Michael J. Fox:

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The Michael J. Fox Foundation:

Navigating Parkinson's disease can be challenging, but we are here to help. Welcome to the Michael J. Fox Foundation Podcast. Tune in as we discuss what you should know today about Parkinson's research, living well with the disease, and the foundation's mission to speed a cure. Free resources like this podcast are always available at michaeljfox.org.

Bryan Roberts:

Hello. Welcome to the Michael J. Fox Foundation Parkinson's Podcast. I'm Bryan Roberts, Associate Dean of the Park School of Communications at Ithaca College. I'm also a member of the Michael J. Fox Foundation Patient Council and guest host of today's episode. I was diagnosed with Parkinson's disease 12 years ago when I was 30. I'm 42 now. I have a very busy life and Parkinson's is just part of it. I see a lot of thinking about what it's like parenting with a chronic disease or a chronic illness, something like Parkinson's.

Bryan Roberts:

Now parenting, as we know, can come with its own challenges, and having a chronic illness can make those challenges even tougher. But there's been an unexpected side effect, and that's actually enriched my relationship with my daughter and with my loved ones around me as I parent with Parkinson's disease. I maybe spend more time in the moment, more time reflecting about the time spent with the individuals I care about. And really, I value every day I'm with them. And to bring that into my parenting only makes me, I like to think, a better father, a more communicative dad, and someone who just loves being around his daughter.

Bryan Roberts:

Earlier, I was able to speak to three adult children of fathers who have Parkinson's about their experience, about what it was like growing up, and really how it's impacted them now as adults in relation to having a father with a chronic illness. And hey, what great timing. This weekend is Father's Day. So let's go to the conversation and I hope you enjoy it as much as I did. Thank you for joining me. Before we really get down to our conversation, can I just ask you to introduce yourselves? Maybe who you are, what you do, where you live, because I always think that's important, and how old you were when your father was diagnosed with Parkinson's disease. So Akbar, could you start us off?

Akbar Gbajabiiamila:

Yeah. So I'm Akbar Gbajabiamila. I host the TV show, American Ninja Warrior. I've now been with the Michael J. Fox Foundation for a couple of years now. And my father was diagnosed back in 1998. Actually, he was misdiagnosed in 1998, properly diagnosed in 2000. And so this was a year after my high school graduation. So I was about 18, 19 years old at the time of his diagnosis. I live in California, the Sunshine State, the real Sunshine State.

Cathy Lee Crane:

So I'm Cathy Lee Crane. I'm an experimental filmmaker, have been doing that for a quarter of a century. I also teach young people how to make movies or how to think about them. I live in Ithaca, New York. I was born and raised in Phoenix, Arizona. And my father was diagnosed with Parkinson's in 2008, and I was 46.

Sam Fox:

So I'm Sam Fox. I'm also in California. I do independent film finance. My dad was diagnosed in 1991 when I was about two years old. And then he came out publicly as having Parkinson's in 1998. So it's been a process. There have been a couple different stages.

Bryan Roberts:

Great. Well, welcome to all three of you. It was interesting, that part that you said misdiagnosed. Because I think it can be challenging to say, "I was diagnosed X, Y date." Oftentimes, it is a process. I remember when I first started experiencing symptoms, I went online to see what could be bothering me. And I remember saying to my wife at the time, I said, "I either may have Parkinson's or I have ovarian cancer." WebMD, you can have anything you want. The good news to that story is that.

Akbar Gbajabiamila:

How did you know it wasn't ovarian cancer?

Cathy Lee Crane:

Exactly.

Bryan Roberts:

Yeah. I was a communications major, so didn't really go into the anatomy. So I think the interesting thing for all three of you is you were each informed of your father's diagnosis at a different stage in your life. And I'm curious if that has an impact on how you experience the disease, how you process it. So Cathy, can you start us off? What was your reaction when you got the news? You were in your 40s, right?

Cathy Lee Crane:

Yeah. Like anything that's heavy in our family, we usually sit down as a family. So I think even though we're all far-flung and around from Hawaii to New York, we're everywhere. So we probably were seated at a living room somewhere. My feelings about it were that it was probably inaccurate, that it seemed, to me, like a strange thing to suggest because he didn't have the thing I only ever associated Parkinson's with, which was tremor. And he didn't have that. So I'm like, "Well, how did they diagnose this as inaccurate?" It took me a while to realize that you're only diagnosed with Parkinson's based on physical symptoms, manifestations. So there were other things that were definitely happening and became more pronounced for my father, specifically his speech.

Bryan Roberts:

Sam, you were quite young. Was there a time that you noticed that your dad had Parkinson's? Or was it just something you grew up with?

Sam Fox:

Yeah, no. For me, my dad was always... There was never a distinction. It was always my dad who has Parkinson's. There was no before. Because I was younger than three when he was diagnosed, and that was after he had been trying to figure out exactly what was going on for a while. So he had been not as symptomatic as he is now because obviously, it's progressive. But he had been symptomatic. So for me, my whole life, my sisters have always called him shaky dad. That's just who he is and part of the identity. So I never had that moment.

Sam Fox:

Well, it's some combination of I never had that one moment where I was presented with this fact, where this is a thing that my dad is going to have to struggle with forever. It was a series of moments. Because every single time, there was some change in his prognosis or there was some difference in circumstance. It interrupted that normality a little bit. But I think probably overall, because there was no before for me, it was just during. It's all been during. I think that's probably put me in a place where it's a little bit different than if I had to have that experience where I had to sit down and have someone give me information. It just was absorbed.

Akbar Gbajabiamila:

For me, I was 18 years old, 18, 19 years old when it happened. But [inaudible 00:07:39] you're old enough to feel like you're on your own, but you're young enough to where you still need your parents. And for me, I still needed my dad, even though I was flexing because my muscles were popping, and I thought I was a big deal because I was going to college playing football. And I remember getting the diagnosis. I got a phone call. My dad was at my [inaudible 00:07:58] game, my younger brother's high school game meeting, passed out. And I thought that was weird because maybe he'd been working-hard or something like that then they took him to the hospital. There was that concern, and I'm just thinking, he'll be all right. Then they said it was a stroke, I'm like, a stroke? Why would he have a stroke a couple years later? It's Parkinson's, and I just couldn't believe it because my dad was still like Superman to me. I think that was the hardest part is thinking that Superman could somehow be affected by anything outside of kryptonite. I didn't want to believe it, and I feel a little shame in saying this, and I think depending on where you are in that stage, and for me, I was at a very vulnerable stage, I think the older you get, the more empathetic because you've had a little bit more life to live and you've seen different things.

Akbar Gbajabiamila:

I didn't have enough repetition to see life, so I thought my dad was taking it. I just said, dad's faking it. He's been working his butt off for so many years to take care of all seven of us. Clearly he's done and he just don't want to say he wants to retire. I swear these are the thoughts that went through my brain. I'm like, come on, Dad. You can. Then it was just a weird thing, but once it kind of set in, maybe about a year later, I think it was after I graduated from college, I graduated in 2001 from San Diego State, and I think it was, then I go, this is a real deal, because at this time, he had stopped working for maybe a couple of years now as a plumber. I go, oh shoot. Two years. This is my dad. I think that's when the reality hit me that this is a big deal. For years and years I just didn't know what to do.

Bryan Roberts:

Yeah. I think that's what interests me so much about the disease. I would say as an academic, I'm fascinated by it. I wish I didn't have it, but I find it very interesting that it's very individual, and I think we approach it differently. Parkinson's, your story really resonates with me because I was diagnosed at 30. I was not the nicest person at 30. I was self-centered. I really cared about my hairline more than anything. Actually, I still do. Life is full of disappointment, but it's humbling. It comes in fits and starts, but I think ultimately you learn to manage it as a family, and that brings me to my next question.

Bryan Roberts:

I just finished a book called Ending Parkinson's disease. In the book, they talk about how Parkinson's, the rate of Parkinson's diagnosis, has doubled, and I believe it says by 2040, it will double again. That's about 12 million people diagnosed. That's staggering. That's a lot of people, but it's also a lot of people who have children. It's a lot of families. I was thinking about that. My question would be, given that there's going to be this rise, if you had to sit down with a family, not just the person, but the entire family, is there advice you would give them knowing what you know about the disease now? Maybe Akbar, do you want to start on this one?

Akbar Gbajabiamila:

I would say lean more on like a... again, I'm saying it because we're talking here, Sam, obviously with your father, but with the Michael J. Fox Foundation, but it's in the tremendous resource. I think once you go online, I think like anything else, like I teach my kids, it can web you in 40 different directions. Maybe even more actually, but it can be overwhelming when you hear somebody says this, but then there's treatment over here. Then that says that, and there's something. Before you know it, you need one main source that allows you to be able to navigate like a point guard, to use a basketball analogy.

Bryan Roberts:

As a Knicks fan, your competent point guard analogy is lost on me.

Akbar Gbajabiamila:

Whoa, whoa, whoa, whoa, whoa, whoa, stop it. It's all about Lakers. It will always be about the Lakers.

Bryan Roberts:

Many family members are surprised and pleased to learn that they can play a role in Parkinson's research and help prevent the disease. For many, research is a way to show support for a loved one. The Parkinson's Progression Markers Initiative, or PPMI, is enrolling family members of people with Parkinson's. People over the age of 60 are especially needed for the study. Get started at michaeljfox.org/podcast-PPMI.

Bryan Roberts:

Sam, do you have any advice you'd give to a family?

Sam Fox:

Yeah. I think what's interesting, the sort of the perspective I have on this, is that in almost any interaction that I have, one of the two or three things that most people know about me, before they've even met me, is that my dad has Parkinson's. I'm in sort of unique position, I think, where a lot of people come up to me who I don't necessarily know or friends of friends and I get this question a lot. I get, hey, my dad was just diagnosed. I'm 15, I'm 18, I'm 20, I'm 30. What does he do? What do I do? Obviously, like Equar said, the first thing that I always do is direct people to the foundation because it is a great resource, but also I think one of the most important things to remember our with Parkinson's, and Kathy, you said this earlier, is that it's such individual disease that you really don't want to see one person who you've heard has Parkinson's and use that as a model; this is what your dad's going to look like in five years, in 10 years.

Sam Fox:

Either way, because you just don't know, and I think that's when you can get into, as a family, a weird sort of head space when you're either looking at someone who's 20 years in and fairly asymptomatic, or you're looking at someone who's 20 years in and severely symptomatic. An important thing in my life that I had to come to grips with is for any given person, you don't know what it's going to look like in five years, and that's A, the scariest thing, but B, also the thing that gives you some hope and also gives you something that you can sit down and talk about as a family is we're going to be there for you, dad, as this goes. We maybe know what it's going to look like tomorrow and then the next day, but once you get farther than that, we don't know. I see a lot of my role, as the son of someone who's going through this, to sort of be there for them.

Sam Fox:

That's the sort of advice that I give a lot of people is just, unfortunately, it's a disease where you have to react a lot more than you'd like to. It's hard to be proactive. Being there for someone, just having that understanding that you don't know what's next, that's the hardest thing to get your head around, but once you get your head around it is the way that you can be the most supportive and be the most at peace with your situation.

Akbar Gbajabiamila:

You said something that's so true. One of the things that I remember, like with Muhammad Ali, the late Muhammad Ali, is that obviously his speech started to deteriorate, and again, that's the image, oh my goodness, this is going to... but that hasn't happened with my father. Now, his speech has slowly started to get softer and softer and sometimes, depending on where he is, higher up. Even with a thick Nigerian accent, I can still understand him, so it's not the same. It's different for everyone. True that.

Cathy Lee Crane:

Yeah. I think it's really important, this idea of it being progressive; that it's not going to be identifiable, it's discreet in any given moment, and I think that two things that stood out for me for my dad's care was, first of all, he was in Phoenix, which is where the Muhammad Ali Center is. There's a lot of doctors there who are quite skilled in the diagnosis and the guidance through medications and new things that are being developed, so he had a great neurologist. That is crucial, I think, to have someone in your camp who's a really great guide in the journey. That was the first thing. The second thing that became clear to me over time was, it essentially is a disease that turns involuntary physical action into voluntary action. Like speech, which would just spills out of us. But suddenly when it becomes truncated or problematized, whatever, through a stuttering, for example, then you have to learn how to enter a word, learn how to enter a sentence, how to sit down, how to speak with greater volume. All of these things that are involuntary, usually. So that's intense. And then at the same time, you start to see, like, my father was older when he was diagnosed. So you're also starting to see other things like a certain loss of executive function. So when you have to be voluntary, it requires that you also have executive function, that was also deteriorating. So my role as his daughter was actually to be his external executive functioner sometimes. Where I'd be like, slow down, take a breath. It's a much more interactive disease actually. I cultivated a much more intimate relationship with my father as a result.

Sam Fox:

To that point, Kathy, I think what has been interesting to me is exactly what you're saying, which is you have to realize. Or it either happens or it doesn't, but at some point you're going to figure out that it takes all of this brain power to be a person with Parkinson's disease. No matter what phase you're at and that's something that can get lost on you, if you're not... Because obviously I'm not going through it, but it's something I talked to my dad about a lot is this, he has to constantly think about every single thing that he does. Whether it's, you said talking, sitting down, the volume of his voice, if he's going to open the fridge, he has to figure out exactly where his hand is going to be to hit that handle.

Sam Fox:

And that makes it so that you're always multitasking in a way that I think a lot of people take for granted when you sort of have... When you don't have Parkinson's, and that for me and my family has been something that's taken us a long time to really come to grips with and be able to help with is, he's always doing something else.

Sam Fox:

You're never going to catch my dad doing one thing because he's, no matter what he's dealing with his disease in some way, shape or form. So you have to understand that the conversation you're having is the second thing, the second most important thing that he's thinking about right now, because the most important thing is, is my left foot where I think it is when I'm about to take this step or whatever. And that to me has been something that even though, obviously I've been in this process for a really long time, has taken me a long time to learn and something that I think that the sooner you can figure out that patience to have with someone with Parkinson's the better. Because what seems like slowness, especially in thought isn't, it's just, you just have to give them a second sometimes because there's so many things that you can't even imagine going on in their brain. And that's something I've learned. Brian, you could probably speak to that a little bit.

Bryan Roberts:

Yeah. That's a great point. I think the challenging thing about Parkinson's too, and perhaps the hopeful thing is, I think all three of you said, if you have a good care team, you can really move things along, right. But you have to come to a place where you're willing to accept a team.

Cathy Lee Crane:

Yeah. I was so surprised with my father's speech decay, because he was an orator at the church and he taught speech and drama for 30 years. So it was a thing that he was about. And so it was very intense to see this decay, but he discovered in Phoenix that he could still sing. So he joined this group called the Tremble Clefs. They were founded in Phoenix and they've been around for 20 years and it's phenomenal. It's just, he sings in a group of diagnosed people with Parkinson's and their caregivers. And it's just a beautiful thing. And there were times where we were like, okay dad, you want to say something, sing it. Because there's just something about that takeoff of song that allows the words to flow. But that was a blessing. That was a real blessing that he had access to the Tremble Clefs.

Bryan Roberts:

It is, there are a lot of things that can surprise you. Like, walking for me can be tough, but dancing, I can do really well. I mean, not everyone would agree with that.

Cathy Lee Crane:

Someone's judging you.

Bryan Roberts:

They're not circles you'd want to be around, but it actually brings me to my next question. So you guys have gone on this journey with Parkinson's. Has there been anything that has surprised you like Sam, you have no clue where this is going to go, but have there been things that maybe are there that you didn't expect to be there or has your expectations been met? What has it been like?

Sam Fox:

Yeah. No, that's a very good question. I think again, what has been, been great for me and I would recommend this to everyone in whatever form it can take. I happen, obviously I've been around my dad my whole life, but I've been around a lot of people with Parkinson's my whole life because of my dad and because of the foundation. So I have really seen every color of the rainbow when it comes to symptoms and what people look like at various stages of the disease. And for me, the surprise isn't necessarily, oh, hey, it can go in this direction. It's just what direction is my dad's specific case going to go in? And I think that being educated and keeping an open mind and understanding, like we keep saying, this is a progressive disease.

Sam Fox:

It's, very hard to say, okay, in five years, this is what your dad is going to look like. And for me, I found the most success in just being where I am now and whatever that looks like, understanding where he is now. And it's definitely been surprising. I mean, Kathy, you were saying your dad was a great orator. I come from a similar thing where my dad obviously has used his expressions and speech his whole life to sort of make his point. So when that started to decay a little bit in recent years, and he started, not being able to act as much as he liked to and it ended up with him channeling his focus into the foundation, which is probably great for everybody who's sitting here.

Sam Fox:

But for me, that was always a surprise. My dad, especially was someone who was so quick, like that was in every sense of the word. He was quick, athletically, he was quick, mentally, everything was very fast and he still is, but you just have to give that second to... The quip doesn't come necessarily as fast and it's not because he didn't think of it five minutes before you said whatever he's reacting to. It's just, maybe it takes him a little bit longer to express it. And that to me has been, the surprise, has been seeing what's still there because everything is still there. It just maybe expresses itself a little bit differently and becoming okay with that. And me becoming okay with that, him becoming okay with that, understanding the changes that are going to come in your general day to day.

Sam Fox:

It's things like, and I talk about this with him all the time. There's certain restaurants that I'm not going to take him to when he comes to LA, because they're just too loud and I'm not going to be able to hear anything he says. And I know that it's going to set up frustration for everybody involved, and things like that. And they're little choices, but that paying attention to, he would never say, I don't want to go to this restaurant, it's too loud in a million years. He doesn't want to be that person. But me sort of understanding, okay, I'm just not going to put him in that position. Those kinds of little things I think go a long way. And that's the kind of thing that I'm constantly reacting to and trying to make sure that I'm there for him.

Bryan Roberts:

That's great. This has been a great discussion. We're almost at the end of our time already. It's been so much fun. We've covered Parkinson's symptoms, the Knicks, and a wide range of other issues, so we'll have to do this again. But Father's Day is approaching this Sunday. Being a parent, not just father, being a parent is challenging, as we all know. Do you have any advice to fathers out there, whether they have Parkinson's, whether they don't, what piece of advice would you give, having a father who was important in your life and obviously very influential? Give you a second to think about it, Kathy Crane, can you start us off?

Cathy Lee Crane:

Well, it's interesting this idea of slowing down, which Parkinson's forces on someone. And so if you don't have Parkinson's, I would strongly recommend that you slow down. So you can have those relationships that occur in the moment. We've all had this experience with the COVID slowdown. It's a totally beautiful orientation for intimate relationships. And I think that the thing about my father who passed away, and I miss him, I miss seeing him. And that is something you don't lose in a father or a parent who has Parkinson's. They are still there. They really are there. Someone told me once, "Yes. Alzheimer's you lose your mind before your body. Parkinson's you lose your body before your mind." And I really knew he was there. I could see him there. So be present, slow down.

Akbar Gbajabiamila:

My dad, he calls me Kemi, "Kemi, slow down, slow down. You go, go, go, go, go, go, go." And so I would say the same thing, during COVID 19, it was a time to go, "You know, what?", a time to take a huge pause and take that time in with family. So I've done that. So yes, I'm with you. Take time to pause.

Cathy Lee Crane:

Yeah.

Sam Fox:

Yeah, absolutely. So I think obviously, like you set out Kathy, you said it really well, but I think another thing to talk about, and gets into advice territory, is something that we've talked about a little bit, which is this openness and honesty that has to come with Parkinson's and with a diagnosis. And I think that for me, a piece of advice is to, for someone who's loved one is going through it, and for someone going through it, is to just really be as honest and open as you can be with the people that you care about. I think that makes things easier for everyone, and I think that's good advice for everyone, regardless of your status with Parkinson's disease. I think the more that you can realize that people want to be there for you, that there are people who care about you and to, for lack of a better word, take advantage of that, and really be open and honest with your symptoms and how you're feeling. That can really help everyone around you deal with the situation and make your life happier, ultimately.

Sam Fox:

And I think that's something that has taken us a while to learn. I mentioned when we first started this conversation, that my dad was diagnosed with Parkinson's in 1991 and came out publicly as having it in 1998, and since then has been really open with everything. Not just with me and my family, but with the world. And I think that has helped him, and I know it's helped me really go through this process because when I have a sense of where he's at, I can deal with it. And I think for him, not to put words in his mouth, but I know that it makes him more comfortable knowing that everyone's on the same page. And knowing that we understand at least a little piece of what he is going through, because he's willing to share that with us. And that to me has meant a lot, and I think that's something that can relate to a lot of aspects of your life, and not just disease management, but family.

Bryan Roberts:

Yeah. I don't have much to add, I think acceptance is probably the best thing you can do, right? If you become comfortable with the disease and I don't see it as a battle, I see it managing it, but good communication with your family. Those seem to be the people who live the best lives with this disease.

Akbar Gbajabiamila:

Let me add one more thing. Take the time to express how much you want to be appreciated. I think it's one of the hardest things for fathers to do. If you look at advertisements and you look at [inaudible 00:28:55], probably one of the more played down things, "Oh, hey, it's Father's Day, get ties, boom." And I think fathers, and even for me too, it's very hard for me to express that I want to be appreciated, but I think every human being, the one thing we have in common, we want to be valued, we want to know that we matter. And I think sometimes in the background, and they think that, "Oh, I'm not supposed to speak up. I'm not supposed to be celebrated." But fathers matter to their kids, to their wife, to the people that they love and love them. So take time to actually say you want to be appreciated.

Bryan Roberts:

Great advice. Well, guys, this has been a blast. We'll have to do it again. Kathy, Sam, Akbar. Thank you so much for your insight, your humor, your time. Well, that was a lively and informative discussion. Parenting with Parkinson's can be challenging, but let's be honest, parenting alone is challenging. I wish you'll realize that we're not in it alone. There are plenty of resources, plenty of support systems to help us all. And we serve as one of those here at the Michael J. Fox Foundation. Check out our 'Ask the MD' videos, third Thursday webinars, blogs, and other educational resources like this podcast at michaeljfox.org. And while you are there, consider enrolling in the Parkinson's progression markers initiative or the PPMI study. Whether you have Parkinson's or not, join this study that could change everything at michaeljfox.org/podcast-ppmi. That link is also below in the show notes. On behalf of all our guests today, and everyone at the Michael J. Fox Foundation, who is here until Parkinson's isn't, I'm Brian Roberts. Thanks for listening and have a very happy Father's Day.

The Michael J. Fox Foundation:

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