



Deep Brain Stimulation Series

A Conversation about Deep Brain Stimulation between a Medtronic Programmer and Person with Parkinson's

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 everyone. My name is Melani Dizon. I'm the Director of Education and Content at the Davis Phinney Foundation, and I am here today to talk about Audie's programming with Deep Brain Stimulation with his doctor Dr. Shahed. How is everybody doing?

Audie Villaflor (Person Living with Parkinson's):

Good.

Melani Dizon:

Great. So, we're going to get into your story, Audie, and your experience with Parkinson's and leading up to Deep Brain Stimulation and all of that. Right now, I just want to start with Dr. Shahed. Can you tell us who you are, what you do your relation to Medtronic, and yeah. How you got connected with Audie?

Joohi Jimenez-Shahed, MD (Medical Director of Movement Disorders Neuromodulation & Brain Circuit Therapeutics at the Icahn School of Medicine at Mount Sinai):

Yeah. Great. Thanks for having me on this program. Let's, good to do another program with you about Deep Brain Stimulation. My favorite topic. So, my name is Joohi Jimenez-Shahed. I'm a movement disorder specialist. I run the Deep Brain Stimulation program at the Icahn School of Mount Sinai Icahn School of Medicine at Mount Sinai in New York City. I have been working with patients with Deep Brain Stimulation for most of my career which is upwards of 15 years now. I'm sure I've lost track of the specific number. But it is certainly a big passion of mine just because of the really significant benefits that patients with Deep Brain Stimulation can experience. And it's really amazing to be able to help these patients through their Parkinson's journey in such a dramatic way. So, it's a big part of what I do and something that I really enjoy.

Melani Dizon:

Great. Well, thank you so much, ADI. And you are with your wife Cora. Thank you both for being here. Adi, can you tell us a little bit about your experience with Parkinson's when it started? What were some of your cardinal symptoms and how it's progressed over time?

Audie Villaflor:

Yes. By the way, my name is Audie Villaflor. I am 59 years old and underwent DBS surgery last November 15, the first part, and November 22. In the second part of the last year, I started to experience hurting three more, 11 years ago. That was in 2012 when I was 48 years old. I noticed this after cleaning up my backyard and cutting down the grade three branch around three inches in diameter. After a week, I feel that my right-hand having spas arm and suspected that it was only overworked, so I just ignore it. As this goes by my whole right hand started shaking, I decided to see the primary doctor knowing what will happen next. Then he referred me to a neurologist who had a private practice here in Brooklyn. He tested me with my own handwriting, tapping my nose to his finger back and forth, ambulating up and down in the hallway in his office, and to my surprise, taking a shot of vodka and observing me after a while if my re will stop a test that takes place in his office. After a few visits, he concluded that I was in, it was an essential tremor and prescribe additional vitamins such as vitamin b12. My tremors continued to advance this time, becoming ineffective, in my left hand and arm. This time we decided to the neuro specialist at Downstate, Dr. Christina Palmese, MD in 2020 14. This time decided to see a neuro specialist downstate Dr. Palmese in 2014 sent to Mount Sinai to take that scan. At that time, I was 50 years old and the c concluding impression was that I have an early stage of Parkinson's I was told by the same doctor, but I'm still in denial. This time. He started me on Sinemet in a month, then a lower dose to come back to him in a month to see if there is some improvement, which felt me, which has then eventually due to stress at work. At times, sometimes I feel that the medication is from Parkinson's.

His prescription was not effective and was before the intensity of tremors and shaking in my hands becomes worse, especially at work. And I let him know what I expected, experienced. I have been experiencing at the time he's been very close and retiring and he told me, wanted me to see a neuro medical specialist that works with my condition very well. And his Dr. Devine is upon meeting her. So, please, I'm so pleased. There's very, she's very thorough. Then she discusses with me about DBS, but at the time I would say that I have hesitation and Evan told her my wife, that this is my brain and not there. So, to say the least. My follow-up with her was continuous and when I developed side effects with one of the medication surgeries made me pass out due to vertigo. When she changed the area, I was supposed to start capsules three times a day, at that time, and they worked with me, without side effects.

One day I woke up and came up with a decision to go for DBS. After telling Dr. Que of my decision, she conveyed to me that she was glad for me. Then she referred me immediately to Dr. Joohi Jimenez and Evan told me that I will regret, I'll not regret, I'll not regret my decision from here, I would say begin my realistic journey because I'm facing the reality that I have Parkinson's and I have to deal with it. Then my first meeting with Dr. Joohi was an event full one, and she discussed about DBS for the very first time and for the very first time, I listened with all my mine and mind and mine it. Then we start the process of preparation for preparation, including meeting with D different neuro doctor teams as a psychiatrist,

psychologist, and psychoanalyst, even mentally meeting, eventually meeting with Dr. Fedor Panov via Zoom as my surgeon and neurosurgeon. Then meeting with them and came decision, which I'm qualified for DBS. So, last November 15 was my first D vs. Surgery, followed after a week by my second part of DBS, which is a very successful surgery with no complications, no side effects, and not even any pain or discomfort. During my hospital stay. On the first day post-surgery, I noticed everyone was constantly neuro-checking me, such as asking my name, where I am and what it is and et cetera. And my first programming with Dr. Joohi-

Cora Villaflor (Care Partner for Audie):

It came last December, December 15.

Audie Villaflor:

I feel very much relieved as soon as they started asking me if I feel something different. I almost told them yes, but now, okay, for the first time, I feel that I have hand tremors are gone. No pain sensation, no other pain whatsoever. I can believe that it is an instant. My tremor is gone deep inside. I'm so happy about it. Then looking back, I told myself why I did not do it soon enough.

Melani Dizon:

Well, thank you. Thank you for that so much. It sounds like you know, it was, it was kind of tough at the beginning. You were told you had an essential tremor. I think that's pretty, pretty common with people in our community and you also said, you know, I think a lot of people experience that I'm over, I'm overworked, I've done so much. This is why my body's reacting like that. Right? Yeah. And it was good that you, that you went back and that you kept going for it and trying to find the right people, to help you out. Cora, what was that experience like for you? Were you noticing when he was noticing, or did you even notice it before?

Cora Villaflor:

I did notice it actually before, but I don't want to scare him because I'm also a part of a medical team. I'm a nurse and then I deal with people with the same condition like him. So, at first, when I first noticed the tremors in his hand while he is driving, because he likes to drive a lot, I saw his pinky starting to stretch up and down, up, and down. Then eventually I come to the decision to ask him, what's wrong with your pinky? Is it painful? And he said, no, are you aware that you're doing something to your, to your fingers? Oh, no, that I'm just trying to relax my fingers. So, I'm, I'm thinking that this is his excuse. Then one day when we woke up, I told him, you know, I notice your hands trembling around my shoulder, what's happening?

And then he told me, oh, yesterday, remember you told me to cut, to cut the vein, you know, from the grape tree. And I was so overworked and maybe that was the reason why I am having

this tremor in my hand. So, as this goes by, I'm trying to observe him, and I notice that it's starting to get, you know, more and more and more. Yeah. So, I then decided we should see our primary doctor. So, we went to see the primary doctor, and that's the part Yeah. That, you know, as, as we see Dr. Ch, he recommended immediately to see a neurologist Yeah. Which happened to work in our hospital. So, that's the story that he mentioned about the vodka thing. Yeah. You know, I thought it was a joke. I said, this is the first time I heard such thing. But he said, no, this is just to see if he is an alcoholic or not. And I was laughing. No, I never drink, I am not a drinker.

Melani Dizon:

Oh, my goodness. That's actually, that's a new one for me. Didn't hear that, actually.

Joohi Jimenez-Shahed:

Yeah. I think sometimes when doctors are trying to distinguish whether somebody has a tremor that's more like an essential tremor, more like Parkinson's, one of the really characteristic features of an essential tremor is that it does respond to alcohol. And so, yeah, I think sometimes doctors may say that a little jokingly sometimes as a little bit of a test. Right? I just to try to get confirmation about whether or not that's the case. So, I think I actually do hear that quite a bit in my,

Melani Dizon:

Okay, that's interesting. So, that's definitely something different, right? If you drink alcohol if you have an essential tremor, it might calm down. Not the case with Parkinson's,

Joohi Jimenez-Shahed:

Not so consistently the case. Yeah,

Melani Dizon:

Yeah. Interesting. And so, it sounds like AUDIE you had quite a few doctors that, you know, you had and seen and that was taken care of you on your way to Dr. Shahed. And when you were thinking about DBS, what brought you to, you know, did you talk to a Medtronic rep? Did your doctor, or your surgeon recommend Medtronic? How did that work and Joohi, what role did you play on his team as he was preparing for DBS?

Joohi Jimenez-Shahed:

Yeah, I think we probably followed the same sort of procedures that we do with, with all patients that are coming in inquiring about DBS, and often that first question and that first visit is mostly about, you know, am I even a DBS candidate? Is it something to really think about?

Can it help me? And so, you know, regardless of what kind of device you're talking about, I think that's just the fundamental question where, where a lot of people begin. And so, it always starts with just a discussion of, you know, what symptoms they've been having, how it's responded to medications, what are the challenges that they're still experiencing. And then, you know, once we really kind of have that conversation about DBS and yes, this is an, you know, reasonable treatment for that individual patient we start scheduling them for the preoperative evaluations.

And we don't really get into a lot of the discussion about the different device types until we're really kind of firmly committed that this is the path that we want to take. So, I think what we did in Addie's case was to yeah, when that first visit, we decided, yes, you've got really bad tremor. It hasn't responded to the meds. You've had side effects. This is a good treatment. Let's go ahead and get you scheduled for all of the preoperative assessments as he described to you. And then when he came back to start doing those, we usually test patients off medications, on medications. And once we've sort of see what that part looks like, and we're even more convinced that this is really a good treatment option for them to pursue, that's when we usually talk about the device types. And I think that was the case.

So, we must have, we, I think Cora, we gave you all the information about the different manufacturers and we talked a little bit about the, you know, different capabilities that the systems have, and you know, how we can use those different capabilities in our programming process. And I've had a lot of experience with sensing devices and really like what that has to offer in terms of guiding our programming and just sort of the overall, you know, kind of programming experience for patients. And so mentioned that to them and suggested that if, you know, they wanted my recommendation, then that's what I would ask them to consider. And that's I think how we ended up with the decision to go for a Medtronic device.

Melani Dizon:

So, for people who don't understand you know, they're in these early stages of looking at this, can you describe like what the sensing functionality does and why you're a fan of it for, especially in this case in particular? Yeah.

Joohi Jimenez-Shahed:

Yeah. So, you know, for a long time, I mean, DBS has been around for a long time, and for the longest time, what we were really doing is just turning on a stimulator, delivering the electricity, and then measuring symptoms by examining our patients, right? So, people are familiar with all the finger tapping and the tremor testing that we do, looking at patients walking and how that pattern changes. And really the programming process for, you know, kind of traditionally up until things like brain sensing were available was very, this just kind of trial-and-error iterative sort of process. So, if you think about a brain wire that's being placed into the head, there are four different contacts on that wire, and you can deliver stimulation at any of those four places.

And what we have to try to do is to test each of those out to say, which is the one where the person is going to get the greatest clinical benefit, and where we might have some limitations in terms of side effects.

And then we kind of put all that information together and then decide, you know, this is how we're going to do the stimulation. So, that process, you know, kind of pre-sensing and pre-using of these newer technologies were taking, you know, upwards of an hour and a half, maybe two hours in some cases, sometimes longer, depending on how well the patient tolerated it. And there was just a lot of like changing and testing and changing and testing, get up and walk, get back and walk. So, you know, frustrating, maybe to a certain extent, tiring for some patients. And what we now can do with these sensing devices is in addition to actually just delivering the stimulation, you can actually record the brain signals. And recording the brain signals gives us the opportunity to sort of see how the brain is reacting to the stimulation.

And so then not only is it just, can we see the tremor get better? Can we see the patient moving faster and moving better? We can actually see the brain responding to it. And there is a lot of evidence that tells us that the places where we see this brain activity on the system when we are after we've implanted, it can help guide us in that decision process. So, now from a programming standpoint, we can cut our programming dimes down quite a bit. We can really home in on where the patient needs to be receiving the stimulation, and it just makes it a much, you know, kind of easier process, a faster process, and you get kind of double confirmation. Not only do you see the patient's tremor getting better, but you also can see the brain reacting in the right direction to the stimulation.

Melani Dizon:

Great. And so, it sounds like, Cora, that you, and Audie went for a month. Was it a month post-op to do the programming? Was the first time you said November to Yes. To December,

Cora Villaflor:

Yes. From November 22nd, we came back on December 15th. Okay. Very first time with Dr. Joohi Shahed. Yes. That's about three weeks.

Melani Dizon:

Okay. And what was the period between the surgery and your first programming visit? Like, how did you feel?

Cora Villaflor:

From the first surgery,

Melani Dizon:

From the surgery to the first programming appointment?

Cora Villaflor:

Well from the first surgery to programming, you know, the first surgery, the first night of the surgery, when I visited him at the Paco unit, which is the post-anesthesia care unit, I woke him up. He was sleeping. I thought he was sleeping. I called his name whispering and he answered. And then I said, oh my God, it's good. And I said, do you know who am I? And then he said, of course, you're Cora. All right, that's good. And then here comes the nurses, the, I think the residents coming into the room asking him what date it is, what's your name? Any pain? No, whatsoever, none. I didn't feel any pain. I said that's great. In the back of my mind. Wow, that's great. And I am observing his hands. If they're having tremors, the tremors are gone. And then he said, I'm so hungry. So, I asked the nurse if he could eat now, because the surgery just, finished. And he was brought upstairs and, oh, we can start with the liquid diet first. Okay. And then she put the I think it's a tickly liquid or something like that, or a jello. He immediately grabbed it and I'm; I'm looking at it, and his hands have no tremors at all.

Melani Dizon:

Oh,

Cora Villaflor:

Oh my God, God, what a wonderful, what, what a miracle it is. Then the next day, the following day, he has to go home, and Dr. Pham says, you're doing great. You absolutely have no complications, not no side effects whatsoever, so you're good to go home. So, we are all happy. And I come I started looking at him completely from the top of his head to the tip of his toes. Then they prepared him, everything like that. They wheeled him. So, we are on our way home. And then I was so, I was so careful with him. I'm, I'm protecting him. Next thing you know, I saw him, and he immediately went up into the car. I said, wait for me, I'm going to help you. He's already in the car, next thing you know, I cannot wait to go home. So, upon reaching home, he was on the phone with his friend right away.

What are you doing? I'm calling them. I'm telling them, I don't have any more tremors. Look at me. And he was so proud. He was so proud to tell them and to show himself. So, in between that day till the day, we saw Dr. Jha Shahed had a little bit minor thing on the tip of his finger, but I, in the, in the back of my mind, it's just, it's just normal because the transmitter is not really connected yet. Yeah. I remember Dr. Hadid telling us in one of our appointments with Dr. Joohi Shahed, that after the surgery there was some inflammation around the area of the brain. So, naturally, the tremors will be a little bit suppressed, and then when the time of healing is starting, then the tremors might come back. remember, you still didn't have the transmitter program yet, right?

Oh, okay. So, then I understand you know, mean mini it's not, it's not a big deal. Yeah. So, when we reached Dr. Joohi Shahed and they start programming it, they were evaluating him asking him if there was any pinning sensation or any indifferent sensation, and he said, none. None whatsoever. So, I was amazed. Yeah. I was so surprised. And I am, you know, I said, oh my God, look at these people. Look at this technology. Look at how God gave us these intellectual persons, Dr. Joohi, and Dr. Knob, they are God-given gifts to us. Yes. We didn't see them. If we didn't pound them, what will be his future? Mm. What will be the future of my husband? Yeah, that's what I was thinking. Oh. And then they continue, and we keep, continue to follow. Yeah. Until I notice as we go by, a lot of improvement is happening once in a while. Dr. Ju says to us that once in a while you will notice it's, remember it's still in the process of programming. Yeah. But then I notice sometimes when he's anxious, like now he's a little bit anxious, a little bit nervous, so he has a little bit of tremors, and that's expected of anyone, even with the normal people. Right. you know, what more for him that he had a device. Right. So, I give him an excuse for that. Yeah.

Melani Dizon:

So, Dr. Shahed, can you talk to us a little bit about what happens at that initial programming appointment?

Joohi Jimenez-Shahed:

Yeah. So, just like they were describing, we usually wait about three, or four weeks after the last brain surgery to make sure that all that kind of healing has happened. What Audie and Cora were describing, there is something that we call a micro lesion effect. And it's exactly what Cora said. There's just a little irritation from having those things put in. So, we want to kind of make sure that that irritation calms down. If we don't wait long enough for that, then sometimes it will sort of confuse our programming a little bit. And we may not kind of get on the best settings as soon as we otherwise would. So, that's why we really wait that time. We ask the patients to come in off their medications. There are two reasons to do that. One is, of course, we want to see the symptoms getting better.

So, if you come in and you've taken your meds and your symptoms are somehow not as bad because of that, then it makes it harder to know exactly how much stimulation we need to give you to control them. And then the other reason is that it's particularly important for the brain sensing because the medications can also affect those brain signals. So, we just wanted to be able to see the fullest extent possible what the response to the stimulation was without the influence of the medication. So, that's why we do that. So, the first thing that we do when the patient comes in is, of course, just make sure that everything went fine with the surgery and check them out, and we examine them and sort of see where we're starting. And then specifically with this Medtronic percept device that does the brain sensing, I start by checking the brain signal.

So, we'll turn, you know, the battery on, it's not, you know, without any stimulation. And just check the brain signals. And we kind of spent a little bit of time, probably in Audie's case it was probably about 15 or 20 minutes just reading all the information off of the device. And then once we do that, we can focus on the area that we want to localize stimulation. So, remember on those four contacts, we'll pick the one where we're seeing the most appropriate brain signals, and then we home in on that area. We start with the left hemisphere which controls the right side of the body. And we just slowly start increasing the stimulation. At the same time as we're increasing the stimulation, we're looking to see that the brain signals are responding, and we're also looking to see that the patient's symptoms are getting better.

So, there is a little bit of examination that goes on as we're kind of titrating that stimulation. And we're also looking for side effects, which fortunately, as you heard, Addie didn't have any that day when we were doing that programming session, we saw a fantastic response in his brain signals and we saw his tremor just kind of melt away, which is really, really amazing. Once we're done with the left hemisphere, then we go to the right hemisphere, which controls your left body, and we do the same thing basically. Once we're done with that, then we kind of turn the stimulation on, on both sides. And kind of a, what, what we think is the most likely, you know, kind of helpful setting that wasn't causing any side effects. And then we make sure just kind of big picture wise, whether the patient's feeling okay, whether they're walking, okay. Whether there are any side effects. And then that's sort of the conclusion of the actual programming. And then we just sort of talk about what we're going to do with medications after that. The last thing we do before the patient leaves is to actually teach them about their patient controller and how to use their patient controller.

Melani Dizon:

So is it in this case it seemed, you know, pretty straightforward and it was a great effect for Adi. Is this typical or is it sort of typical that, you know, each situation is different just because every person with Parkinson's presents so differently?

Joohi Jimenez-Shahed:

Yeah, I mean, I think you're, you're absolutely right about that. It's, it is that you know, the patients may be different in terms of what their symptoms are. It may be different in terms of how, you know, they're tolerating the stimulation. Sometimes if there's, you know, subtle differences and where the electrodes are placed, we might have a few more challenges in terms of, you know, side effects or testing for those or, or really, you know, making sure that we can get the clinical benefits that we want. So, we might have to work a little longer or a little harder and in some of those cases to kind of get it fine-tuned just properly. So, you know, it is like I said, a lot smoother, a lot easier when you have this ability to do the brain sensing. But I certainly had some patients where we weren't able to take full advantage of that for one reason or another. And so, then we had to kind of go back to our usual methods of testing. And I think that's sort of the great thing. There isn't anything you know; we can always fall back on

our usual practices if that particular technology isn't helping us in the way that we need. Thankfully that's not very often, but we can still get the results that we need to get for the patients.

Melani Dizon:

Yeah. So, how many appointments does it take on average to get things, you know, dialed in so that, you know, it's like maybe you don't see them as often?

Joohi Jimenez-Shahed:

Yeah, so my usual practice is to set patients up for six monthly appointments. So, we do the first programming and then a month later, months later, et cetera, until we've got to six months. So, I think it, again, just depends on patient to patient how long it actually takes. But six months really kind of covers, you know, the vast majority of patients to get it, you know, as, as, as get it set where we need where we need it to be. But the reason for that is that we can't just dial it up and get to the right settings right away. If we try to really go too high and we're not being mindful of how the stimulation may interact with medications, then we might end up with some problems there. With both things kind of working together. We can't reduce the medications too quickly because sometimes patients will have significant either withdrawal effects or side effects from doing that too quickly. So, there has to be this balancing and so it's like a little bit of stimulation, a little bit of medication adjustment, a little bit of stimulation adjustment, a little bit of medication adjustment and, you know, you, you get there eventually. And that can take up to six months. I think in Addie's case it was like three visits, so we didn't need to. Okay.

Melani Dizon:

Real quick before we go to Addie, you were talking about side effects. So, what, what were the side effects that you would notice and say, oh, something's going on? Yeah,

Joohi Jimenez-Shahed:

I think side effects may depend on the part of the brain that is being stimulated. So, there are two major brain targets. The one that ADI has is something called the subthalamic nucleus or the STN. Some of the common side effects that you might see in that location are things like slurring of the speech. Patients may have some tightening sensations. It may affect their vision if, you know, certain settings are, are kind of too high or you're too close to certain tracks. What else? I said, oh, changes in the walking and balance that are kind of like different from what we would expect in Parkinson's itself. So, things like that, which thankfully are all very transient, right? I mean, if we know that it's from the stimulation, we can just turn the stimulation down or adjust the stimulation. So, that, you know, is sometimes you know, it may be something that we run into, but it doesn't necessarily mean that it's going to be a problem for the patient.

Melani Dizon:

Yeah. Okay. So, Adi, it sounds like you are like the model patient, and everything was, was going quite well. Can you talk a little bit about what that programming process was like for you the first time and then the subsequent times that you went?

Audie Villaflor:

Yeah. The first time for my programming appointment, I notice after the programming, I notice when I sleep at night, I stop shaking my hand, both hands. It's a big help. But before that, before I sleep, I notice both my hands are shaking. So, for the first programming, it's gone. Wow. And we have a Christmas party with my family. Thank everybody. My surprises. It's a sort of Thanksgiving too.

Melani Dizon:

Yeah. Oh yeah.

Audie Villaflor:

Very happy.

Melani Dizon:

So, did that just improve your sleep right off the bat? I mean, was that getting in the way now?

Audie Villaflor:

Yeah, now I have to sleep. Before I cannot sleep without shaking my hand. Before first, before sleeping both hands.

Cora Villaflor:

Sometimes he will ask me to please massage my arms, and my hands before the programming, before the surgery, I will have to, because he said it's starting to become spastic. So, I have all sorts of concoctions, Bengay, Icy Hot, and all those things too. I said, do you have any pain? No. It's sort of like spastic, so would you please relax it? So, I used to put it on both hands. So, and then until I will see him sleep. But after the programming, oh, my work is lessened. Because I don't have to do it every night before you go to sleep.

Melani Dizon:

Right? Yeah. His hands are so good. He can be massaging your hands, right?

Cora Villaflor:

Yes. Yes. Actually, sometimes I ask him to scratch my back. Now it's useful.

Melani Dizon:

Right.

Cora Villaflor:

Or he will say, no, I can't do that. You know, I'm shaking. Oh, what's that's better because you don't have to do it. I need to move naturally. I'm so happy for him, honestly.

Melani Dizon:

Yes. What do you think ADI what do you think is important for people who are considering Deep Brain Stimulation and have heard a lot about programming and are just so curious? What do you think is important for them to know?

Audie Villaflor:

Once they were advised by the neurologists, they have to follow up with what they said and advised them to undergo DBS. mostly, especially when you are qualified for this procedure, to consider this procedure with your right neurosurgeon.

Cora Villaflor:

And the right motor nerve doctor

Audie Villaflor:

And the right, the right motor nerve doctor, I'm very confident you will benefit from this procedure. Above all, I thank God for my family, for their emotional support boundaries, love for helping me, directing to me their intellectual, dedicated doctors who are among passionate well-being commended and thank them as well for they are the reason why I'm enjoying living life again, being appreciated and seeing the beauty of every little thing that surrounds me. It is true in the dead to live your life today to the fullest, we're still looking forward to what the future holds. As, for me, I felt being useful not only for myself, but for everyone. This is certainly an awakening.

Cora Villaflor:

Life.

Audie Villaflor:

Life is a very life experience for me. Thank you for Dr. Joohi.



Melani Dizon:

Right. I love that. He

Cora Villaflor:

Constantly, he is mentioning that to his friends, that without these doctors who are dedicated, and very intellectual, and with the surrounding family, family surrounding them we are so lucky enough to find them because we are blessed to have them. And we will be grateful forever as long as we believe in both of them, Dr. Jha Shahi and Dr. Ken because they are not only intellectual, and compassionate, they are a god's given give to us.

Melani Dizon:

Yeah. Yes. There are the angels right on earth, right? Yes.

Cora Villaflor:

Yes, that's true.

Cora Villaflor:

Thank you for giving us this opportunity to tell everybody well, how good they are. They are really good. Fabulous

Melani Dizon:

Joohi, last question for you. After the initial programming, how do programming needs to change over time? So, he had a pretty great experience with three- or four-month sessions, and what is, and what is the expectation over the next many years?

Joohi Jimenez-Shahed:

Yeah, so I guess, you know, the part we didn't really get to touch on too much with Addie's case is that we were able to reduce his medications quite significantly. And so, you know, what we expect to see with that is over time it may be that the settings that we have chosen that are seeming to work really well right now may not be as effective anymore. And I think just like you notice some slow progression of Parkinson's, even before the Deep Brain Stimulation, we continue to see that Parkinson's progression. So, it kind of makes sense that just like we adjust medications over time, that we're probably going to need to adjust stimulation over time. There are certain symptoms when they come back that will be easy to you know, kind of fix again or control again with a stimulator adjustment.

There are some that are going to be a little bit harder. And those are generally the things that become more problematic for patients in kind of the chronic longer-term phases of Parkinson's disease. So, things like speech issues, swallowing issues, and balance issues, these are sometimes things that patients will start to experience more of even after the DBS, and then those may not respond as well to the stimulation. So, I think that you know, it's a great tool to have and I think, you know, when we're using it for patients who have already been using multiple doses of medications per day, having those dyskinesias, having those fluctuations, having that tremor that isn't getting well controlled, we expect to see those symptoms continuing to be very well controlled over time. It's just a progression of the other things and, you know, just a little bit of need to kind of adjust the stimulation over time gradually.

Melani Dizon:

Yeah. So, it's sort of them, you know, the rest of it is just this balance of medications and stimulations and more of one less of the other and just back and forth till you are finding the Yeah, right. Settings and medication. But the fact that you know, you had, you kind of got your life back right now, right? Just things feel so different and you're more hopeful and now you feel like you have, right, some control over what's going to happen. That's really exciting and I'm so glad that you found Dr. Shahed. She's pretty great. She's we like her around here, so we're very happy that you found her and we're glad that you had a really nice outcome. So, thank you so much for taking the time to talk to us today. Adi and Cora and Dr. Shahed. We really appreciate it. There are so many questions about DBS, and we really hope this will help our community very much.

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