



**The Victory Summit® Virtual Event: How to Live Well with Parkinson's
"Communication and Parkinson's"**

Recorded on April 2, 2021
Davis Phinney Foundation

Kat Hill (Davis Phinney Foundation Ambassador, YOPD Council Leader, and YOPD Women's Council Leader):

I want to introduce our panel.

Cidney Donahoo and her and her husband Pat are here with us today they are both Davis Phinney ambassadors and on the board of directors for the Davis Phinney Foundation. And also, we've got Pat and, excuse me, Pete Huley and his daughter Krista Ingle are on also to share that communication dynamic so it's really really nice to meet you. Pete and Krista, and nice to see you again Pat.

Before we dive into the questions, I'd love for you to share a little bit about yourselves and why you joined us on the panel today to talk about communication. Why don't I have a Cidney start us off.

Cidney Donahoo (Davis Phinney Foundation Ambassador and Board of Directors Member):

Okay, thank you, Kat, it's good to see you and it's great to be here today. It's just fun to, it's always fun to get together with my DPF friends, you know, and really, I just hope that whatever we are able to say today that we're able to reach somebody who may be struggling in the area of communication, I think I was telling Pat, I said, you know, communication is a dance, and sometimes we step on each other's feet. But the great thing is that you can always get back and start the dance again. So anyway, just hope, hoping to reach some people who need it, and help lives.

Kat Hill:

Great. Pat, do you have anything to add to that?

Pat Donahoo (Davis Phinney Foundation Ambassador and Board of Directors Member):

Yes, good, good morning, I echo Cidney's response on the dance, and also reaching people here today. We're just thrilled to be a part of this group and why are we here is because we were asked to be, and of course, if we're asked the answer is always yes, and we're just excited to be able to be a part of this and to help any way we can. We do communicate, everybody communicates every day, it's just a matter of how we go about doing it with our individuals with Parkinson's.

Kat Hill:



Yeah, yeah. Pete, how about you? Welcome.

Pete Huley (Davis Phinney Foundation Ambassador):

Well, good morning. I'm here again, because I was asked to be here, but I'm very much looking forward to the opportunity. I've never done anything like this before and I very much look forward to talking about communication and trying to reach out to those with Parkinson's because I think it's an excellent opportunity to do that.

Kat Hill:

Hi, great and Krista?

Krista Ingle (Daughter of Pete Huley, Friend of Davis Phinney Foundation):

Hi. Thank you. I'll echo what everyone else said. I'm here because I was asked and of course I would say yes to anything with the Davis Phinney Foundation.

I also have a background as a speech and language pathologist, I don't practice anymore, but communication is kind of in my DNA, I guess, and I also happen to have several, just sort of randomly, several friends who are in the same position that I am where a parent has been diagnosed with Parkinson's and I'm seeing so many different communication dynamics.

I don't know I just thought it would be... it's clearly a relevant topic.

Kat Hill:

Yeah, I think communication is relevant to everything, and particularly in the dance of chronic illness, I'm going to quote Cidney there.

So, Pat and Krista, maybe I'll have you start off here a little bit and share a little bit about how the two of you do the dance with one another in terms of communicating about progression of symptoms, when you're noticing different things. Pete, do you bring it up? Krista, do you bring it up? Do you connect maybe before doctor's appointments or how does that go?

Pete Huley:

Well, I can start. First, Krista and I are a few miles apart, she's in Colorado I'm in North Carolina.

In particular, this past year, observation of changes has been tough to come by. I think I'm pretty open about communicating if something additional is going on with me because I've found that Krista and her sister Colleen are both are very quick to jump in with assistance and help and things which I may not have even thought about. So, I try to bring up things when I think of them. Other than that, it's just kind of hit or miss.

Kat Hill:

And are you comfortable if Krista asks you questions about it or do you prefer to initiate the conversation?

Pete Huley:

Oh no I'm very comfortable to be asked. In fact, when I first got diagnosed, Krista said, well you have to go to LSVT training and I didn't know what that was, so that was the beginning of learning for me but yeah, she just would jump in, and later when I was out there visiting, she said, why don't you start boxing over at the corner Boxing Club and I said, okay, I haven't tried that before. So, she's very active in jumping in.

Kat Hill:

Krista, how's it for you being far away?

Krista Ingle:

Oh, it is tough. You know, we had a pretty good routine, up until 2020 of getting back east, you know, three or four times a year. We do check in over the phone and whatnot pretty regularly but with the pandemic that sort of ability to have a physical, visual, you know, emotional check in, has been kind of diminished so it's been it's been tricky. I feel very lucky, and this is, in comparison to some of my friends that I've mentioned before, I feel very lucky that my dad is very, I perceive that he's very open about, you know, the symptoms that he's experiencing, and the plan that he has for what he's going to do next.

He's always sort of approached things in that way, like, learn about it, and act on it, learn some more, an act on it and so I feel really lucky there. I'm not sure if I totally answered the question but ...

Kat Hill:

You did. Yeah. I think being far away, my dad had Parkinson's and lived far away, and I found that it was important to ask questions in a good time, when he was able to hear it, and also be honest about my need to know so that I could help advocate and not because I was trying to be nosy, perhaps.

Krista Ingle:

Right, exactly. Well, and I don't want to diminish the role of my mother either. She could easily be on this panel as well. You know, I think we are lucky in that we have a pretty good family dynamic; you know pre-Parkinson's. And so, we've really been able to rely on that.

I count on my mom to, you know, push my dad to say things that need to be said, if that's something that needs to happen. We're not like a you know talk around people behind your back, type of family.



But I do count on her as you know as my dad's life partner to really be supportive in that way as well and keep the lines of communication open.

Kat Hill:

So, I think that's a really, really important point that if you haven't concern, either one of you you're both able to voice that in directly deal with it head on rather than talking around getting information maybe from your mom rather than going straight to your dad, I think that's a helpful open communication style.

Thank you.

All right, Cidney and Pat, are you ready to be on the hot seat?

I'd like to hear about how you how you communicate about Cidney's Parkinson's over the years and how you share those things with one another?

Pat Donahoo:

Well, the first time I saw a symptom of Cidney's we were in Washington DC, enjoying the sites, we had just left the White House and we were walking to the Washington Monument, and I had fallen a little bit behind and I'm watching Cidney, and her arm is kind of sticking out.

And I asked her, I came up and asked her straight out, why are you walking funny?

So, that was my first experience doing that, I mean as far as talking to her about something we didn't know about. That was that began a four-year process of getting a diagnosis and moving forward with to where we are today. Her diagnosis was in 2010. And so, we've danced a lot. In fact, we probably danced a little bit yesterday, and this morning.

You know, knowing Cidney sometimes, I have to hold back, and observe and look at you know, any progressions and things like that, questions that I might come up with. I have to, I need to be cognizant of her feelings. Because, like so many of our people with Parkinson's, especially as we get older, we get more set, and we get a little bit stubborn.

And that's okay, but we as a care partner, we want to be able to express what we're seeing and how we can help. And sometimes we have to step back a little bit and watch, and observe and then at the right time, be able to, you know, at the right time, meaning that you've set aside some time to talk about what's going on. For instance, we talked about this yesterday I'm concerned about how Cidney is getting up out of off of the couch or out of bed, things like that these days. There's more to it, you know, my question to her is, is it a Parkinson's thing or is it something else? What part of what I'm seeing is going on here, and then we have the conversation.

Kat Hill:

Cid, you want to jump in? I'd love to hear how that feels for you when Pat, even back in Washington DC when he noticed your hand was doing something funny, how did that feel him bringing that up, even yesterday talking about getting off of the sofa or out of bed?

Cidney Donahoo:

Well honestly back in, in Washington DC what, gosh almost 15 years ago, I had no idea what he was talking about, it was not something that I even noticed so I just I just said, I don't know, I have no idea.

But then again, little things kept happening after that. At this point, so I think it's really true about, you know, being a little bit cognizant of how the person with Parkinson's feels, because you probably know this and probably everybody on here with Parkinson's knows so we can be a little bit sensitive about, you know, progression. And if it's something major, then, we may be in a little bit of a denial, and we may snap back if we are not listened to in a more of an empathetic way.

So yeah, and he's mentioned me getting off the couch before and initially I'm like well it's because I have this groin muscle problem. And that's probably has more to do with it than anything.

But being able for him to take the time and be empathetic and think about when to bring it up rather than just saying why are you having such problems getting off the couch? You know.

Kat Hill:

Right, right in the moment. I know for me, so I've been married for 31 years to my wonderful partner Ken, and in the moment when I'm having trouble getting off the couch, is not the time I want to talk about why I'm having trouble getting off the couch.

So, I think picking timing perhaps when you're living in the same house with one another, like maybe over a nice dinner where everybody's emotions are kind of level but not in the midst of frustration. Cidney, would you agree with that, like you said, trying to be empathetic but also timing right? The dance is about timing.

Cidney Donahoo:

Definitely. It is definitely about timing.

Kat Hill:

Do you set aside time before your like appointments with your neurologist, this is a question for all our panelists, do you try to check in with one another, before certain times about things and set aside a little bit of time to dialogue it, like before you're checking in with your doc, maybe? Go ahead, Cid.

Cidney Donahoo:

Um, yeah, we've done that and honestly, when I was first diagnosed, I would go to the doctor by myself, Pat was, well he still works, but he was working and I was, you know, I was pretty mobile and I'm still mobile enough, but we decided several years ago that regardless of how I feel, he's gonna go to the appointments with me.

Kat Hill:

Is that helpful for you, Pat to hear the information at the appointment.?

Pat Donahoo:

It's twofold. Actually, there's questions that we've talked about that she'll forget to talk about with the doctor. And so, with being there I'm able to ask and then I may ask other things that that I've been thinking about as well. And so, we'll generally talk on the way, we'll talk the day before, we want to make sure that we have our ducks in a row.

Kat Hill:

And how about you Krista and Pete? So, you're in different places, do you get involved in that conversation at all Krista or do you kind of leave that to your mom and your dad to kind of strategize?

Krista Ingle:

It's mostly my mom and dad, go to the appointments, together, as far as I'm aware. Dad does let us know when the appointments are upcoming and, you know, and always gives us the debriefing at the end.

So, I do feel, you know kept in the loop in that way, but not particularly like I have any responsibility.

Kat Hill:

Got it, got it. Pete How does that work for you? Do you find it helpful to have your wife go and then be able to feed information back to the kids? You're on mute. Pete, can you unmute yourself?

Pete Huley:

Yeah, very much so because it's something, years ago I had another medical condition and it was very important to have both of us in the office at the same time so we're hearing that information and we can kind of put our heads back together but we, as it turns out, I have to drive about 250 miles to go to my neurologist, and this past year has been a benefit, and that we've been doing that online.



So, don't have to go anywhere but it's very important I think to have both of us there because we can talk about it before we go. I make a list of things I want to talk about and check those off as we're going through the office visit.

But then when we're done, we kind of do a little talk about what we just did and also while we're in the office I make sure that she speaks up about anything she's observed, because I think that's very important.

Kat Hill:

Yeah, and I often find that if I have my, you know, my husband with me that the neurologist will engage in questions for him as well, have you noticed, or do you see or, though most of the visit is directly with me.

Cidney and Pat, how do you disseminate information to your children? I'm curious to know, do they ask pretty directly if they're concerned, or do you have kind of powwows about it, pardon the expression, but like a dinner time together, you know where you sit down and chat about it?

Cidney Donahoo:

Um, well we don't but I think that's a really good idea. We have kids that live here with us in Las Vegas and kids that live around, and so I think the kids here know more about what's going on than the ones that live far out, but it's really kind of informal.

They may ask questions, but honestly, they don't ask a lot. And I think part of that is because I don't always look like I have Parkinson's. I feel like I have Parkinson's. And so, they don't always see, so they don't think to ask. Pat, did you want to add to that?

Pat Donahoo:

Well, I mean, we are a blended family of course so Cidney's three children live here in Las Vegas and my three children are spread out among other states, one of which is in Colorado and I was there last weekend with our number 11 grandchild coming in, so, anyway, throwing that one out there. It was fun. But the thing is that, you know, Cidney doesn't look like it, but they know that she has it, so our kids outside of the area will ask how she's doing.

Kat Hill:

Do they ask you or do they ask Cidney?

Pat Donahoo:

Well depends on who's talking to them.

Yeah, I mean, usually it's me, but you know we have five grandchildren coming today from out of town, that will be here today, and they'll ask questions and my daughter and

her husband will ask questions and we'll be able to get more of a hands on look at things and how things are.

Kat Hill:

I suspect the discussion is often around all those grandchildren around a disease process which is probably good, but I'm curious about how we disseminate information to our loved ones a little bit.

Pat Donahoo:

It's, you know, the biggest challenge that I find I have with it is disseminating it to my family, my mom, my brothers, my, you know my siblings and so forth.

I mean it's been an interesting road, since the beginning. My mom has been very supportive, but I don't think she fully understands what it all means because again Cidney looks fine. We ride our bikes; we ride a tandem across Iowa every year except for maybe not this year I hear.

But we do all sorts of things together here in the area and we participate as much as we can. So, when you're doing those things, people don't really see what's going on but I wanted to just point out that the fact that you know as a care partner, it's important to understand that our people with Parkinson's, have a diagnosis, and they have a disease and it belongs to them.

I went through a big undertaking of learning that. It took me a few years because I always want to fix things. And I couldn't fix Cidney and her diagnosis.

I just made it worse, because it adds that level of stress and things.

And so, you know, going out to care partners, you know sometimes we need to get a little bit of help. Sometimes we need to communicate to others what's going on with us and as well as the people with Parkinson's need to communicate with others, meaning a counselor or something, so, a trusted person that can give us an insight, to help in that communication process, and having done that and having gone through that process over a number of years and to where we are today has been just tremendous amount of growth for both of us mainly for me, but I'm watching Cidney talk and going oh my gosh how did she get so good at this?

Kat Hill:

And Pat you bring up a really good point, I'd like to hear to how you choose, Cidney, how do you choose to communicate about the disease process to people who don't know what Parkinson's is? You know, this is a good opportunity to share with our community how they might share that information.

Cidney Donahoo:



You know, I think it depends on who you're talking to, whether it's somebody close, whether somebody in passing, you know it depends on your relationship with them.

You know, I'm going to give as much information as I can that is comfortable and applicable. So, for somebody in passing or maybe there's something happened that well I have Parkinson's and that's why, whatever happened...

Kat Hill:

My hands shaking. I was getting a suitcase out somewhere, the other day and I had a shaky hand, I just said please excuse me I've got Parkinson's disease. This is going to take me a minute.

Cidney Donahoo:

Yeah, and I always try and say that in, Oh I have Parkinson's disease, but rather just in a matter-of-fact way, right. With friends, you know, there's so many intricacies of Parkinson's, you have to kind of pick and choose what is important for that person. You know, for friends, I may have to explain to them that sometimes I have a hard time finding my words, if I'm really tired, don't ask me to explain a whole lot of things, I'm not going to be a big part of the conversation. To closer family members, I'm going to explain to them more of the intricacies. You know I'm having some dyskinesia issues, or whatever.

So, I just think it really depends on who you're talking to.

Kat Hill:

Sure. I agree Cidney. I think that's really true. Pete, how do you handle that in your life and in your day-to-day world? I know COVID, it has made us less out in the world but how do you share it with others in your day to day?

Pete Huley:

Well, there's a couple things that I want to throw in and some of them had to do with mechanics for communication for me in particular.

I don't hear all that well. So, it's very important that I keep my hearing aid turned up and up to the best ones I can get, because otherwise, you're not hearing the person you're trying to talk with, so you're not understanding what they're even asking.

So, one is making sure that you're hearing is good. And secondly, my voice as part of the disease kind of dropped off. And so, it's now more on me to be very intentional about keeping my volume up and active, otherwise I'm just sitting here mumbling to myself and nobody knows what I'm saying.

So, I got to make sure that the input and the output are working technically, and then if depending on what the situation is I'll go into, like when getting the vaccination I told the person I had Parkinson's so they wouldn't think I was too nervous about getting the vaccination.

Kat Hill:

Yeah, yeah, that's the least of your worries, right?

Pete Huley:

And then I might tend to use email or messaging more to get messages out because the voice doesn't work as well and ears don't work as well as they should, even under the best of circumstances.

Kat Hill:

Yeah. Fair enough. Fair enough. All right, I have one other kind of big one to tackle and this is coming from my own long marriage here. So, there are times where Ken might bring something up that frustrates me in the moment and I feel like it's my problem, my issue. Don't ask me again if I've taken my medicine, or you know what's going on with me and I know that for me, I have to let myself feel it, and then tell him, honey I'm not ready to talk about this or can we talk about it later? How do you guys deal with that? Cid, Pat, you know if you're frustrated in the moment, Cidney, how do you do that without taking somebody's head off?

Cidney Donahoo:

Yeah, I sometimes, you know, do take somebody's head off but I think I'm more like you where I just have to stop and say, you know I'm just not ready to talk about it. We need some time. And I don't always know how much time it's going to take.

Kat Hill:

Right. Fair enough. Pat, if she does that, are you comfortable circling back around if you need an answer, or do you wait for her to bring it up?

Pat Donahoo:

Am I comfortable? No, I want to fix it now.

Kat Hill:

Fair enough.

Pat Donahoo:

But I am learning to circle back, I am learning to be patient and handle those things where if she doesn't want to talk about it then that's fine it's, you know, if she if it's a big deal, I'll know if it's a big deal.

Kat Hill:



And is that part of the agreement too, as part of your agreement, and this is for all the people with Parkinson's, that if there's a big issue that you agree that you'll bring it up so that our care partners don't have to worry?

Cidney Donahoo:

Yeah, I think it's important that our partners cannot read our minds. They just don't always know. And so, I think that was part of the dance that we really had to learn. You know, was to not think that the other person knows what's going on, that they're not intentionally trying to either ignore annoy us or bother us or push us, it's just that they don't know.

Kat Hill:

Mm hmm. How about for you, Pete?

Pete Huley:

Well, I have always asked Tracy to tell me if I'm dragging my feet, if I'm not standing up well, you know, we've got some little code words that we use to get me to get my posture right, and if I'm not speaking loud enough. I hear them too, that you need to bring the volume up, and so I welcome that input, because I need the feedback otherwise you tend to this sort of crumble down into yourself and it's hard to think about all the things that you need to do that you didn't used to have to think about. So, you need to get someone to help you keep on track.

Kat Hill:

Yeah. Oh, I want to thank you all for coming and talking about some of the easy and some of the tough things about communication, and I could probably talk about this all day with you all.

But I think for the sake of our program and for the sake of us needing to maybe get up and stretch our legs and taking a little break, I'm going to wrap us up. Thank you so much for joining us today, you guys.

We hope we shared some tidbits with you all, our listeners.

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