



**The Victory Summit® Virtual Event: YOPD
Reinvention of Self**

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Davis Phinney Foundation

Amy Montemarano, JD (Davis Phinney Foundation Ambassador, YOPD Council Member):
I want to introduce Mr. Luke, who moved across the country and made an enormous change in your life. Externally, and also internally at your diagnosis and so I was hoping that you could just tell us about when you were diagnosed and the emotions that you went through after that.

Luke Waaler (Senior User Experience Designer):

Yeah, sure. Thanks very much Amy, it's great to be here, and thanks to the Davis Phinney Foundation for having me. And also, thanks to Dr. Cole, a lot of what he said parallels my own story. So, and I'm sure with a lot of folks that are that are dialing in today, so my experience was fairly similar. In the spring of 2016, when my then girlfriend Jennifer, she noticed, kind of a strange thing that walked in my arms weren't swinging and maybe after particularly after a workout, one of my arms would have a tremor to it.

And we looked up, what are kind of Hallmark symptoms of Parkinson's disease, and she would list them off and I would say yes or no, yes or no. And a lot of those were yeses and we said well we better go check this out so similar to Dr. Cole just went to the family doctor and he said, well, I'm not going to rule anything out, so maybe better go see a neurologist. So, it was actually diagnosed on, believe it or not, James Parkinson's birthday, April 11, of all things, and similar to a lot of folks on this call the trajectory of my life changed on that day. Of course.

So, in terms of emotion. I felt lost it felt kind of scared of the unknown, not knowing a lot about the disease, and, where it would take me and what would happen next. And, and I think I lost some measure of self confidence in myself and my abilities, and that sort of that sort of feeling I guess, is where I started.

And I can keep going on with that but if you get other questions, I can keep going or respond to your questions.

Amy Montemarano:

So, when we were talking, we talked about taking that first step. and what that requires in terms of courage. So, that first step of moving forward, out of your old life and into your new life. Do you remember that moment when you decided to do that?

Luke Waaler:



Yeah, well, so I had been working in Colorado. And I said leave my job in 2018 it just wasn't a good fit for me. And I thought I was going to live the rest of my life in Colorado and that's where I live out my days and that sort of thing.

But in the meantime, we decided that as time went on and I wasn't finding job opportunities that I wanted to that other places, started popping up on our radar and North Carolina was one of those places that came up.

And one day my wife sent me a text for a job opening for an aerospace company in Charlotte, and I thought well this sounds kind of interesting. Let's take a look at this and so I applied for it, and they did a phone screen and I flew out for an interview and in a matter of a few very short weeks I was made the offer and so then we had a choice to make.

And we decided that would be best for us to make a change, and it was a really big step and well what may seem like a small step for for others was a giant leap for me so very big change.

Amy Montemarano:

Were you worried at all about the job interview and disclosing or not disclosing?

Luke Waaler:

I remember during the phone screen that my Sinemet had started to wear off after it's maybe an hour phone screen and I hadn't timed it just right or I had too much protein beforehand or something.

And so, I'm sure people are familiar with this, half of your brain is trying to concentrate and answer the questions in the interview, and the other half of your brain is trying to keep your body from shaking on the camera.

So, I distinctly remember that during one of the interviews. And then pause there, it was while after I started the job in Charlotte. I didn't disclose my diagnosis for about six months, maybe, and then recognized that it was becoming more and more difficult to hide my tremor while is in the office, and decided to pull together, my closest teammates and say hey, this is what's going on. I've got this, this illness and I manage it through medication.

But every once in a while, you might see a tremor and that's that's what's going on. And bless their hearts all of the people on my team said okay that's fine. Now let's move on to the project and, and that was it. So, I'd really built it up in my mind is this this very scary event and wondering what people would think, and they were all just very casual about it. Not that they didn't care. They just sort of said, well it doesn't change what we think of you, you're still our designer, and we still have work to do. So, let's get back to work.

Amy Montemarano:



And you're still working now right?

Luke Waaler:

I'm still working there. Yes.

Amy Montemarano:

So what advice do you have for people who are working full time and managing symptoms?

Luke Waaler:

I think the first thing to say is it's different for everyone. What Dr. Cole said was very interesting about the freedom that he felt, and that resonates with me is getting that feeling of freedom.

The interesting thing was that maybe a month or so after I revealed my diagnosis was when COVID hit, and I've been working from home ever since for the last 14 months or so and so on the zoom call, it's actually a little easier to hide Parkinson's symptoms than being in an office across the table from somebody, so the people I told about the diagnosis at the time, that's sort of my circle of trust that hasn't expanded since then.

So, I guess, to answer your question, it's sort of a case-by-case basis. And I don't, I don't have any hard and fast rules for when to share your diagnosis or when not to.

Amy Montemarano:

It's interesting that you say that because I've been getting some inquiries from people who have not disclosed during the pandemic because zoom is so much easier to hide it, and now that they're headed back into the office, everyone's wondering what to do, what to say. It's been an unusual, there's been a lot of calls in that area, so it's probably something we should talk about more but so now you're over here, you're over in the east coast, you've made that big jump. And how was changing your medical practitioner process. How was, was that difficult?

Luke Waaler:

Yeah, it was more difficult than I thought. I think that's one of the things that people don't necessarily take into account when they move from one community to another is finding a new insurance agent for your car, a new dentist for your family, you know a new primary care physician and movement disorder specialist and all these things that you don't really think of. The first movement disorder specialist that I found just through a Google search of ones in the area. He was sort of a younger guy, meaning younger than me.

And during my first appointment I said you know I'm glad I found you through my Google Search. I'm glad to see you're kind of a younger guy. I can see us going on this trajectory together this path together for the next 20, 30 years or so, with you being my provider. And he



said, well, thank you very much that's nice you to say but I got bad news. I'm leaving the state, and this is going to be our last appointment together.

So, I had to start my search all over again but I'm very content with the fella I've got now.

Amy Montemarano:

I, again when you and I started talking about this, I had just, I'm a member of a jillion Facebook group for people with Parkinson's and other things which I'm learning from all of you today is a really good way to get through this journey together.

And the day that you and I spoke a question came across one of the groups, I wish I remembered who said it because it's a really good quote and he said, for me, Parkinson's is turning out to be the result of a lifelong struggle for the freedom and safety to be my authentic self.

Does that sound anything like what you feel too?

Luke Waaler:

Yeah, yeah. Freedom, authenticity, safety, those are kind of related in a relationship standpoint, you want you want to have that freedom to feel authentic and to be, you need to have that safe space with whoever you're talking with to be authentic and and reveal as much as you're comfortable revealing and being vulnerable. And that I think can can lead to some freedom.

Amy Montemarano:

Do you think you're a different person now than you were before diagnosis?

Luke Waaler:

I would say definitely in several different ways. Physically obviously there's been changes and Sinemet has helped manage those symptoms. I think self-confidence is still an issue. And I'm certainly far from perfect. I deal with depression. And the exercise seems to help that. I try to do that as consistently as I can. But there's certainly things that have changed.

As Dr. Cole mentioned, you know, today's what we have. So, I think it's sort of, his comment about having one eye on the horizon that kind of resonates with me as well.

Well, maybe that horizon isn't quite as far as we thought it was and let's focus more on today and even this morning, when my wife and I were watching some of the earlier speakers and they said, don't put off that vacation that you want to take when you retire. Go ahead and enjoy life now. My wife always says don't put don't postpone joy, let's get out there and take that trip, especially now that COVID is starting to get in our rearview mirror.

Amy Montemarano:



And you also had a great quote, which I didn't write down. Do you remember what it was? It was about respect and honoring, but not fearing, right?

Luke Waaler:

You know, early in my diagnosis, as we researched what Parkinson's was all about we decided that we will respect Parkinson's, but we were not going to fear it. I'm just sort of taking it head on. And, and understanding that you know there's there's doctors here to help there's there's people, other folks within the tribe it's Davis likes to describe it.

So we've got tools in our tool belt that we can use to fight against it, certainly respect it but you don't have to fear it.

Amy Montemarano:

I love that. And if there are other people out there are people in the audience who are thinking about making a big change in their lives like you did. What advice would you give them?

Luke Waaler:

I think I'd start off by saying, life is short, you know, you only go around once. So, if you have any question, go for it. You don't want to have regrets you don't want to grow up to be 85 years old and say, doggone it I took too many chances with my life you know and too many things I think it's good to take those chances and not have regrets.

Amy Montemarano:

Is there any advice that you would have given yourself, knowing what you know now?

Luke Waaler:

Yeah, I'd start by saying, although currently Parkinson's is in treatable it is manageable. So, relax Luke you're going to be okay. You don't have to panic, either keep exercising or start exercising to slow the progression. And then live, love, and be grateful for what you do have. Today is what we have.

Amy Montemarano:

Yeah, we have some points on the PowerPoints, I don't know if we can bring that up again, that are drawn from the Luke's experience, and the different ways of looking at having Parkinson's. And we talked a little bit about this before, which is, I read a lot about what people say on their deathbed, there's a lot of books out there right because you're talking about regrets, no regrets life right, and from my reading which of course is was not an academic study was just me reading a few books but from my reading, these were the top four regrets that people say at the end of their life. I wish I wasn't so hard on my loved ones. I wish I had let myself be happier. I wished I'd had the courage to pursue my dreams. I wish I had slowed down and not worked so hard.



And those struck me really really deeply, especially the one about letting yourself be happier. And I think that's what Luke, I think that's what you're talking about right is just giving yourself permission to not stress, and just enjoy the moments that you maybe flew by before, right?

Luke Waaler:

Yeah, even something as simple as as sitting down for a meal. When you go to a restaurant you know you go to your favorite restaurant and you order your favorite meal. And then you wolf it down and the moment is over and about two or three minutes and I'm trying to get myself to just slow down and enjoy the moment and relax and enjoy every every morsel, every bite and just enjoy.

Amy Montemarano:

Savor. Yeah, the savor.

Luke Waaler:

Yeah, yeah.

Amy Montemarano:

And part of the post traumatic growth concept, which really just means that something that's been known forever, is that when people go through a difficult time, whether that's trauma or other kind of struggle in your life that they can change, and that change can be good, not necessarily always just damaging. They've known about that forever but they're just starting to research on why that is.

And they took a look at these mindset shifts, which is your life can get better in these areas your relationships get stronger, which I think Luke you were describing that a little bit too.

And then sitting down and savoring your dinner right greater appreciation of beauty and joyful moments. I have found post diagnosis that the moments in my life where I feel happy are scaled way up. I'm not saying that there's more of them.

But the level of joy and happiness that I feel is sort of like off the charts now because of, you know, the gratitude I guess that comes in.

Luke Waaler:

Yeah.

Amy Montemarano:

And the catchphrase for post traumatic growth is, is this, it is, "I am more vulnerable than I thought. But much stronger than I ever imagined." And I also think that it's that awareness of this of your inner strength that gives you the power to feel good. Right.



Luke Waaler:

Yeah. Very well said, yeah. Going back to the first bullet point under the one of my relationships get stronger. I would even add as a symbol of new relationships that you never thought you'd have, people that I met through the Parkinson's community are just tremendous people. And they're people I probably never would have met otherwise and I'm just so grateful for this entire new batch of friends that I've made.

Amy Montemarano:

Yeah, I don't mean to sound flippant because I often do, but my occupational therapist who saved my life by being flippant with this heavy topic, said to me, at one point, you know, all the cool kids have Parkinson's, which is kind of like yeah they are they're all, they're all you know this community is just full of so many kind hearted people full of integrity, and so much wisdom and so much to learn from and I'm so grateful to be a part of it.

Does anybody else have questions for Luke? or Luke, do you have any ideas about what what's next for you?

Luke Waaler:

That's a great question. Continue to explore the Carolinas we haven't really had a chance to do that since Covid hit just shortly after we moved here.

Amy Montemarano:

Yeah, getting outside right I mean that's really important to do that. I think it's that book that Mel recommended that nature book which I probably got about how therapeutic it is in nature. A lot of us have been so shut in for the last year.

Luke Waaler:

Exactly, Yeah, I'm looking forward to that too. The nature fix. Yeah, I have it, it's upstairs. And people talk about how they told their kids. Luke, kids? You have cats?

Luke Waaler:

We do, we have three cats. We never did tell them about the diagnosis, but they I'm sure that they knew it before you probably did, they're pretty smart.

Amy Montemarano:

I can talk a little bit about how I told my kids they were in middle school at the time. I can't remember what ages maybe 10 and 12 or something like that. I told him right away. I sandwiched the bad news, with positive news on either side. And I showed them examples of people who have had Parkinson's and have lived a long time.

Someone who inspires me a lot is Janet Reno. She was diagnosed in her very first year as the Attorney General of the United States and she spent another nine years in that role.

So you can imagine how stressful that job was. And if you ever watch the Saturday Night Live skits where Will Ferrell, I think, plays her, and she, and it's and it's the Janet Reno Dance Party, which reminds me of all the dancers here. It's really funny, anyway. But yeah I think being honest and showing them, you're still their parent, you know, in a confident way, just, again, I think I said at the beginning, I think you owe it to your family to enjoy the moments, that helps them. And for a lot of us I think it's a lot harder on our loved ones and it is on us.

Luke Waaler:

Yeah, yeah, yeah, a lot of times you forget when you're diagnosed it's almost as if they got a diagnosis at the same time.

Amy Montemarano:

Yeah. And so if anybody else in the audience has anything to say about telling your kids, I think that's a really important topic of conversation.

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

So, Carol is asking, how does humor play a role in your everyday lives?

Amy Montemarano:

Oh, hey Carol. Luke's got a dry sense of humor, it comes out very subtly.

Luke Waaler:

Yeah, I think I use humor in two ways. Number one is as a stress deflector, and number two build relationships or start relationships. I probably come across as somewhat quiet at first but as soon as I'm comfortable, I'll let out some of the worst jokes you'll ever hear so, yeah.

Amy Montemarano:

And that helps.

Luke Waaler:

And that helps.

Amy Montemarano:

And Carol, who we all know, as our ambassador who wrote a great book ribbon of road ahead about walking the Camino. Also, I know she uses a lot of humor in her book, and in her life, and I appreciate that as well. It's one more thing about this community that I really like is that kind of like going through a bonding experience together and I hate to call it gallows humor, but something along those lines, is a a real bond that we all share. I think it really helps.

Luke Waaler:

Yeah, I agree.

Amy Montemarano:

And we are at 2:40. So I think we're taking a little break here if anyone has any. Actually there's one question for you Luke, this is, I think is a really good question. Is there a checklist you have to assess a new movement disorder specialist or neurologists things that you learned when you had to start over to look for new one.

Luke Waaler:

No, is the short answer. If they're board certified that seems to carry some good weight. I think for me it's important that they're easily accessible. So if it's a three hour drive you're less likely to go make an appointment there. But if they're, you know, within your area, certainly that makes a big difference. And other than that it's, I felt like it was a little bit of a crapshoot to figure out, you know if you're going to get along with this person and if they're going to talk on the same level as you.

If you can establish that relationship but I'm sorry I don't really have a checklist per se.

Amy Montemarano:

Yeah, I don't think any of us have a checklist right, there's so many different styles of neurologists. I've been through three so far, and they were having wildly different styles. And I think it's another area of advocacy that would be really helpful, especially after hearing, Dr. Savica talk about how good you know a neurologist can be when they're really focused on custom prescription and treatment.

And that would be fabulous if we have a unified system of neurologists who did that.

Luke Waaler:

Yeah, I do have one very quick funny story, in my first visit with my new movement disorder specialist was over the phone. It was a zoom call over the phone, and he wanted to see these typical exercises you know how well you do with those sort of things. And part of it was a toe tapping exercise, so I held the phone, pointing down at my feet, and before he asked me to start the exercise, he said, hey, did you guys get that rug from Wayfair because we've got the same rug in our house.

And it was just a great way to break the ice and I knew from that on that this guy, he and I could get along just fine.

Amy Montemarano:

That's good to hear. That's good to hear. Yeah. Thank you, Luke. I love hearing your story because it was it was that temptation to sort of, like, start something big and something now, and you've done it, and so it's very inspiring.



Luke Waaler:

Thank you, Amy. I appreciate the opportunity.

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