first programming session, but over the course of those subsequent months. There's often something that the medication that levodopa is still doing that the stimulation may not help with. So those are a lot of the non-motor things that we didn't talk about that DBS tends to fall short about helping with, you may rely on the meds for control of some of those symptoms. But even for the motor symptoms, the combination of meds and stim may provide a better mesh to give you more even control, so there are scenarios where we wean it off entirely. More commonly it's a reduction in a relatively substantial reduction in the meds after surgery, after programming.

Donna Rajkovic: We can go on and on. I can't believe an hour's gone by already. I'd like to thank everyone again for being part of our community and for joining us today. And thank you to our panelists for sharing your time and expertise. We hope that you found today's discussion helpful. Thank you, and have a great day.

Speaker 1: Did you enjoy this podcast? Share it with a friend or leave a review on iTunes. It helps listeners like you find and support our mission. Learn more about The Michael J. Fox Foundation at [michaeljfox.org](http://michaeljfox.org). Thanks for listening.

Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about The Michael J. Fox Foundation's work and how you can help speed a cure at [michaeljfox.org](http://michaeljfox.org).

