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Speaker 2: Navigating Parkinson's disease can be challenging, but we're here to help. Welcome to The Michael J. Fox Foundation podcast. Tune in as we discuss what you should know today about Parkinson's research, living well with the disease, and the Foundation's mission to speed a cure. Free resources like this podcast are always available at [michaeljfox.org](http://michaeljfox.org).

Larry Gifford: Hi, thanks for tuning in. I'm Larry Gifford, co-founder of PD Avengers and a member of The Michael J. Fox Patient Council. I was diagnosed with Parkinson's disease in 2017 and had deep brain stimulation, or DBS, surgery in 2023. It's so good to be here with you all today to answer community questions about that process. Before we get started, let me welcome our guests. Dr Ajmal Zemmar is an assistant professor of neurosurgery at the University of Louisville School of Medicine and a practicing surgeon. Thank you for being here today.

Ajmal Zemmar, MD: Thank you.

Larry Gifford: Doctor Pavan Vaswani is a movement disorder specialist and assistant professor of clinical neurology at Penn Medicine. He's also a class of 2022 Edmond J. Safra Fellow, which is a program to expand global network of movement disorder specialists. Thanks for joining us.

Pavan Vaswani, MD: Thanks for having me.

Larry Gifford: And we also have Becca Miller, who is a licensed clinical psychologist and associate professor of the Department of Psychiatry at the Yale School of Medicine. She is a fellow member of The Michael J. Fox Foundation Patient Council diagnosed with Parkinson's in 2013 at the age of 39. She had DBS surgery in 2021 and just this past year. Welcome, Becca.

Becca Miller, PhD: Hi, Larry, great to be here.

Larry Gifford: So let's get started. Dr. Vaswani, can you lay out the groundwork for our audience and explain what DBS is and how it's used to treat Parkinson's?

Pavan Vaswani, MD: Sure. Yeah, I'm happy to. So I could probably talk about this for an hour. I usually do with my patients, but I'll try to be brief today just so we can move on to some of the other questions. But in brief, DBS is a brain surgery. It's a small brain surgery in the scheme of things where a wire is placed into the head into a part of the brain involved in the Parkinson's circuit, and that wire has some electrical contacts. Surgeons or colleagues, Dr. Zemmar, would put a battery pack in the chest, connect those wires up, and then we use a little bit of electricity at the tip of that wire to make the Parkinson's circuit fire more normally. And the end goal is really to make people feel and move better. And so DBS is a really good procedure for the right person at the right time to treat a few things in folks with Parkinson's disease.

DBS is very, very good for people with tremor. In fact, it helps tremor more than most medications do. DBS is good for people where medicines work, but you have those ons and offs, those ups and downs, you get dyskinesia, and you get off time, either predictably or unpredictably. DBS, because it's that steady electrical pulses, gives you a little bit of a smoother day, gives you more hours of good on time per day. So tremor better than meds, gives you your med response in a steadier way, and then it helps you take less medication as well. And so for someone where those goals make sense, it's a really, really powerful procedure and one that with the right person, the right time, the right surgical team, the right neurology team, the right care team, family and friends can really have a powerful impact on people's lives.

Larry Gifford: That's great. Thank you. This is a subject that goes on and on and on and on. And The Michael J. Fox Foundation has put together a comprehensive guide and hosted a webinar on the topic earlier this year. You can find links to both those in the show notes. But today we're going to focus on one part of this process, the surgery day. This episode is ask us anything about DBS surgery day. So I hope you're ready. And it's something that looms in many people's minds and can be the thing that they're most nervous about. When we asked our community for questions about DBS surgery, one major theme people asked about was how mentally and emotionally to prepare for brain surgery. Becca, we've known each other for a while now, and despite your dyskinesia, you weren't too keen on DBS for a while. What changed?

Becca Miller, PhD: I couldn't even think about it or even look into any of the research. There are two spots that you can potentially have the surgery target, STN and GPI. I couldn't even remember those initials because I was so nervous. But when we met actually in Kyoto in 2019, I realized how much meds I was taking in comparison to all my fellow Parkinson's folks and also my dyskinesias were so bad. Even then, I still had to convince myself. So I said, "You know what? I'm going to keep a record of how often I am on and off and how my dyskinesias are."

So I took out my notes app on my phone, and I kept track for several days. And then one day my dyskinesias were so bad that I ended up deleting the whole thing by a series of missed taps. I think that's a sign that this might be the right time for me. And my daughter was nine at the time, and so I was really trying to wait until she was a little bit older and so that she might be able to better understand. And those were really my convincing factors.

Larry Gifford: That's great. Before we move on, Ajmal, can you define the GPI and the STN, what that means?

Ajmal Zemmar, MD: So the GPI stands for globus pallidus interna, and the STN stands for subthalamic nucleus. Those are both important relay centers in the movement circuit of the brain. So the idea basically is that there is dysregulation of these centers. And essentially if you stimulate and you put a deep brain simulator in, you essentially, in very simple terms, you have to think about, you're re-syncing these circuits into being in a healthy rhythm and healthy orchestrator inside the movement planning and movement execution circuit of the brain.

Larry Gifford: Becca, do you remember your first surgery day, how you felt?

Becca Miller, PhD: I do. I was pretty terrified, but I tried to make it fun for myself in a way. I had my best friend from childhood there with me, and I wore fun socks. I wore a funny T-shirt and funny earrings, all these things to just try and make it a little bit easier on myself. But it was really a scary experience, I have to say. My surgeon and my care team were so supportive and so great.

Larry Gifford: I think I had a very similar experience minus the socks. I did make a playlist, and I started with Staying Alive. I dedicated it to the surgeon before the surgery started, and he thought that was funny. But I think that I was more nervous about the frame than I was about the brain surgery. Can you talk about what the frame is and why I was scared?

Ajmal Zemmar, MD: Yeah. So if you imagine that the brain would consist of GPS coordinates, and we call them XYZ coordinates, this is a geometric system. And you're putting these leads into a location, and you have to have a reference system to see, how do I use my GPI to put then leads into their appropriate spot? So the frame, you can think of it in very simplistic ways, as a GPS system that lets us exactly determine where in the brain the centers, the GPI or the STN, are. So there's different kinds of frames in today's world. The majority of centers uses what's called the Leksell frame, which probably both of you have had. It's screwed to the head, and it's a little heavy.

Larry Gifford: It is screwed to the head.

Ajmal Zemmar, MD: Yes, that's right, which most of neurosurgery is done that way in today's world. We often have something screwed to the head. When you're asleep, something has to hold the head still. This is the same principle essentially since some centers you can do this asleep, and some centers you do it awake. But the frame, as with most neurosurgical procedures, is being applied to the head. Now different forms exist. One of them is the Leksell frame. Again, that's the majority that's used. It's a little heavy and can be uncomfortable for patients to wear throughout the surgery. And you're fixed against the OR bed, and you can't move during the surgery.

So it's very important for patients, when the case starts, to make sure that they're in a comfortable position. Neck pain can be an issue. Make sure to always communicate that to your surgeon and take your time in the beginning of the case to do that. There's other types of frames. We here in Louisville use what's called the Starfix frame, which is essentially mounted to your head, and you can move your head freely. It's very lightweight. Patients like that. It's custom-made for each case. So there's several kinds that exist today.

Larry Gifford: Mine was the heavy one.

Pavan Vaswani, MD: I should say. When they screw it in as a non-surgeon observer too, there's plenty of numbing medicine and lidocaine and let it kick in. And so it's not like someone's screwing something in without anything on board.

- Larry Gifford: All right, so this is for both doctors. How do patients feel the morning of their brain surgery typically?
- Pavan Vaswani, MD: I'll say most of my patients are a bit nervous. It's pretty normal. Like you guys described, you've lived there, I just get to chat with folks. But most people are pretty nervous. Some people are really excited. For folks that have been going through quite a bit, it's a big day to get something that can make a big difference. So I think people are nervous, excited. You have to get up pretty early, so most people are a little tired too. And then that's been the experience I've had. And we try to stop by and reassure folks and help them get through the morning and through the procedure.
- Ajmal Zemmar, MD: I can share that. I think it's very normal, and if Dr. Vaswani or myself were in the patient side, we would probably also be nervous. It's very normal to be nervous. My daughter recently has had ear tubes put in, which is very, very simple, but I was still nervous. And that's very normal, and I think it's our job as a caretaker and a physician to, as much as possible, take that away and reassure the patient and talk to them before the case. And that does often a big difference, I feel.
- Larry Gifford: What role does the surgical team have at calming the nerves and keeping patients cool-headed?
- Ajmal Zemmar, MD: Well, I think just reassurance. When you go and make sure that, are there any open questions? Just the patient coming into the hospital and seeing that there's a routine and there's a flow, and these guys know what they're doing, and it's not like a zoo, and nobody was expecting them and things. So if they see things like that, that this is a center that has experience in the surgery, everybody's calm, everybody knows what they're doing, and the surgeon walks in, and the neurologist walks in and answers all the questions. Uncertainty is a big recipe for being nervous, and I think if we can take that away and calm the patient in those terms, that I think is helpful.
- Larry Gifford: I think that's really important, what you just said. That does calm you down. When the surgeon comes in and goes, "We're going to do this. Here's this person, they do this." They introduce the whole surgical team in three seconds, but you feel like these people must do this every day for 1,000 times a year. You feel comforted by the fact that they know what they're doing.
- Pavan Vaswani, MD: And I'll say, this isn't the conversation we're having the morning of the surgery, but this isn't something that is new or experimental or that we don't do all the time. In fact, I think as a field globally, we crossed 100,000 cases in 2015 or '16. I haven't found a place that's officially reported it, but just knowing what the numbers are, we're probably close to 200,000 cases globally, if not past it at this point. And so as a field, this is something we do all the time. This is something Dr. Zemmar does all the time. This is something that I have sent patients for all the time. And this isn't new, it's not experimental, and it's a fine-tuned orchestra. Everyone's working together to make this happen smoothly for folks.
- Larry Gifford: Well, I know when I was first diagnosed with Parkinson's I was like, "Heck no, I'm not getting brain surgery, not this guy," until I needed it. And now I can't

imagine life without it. I get questions all the time, and I'll just fire a couple at you. Should I shave my head?

Ajmal Zemmar, MD: So there is enough evidence today that shows that shaving or not shaving has the same amount of infection risk and any other risk, that makes no difference on the medical point of view. I let the patients choose. I think it's cosmetically what they like to do. If a female patient comes and has beautiful long hair, and you go ahead and you shave the hair off, it has stigmatizing consequences for that patient. The patient walks afterwards out and has to explain to everybody why this happened.

And I often hear from patients who have long hair that they want to keep it, and I keep it for them. I just make a little strip, shave that piece off and have access to ... Basically what we need to shave off is the part where we're doing the incision, and that's not the whole head. So on the contrary, I have male patients who have sometimes short hair, and if you have three, four different spots where the short hair's shaved off and you see it, they don't like that. So for them it's nicer to just say, "I'll shave it off." It's really patient preference at the end of the day.

Larry Gifford: And is there anything specific they should wear?

Pavan Vaswani, MD: No, the hospital's going to have you change into a gown anyways, and so wear something comfortable. I wouldn't bring your antique grandmother's family heirloom diamond ring just because you have to keep track of those things. So maybe leave that at home or with someone safe, but whatever's comfortable is what I tend to recommend to folks.

Ajmal Zemmar, MD: I always say it's the most expensive haircut you'll ever get per minute.

Larry Gifford: What about medications? So often we hear these stories about hospitals not wanting patients to take their own medicines when it comes to Parkinson's. And if you're on a bunch of different meds, should you bring them to the hospital? How does that work?

Pavan Vaswani, MD: There's a couple of parts to this, I think. So one is yes, hospitals don't want you to take your own pills, and that's because we got to make sure you're taking the right thing at the right time. We want to make sure there's not interactions with other things, anesthesia for example. So while you can bring your meds to the hospital and have folks check them, and that's actually a nice way to make sure folks have an accurate medication list, so I actually recommend that people do it. You should not take them without it going through the processes. If you are on anything unusual or a little expensive, for example, brand name medications like Rytary, Gocovri, et cetera, the hospitals don't always have them on formulary, so it is nice to bring those. They'll have the pharmacist verify them before they give them to you. So bring your meds just to have a med list, but don't take them unless it's going through the official processes. That's important.

Usually morning of surgery, we like you to not take your pills. Now do whatever the center you're getting it at recommends, but generally folks say morning of

don't take your Parkinson's medicines. We know it's uncomfortable. We don't like to put people who that for no reason. And the reason for that is we're using a couple of methods in the operating room to check that the wire is in the right place, listening to some of the brain activity, in some cases actually turning on the electricity while you're in the operating room. That's what awake surgery means, and we may get to that in a little bit. And so it's nice to be able to see what your Parkinson's looks like without the meds to see if the stimulation does something on the quick check in the operating room. And so those are some of the reasons we want people to be off their meds that morning. So that's generally what's recommended.

Larry Gifford: Then generally, how long does the surgery take?

Ajmal Zemmar, MD: Just one more note to the previous question. I think what I do is there's stage one where we place these leads and stage two where we place a battery. In stage two we place a battery. There's no need to hold your medications, it's discomfoting for a patient. In stage one, as Dr. Vaswani mentioned, the real purpose of doing this is because we essentially want your raw symptoms. We don't want them to be masked by medication. We want your symptoms to show up in the surgery room so we can use deep brain stimulation to test it to essentially get rid of the symptoms without having side effects. That's the purpose of not taking the medication.

The surgery, in general, if it's a unilateral case, for me it's somewhat around two to two-and-a-half hours. And then if it's a bilateral case, an hour or hour-and-a-half is added to that. So if you have a bilateral case, something around maybe three-and-a-half, four hours or so, that's the length of it. And for the battery, usually it's one to one-and-a-half hours to place a battery. And then in addition to that comes the anesthesia time. So if your loved one is away from you for more than one-and-a-half hours for a battery replacement, do not worry because anesthesia takes that time and the preparations take the time and things like that.

Larry Gifford: Now explain the difference between unilateral and bilateral.

Ajmal Zemmar, MD: Unilateral means one side. Bilateral means both sides. So if really there's evidence that only one side is of issue and the other side is not, sometimes the decision can be to say, "Let's just place one lead." Often we place two leads. And then if we have concern that the patient may have risks such as cognitive issues, we would say, "Let's stage it," meaning one lead is placed today and the next lead is placed a week later or so. And then if the patient can tolerate both leads on the same day well and there's no concern for any side effects, cognitive issues, anything else, we usually like to go and place both leads on the same day.

Becca Miller, PhD: I had one done, and then because only my right side was affected by Parkinson's for a long, long time, so I just had the left surgery done first, thinking that I could wait probably until I needed my battery replaced to do the other side. It didn't work out that way. It was just a couple of years by the time my left side started catching up with my right in terms of symptoms, so I decided to have the second surgery this year. But because my symptoms were still pretty much on one side, I thought, I'll just have one. But it is harder then after the surgery, if you just have

one side, to manage with the stimulation and the medication together. And my neurologist had a really challenging time balancing that out as opposed to just having both sides, and then you just manage with the stimulation.

Pavan Vaswani, MD: Just to highlight what you're getting at because I have a patient for whom this happened recently, sometimes if you do actually have the little symptoms on the other side, we didn't appreciate them. Maybe the meds were really working well for that side, and so you didn't get it done necessarily. Sometimes we treat the one side with the DBS, and then you need the meds for the non-DBS side. You take the pills, and then you get dyskinesias on one and you manage to treat the other. Now that said, it's a very personal choice, and this is not a everyone should get both or everyone should get one discussion. This is a really personal and very much depends on your personal case.

And so this is something you, your neurologist, your neurosurgeon, your care partner, the whole team is going to be talking about and thinking about. Sometimes we do the second side just because seeing a flicker of symptoms, just planning for the future. Sometimes, as Dr. Zemmar said, it's truly on one side, might as well do just the one side that's really bothered. So I will just emphasize that this is very much a personal choice that requires some careful thought with your team and the doctors that know you well.

Larry Gifford: My wife and I, we had a lot of conversations around the surgery and everything that went into it. And she was great the day of. Her role was being my advocate to the nurses and whatnot and also my communication. So she was communicating with the family and with the friends. She had a WhatsApp group set up, so she just had to text people. She didn't talk to anybody. And she actually went home during the surgery because I went in at 9:00 and didn't get out until 6:00, and then they had to get my room ready and everything else. So she was great though. And she and my son came the morning before the surgery and met me in pre-op, the morning of the surgery rather, and met me in pre-op and were able to hold my hand. And I had the frame on so I couldn't see them really, but it was just nice knowing they were there. So I think the hospitals, for the most part, do whatever they can do to make you feel as comfortable as possible.

Becca Miller, PhD: I had the same, Larry. My best friend was there. She was communicating with other friends through CaringBridge, which is a website that could update everyone at once as opposed to having everyone individually text her, because people just want to know that you're doing okay. And then I think the most impactful thing for me was during the surgery, I had my surgery awake, my device tech actually held my hand through the surgery and listened to my jokes that I was telling when I was awake during the surgery and reassuring me while they were doing all the testing. And that really meant so much to me.

Pavan Vaswani, MD: Can I ask what you both remember about the awake part? What do you remember during the surgery?

Becca Miller, PhD: Well, I had a really interesting experience where while awake first, I heard my brain, the noises in my brain as they were trying to make sure that they had the right spot, and then they went through a series of tests. And then when they

turned up the stimulation, I actually couldn't talk. So they ended up changing the placement of the lead at that point. So for me, it became really important that I had it awake because from my surgeon's experience and from the MRI et cetera, it would have gone in one spot that would've given me really bad side effects of it when it was turned up. So I'm a big advocate for that. I know not everybody feels the same way or feels comfortable doing the surgery that way, and there are lots of different techniques that are emerging that mean that you don't have to do it awake. But for me, so I remember a lot. I think I was probably awake for about an hour during the surgery.

Larry Gifford: And I remember Nurse Nancy was holding my hand the whole time and scratching my nose because you can't lift your hands above your shoulders because you have to keep it clean. And then as they were placing the leads, trying to find the right placement, he was having me speak because he knew my voice was really important to me. So he'd go, "Say 1, 2, 3." I'd go, "1, 2, 3," but it would come out "1, 2, 3." He goes, "Do it again," or "4, 5, 6." And so I did that 10 times until he hit the right spot, and he goes, "We got it, let's move on," and then they went to the other side. But I remember I got really sleepy after that first placement because that was hard work, getting that first placement in there. And then I was like, "I'm ready to be knocked out." But I do-

Becca Miller, PhD: Yeah, speaking about your brain being tired, your brain was exhausted.

Larry Gifford: And I had a playlist, and at one point the entire surgical team started singing Hamilton out loud. It was pretty funny. And so I would do it again in a heartbeat.

Becca Miller, PhD: I would too. It's not an easy experience, and the recovery takes a little while, but I think for me it's been totally worth it. I had such bad dyskinesias that it was so hard for me to plan and do anything, especially as a single mom with my younger daughter, and trying to do any kind of activity or go out with her, or as I said, go apple picking or anything like that wasn't possible because I couldn't plan anything because I didn't know where I'd be in my med cycle or how dyskinetic I'd be, et cetera, whether I'd be able to drive because of that, all those kinds of things. And then now I just have so much more predictability. It actually caused other side effects, so it's not perfect, but it caused some restlessness. It caused some different kinds of side effects that I've adjusted to and managed, but overall it's been a positive, positive experience.

Larry Gifford: Dr. Zemmar, another question that comes up from the community is about that expectation setting as they prepare for surgery day. What is a realistic expectation for what DBS can do for a person with Parkinson's?

Ajmal Zemmar, MD: So DBS can primarily address tremor, stiffness, slowness of movement, mostly in the hands, and medication-induced uncontrolled movements that we call dyskinesias. These can be addressed well with DBS. Gait is, for example, one symptom, that freezing of gait in Parkinsonian patients, that I always tell my patients, "DBS may help, we don't know, but I would not do it for that reason." It's very unlikely for DBS to help with freezing of gait. There's some research going on right now. There are studies going on, especially also with spinal cord



stimulation that may help, but DBS, I don't believe the patient should go ahead with the expectation that it helps with gait freezing.

Similar, cognitive issues that patients may have, sometimes I was asked about orthostatic hypotension in Parkinson's. There's very little literature existing right now that DBS could do anything about that. So as long as it's not proven, I like to tell my patients I would not do it for those reasons. Really what the evidence is very strong for are those four symptoms. It's tremor, rigidity, bradykinesia and medication-induced dyskinesias.

Larry Gifford: And so it's not a cure-all, and it's not for everybody.

Ajmal Zemmar, MD: No DBS is not a cure. That's very important to understand, and neither is medications. So often in medicine, we use measures to manage symptoms. While DBS can make life more comfortable and address these symptoms, it doesn't cure them. That, I think, is a very important distinction to make.

Pavan Vaswani, MD: I actually tell my patients it's kind of like a medication in a way. It's got a dose. I've got to adjust that dose and find the right dose for you afterwards. And so it's not going to immediately work. It's got formulations. I can change the programming, change the type of stimulation. It's just like the formulations we have of the medicines you take. And it's got benefits, and it's got risks. The medicines work for some things, they don't work for others. They have side effects, and DBS has the side effects that you can get from the stimulation and from the surgery. And so we think about it that way as a treatment. It's got things that it works for, things that it doesn't work for, things that are side effects. Now it's very good treatment, again, for the right person at the right time for the right reasons, but it is a lot like the other treatments we have, that you have to think about the balance of all of those things together.

Larry Gifford: Well, and I think that one of the things about DBS is you don't know what all it could affect, but you know those four things it will affect.

Ajmal Zemmar, MD: That's correct. I think in terms of side effects, we have a good idea of what it could do. So it's not like there's a surprise, they could do all these things to you and you don't know what it does. We have a pretty good idea of the side effects that DBS could do, and we test for those in the operating room if the surgery is done awake. So the goal of our awake surgery essentially is to get rid of the symptoms that the patient is bothered by and avoid having side effects that the stimulation could do. That's what the neurologist and the surgeon try to do in an awake case. I just wanted to make clear that it's not something where it could do all these things to us and patients get concerned about that. I think we have a pretty good idea of the things that it can do and to avoid them.

Larry Gifford: Quick question. We've mentioned it several times here, the awake versus the asleep. From your perspective, is one better than the other?

Ajmal Zemmar, MD: So in my personal cases that I've done now, I've kept tracking them to say asleep, essentially what you do is you plan a location before the case, and you place the

lead at that location. The difference in awake surgery is that let's imagine you're driving from New York City to Washington D.C. You can say along the way, "There is this city and that town and this place coming," and you know on your route what's coming. So when you place the lead, you have structures along your path from entering the brain to getting to your destination to verify, these are the places I want to see before I'm getting on my destination, meaning they confirm that my journey is right. So that's called microelectrode recording in this case. This is what you hear when we hear these sounds on your brain.

So we go from place to place to place to make sure that we are along the right track, along the right route. Once we are at the route, we can go ahead and test stimulate, so we are mimicking what DBS could do for you. If the patient tells me the predominant symptom they have is tremor, I want to make sure in the surgery room that I sustain that tremor, I control it, and I do not get the side effects that the patient could have from stimulation. So in an asleep case, you cannot do that. You cannot test how often are we in the right location without having microelectrode recording, without having the Google Maps telling us what comes from New York to Washington. I've done this for myself. Basically what I've done is to say, "How many times did I have to correct the position of the lead based on the recordings that I do in the case?"

In my personal experience, this has been about 13%, one-three. So I tell my patients that based on my experience, there is a 13% chance that I don't place the lead in the right location. Now this lead is not going to be placed, you want to be in Washington, D.C. and end up in Los Angeles. It's not that big of a difference, but it's usually one, two millimeters or so difference, but those can make a big difference in the brain. It can A, cause side effects. It can B, cause the lifetime of the battery to be longer if you place it optimally because you need less energy to stimulate, and the battery will last longer.

With the newer advances, so maybe the most significant one is that we have directional leads today. So whereas before your lead would just spread in all directions, the current, today you can steer it. And say, so let's say I am two millimeters off in one direction, I am steering my stimulation towards the target where I want to go, and I don't get side effects towards the other areas. So there is that stuff. Despite all of it, I think these things minimize the risk to have a misplaced lead. I let my patient choose. I think the bottom line is this, if you know that you are scared to death to do an awake brain surgery case, then communicate with your surgeon and say, "I would rather do asleep." The surgeon will tell you the downsides of it, and that's fine.

If you say, "Hey look, I really want the most accurate placement. I want a test in the OR, I think I'll be fine to do the surgery awake," then I would go for the awake option. And I tell my patients, they often ask me say, "Well, this is easy for you to say. Can I be scared? Can I not be scared and do it anyway? What is it like?" It's really not much different from being at the dentist. At the dentist you feel the burn and a little bit the burn when you get numbing medication. It's the same in this case. And you hear the dentist drilling when they drill on your teeth, and it's pretty much the same in this case. And as the rest, there are no pain sensors inside the brain. So awake brain surgery really sounds much more

dramatic than it actually is. And I'm going to ask you both, you went through it, how much fear did you have before? And afterwards when you were done, was this fear justified, or was it all much less than you actually thought it was?

Larry Gifford: No, it was much less than I thought it was. And you're right, it's just like being at the dentist. They do topical local anesthetics or whatever. They're drilling, and you can't feel it. There's really no pain to it. And even afterwards, I took Advil for a headache, and that was it. The hardest part was the chest. The chest and the wires were the most painful part of the surgery.

Becca Miller, PhD: I'd say it's definitely much less scary. I think for me, I'm a psychologist, I was really interested in being awake during brain surgery, to be honest, because I thought it'd be fascinating to find out what it would be like. And I had always read Oliver Sacks and *The Man Who Mistook His Wife for a Hat* and reading about other surgeries, et cetera, brain surgeries and how they test during the surgery, and I thought, that's fascinating. If I'm going to have to have this, if I have to have this disease and have to have this surgery, I want to find out what it's like. So I think trying to take that perspective on it versus it is psychologically scary. It's not painful in a physical sense, but it is psychologically scary to think that you're in the OR with your brain open and whatever. But I just found it really interesting. And I'm a control freak, and I wanted to have more control over what happened.

Larry Gifford: It's a very vulnerable position for someone to be in.

Ajmal Zemmar, MD: I think as with a lot of things in life, the anticipated fear is much more than the actual fear turns out to be.

Pavan Vaswani, MD: And I'll say I polled my patients afterwards and say, "Hey, how was it?" I wasn't the surgeon. I didn't have skin in the game in terms of that regard. "How did it go? What did you think?" And half of them say they remember it or it was a little foggy, but they half remember it and half don't. And the ones that remember it say, "It wasn't too bad," just like you guys are describing. And certainly there's some exceptional cases, and I think one of the themes here is that everyone's journey is a little bit different, so work with your team that way.

Larry Gifford: So what is the risk?

Ajmal Zemmar, MD: So I tell my patients often that there's general risks, as with every surgery. Every brain surgery you have a general risk of infection, bleeding, seizures. That's no difference in DBS. The specific cases for DBS, one, I would say so in terms of risk, in general, overall, DBS is among the safest surgeries we do as a neurosurgeon. The risk portfolio is very, very much on the safe side. We do way more complex things than DBS, and we have way more complex side effect portfolios than we have with DBS. The majority of patients that I've seen and colleagues that I know, they go home a day after surgery usually. Brain surgery always sounds dramatic. Once again, I think the fear, the anticipated fear of hearing that word is actually worse than what the risks in the surgery truly are.

Becca Miller, PhD: I stayed in the hospital for less than 24 hours for each of my surgeries, and people were so shocked to hear that I was home already and walking around and doing things. But I felt fine. It was pretty amazing.

Larry Gifford: The whole reason I did awake surgery is just for the bragging right. All right. We are running out of time. Becca, I want to talk to you about what you want to communicate to our audience about DBS surgery day.

Becca Miller, PhD: About surgery day? I think gather your friends and family around you, have your supports in place, and find ways to reassure yourself. It's really not as bad as ... It's a scary thing, but it's got lots of benefits at the end.

Larry Gifford: And doctors, do you have a final word?

Pavan Vaswani, MD: And I'll say I think it takes a team. It takes a team of the patient and their care partners and their caregivers. I think they're at the core of the team, and then you're going to meet a team of other folks that are going to be involved, the surgeon and the whole surgical team, which is a huge orchestra of people who really know what they're doing. The neurology team, from the DBS manufacturers, you're going to meet some representatives as well. And it does really take that team before the surgery to think about, again, if the surgery is right for you, when you should have it, really thinking about your individual case. The day of the surgery, of course, and then after the surgery, you're going to be working with that whole team to optimize it and make it work as well as it can for you. So it's going to take a team, you're going to meet that team, and you already have much of that team, and just rely on that team and trust them to help you make the right decisions and get through the process.

Ajmal Zemmar, MD: My final award would be I think if I was in the shoes of a patient, and I would rightfully so be very nervous about undergoing this procedure, I would like to tell you to not let the fear prevent you from having the surgery.

Larry Gifford: Thank you all. I do want to say this is one day in a lifelong decision of DBS. So we went deep on the day, but there's so many more parts of this DBS journey that we could talk about. It's an ongoing process. But for more information on other parts of this DBS process, visit the show notes for links to Michael J. Fox Foundation's webinar on the process of deciding to do DBS and also MJF's newly updated comprehensive guide on DBS. Also, for more in-depth detailed discussions about DBS, my wife Rebecca and I documented our DBS journey in the final nine episodes of the podcast When Life Gives You Parkinson's available wherever you listen to podcasts. Panelists, thanks so much for joining us.

Becca Miller, PhD: Thank you, Larry.

Ajmal Zemmar, MD: Thank you.

Pavan Vaswani, MD: Thanks for having us.

Larry Gifford: And thank you to all of our listeners. If you like what you heard, please rate and review the show. It helps listeners like you find our content. Have a great day. We'll talk to you soon.

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