

Family Dynamics of Parkinson's

Living Well with a Teenaged Care Partner

Davis Phinney Foundation

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

Chris Krueger (Manager, Educational Content):

Hello everybody, and welcome. I'm Chris Krueger, program manager for educational content with the Davis Phinney Foundation, and I was diagnosed with Parkinson's in 2020. I'm here today with Kirsti Peterson and her son Elliott to talk about navigating family dynamics amidst some of the gnarlier challenges of Parkinson's. Kirsti, why don't we start with your story? So, you live with Parkinson's, and maybe we should start with your diagnosis and how did that come about?

Kirsti Peterson:

Sure. So, I was diagnosed in 2016, so, gosh, seven and a half years ago at the age of 46. I'm now 53. And I would say that my journey to get diagnosed probably took about three years. In my early forties, I started to seek treatment for, or help to understand, some cramping in my right thigh and also my right shin. And some friends of mine pointed out that my right arm wasn't swinging, even though I really didn't notice it. And I went to, I think, three orthos because I'm a runner, and so I thought that maybe it was something orthopedic. And so, I went to three orthopedists to diagnose me with everything from a pinched nerve to a disc, you know, disc degeneration in my back. And it wasn't until my brother-in-law, who's a doctor, said, you know, I think you might want to get a brain MRI just to rule out a tumor or MS and go see a neurologist.

So, I did get a brain MRI, and obviously, Parkinson's did not show up, but it certainly eliminated that I had a tumor or MS. And then, I went to see a neurologist who put me on carbidopa-levodopa. But and this is kind of a common theme of mine, I'm not really a good researcher, and so, I'm, oh, okay. I just, if I had Googled that I had been put on carbidopa-levodopa, I would've known what my diagnosis was. But anyway, he referred me to a regular neurologist, and he referred me to a movement disorder specialist.

Chris Krueger:

Well, wait, I want to pump the brakes for a second. So, they didn't even tell you why they had given you that prescription. Wow, that's wild. Okay, so sorry to interrupt, but that's just a remarkable thing. Okay. So, you went to the movement disorder specialist, and what happened then?

Kirsti Peterson:

I kind of understand maybe a little bit where the neurologist was coming from; maybe he didn't feel qualified. Sure. So anyway, then it took about seven or eight months to get into a movement disorder specialist. And it wasn't until a friend of mine who reps Botox for this particular MDS got me in. And anyway, he very, I mean, I'm sure walking in the door, he probably knew what I had. But it was kind of funny because when I was in the lobby filling out the paperwork and, it said, you know, "Hey, fill out this form if you have Parkinson's disease." And I'm, "Oh God, thank goodness that's not me." So, I literally had zero clue.

Chris Krueger:

Wow.

Kirsti Peterson:

Until that date of diagnosis.

Chris Krueger:

Okay. So, you were taking levodopa, and you, are that what you stayed on after the movement disorder specialist visit?

Kirsti Peterson:

And that physician also prescribed within well after they diagnosed me, they said, come back after a month, and they asked, you know, kind of what my symptoms were. They put me immediately, not only on the carbidopa-levodopa but on, I think, amantadine and on Mirapex just to try kind of to attack all the symptoms at one time.

Chris Krueger:

Okay. And so, thereafter, you also started to participate in some clinical trials or at least one clinical trial, right? So, how did you decide to do that, and what was that? You know, how did that go for you?

Kirsti Peterson:

So well, first of all, after the diagnosis, I'm, okay, I was relieved because I'm like, okay, I'm not crazy. This kind of makes sense. And then I also, you know, said, I'm going to fight this thing. And I think part of fighting it was kind of this multi-, I was very kind of organized type a person, and I just had all these things that I was going to do within, and I was going to have this thing licked in a year. But one of the things that I was going to do was make sure that I gave back. And that involved pretty quickly getting involved in some research trials.

Chris Krueger:

And so, let me actually pump the brakes again for a quick second and say, Elliott, how old were you at this time?

Elliott Peterson:

So, I remember I was, I think, 13 when she actually got diagnosed, but I also remember that for a couple of years, four or five years before then, she was just kind of sick and seeking help and treatment and in turn, a diagnosis in the end. And then she finally got diagnosed when I was 13. And I remember the conversation very vividly with our family. And it didn't really make much sense to me or really anybody in our family. I was just very confused; my notion of Parkinson's was that it was, you know, more, more older people getting diagnosed. So, it was just kind of a shock at first to me. And we all didn't really know what to do or what to expect or where to go from there. So, I was 13, and it was just kind of strange at first, for sure.

Chris Krueger:

So, did you know anything about what was going on as far as any of the doctor's visits? Did you go to any of them, or what was that like for you?

Elliott Peterson:

I remember even before she got diagnosed, I remember she was just going to, you know, this doctor, this neurologist here and there and there to physical therapy. Physical therapy, just everything. And then I was also confused then because I was, why? I know she's sick, but then why isn't there anything being done about it or a diagnosis? And then, even after she got diagnosed, I think it even heightened a little bit. She probably sought out more help and more treatment from doctors. And then it probably, made it even more confusing for me because she got diagnosed, and then now she's going to more doctors, even though she [...].

Chris Krueger:

You thought this was supposed to solve the problem, not lead to more issues. Okay. Did you know when your mom started to think about clinical trials? Were you aware of any of that?

Elliott Peterson:

I slightly was, but I had my own things going on, of course. Because I was, you know, getting into high school and all that. And I had—

Chris Krueger:

Nothing goes on at that time of life. There's, it must have been a really easy time for everybody.

Elliott Peterson:

Exactly. But I had my own thing going on, but I would come home every day, and she would maybe talk a little bit about her new, I don't know, just her experience throughout the day and whatnot. But I think she went on the trial when I was about 15 or 16. And I didn't really think too much about it. I remember she was explaining to me how it all worked. This was also very weird to me because it was very invasive, the way your day-to-day process, throughout putting the pump. She'll probably explain better than me, but it just didn't seem right at the moment. And again, I was just very, very confused.

Chris Krueger:

So, maybe we should go back and talk a little about the trial. So, what was the point? You wanted to give, Kirsti, back and you thought, okay, one way to do this is clinical trial participation to help with research. And so, what did you end up with? What trial? What did you end up pursuing?

Kirsti Peterson:

And maybe just make a couple of points or caveats. Sure. We're talking about family situ. I also am very much a, my kids like to say "TMI mom." I'm very open with my kids, and I always have been. So, the minute I got diagnosed, I came home. I'm I didn't, even in the drive home [thinking] everybody needs to gather. And I didn't even really think through it in hindsight, telling them I just blurted it out. So, it was, I don't know. That's just, that's just kind of who I am. And in terms of the trial, I think maybe a little bit more about my own just affect or personality, I tend to be pretty optimistic. I tend to be pretty trusting. I don't—I maybe am slightly spontaneous or, you know, just kind of...anyway. I tend to be pretty optimistic and positive and maybe a little bit naive.

But anyway, this trial came up, and I'm like, oh gosh, I get a chance to give back. If I also recall some reassurances that this is totally safe because it's been approved in Canada and Europe, I believe. And, you know, this is just kind of a formality. And you know, also some incentives, oh, when the trial's over and it's approved, you can get the drug for free. And it was \$5,000 a month. So, there was kind of a lot of, maybe, cheerleading and me being fairly trusting. and in addition to the pump, I was also on, you know, amantadine. I was on [...]; I was on carbidopa-levodopa. I was on a lot of Parkinson's medications. And I don't, I think the combination of all of those things, I mean, I was suffering from hallucinations. I was seeing cats; I was seeing dead people. I was feeling presence. I don't think that was necessarily from the FDA trial drug, but it was all of this combination of things. And then I think that my doctor kept saying, "Oh, we just need more medication," because you're, everybody, everybody seems to love this drug. And I don't know, kind of why you're, you know. So, anyway, let's just give you more, let's give you more, let's give you more because we could adjust how much I got.

Chris Krueger:

This is the trial, the trial supervising physician who's changing your dosage, or is this your movement disorder specialist?

Kirsti Peterson:

This is the trial [...]. Okay. The trial doctors.

Chris Krueger:

Okay. Okay. So, things are moving around. You're having some issues with some side effects and hallucinations, and you're seeing cats, and so, this is, this is a complicated experience for you. And how long is this? So, this occurs in the first week. This occurs for two weeks. And how long has this trial been running for you?

Kirsti Peterson:

So I was on the drug—and I'll describe at some point the end of it—for about nine months. And I would say pretty rapidly, I mean, within maybe the first month or two. The other thing that I now know in hindsight about impulse control disorders is that I was having some major impulse control, specifically around sex and watching porn, which I'd never done before in my life. And then also shopping, which I know might be familiar to some people about impulse control.

Chris Krueger:

You were on a dopamine agonist, as you said. Is that what you said? So, you didn't have any of these issues with just the Mirapex; once the trial started, this started to come up. Or was this happening before a little bit ago now that you know what was going on? A little bit?

Kirsti Peterson:

Maybe, a little bit, a little bit for sure, maybe in the shopping area and then also in something I know now is called punting. So, it's which is just doing tasks habitually, you know, with, with abandon. And this is, and Elliott, maybe you can describe. So, I was sorting my entire house by colors, orange, and pink, I mean everything from furniture to pens to pillows, and that was kind of my break from reality.

Chris Krueger:

Okay. So, there's a lot going on during this trial, and you're experiencing things you didn't know were issues you might face. And I imagine, Elliott, you didn't have any sense that these were issues that might occur. So, you come home, and everything that's yellow is in the same room, or well, you know, however it goes. What does this mean? How do you experience this?

Elliott Peterson:

So, I'd like to backtrack a little bit too.

Chris Krueger:

Oh, sure!

Elliott Peterson:

When she got diagnosed, she kind of was seeking out all these doctors, and then they would prescribe her medications to kind of fix some of her symptoms or whatnot. But it would give her more side effects, and then they would prescribe more on top of each other. So, then that's when, in hindsight, she realized that her behavior was becoming more sporadic, and she was just not; it wasn't right, I guess. And then she went on this trial, and then it just perpetuated her symptoms, and her side effects just heightened, tenfold basically. And I didn't really realize what was happening because it was kind of gradual; every day, something was different. I would come home to who knows, God knows what, but I didn't really realize something was really wrong until I came home from school one day, and all I wanted to do was get up to my room, which is up those stairs right there.

And I couldn't move because everything was scattered everywhere. And it was kind of a nightmare in a sense. It was actually a really traumatizing experience for me. Because all I wanted to do was go to my room after school, and I couldn't even physically get there, let alone understand what was happening. But then, again, I didn't really want to confront her about it at all. So, I don't know exactly know what I did, but I think I just shimmied my way to my room and kind of, I don't even know, shut off everything.

Chris Krueger:

So, you're 15 or 16 years old, and you come home, and you can't even get to your room. And who knows what happened to you that day. Maybe you do remember what happened to you that day in school or wherever you were with your friends. And then, man, that just sounds so hard. I mean, for both of you, of course, but I mean, in particular, you come home, you don't even know what's going on, either one of you really. But then, Elliott, you can't even get to your room. So, you get upstairs, and that's the end of that day, maybe. But so, what happens in the bigger picture? I mean, how long does this sort of go? Does this go the whole nine months that this is sort of accelerating complicated?

Elliott Peterson:

I'd say it probably was pretty accelerating and complicated. But I didn't, at the moment, it was just very hard to conceptualize what was going on. So, mainly, what we have learned from all this comes from hindsight. Because at the moment, we didn't really know what to do or what was the root cause of all this because there were a lot of different facets that were going into her general behavior and stuff. And there are a lot of other things going on in our lives that we had to worry about, but so it was just really hard to kind of solve the issue at hand, I guess. And it really just took some time to realize what was really going on and what was wrong.

Kirsti Peterson:

And in fact, I think it's, it kind of started with maybe trying to figure out what was going wrong was my sister who's I mentioned, well she's a doctor, but also, she doesn't live here, but she was kind of maybe visiting or hearing from my ex-husband or my kids or something. And so, she actually did some looking up, including on Davis Phinney. You know, "every victory counts." There's a thing about impulse control thing disorder with dopamine agonists. And so, she sort of started getting to call the neuro, the trial researcher, and stuff. She actually does have a text message that she received back from them in February, but I didn't go off of it until April or May when I was walking my dog. And I just kind of had this aha moment of, "oh my gosh, I got to get off this trial."

Chris Krueger:

So, you didn't finish the trial; you stopped early.

Kirsti Peterson:

I just quit.

Chris Krueger:

Oh, well, that, I mean, you know, and just from looking from the outside, and that sounds a reasonable decision in that case. Wow.

Kirsti Peterson:

I didn't titrate down. I just said I see. Done. So, anyway-

Chris Krueger:

Maybe it wasn't the optimal way, but it does sound like the right decision for you at the moment and for your family. So, I'm really interested in how you navigate that because it sounds really, really complicated. I mean, you're, you've got, you've got impulse control disorders that are involving some shopping issues and some, and some sexuality issues, and you've got some punding behavior, which is not something that gets talked about very often, but, you know, you're, so, I don't know what the tasks were that you were doing, but you're doing these repetitive tasks and you're you know, they don't really have a purpose and, but they're so compelling. Right. And they're complicated tasks sometimes, too. So, literally—

Kirsti Peterson:

Moving couches up and down stairs, I mean, anyway, sorry.

Chris Krueger:

That, well, so that, I wish that I felt so compelled to exercise in a certain way, but I suppose I don't want it to be compelling, you know, totally compelling in the way that a punding

circumstance would be. But so, what do you do to navigate this together? I mean, how, what does this look like on a daily basis, and how do you interact together about this at the time?

Elliott Peterson:

I mean, at the time, of course, we kind of really only had each other in a sense. Because this is really hard on me. And, of course, it was really hard on her. And I feel, in hindsight, too, that I was kind of the only one who could handle it emotionally. Because that's just not who my brother and my father are. And I didn't really know that I really had these abilities until I was confronted with them. And I'm very grateful to have learned what I've learned from all this experience. And I wouldn't know what I was capable of doing, but while it was happening, I didn't really realize that I was doing this. It was just kind of, again, day-to-day life. Oh, I just kind of had to come home because I was dependent. So, I had just had to come home and kind of see what happens or see what I have to do, or, you know, every day was, you know, something completely different.

Kirsti Peterson:

And I don't, I don't want to totally speak for you, but, you know, he was also dealing with, unfortunately, some con, you know, a series of concussions, including one from a car accident that was pretty bad when he got hit by a drunk driver. And so, he was also dealing with, and then subsequent to that, he, you know, couldn't play hockey anymore, which had been really his life or, you know, a really important thing in his life. And, you know, and then, Covid is a whole another story. So, it was kind of this, this on, I mean, he handled it.

Chris Krueger:

One thing after another. I mean, it's—

Kirsti Peterson:

But I mean, he, that's why I'm, Elliott is just the most amazing person. And, you know, I guess I may be slightly biased, but, you know, to go through all of—well, some other stuff happened as well if we want to, I had a grand mal seizure, and he witnessed that. Anyway, so to come down, see your mom seizing up, and, I don't know, 10 EMTs in our living room and taking me off to the ER. So, there were a few years of a lot of traumatic events, I guess that happened, for sure.

Chris Krueger:

And maybe you didn't know this at the time, but, you know, I think you're, it sounds, it would be fair to say that you were, you mom's care partner, Elliott, and you may not have known, it sounds you didn't recognize it then. Do you, I mean, is that how you feel about it looking back on it now and even today? I mean, do you think that that's an accurate description of what you were doing and what you are doing now in fruition?

Elliott Peterson:

I was definitely her caregiver for sure. And it was definitely more emotionally than, physically than, you know, getting her something to eat or something that. It was more just being there for her. And I forgot where I was going—

Kirsti Peterson:

It is not really fair to put an adolescent child through that.

Chris Krueger:

So, what's amazing to me about this is that all these things would've just ripped most people completely apart from each other and maybe from themselves, right? So, it's really remarkable to me that you can, you're, you're sitting there together, and you seem to have such a great rapport. You seem to really care very deeply and love each other very much independently of the fact that all these things could have been, I mean, they must have been just so incredibly difficult to manage and to and to go through together. So, I guess—

Kirsti Peterson:

I think one of the things we talk about is that we have this shared experience, and nobody else can understand. I mean, so, friends, you know, I've unfortunately lost some friendships and over kind of, because people don't really understand or couldn't really handle it. And, you know, some family, you know, I mean, they try to be understanding, but I mean, nobody really understands besides Elliot. So, maybe it's that shared experience. Does that make sense?

Elliott Peterson:

It makes a lot of sense. And I guess I didn't know I was a caregiver at the time, but then she kind of brought it up a little bit, and I was like, that kind of makes sense. But it didn't really, truly hit me until I don't know, about, probably six months ago to about now. And I do kind of see myself as a caregiver to an extent, but I might not identify as one, but I'm just kind of here.

Chris Krueger:

You can just see it as that's a part of what your relationship involves. So, now, you just get back to the sort of core of the story for a second. So, you leave the trial. And you know, maybe there are some issues as, as far as how that the immediate moments after that, just given the fact that you left sort of suddenly, but that's not the end of the story, right? I mean, that was, that was a little while ago. How long ago was that?

Kirsti Peterson:

Let's see here. It's maybe been four years since I got off.

Chris Krueger:

And so, what's happened since then? I mean what, where do things stand now for you with regard to your Parkinson's, Kirsti?

Kirsti Peterson:

Well, the biggest game changer, I believe, besides getting off of those dopamine agonists, which I'll never go on again in my life, is understanding that. But I had DBS two years ago in June, and it has been a, it's given me back my life, really. So, that's been a great experience for me.

Chris Krueger:

What was your, how did you decide to do that? What was your thought process behind that? I mean, it sounds like your experience was pretty complicated, so maybe you were, maybe it was very clear to you that this was the way to go but tell me about the decision-making process about that.

Kirsti Peterson:

Maybe it's kind of back to my old; I don't really research things. I just kind of intuitively arrive at them. And I cannot always, not always, I mean, as soon as maybe I heard about DBS, I'm, and I'm going to do that, I didn't really put a lot of thought into it. Or research, or again, here I am, trusting surgeons and doctors. But I was, before I had the DBS, I mean, I was pretty sick. I mean, I could not really even walk. I barely could walk around the block without a walker. I was using a cane. I was extremely fatigued. I had to quit my job about five years ago just because of fatigue. My cognition, executive functioning was not good. I was really struggling, struggling a lot. And so, I don't know. The DBS is just kind of, let's do it.

Chris Krueger:

And so, Elliot, what was your experience leading up to this? I mean, so this is a pretty dramatic situation again, right? Your mom is not able to walk around the block. She's left her job, she's gotten out of this clinical trial, and there you are in your, and what's your experience?

Elliott Peterson:

So, I kind of repressed a lot of the things that happened, and I didn't really know or realize just how much they affected me, who I am, my emotional state, or my overall well-being, I guess. And I kind of held a lot of it in, which, of course, is not a good thing. Mm-Hmm. But, because I would try to tell some of my friends what was going on, and they might recognize it and, you know, they might say, oh, that's horrible. But nobody really understood what was going on with me as well at the time. I really had no idea what was going on. So, it was just really hard. I

would try to seek help, but it was to no avail because nobody would really, truly understand. So, I couldn't really connect with anybody.

Kirsti Peterson:

I think one example—and where Elliott maybe was keeping this in—where I tend to tell everybody about my Parkinson's, but I think in one of your classes at George Washington High School, there was a topic or a subject about Parkinson's. And I said, oh, does your teacher even know that your mom has Parkinson's or your friends? And you said no, you didn't share that.

Elliott Peterson:

No, I didn't. I didn't really tell anybody except for my closest friends. But then again, I wouldn't tell them these very specific details, such as coming home to the house in shambles. I don't think I really told anybody about that or very specific things that were going on in my life. It was more a general, generally telling them what was going on, but then it didn't really feel any that it reciprocated with anybody.

Kirsti Peterson:

Were you embarrassed and ashamed as well?

Elliott Peterson:

I don't know if embarrassed and ashamed are the right words, but I just, for some reason, didn't really want people to know; I didn't really want sympathy. Mm-Hmm. I was more seeking empathy and a true somebody who could truly understand what was going on. Because I didn't really value, you know, surface level sympathy at that moment. And that's not what I needed.

Kirsti Peterson:

And you didn't want, neither of us, I don't think, wanted pity.

Elliott Peterson:

Or publicity. I don't know everybody to know.

Chris Krueger:

So, what do you think? Do you have any? I mean, this is a, maybe a complicated question, but do you, is there anything that you are now being able to look back on it, that you're, oh, wow, I really wish I would've had this thing then. I mean, is there anything you think could have really helped you that you didn't have access to? or that you didn't do either? That could be for either one of you. I guess. I mean, it's a very complicated situation.

Elliott Peterson:

I think I needed a sense of community. Mm. Just some very understanding. Not even if they've been through what I have or even if they've been through something sort of similar to a sick parent, but I needed, really needed, a sense of community where I could explain what was going on. They might not understand again, but they would—they would listen and try to understand just so I could just release just even the slightest amount of stuff that I was holding in. So, just a loving community and an accepting community would be good.

Kirsti Peterson:

And I think maybe we experienced that at the World Parkinson's Congress just in July, Chris, when we were having dinner that last night with people from the Davis Phinney Foundation and Elliott felt safe, or I don't know, maybe to say, "hey, I'm going just to tell my story because I feel this is a group that understands." So, kind of being in this, this Parkinson's bubble is kind of the safety zone. And people, you know, even people maybe that don't have Parkinson's, but they're certainly working with people with Parkinson's every day. They, they get it.

Elliott Peterson:

We just had a really open conversation, and that was what I even needed that at the time. That was not that long ago. And I was, I still hold a lot of this stuff in, but a community such as that is certainly beneficial to my certain situation. Just so I can just openly talk about it. And you're definitely, that community would definitely be more understanding than even my friends or some family members as well.

Chris Krueger:

And do you think that's the same situation for you, Kirsti, that that's really something that would've been helpful to you? Or was there something else that would, I mean, obviously community's useful for people to have an understanding with, with, with others? That's generally good. But what is, is there anything you look back on about your situation, Kirsti, and you think something else could have been helpful? Or maybe Elliot, maybe there's something else for you, too.

Kirsti Peterson:

So, I think, well, and I also gave some feedback to the research and in terms of the FDA triadic, probably should have never been allowed to just do it on my own without somebody, a requirement that somebody's at every appointment so they can just—

Chris Krueger:

Oh, you mean, is a care somebody from your family or another someone else going to these, these visits with you?

Kirsti Peterson:

Right. But so, I mentioned at the beginning about how I was going to tackle this PD thing and have it all resolved in a year. But I think one of the things I did first was getting involved in the PD community. And I think, and these are in no particular order, but the thing that saved me back then is definitely the Parkinson's community. And I tell some people, I don't know if I wouldn't have Parkinson's because I wouldn't have met all these great people. And it's through Art is Action, which is a Parkinson's dance community through the Davis Phinney Foundation, through another local PD Parkinson's Association of the Rockies, through some ad hoc things. So, I'm definitely, that is something I guess immediately that I've reached out to immediately.

And they've, and the Parkinson's community has, really been a game changer for me, and the DBS. And I think the other thing is that I didn't tell my neurologist; I mean, in fairness, I didn't tell my neurologist maybe everything that was going on because there was a lot of shame. [...] means, first of all, cognitively, I just wasn't connecting the two things, but I think there was just a lot of shame and embarrassment. And so, that's, I guess, one of the reasons why I'm hoping to tell my story through formats like this, and I'm trying to write a memoir that's been kind of hit-and-miss. But, you know, just, well.

Chris Krueger:

Cognitive function and, you know, can get a little complicated.

Kirsti Peterson:

But I just want to share my story because there's no shame in this. And there are things that happened to me, and I think that me telling my story and Elliott being willing to tell his that, you know. Hopefully, it just resonates with some people.

Chris Krueger:

So, I want to jump back to something about what Elliott what you were saying about, you know, the community. Do you think you would have an [...] if somebody's like, hey, Elliott, there's this group of people that meet, and there are people whose parents have chronic health? Do you think you would've done it then?

Elliott Peterson:

So, I definitely would not have done that.

Kirsti Peterson:

Right. Being honest.

Elliott Peterson:

Even my mom, a couple of years ago, was, I know some people who been through [this] whose children have been through something similar to this. And again, I kind of didn't really want to

talk to them or kind of push that away because, I don't know, I was very depressed just to be very straight up and honest. I was very depressed during that time. And just for me personally, I don't know if anybody else feels this way, but when I'm at my lowest, I don't even know if there is helping to be had; even if there is help, I probably won't seek it out. Because I'm just, I was just very isolated, and I just didn't really want people to help me, even though I absolutely needed the help. So, I definitely wouldn't have at that very moment in time. But now I probably would be more likely to.

Chris Krueger:

Yes. That's really complicated, right? Because you look at it and you're, on the one hand, I needed support. On the other hand, I was, that's just not where I was at that moment. So, that's a really, really, really hard moment for sure. And I guess I'm—

Kirsti Peterson:

For instance, I had met with somebody in one of my young onset groups, and his, he was talking about his, he was maybe diagnosed about a year ago, and he was saying that his, you know, late teen, early adult kids didn't really understand. I said, oh, I asked Elliott, I said, “would you be willing to talk to him?” And he said, “sure.” So, I think that's maybe changed a tiny bit for you.

Chris Krueger:

And I want to you know, when we were talking about whether this was a call that, and in a, in a video, we might want to record together, Elliott, you said something that was interesting to me that I wanted to ask you about, which was that you said you wanted—you realized recently that you needed a break. And I'm wondering how you realized that, how did you take it, and what was going on around that? Can you just talk a little bit about that? Because I thought that was really interesting.

Elliott Peterson:

So, I guess I've been living with just my mom, not my father, my brother for, I don't know, four, four or five years now. And it's just been us two, and we get Covid.

Chris Krueger:

True, us, too, in Covid. That's the story of our, of so many people's lives.

Elliott Peterson:

So, I've spent a lot of time just with her, which isn't necessarily a bad thing, but I'd started to think I'm not a very aggressive person or an angry person, but I started to see myself getting very just angry at her behavior. I was just kind of tired, I guess, of dealing with this every single day. So, then that manifested as being very passive-aggressive or bickering back and forth. And

there's not very healthy, I guess. So, I didn't really come to the realization that I needed space because I've been kind of putting a lot of my energy into helping her out. And I didn't really understand that. I have my own life that I need to live, and I have my own passions I need to pursue. And I didn't really realize that me being here was kind of getting in the way of that a little bit until, I don't know, probably a year ago.

Chris Krueger:

So, it's a continuing journey, it sounds, and you're still working through it all together, even though maybe there's some more space that's going to develop. And I guess I wanted to ask a peculiar question, maybe to start to wrap up our conversation, and I wonder if either of you has a perspective about it. I guess I'll ask it in two ways, and I'll point it to you first. Elliott, do you have anything that you would recommend to somebody who might be going through something similar to what you're going through or what you might recommend to a parent who has a child who is maybe a teenager younger or, you know, still living with them and anything you would say might be useful for them to think about or to know?

Elliott Peterson:

I mean, that's a very open-ended question. But I think just a very simple kind of answer to that is that honesty is probably just the best thing that can help any relationship, no matter how complicated it is or what's going on. But pure honesty is kind of hard to come by, and it's a very important thing in the glue of really any relationship. So, just be upfront and honest about how you feel and how you feel about the other person. And it just, it's so much healthier than, than I don't know, living in deception and especially lying to yourself. That's just not healthy at all. And it, there's no longevity in that. So, just being honest with yourself and with everybody around you is, that's just my biggest advice.

Chris Krueger:

I mean, that's sage advice right there. That's the advice of somebody who's been through some things and is curious. Do you have anything that you would say to either somebody who has been in a situation like yours or to a young person who's living with a parent who is going through Parkinson's? And I guess there's one other piece I'd like to, and I'm sorry to do this to you because I'm adding something to the question for you. But I also wonder if you might have any words about, you know, looking back, I mean, obviously, the clinical trial experience for you is hard, but I'm interested in knowing if you have anything that you'd do just as a way of just sort of closing that story, what would you recommend somebody think about on that front that you maybe didn't think about before you participated? Because I get the sense that you wouldn't say clinical trial participation is not something you would recommend, but in your particular case, it didn't go. So, the three things would be, do you have anything for a parent, anything for a child, and anything that you might want to share about your thoughts about clinical trials?

Kirsti Peterson:

I guess, as a parent, just love your children, you know, and I promise I wasn't getting [...] in this, but I just, I think that having kids, you know, and my kids are the most, I mean, they are the most important thing to me, hands down. And I know, I know that they love me so much unconditionally, just I love them unconditionally. So, also, maybe listen to your kids because they have some wisdom no matter what age they are. So, love and listen as a parent, as advice to a kid, you know, I'm, first of all, my heart goes out to you if you have to ex—I mean, this is not fair, this is not fair on Elliott, it's not fair on his older brother Hawking.

It's not fair on their father. It's not. It's just, I mean, it sucks in some ways. However, I just know that your parents love you and they're trying their best, the best that they can. So, and in terms of the trial for me now, I'm participating in trials that aren't invasive, maybe interviews or, you know, online kind of survey things. So, I'm still doing trials. I've just chosen for myself not to do anything that's invasive or take a medication just because which is unfortunate. But I just, that's a choice that I've made for myself. But I certainly am not going to; I mean, thank goodness for the people who did do the trials for the drugs that I am on that do work for me. So, I have a ton of gratitude towards those individuals. Because otherwise, we wouldn't have, you know, a lot of the drugs that we do in the PD community. But maybe my advice on that is maybe to do your homework a little bit more than I did.

Chris Krueger:

Well, and I also think that the advice you gave earlier a little bit just was, was really important too, that the idea that doesn't, if you can bring somebody with you, bring somebody with you, and certainly involve them as much as you can in being open and honest as, as Elliott was recommending. You know, I guess I just want to say, you know, in response to Elliott, your observation about the [...] sharing your story, you know, we did, we, we met in Barcelona. It was such an honor to get to spend time with you all and that you were willing to share your story with the group of us over dinner. And then also just as you're willing to share it again now in a broader sense, I mean, it's really, I'm really grateful for your time and courage, both of you. And thanks so much for taking the time to share your story.

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