



Deep Brain Stimulation Surgery Series

A Talk with a Movement Disorder Specialist and Neurosurgeon about Boston Scientific's DBS

Davis Phinney Foundation

Note: This is not a flawless, word-for-word transcript, but it's close.

Melani Dizon (Director of Education and Content, Davis Phinney Foundation):

Hello and welcome. My name is Melani Dizon. I'm the Director of Education and Content at the Davis Phinney Foundation. And today I am here with Dr. Britt Stone and Dr. Francisco Ponce. How are you doing today?

Britt Stone, MD (Assistant Clinical Professor, Clinical Director--Vanderbilt Neurology Main Campus Clinics):
Doing well, how are you?

Melani Dizon:

Excellent, excellent. So, we're going to be talking about DBS what it is, who it's for? It's not for the symptoms. It helps the symptoms; it doesn't tend to help and everything in between. So, I have a movement disorder specialist and I have a DBS surgeon, and we're going to talk about their relationship, how they work together, the whole process of it. It's for those of you who are interested in DBS and who have been told about it, but don't know much. And for those of you who are sort of in that deciding stage. So, let's start with you, Dr. Ponte. Can you let us know who you are and what role you play with DBS?

Francisco A. Ponce, MD, FAANS (Associate Professor of Neurosurgery, Program Director, Neurosurgery Residency Chief, Stereotactic and Functional Neurosurgery):

I'm a neurosurgeon in Phoenix, Arizona. And I tell patients that my responsibility is to place the electrode safely and accurately and really help empower the neurologist to deliver this electrical therapy that the neurologist recommends as the next step in their journey.

Melani Dizon:

Great. Thank you. And Dr. Stone, what about you?

Britt Stone:

I'm a movement disorders neurologist at Vanderbilt University in Nashville, Tennessee. And I am a person that has kind of the long-term relationship with patients who get deep brain stimulation by programming the electrodes that our neurosurgeons place.

Melani Dizon:

Okay, great. And you two know each other?

Francisco Ponce:

Yes.

Melani Dizon:

And so, how does the relationship work team-wise, like with you two?

Britt Stone:

Well, I mean, I guess I would say that with the neurosurgeons we work with, it's a, it's a collaborative effort of kind of deciding who the best patients are for surgery first, because when you have that as a foundation, then you kind of can, can be hopeful about the outcomes being the way that you want. And then once that is decided, figuring out where the electrodes are going to be placed. And then for some of our neuro neurologists, they're actually in the operating rooms with the neurosurgeons too, during those procedures, sometimes not. So, it ends up being kind of a collaboration between, between us as to how we choose our patients and then moving forward how we manage that.

Melani Dizon:

Okay, great. Is there ever a situation Dr. Ponce where you get, where you have a neurologist and you guys aren't on the same page?

Francisco Ponce:

It's rare. So, we have a, at Barrow, we have twice a month we have a consensus meeting. So, it's the neurologists, the neuropsychologists, the physical therapists, and the neurosurgeon, we all get together. And we have multiple movement disorder neurologists. And so, the neurologist or the fellow will present the patient and will all kind of weigh in. And there's, you know, we look to see what their priorities are, what their goals are, right? The goal of DBS therapy is to improve the quality of life. But that assumes that what DBS helps with will have that, an impactful effect on their quality of life and what stage they are in the disease matters. So, or if what really bothers them is something that DBS won't help, the physical therapist may have identified that, and they, they chime in and they, they offer that up.

And then there's a question of which what we're trying to accomplish with t b s beyond controlled motor symptoms. And that draws into which target we use surgically. So, we can discuss do we go to one side, two side globus pallidus, Subic nucleus, you know, two targets that we use that are FDA approved for Parkinson's. So, but it's it really is a consensus. I think

that the times of disagreement are usually surrounding the degree of cognitive impairment that the patient may have. And it's not really disagreement, it's more just us getting on the same page of, you know, this patient looks a little bit higher risk than we may be comfortable for medical risks as well. You know, if somebody, it's just not worth getting, taking them off anticoagulation for surgery, for example. So, anticoagulation for surgery, dementia, you know that's a contraindication. But if they look like they're, you know, months away from dementia and surgery is more than likely going to push them into dementia, those would be reasons why we would not do surgery. So, every patient for Parkinson's sees a neuropsychologist beforehand, that's standard of care. And their perspective weighs heavily at our consensus meetings.

Melani Dizon:

That's great. I do think it's you know, sort of a feeling of relief when people are, are wondering about this to know, hey, there's like an entire room of people who are talking about your case, looking at ev- you from every angle and deciding whether they think this is the best road for you. So, I think that because DBS kind of gets thrown around so much in our community, oh, I decided to do it, or I'm not doing it. It's a pretty big deal. And the teams that are working on this are, you know, taking all of the steps and talking to every single person who's on the care team to figure out if this is the right thing for you. So, let's go back a little bit, Dr. Stone, and talk about the situations where you might say, bring up deep brain stimulation. What are the symptoms that that person might be showing? Does there have to do with age and, you know, we talked about cognitive decline. What are some things that you're looking at?

Britt Stone:

Sure. So, you know, whenever I have patients who are living with Parkinson's disease, often, if it's someone that, that I'm newly diagnosing depending on when they're coming in with their symptoms, we kind of lay the landscape of the ways that we have the certain therapies to treat symptoms. And so, often, even if they might not be a candidate right away, I say, and then this might be something we'll be considering down the line, and the times I think about this are when tremor doesn't respond to medication. Because that's often a symptom that might not always be as responsive to levodopa. Or if people have what we call motor fluctuations, so their medicines work, but they don't last as long, and so, they're having to take their medicines every hour and a half or two hours, and they either have these wearing off episodes or then these uncontrollable movements that are different from tremor that we call dyskinesia that can also be very impactful to quality of life. Another symptom is something called dystonia, which can be painful. And that's kind of an abnormal posturing. So, toque curling or an arm or leg that pulls in when people are trying to do things or a head or neck in a strange position. Excessive blinking, any of these kinds of things can other, can be other symptoms with Parkinson's that people can get benefit from with their deep brain stimulation.

Melani Dizon:

Okay. So, what about the idea, I don't know, this is maybe just off the table these days, but in earlier days it was always, hey, if you're not levodopa responsive, you're not going to respond to DBS. Is that still a question or is it really, there's just too much differentiation between each person that that's not really a thing anymore?

Britt Stone:

I'd say that's still a question. You know, I think what we know is that tremor, for example, is kind of controlled by multiple neurotransmitters and might not be very dopamine responsive. So, if people have rigidity and slowness of movement and they have Parkinson's disease, like by definition they're going to be dopamine response, you know, responsive. However, now you might have people who might have intolerance to levodopa where you see the symptoms of Parkinsonian, it doesn't look like it's an atypical Parkinsonism, but they just get really bad side effects from their levodopa. Whether that's a strange thing, like really elevated blood pressures, which I've seen a few times for people who have lots of nausea and other symptoms from the medicine. So, you can't really push it up the way you'd like. And so, that's not necessarily that they're not dopamine responsive, they might just be intolerant.

Melani Dizon:

Okay. And in the past is there, have you changed anything in your practice in terms of, hey, you know, 10, 15 years ago I used to hold off on DBS and now I'm going a little bit earlier.

Britt Stone:

I definitely remember in training thinking this is something that you wait for. And I think as I've been in practice, I've realized this is something that we should be introducing when we start to see these impacts in quality of life. Because the goal of DBS therapy is to elevate the quality of life for as long as you can, which is kind of in the middle of the disease of Parkinson's, to be honest, because there's this threshold where when you have, when more non-motor symptoms that might not respond as well or might be worse from deep brain stimulation, or you had this cognitive impairment that might not make it a wise decision, you might have missed that window. Or maybe you could have extended someone's, you know, quality of life benefit for longer.

Melani Dizon:

Right. so, I was talking to a couple yesterday and I, and a device rep, and I thought it was really interesting because they were all on a different page in terms of, you better get DBS, I don't want to get DBS and all of this. Are there any ethical considerations and that come up when it comes to the person living with Parkinson's, the care team, the care partner, and what are those and how do you, how do you determine what's the best route?

Britt Stone:

So, I'd say to echo Dr. Pane, we do a very similar thing of Vanderbilt with the DBS conference. And so, that's a time where if we have any ethical quandaries about people, like, I don't know if this person can consent, but their loved one really wants them to get it, or, you know other questions that kind of come up. People have, you know, unmanaged psychiatric illnesses and we don't know how they're going to tolerate the surgery, or we don't know if they understand what the DBS really can do for them, and they think it's going to be a solution and not just one more symptom manager. Right. and so, we try to be really, really transparent about that when we're talking about going for a major surgery and make sure that everyone on the team is aware of what those kind of interpersonal issues might be.

Britt Stone:

You know, when you think about medical ethics, first do no harm, and things like autonomy and making sure people have informed consent, like this is always really, really important. And so, that's why the cognitive piece is a huge part, right? Because the person that's going to be getting the procedure you either want them or the person who has their proxy and is speaking for their best interest to be the person who's making that a very well-informed decision about what's happening. I never want people to feel that they, and I tell them, I'm not twisting your arm for this surgery because it's elective. So, if you, this is what we can offer, what are your goals? And at the end of the day, I want you to be fully on, on board or not. And if you're not on board, take your time to get there because you want to be able to actually be, accept any risk that also can come with a procedure as well.

Melani Dizon:

Right. Dr. Ponce, you mentioned the two different targets. Can you talk a little bit about each one? What does, how do you decide which is the better target? Is it age, is it a symptom?

Francisco Ponce:

Yeah, so we have two targets, and you know, one, when looking at these patients, one of the best predictors I've found in how these patients do is their level of insight coming into the surgery. And it really depends upon the education they get from their neurologist about what is medication responsive, you know, what's, what's, what's so responsible, what's not. You know, I've had patients who have no clue what's going on because of whatever with their com, you know, some neurologist, not a specialist, and they come in, I'm here because medications don't help me. And that's, you know, just kind of what you've first said. You're like, wait, no, that's the definition. And then there's a caveat, right? Medication refractory tremors, you know, tremors that don't res don't respond, and we can do better than medication with DBS for those tremors.

You have patients who have side effects, right? But in terms of those patients who say, I don't want surgery, a lot of that ends up being education. And you know, because at some point it's assumed risk, right? You weigh the risk, it's calculated, and you make sure that they have the information they need to make that decision. But I, but the reason why the FDA supports the use of this therapy is because of proven improvements in quality of life. And so, oftentimes when they don't want it part of it is just awareness, education, and insight and what it's going to do for them. You know, it's not a treatment of last resort. It's not experimental. And if anything, we usually feel like earlier and younger is better as long as we, I think the reason a wait primarily is just to establish the diagnosis.

You know, to sometimes it take, can take a few years before a movement disorder specialist, even the best diagnostician feels fully confident that it is indeed the diagnosis. So, when we see a patient and we start talking about surgery, we look at beyond just, you know, controlling the tremor, their stiffness, their slowness what other factors there are. And Dr. Stone mentioned, you know, patients who are having to take their medications all the time, right? You know, patients who have alarms every hour and a half, and to remind them to take their medication, they wake up to you know, two, three times a night taking their medication. And for those patients, it's a real priority to lower the amount of medication they take, right? So, the sub-nucleus we know has quite a very dramatic effect, and the ability of the neurologist to subsequently lower the medication.

And so, that's a priority. We're going to really; we're going to consider that target. On the flip side, if their medication is, you know, four times a day, something, you know, moderate, but they're having very troublesome dyskinesias and we want to nail those dyskinesia no matter what the globus pallidus the other target, you turn on the electrode in that area and the dyskinesias disappear. Now remember, dyskinesia are a side effect of medication, right? So, if you take a lot of medication, you can become dyskinetic, right? So, one way to lower the dyskinesia is to lower the medication or just to go after the dyskinesia directly. So those are an indirect versus a direct mechanism that these two targets have. So, we look at, all right, we don't want to like run the risk that we don't control dyskinesia, let's do globus pallidus. We definitely need to get this patient off this high dose of medication.

Or say the patient is one of these patients we just discussed that they have side effects of medication that tolerate the, you know, the blood pressure, whatnot with these patients, we don't even have the option to ramp up the medication because of their side effects. So, STN would be a good option for them as well. You know, we look at things like mood cognition speech. Those are kind of three side effects that we think are more associated with the sub-nucleus. But I don't, one of our, we have our neuropsychologists here has done a lot of the research looking at this and the psychological side. And he says that from a strict quality of research point of view, we, they don't have what they, they, they, they don't have the data to say at, at a level one proof, you know, evidence that there's a significant cognitive difference between STN and GPI. This again goes back to the art of neurology. Once you turn on this

device, these patients who are on massive doses, if you withdraw them from these medications too quickly, they can get depressed. They can feel cognitively slower. So sometimes you can mitigate some of these side effects just from a less, less overly zealous approach toward medication reduction once you start the electrical stimulation of the therapy.

Melani Dizon:

Okay. So, I'm trying to think of which direction I want to go first. Let's, let's talk a little bit about the Boston Scientific device. So, Boston Scientific makes the Versace versa size, that's how you say it, genius. What do you like about that? Can you talk to us about what makes this device unique, Dr. Ponce?

Francisco Ponce:

Sure. yeah. So, so I start off doing an awake DBS surgery, and then I started-

Melani Dizon:

Okay, so that was my other question. Like we, I want to talk about, it ties into this, it's the both of them, right? Okay. Yeah.

Francisco Ponce:

So, the, well, I guess the first one is a very kind of cosmetic element, which is when you look at the actual generators the shape of the rechargeable Boston is just perfect. I mean, if I had to like, think of having to live with an internal pulse generator, a pacemaker here for the rest of my life, like, I wouldn't think too hard about the Boston one. I think the other ones are like a little bit more of that body dysmorphic syndrome of like, oh my gosh, I'm going to have this underneath me from the rechargeable for Boston, the, just the depth, the shape, the roundness, the size, everything is, I think from a kind of cosmetic comfort point of view is just right. I think what's in the device is pretty remarkable. So, I transitioned over my 12 years of practice to doing all asleep DBS. My patients are under anesthesia, and I use it.

Melani Dizon:

Wait, now you're all asleep? Yeah. Oh, wow. Okay.

Francisco Ponce:

Yeah, so it's a, I can get into that a little bit more, but so far as the Boston system, I pick where I want to place the lead based on the patient's M R I. And I don't use cellular recordings or test intraoperative testing of symptoms because they're under anesthesia. I use an intraoperative CT to verify that the spot I picked on their MRI was able to place electrodes. So, so I do image-based surgery. And so, what I really like about the Boston system, it's very complimentary to

that approach. They have an image-based programming platform. So, it kind of takes some of the trial and error out of programming because the platform actually incorporates the information from the post-operative imaging where the electrode is relative to the pre-operative MRI to guide post-operative programming. So, I choose where to place the lead based on an MRI and they offer recommendations on how to program based upon the location on an MRI. So, so I like the image-based programming approach that the platform provides.

Melani Dizon:

Okay. So, are you finding now with a sleep that you're, the target is just better, like you're nailing it more, it's just more precise and so, that the outcomes are better? Or what made the switch?

Francisco Ponce:

So, when I was doing, so the idea of behind awake surgery, right? Is that you want to find data points in surgery that can inform predict whether you're in the right spot. The converses of that is also, you want information that you can use to tell you when you're in the wrong spot, right? And so, that you can reposition there at the time of surgery rather than having to come back to surgery, right? So, you want something that tells you, all right, you missed the target, you know, and then you can reposition. And the origins of DBS started before we had really good quality MRIs and we didn't really understand those structures as well as we do now. You know, we're like decades into DBS, we have a, we have an understanding of what works and doesn't work, and a lot of that correlates with where that electrode is on the MRI anatomy.

So the same then, the basis upon which I would reposition on an awake patient matches the basis upon which I would reposition for an sleep patient, which is basically saying that if evaluating recordings and tremor control and side effects makes me move the electrode anterior forward, what I was actually able to study, and we republished on this, the same patient, presumably a quo patient would be, you get a scan and the scan would show that it was deflected posteriorly. So, the scan tells me to reposition anteriorly rather than side effect or lack of benefit, or cellular recordings telling me to reposition anteriorly. So, so kind of in that in-between zone when I was doing both, I found that I was repositioning in the same direction based upon whether it was imaging, which is what a sleep is based upon test stimulation, which is symptoms or side effects or electrophysiology, which is C level recordings.

And I just found that it was it made the operation a lot more accessible to patients. Patients were being offered it earlier by their neurologist and accepting in more, you know, I don't think awake surgery is that scary in retrospect. I think it's a patient's tolerated well. So afterwards they said, oh, it wasn't that bad. But it's, I always think of it as like the patient who, or the, you know, the kid who waits in line for the triple corkscrew you know, rollercoaster and there's that self-selection, right? You're like, I'm going to do this, this is right for me. Versus the one who

kind of gets to the front of the line and says, I'm just going to walk right across to the exit. You know, I get what it's, what the virtue, but thanks, but no thanks, not for me.

Yeah. So, I think it just makes it a bit more accessible and it's also a bit more standardized. We do less second passes and less repositioning. And part of it is just because with the, a slip technique, I think allows us to optimize the stereotactic accuracy of our surgical tools in a way that having a patient awake for longer, losing spinal fluid, having brain shift, you know, just I think that there's a little more surgical error that is introduced that you have to end up correcting for on an awake patient. So, all those kind of forces resulted in finding that we have very consistent functional outcomes, which is, you know, how they're doing six weeks after surgery. And surgical outcomes meaning kind of how long the take case takes, how many, you know, positionings we have to do when I transition to sleep.

Melani Dizon:

Okay. So, Dr. Stone, when you, when you start talking to people about it and you say, you know, there's a couple of options, what feedback do you get? Are you typically more people like an awake that's so scary, or are they, they've just heard about it so much that it doesn't seem like such a big deal?

Britt Stone:

You know to Dr. Ponce's point; I think a lot of it depends on exposure. There are people who know someone who's had DBS surgery, so they're like, oh, okay. And they told me it wasn't that bad and I'm fine. There are people who are claustrophobic or have anxiety, and that is the population who, you know, asleep is a great option for, because they really, if they knew that they didn't have to worry about being awake, they would go for the procedure. Whereas that idea of being awake just kind of psyches them out. Yeah. But I would venture to say that with that before, besides that demographic, most people are, are amenable to being awake.

Melani Dizon:

Okay. So, is it pretty split for you when you're with your patients? So, they half and half or-?

Britt Stone:

Well, I mean, I'd say it's probably more awake just because the center I'm at does more awake than asleep. but they will do asleep if that's something, you know, if that's kind of the turning point for a patient. Where I practiced before the surgeon I worked with did a lot of asleep. And in my comparison point, that kind of is what shaped my exposure to that. Because I was a little, like, I don't know about this, but that was, that was what kind of clued me into wow, the outcomes really are the same. And, and that was a very reassuring thing to kind of get to see in real-time.

Melani Dizon:

Yeah. Dr. Ponce, do you ever, or how often would you say that you're doing both targets for somebody?

Francisco Ponce:

Both targets for the same person? like rarely.

Melani Dizon:

Okay. Yeah, I just heard, I was talking to somebody yesterday and they're like, well, I have one that dystonia in the globus pallidus. I was like, okay. So-

Francisco Ponce:

Yeah, no, that, that can be, I think that would be a bit challenging for Dr. Stone to program. I think you know, for example, I think that this actually ties into like whether I do one side or two sides. Say somebody has like, they're like, you know, it's my right side that really bothers me. I just need unilateral. I just need the left side. You do the unilateral and then Dr. Stone can lower the medication that they're taking so much of, and now that they have lower medication, they're like, oh, you know what? Now that I'm not taking as much medication, I'm sorry, I noticed that left side. Oh, yeah, six months later, they're getting the second side done. So, the and I think similarly because you have those different mechanisms of action by which the tremor, stiffness and slowness are controlled by the two targets, one by medication permitting medication reduction, the other having a directive effect on dyskinesia, I think you end up having a little bit of LOP side in this.

So, the, it's, I have a few patients, a small number of patients who kind of, I guess I've described it more of a salvage think outside of the box approach, where they have a third or fourth electrode where, you know, they have bilateral STN and they're dis there, they're dyskinesias are bad in one side. So, we do, we add a GPI, or they have dystonia, and the neurologist wants to try that. I've had some others that had side effects from STN, and when they turn off the device, their speech gets better. So, we know it's a side effect of stimulation versus just, you know, sometimes this, the speech doesn't get better when you turn it off. And so, we actually place globus pallidus in and we kind of weaned, but they're getting the benefit, right?

They can't live without STN stimulation. But they can't, but living with it impacts their quality of life, speech impacts the quality of life so that they, those have like three of those where they basically weaned off the STN because they don't want to, they wanted to hedge their bets, right? They don't want to lose it all. And then as, as they as g kind of took over. And so, so It's more of these, you know, and I think that's where the team approach with the neurologist were like, you know, I'm thinking about doing this for this patient. What do you think? You know, we

look at the electrodes, we make sure that we're not going to break a good electrode and trying to put a third one. And it's, it makes it a little bit more interesting than just kind of the, you know, day in, day out, you know, on-label strict on-label surgery. So, in summary, it's been more in a, in a think outside the box kind of salvage situation on somebody who's doing well, but we think they could actually do better. But it's typically unusual.

Melani Dizon:

Okay. And then, so if somebody is it true that for the asleep, it's often just the whole thing at once, both sides do the whole thing, but that if they're awake, usually do one side and then they come back for the other side, or then that's usually more procedures or is that not the case?

Francisco Ponce:

There's a lot of factors that go into that. I don't know. Dr. Stone is, are you guys unilateral bilateral at Vanderbilt? Typically?

Melani Dizon:

We're bilateral.

Francisco Ponce:

Okay. It's good. So, we can pile against the unilateral centers then. So, we're on the same side on this one. The I so say, say it takes a surgeon, you know, six hours to get the right spot on once. So, okay, so it takes me about between an hour and an hour and a half to do a bilateral operation, start to finish. Patients are typically in the operating room for twice that amount. So actually, the time spent, the operating room, only half of that here is done operating. A lot of it is set up, you know, putting the frame on, getting the scan you know, waking the patient up. And so, so I can place that second electrode very efficiently, right? It all can happen within an hour, hour, and a half.

And this is not operating quickly, right? This is more just efficient moves, knowing what I want to do, and this is how long it takes to make a whole, you know, put the locking mechanism, deliver the electrode check, do the second side. Now if it takes somebody, you know, six hours to do a single side, that patient's getting kind of antsy at that point. And so, and traditionally that's what, how it was done before we had a better understanding of anatomy and kind of where you were targeting. So, there it makes sense, right? The patient's like, you know what, I'm done with this. So, you say, look for your safety and your comfort, we're only going to do one side at a time. That's one rationale, right? Another one is the cost. These are not cheap devices, right?

And Medicare kind of fixes how much they reimburse a hospital, how much that covers the device depends. And so, the most favorable flow for a hospital system would be you put an electrode, come back later, put a battery, come back later, put an electrode, come back later, put a battery that's four surgeries to get a complete implant, versus two if you do bilateral and you come back two weeks later for the battery. So, and it's unfortunate because a lot of the coding that governs how hospitals are reimbursed for this were determined back in the nineties and they've not really been updated. And that basically sets the first operation as an inpatient only operation. And the second operation is outpatient only. And what I tell my patients is that's why we have to separate the two, because there's not a mechanism to do this otherwise, that makes any financial sense for the hospital. So that's our compromise leads two, two leads then come back later for the battery. But there are some places that break this into four separate operations.

Melani Dizon:

Okay. so, Dr. Stone, when it does come to the battery, what are some things that people with Parkinson's should take into consideration when deciding the battery they want.

Britt Stone:

Yeah. Thinking about a primary versus a rechargeable, you know, if you have someone who has a lot of support, doesn't have any cognitive issues and really just wants to like, you know, they are very aware and tech-savvy, rechargeable is great because, you know, while you're having your tea in the morning, you just put your little sh-, you know, little shawl on and you charge and half an hour, an hour you're good to go for the week, right? Then we have other patients who maybe the people that help, you know, caregiving and such aren't as, as, you know, comfortable with what to do with the technology or, you know, it's just a bit overwhelming. Or they might be in a facility, you know, nursing home or, or something along those lines where a primary is really great.

Also, if they maybe are using very large amounts of stimulation, a rechargeable is nice because then you don't have to worry about having to get a primary changed, you know, every couple of years or three, you know, three, two to three years as opposed to five years. And a rechargeable can last, you know, 10 to 15 years depending. And so, it's kind of that timeframe as well, how, you know, how old someone is and if you just want to place it and not have to worry about it until it's time to get it replaced like then, then a primary can be very handy. So, we always kind of give those options to people based on kind of what their life is like. In addition, when people see the sizes of the batteries or the IPGs, they sometimes are like, oh, I cut that. That looks like, you know, I'm a very small person. I think I prefer something a little bit smaller, a little more comfortable. That's something that people think a lot about as well. So,

Melani Dizon:

Yeah. So, when Dr. Ponce is finished with the surgeries, do you also do programming as well? Or you're somebody in your office? Dr. So does programming.

Britt Stone:

Yes. So, I am one of, how many of us are, are there now maybe 10 or 11 movement disorders, neurologist, And so, all of Us program.

Melani Dizon:

Okay. Okay.

Britt Stone:

And yeah. Yeah. So, we have a nice cohort of us. And we all program, actually we have a DBS clinic with our surgeons on like Tuesday and Thursday mornings. And so, all of us and the nurses are all in the clinic together. So, it's great, you know, if someone's gone through testing and then they're meeting the neurosurgeon for the first time you know, often if there's another question, we'll do a dual visit where they'll still, they'll see us and then they'll see the neurosurgeon for a bit or after they've gotten their electrodes placed and there I P G in, they'll make sure their wounds and everything have clean, you know, have healed nicely. And then they'll see us for their initial programming. So, it's a really nice kind of, you know, full circle where people kind of get to see everybody.

Melani Dizon:

Yeah. Everyone watching is like, I'm going to Vanderbilt, how do I get in? Okay. So, the question, so when somebody comes to you, what are, what is, I'm going to talk to a programmer too, but I just wanted to hear from you like, what are some of the biggest issues initially when somebody comes for programming? And then how long does it typically take for somebody to feel like, okay, had my surgery now I'm starting to feel like this is totally worth it. I'm so glad I did this.

Britt Stone:

So, I would say, I think one thing we normally do is the first I tell people we are now at the start of a marathon, you know, that having this disease in itself is a marathon, but then having the deep brain stimulation surgery is a part of that as well. And it's not a sprint. And that this is an adaptable therapy. So, you know, I always kind of, I like to undersell overdeliver, that's my strategy. And a lot of times people, you know, the first visit's always really gratifying when you see that tremor that didn't respond to anything disappear for the first time. Right. You know, people get very emotional. And I often tell them, depending on what target they have, so STN

versus GPI, they might see things really instantaneously with their subthalamic nucleus with the stimulation there as opposed to the globus pallidus, which might take a little longer.

So, sometimes I tell people, you know, we've done some adjustments, we're going to live here for a little bit. You might not notice anything right away, but as you live at the stimulation for a couple of days at home, you might start to notice things. And so, then people will write in like, oh my goodness, you're right now, you know, my rigidity is better, or my dystonia's better, or I've gone up a couple clicks and now I see something. And I usually try to get people in about every six weeks for the first three to four sessions to really kind of adjust and we slowly, you know, come down on medicines we don't try, you know, I tell them we're not just going to take everything away. We're going to address each med at a time and we're going to back down as we go. And if you notice that something gets worse and going up on stem isn't helpful, stay there. Let me know. We'll address it on the next visit. Right. so, it's really close watching as we're incrementally adjusting, usually for the first few sessions. And then often after about the third or fourth, like people kind of start to hit a plateau of like, oh, I think I'm doing pretty good.

Melani Dizon:

And then let's say they get to that point how frequently do they have to reprogram?

Britt Stone:

So I like to give people if they want a bit of room to go up and down anyway and not just know how to turn off and turn on their device. And so, I'll tell them, you know if you notice that when you're stressed out or doing something in particular that your tremor comes out or that you're wearing off and you, before you go take that med, go up a couple of clicks and see if that makes a difference. Right. so, I have people who don't touch their stimulator and they will come to visits every three to four months for maintenance and they might, we might have hit a setting where they don't ever really have to touch it very much anymore. And then there are some people, and it's usually I find if it's kind of a sneaky tremor, because sometimes people with Parkinson's will have this mixed tremor as well, where it can be a little dystonic or they might have a little essential tremor too.

And so, then you start to see things un you know, come out that maybe you didn't see before. And so, then when you're just kind of like, okay, now we're going to see if we can adjust a little bit more and see if that helps. And so, sometimes people have to go up a little bit you know, on their own and they'll tell me like, I've done up a little bit, but I think I think I'm good now or I need a little bit more room to go up. And I think something that I do find that's interesting about Parkinson's disease in DBS is that there often will be a time where we really get really good management of symptoms that the DBS manages and then the non-motor symptoms of Parkinson's or other Parkinsonian issues that DBS isn't as great at capturing start to really show themselves. And we have to really kind of reset the expectation of what the DBS does and doesn't, doesn't solve.

Melani Dizon:

Yeah. Dr. Ponce, what would you, what happens when somebody just does not, it just doesn't go well for whatever reason they have had a bad experience, the programming hasn't worked and it's just they're worse off after DBS after, you know, years, what are, what are the options that people have?

Francisco Ponce:

So, the option would be one make sure that the diagnosis is correct. So, you know, having a reassessment of what their motor, their movement disorder is that that can, that can happen where if you, if you don't treat, you may treat something that looks like Parkinson's disease but is not Parkinson's disease and you may have like a, you know, six months, a year of response and then it wears off. And so, reassessing the disease. The next one is, you know, reassessing medication management, seeing if you know, programming or medication can be optimized, getting another set of eyes on that. But getting a scan and doing a serotech analysis of where the electrodes are. So, we can get an outpatient scan loaded up on our planning station and formatted and say, all right, look, this looks like it's in this area.

If you have an MRI from before surgery, you can see what it looked like on the MRI, but you can also just measure. And I think combining an analysis of the imaging with a profile of the side effects that you can kind of provoke at different amplitudes can give you a sense of the geography where it's located. And that would be how you would reassess whether it's an appropriate location. And then you can either reposition it within the same target or consider a different target. Because if it is Parkinson's disease and provided the symptoms you're trying to treat, are the symptoms that the patient stands the benefit from so far as quality? You know, DBS doesn't help with dementia, right? If they're, if they're an appropriate candidate there's no reason this won't help.

So that's kind of the direction we go when we see a patient who's not res- what you're describing. Because otherwise, these patients do really well. I mean, with the right patient and an uncomplicated surgery, this should be like, this is, you know, it's, it should, it's like, I think it's one of the highest satisfaction rates of like any surgery for patients because it's going to work. So, I think that unknown for a patient of like, what if this doesn't work for me? I think in general that's very unlikely if the patient's well selected and the operation's done appropriately.

Melani Dizon:

Okay. And then, but on the off chance that just none of those things work, it's basically you could just go in and remove it. You can remove it, the leads removed, yeah. Okay. Yeah. Have you, has there any difference that you've noticed in your practice between, hey, people who are diagnosed with young onset maybe you know, thirties, or forties versus people diagnosed

later? Is there a different response? Are you finding, oh, this is, you know, we typically are using this target and you know, that kind of thing, which either of you actually?

Francisco Ponce:

You know, so one of the appeals of DBS compared to other therapies and surgical treatments, is that it's non-destructive, right? It's non-ablative, it's adjustable, and it's reversible, right? So, if you take it out, it's like, you know, it was never, it was never there. I think because of the ability to lower medication with STN I think we see younger patients; I think there's a mix. Younger patients seem to do well with STN because of that. Because long term it's going to provide a lot of benefit like that. I think that may be center dependent. I think there's also the earlier you do it and in Dr. Stone's Center is one of the leaders supports exploring kind of this earlier time points of intervention. The longer you wait, the more of a wow effect you're going to get, right?

But this because it's going to be, oh wow, I was miserable and now I'm better. Whereas if you do it earlier, you may have a beneficial effect in kind of stabilizing their social element, you know, side of their life, their, they're their employment, right? They may be able to work longer but that wow effect may not be as dramatic, right? They're just starting to kind of chase their symptoms with motor fluctuations or getting dyskinesias. But it's not going to be as dramatic as if you wait longer. I think people in their mid-seventies and beyond that's where I start saying, you know what My plan A is going to be to keep you for two nights in the hospital because, you know, the swelling in the brain, it isn't always a symptom. It's usually not symptomatic. If anything, the symptoms, and any operation is going to result in some swelling, right?

And I tell my patients, if you get knee surgery, you're not going to be surprised when you have some swelling and you have a limited range of motion and hurts. Right? And you're not going to walk on it. All that stuff is in the brain. We don't have pain fibers, right? It's not the pain that's going to slow you down. The same kind of trauma of surgery in the brain. It's the brain tissue and the manifestation of that swelling can be being slower cognitively having a seizure having a speech problem just from the swelling being close to the speech area. And as the swelling goes down, that gets better, and I know how to navigate those expectations if that happens. I see those kinds of side effects more in patients with Parkinson's than with essential tremors probably. Because Parkinson's is more of a global disease of the brain than our central tremor.

And I see it more in patients kind of in 6-75 and beyond because I think cognitively they're a little bit more vulnerable that they're more sensitive to that swelling than somebody who's 65. And so, that's why, you know, we don't say there's a hard cutoff for age, but I do more expectation management. And so, 75 and beyond for Parkinson's, that's where I'm like, all right, let's plan on two nights. You know, like, you may look great the morning after surgery, but then you go home, you're agitated, you're not eating, and your family doesn't know what to do with you. And so, we navigate those patients a little bit differently. I think with those younger patients. I think being with a movement that's sort of specialist is key because they can really

serve as their champion in navigating for DBS therapy when the time comes instead of waiting too long.

Melani Dizon:

Anything to add to that, Dr. Stone?

Britt Stone:

I would totally agree. You know, I think that sometimes how it can take a while for people to get to DBS because if they don't see a movement disorder specialist or someone who knows to even offer that to them, they might not even realize that that's possible for them where they currently are. And I have done a lot of kind of debunking where people are like, well isn't this something for like at the end? And I'm like, no, no, no, it's not. And here's how the research has shown, you know, what this can do for you now and this is what's going on. I think that being able to educate people to that point is really contingent on us even having had that relationship where then they, they can trust, oh, okay, this is something that can, that can work for me.

And I think with younger patients too, you know, we're not as worried about kind of postural stability because you know, that fourth symptom of PD, that kind of, that loss of postural reflexes and imbalance, which DBS does not make better and if anything can sometimes make a little worse. That is something that with the STN the younger people, I don't have to worry about that as much. And so, that is another reason why sometimes they'll go for that target. At our center and older people, we see the pool test and we're like, oh no, even when they're on, like, they're about to timber into the wall back here, so maybe we should go for GPS at this stage. And so, it's a lot of kind of making sure that we're not adding insult to injury and how do we make you know, someone's day-to-day as good as it can be for as long as we can.

Melani Dizon:

Right. So, a couple of the side effects, or I don't know, side effects outcomes that I hear about a lot from people who got DBS are things like excessive weight gain, voice is terrible stiffness. So how, when those things, when it's like a clear indication that those got worse, but your motor got better, you don't have dyskinesia. Like how do you work with those? How do you, how do you help a patient with that?

Britt Stone:

I think one thing too is k is you know, kind of being able to parts out for people what is their Parkinson's disease? What is, what deep brain stimulation does or doesn't do, right? So, like excessive weight gain. I've actually never heard of this being an issue from people with DBS or stiffness. You know, if anything I would expect for stiffness to improve if it's Caldwell rigidity, right? You know, since that's being, you know, a park, a Parkinsonian symptom and I don't

know, maybe if for some things it's like, well, what kind of medications are you on? Are your medicines optimized? Is there a mood component to the successive weight gain? Like, are you apathetic and not moving around and exercising anymore? are you eating as a coping mechanism? Like, what else is going on? Because also people with PD, like I, a lot of times I'm trying to get their calorie intake right, right?

You know, not the other way around. Right. So, I think that making sure that you, that we can kind of clarify what is going on that is actually DBS related or not. And it can be hard when there's this temporal relationship and you're like, well, everything got worse after this, but sometimes it's not because of that thing. Now as for speech and voice change, that is definitely something that people have had it have been reporting back to me. That's been a complaint. And what we'll sometimes do to really get a better idea is, well, let's turn the stimulator off. Okay, now let's talk, and let's see what happens. Like, do this for a day or so, what gets better and what doesn't? And a lot of times people are like, oh yeah, my speech is still kind of thick. Well, that could be your Parkinson's.

We know that you can get some slurred speech with Parkinson's disease. We know you can, you know, you can have some word finding difficulty or some kind of stuttering with, you know, with your speech as part of the disease. But also, we know that with DBS, depending on stimulation, it can also make your speech thicker or, or more difficult, you know, to kind of enunciate what you're trying to say. And so, I just try to really make sure that we can, we can see that on-off stem, what gets better, what doesn't. And when things don't change with the stimulation off, we can easily say, well, we know the stimulation isn't the culprit.

Melani Dizon:

Okay. Great. so, this is really helpful Dr. Ponte. Is there anything you think that this, our community should know about DBS before we wrap up?

Francisco Ponce:

Yeah, I think it's important for them to know. It's important. There's no reason to wait too long. You know, the goal is quality of life improvement. I mean, this is, it's on label for improvement, quality of life. So, you don't, you don't have to live this way. You know, these things that we know DBS can help with will help those aspects of the disease in a way that's very predictable. You know, I often hear people say, you know, that's not for me, or, you know, I'm not there yet. But I think the more people learn about the therapy, the less scary it becomes. And I think things like this are what make the therapy more accessible. It, the goal is kind of to demystify it because it's what we do every day, but for a patient's a major point in their journey with Parkinson's.

Melani Dizon:



Yeah. Great. What about you Dr. Pon-Stone?

Britt Stone:

I would completely echo what Dr. Ponce said. You know, I think that if you or someone living with Parkinson's and you know, you have more questions, be very candid and get all the information you can, you know, from your movement disorder specialist. And you know, I think the thing to keep in mind is that ultimately it's your decision. You want to be at peace with what you decide, but you want to make sure that it's an informed one and that it's not one coming from fear in either direction, right? It's just what is the next step that's going to make my quality of life better.

Melani Dizon:

Great. Well, thank you both so much. I really appreciate it. I know our community's going to love it and I'm just really grateful for doing this.

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