



The Victory Summit® Virtual Event: Care Partners

Care Partner Q & A

Recorded on November 13, 2021

Davis Phinney Foundation

Gail Gitin (Ambassador, Davis Phinney Foundation):

Hi I'm Gail Gitin. I am very involved with the Davis Phinney Foundation. I was married for 52 wonderful years with a man who passed away from Parkinson's just one year ago. And I don't know, I just can't leave the organization because it did so much for us. And it really helped me through some really rough times. So I feel that I want to keep working with them.

Connie Carpenter Phinney (Board Chair, Davis Phinney Foundation):

Pat, why don't you introduce yourself.

Pat Donahoo (Ambassador, Davis Phinney Foundation):

Well, hi, I'm Pat Donahoo. I'm a care partner to my wife, Cidney. We're both ambassadors like Connie mentioned. And she was diagnosed in 2010 and it's been a journey and it's continuing, and we love it and hate it. Welcome everybody.

Connie Carpenter Phinney:

Go, Gail.

Gail Gitin:

One of the things that was said this morning, someone said Parkinson's is predictably unpredictable. I really liked that.

Pat Donahoo:

Yeah. I call it sometimes it slaps you in the face without you knowing it's coming.

Connie Carpenter Phinney:

Yeah, no, that's true. And I mean, you just lay some plans down and then all of a sudden you know, you gotta just call an audible as they say, in football parlance. And since it's you know, college football day, we might as well use that, but you know, call an audible and not even be too apologetic about it because you know what, there's a lot of events that, you know, you can easily say no to, and the ones that you really want to go to and can't get to, you know, it's unfortunate, but there's also other ways, you know, you can connect via FaceTime or zoom with people at the event that maybe you're missing, especially if it's like a family event or something, you know? I think that there's, you know, in this day and age, there's so many ways to work around it. Somebody just asked, can you describe how your role



as a caretaker has evolved through your journey? Who wants to hit on that one first? That's a good question.

Pat Donahoo:

It's still evolving. That's the thing. You know, I started off on this, what are we supposed to call it now, Connie?

Connie Carpenter Phinney:

I don't know. Just some people don't like journey. It is a journey. I mean, life is a journey, come on.

Pat Donahoo:

So anyway, I call it the journey. But anyway, trying to fix it and trying to fix the problem, trying to fix the everything. And you know, I learned that you can't fix it. I think that was, I think one of our speakers today mentioned that and it's just, it continues to evolve. Right now we're going through anxiety and things like that. Areas that you know, it's just like, oh my gosh, what did I do? The anxiety that, you know, it's like the iceberg where you don't see everything down below the water and everything that you don't that isn't part of the visible parts of Parkinson's right now, we're looking at educating the close members of our team that don't understand all of those things, because, you know, as we talked in the last, in our last monthly meetup, my daughter and her family has invited me to go with them on a trip to Hawaii in December. And that has created a whole lot of anxiety. And my wife, she finally said, well, yeah, go ahead and go. And then I said, cool. I felt that relax. I felt relaxed enough that we made the plans and then the anxiety just erupted. And so we were able to make new plans and pivot and...

Connie Carpenter Phinney:

Anxiety in you or anxiety in...

Pat Donahoo:

Anxiety in her. That's the Parkinson's anxiety that was talked about today. That's why I was on the edge of my seat when they're talking about, when she was talking about anxiety and taking care of yourself and taking care of your person with Parkinson's. And that it's a real thing. And that's part of my evolving right now.

Connie Carpenter Phinney:

Yeah. I think too, and I guess we're not going to do survey, but I'm going to guess since we asked this at the start, you know, so many of the people that were signing on today, many of you were first timers to the Victory Summit and to this format, but many of you have been living with Parkinson's, a person with Parkinson's for a very long time. And I would encourage, when you talk about the journey or your role, I think one of the things that Davis and I have realized that's helpful is sometimes you just gotta call for a reset, you gotta hit that reset button. And, you know, you might've dug a little bit of a hole for yourself, whether it's an anxiety hole or a, you know, apathy hole or, you know, whatever, give yourself permission to just sort of put that behind you and with your person with Parkinson's and just really have those important conversations around, you know, this is hard. I know it's hard for you and I don't know what it feels like to be you.

I say that a lot to Davis, you know, I don't know what it feels like to be you. And I know a lot of times your person with Parkinson's actually, while they're not feeling very good themselves, they're also feeling not so good about what they've brought to your life. And so it's important to talk about that, to acknowledge that, you know, yeah, this is hard. It's not what I thought. And here's how I think we can make it better. You know, when you learn something new or you want to try something new is to use that kind of phraseology to get started you know, maybe a fresh track because the Parkinson's does change. And that's why, when I wrote the little pamphlet, the handout, it was called Rewriting the Rule Book, because I felt like the rules are changing so fast, you know?

Let me give one example, Gail, and then I'll throw it to you is the Olympics have changed so much because of COVID this last year in Tokyo and now going winter Olympics are in Beijing. And I just got the, I follow all the kind of tangential stuff that goes on within the Olympic movement, and I got their updated playbook. And I love that because it's a playbook around how the athletes are going to be dealt with in terms of COVID and you know, what the rules are and you know, how to best prepare and how they're going to do the distancing and all that stuff. But it's like, we need that too, right? We need updated playbooks, like kind of regularly. And so I would encourage all of you, if you haven't thought in those terms, the terms of, you know, I need to write down my thoughts like what's working. I think that came up today is talk about what's working and talk about what's not working. And you know, let's not do this anymore. Let's not have these arguments that are going to trigger your symptoms because then I feel guilty. And then you feel guilty that I feel guilty. You know, it's just this vicious circle. Right? So Gail, what do you got? You were going to add something to that.

Gail Gitin:

Well, you were talking about the journey. So, the first part of my journey was not quite understanding what was going on. So that was just confusion. When my husband was diagnosed, then there was denial that came into the picture, as his, and I didn't really want to share it with anyone. I asked him not to tell anyone, and I didn't want to tell anyone because I was in denial, figuring I can hide his symptoms. That was a job for me to hide his symptoms. So I gave myself a job right then and there. Then as that progressed, I had the journey of him telling me, Gail, you don't, you have to understand, I'm not doing this on purpose. I'm not being slow getting ready, or I'm not sitting at the table staring when there are things to be done. So I had to begin to understand that. At first, I refused to read anything about Parkinson's because there aren't too many happy examples of Parkinson's.

So I thought I would stop reading about it, but of course, as things progressed, I then realized it's very important to me to understand so that I can be more tolerant of the things that are irritating me and understanding it. So I went from denying to then getting involved in reading it. And then of course, as my husband became worse and worse, I then became a caregiver. And then I did a lot of reading. Then I really jumped into it with, well, the Davis Phinney Foundation, everything like that. So I could actually empathize with him. You know, there was a whole empathy and sympathy, but and really understanding, which made it easier for me because I didn't take things personally. And also, I didn't, I stopped trying to control his disease. I went with it and realized that things are going to happen, and I can't control it. So I gave myself that ability to throw away the guilt and just do the best job that I can do. So that was my journey.



Connie Carpenter Phinney:

Yeah. Huh. I think that's a good point too. Like you, we do go through, I think some of the stages that the newly diagnosed go through, right? Like confusion, denial, resistance. I would say too, and I meant to say this during my talk earlier is that one of the best things you can do for yourself is to avoid negativity around you. And that would be like watching the news or don't watch the news, you know, don't keep your TV on all day to you know, a news channel that is really only designed to bring you the bad news, you know, and change your point of view too, so that you can keep yourself more upbeat, because I think that's a big part of grappling and dealing with this successfully. I'd also like to throw out there, Pat, you actually changed jobs in order to better accommodate your person with Parkinson's, would you like to talk about that a little, because I think that's another interesting aspect. And again, you know, many people on the call are maybe past their prime work years, but you did a pivot fairly late in your life to make your family situation work.

Pat Donahoo:

Yeah, to say the least. I actually was in a, I had a career in advertising and radio and television and for a long time, 30 years about, and when Parkinson's came, I knew, we knew that something had to change because of the stress that I would bring home. You know, you're only as good as your last sale. And sometimes I'd bring that home and I'd bring work home and that was needing, we needed to make a change on that because of the stress, because of the negativity or what have you, that might be coming around with that. And so we started looking at it and eventually what I did is I went back to school. I was well into my fifties. And I went back to school, I now have a master's degree in special education and I'm a special education teacher at a high school here in Las Vegas.

And I'm loving it. And it also gives us, it provides us you know, it still has its stresses, but it provides us with the opportunity, number one, to have the benefit of a decent insurance program which is important. And the other thing is that it allows for our schedule to take time in the summers to take time, to get out of the, we're in the middle of the desert. And I don't know if your person with Parkinson's likes the heat, mine doesn't and so we get out and go up to Colorado and we actually ride our bikes all over the place, but yeah, that's just really how it's evolved. And, but changing that job was a big deal. I'm now six years, I'm in my sixth year of teaching and I'm the oldest teacher with the youngest amount of years with the least experience.

Connie Carpenter Phinney:

The least experience, yeah. But I think it's also just like everything that we do as a care partner with our person or around, you know, life choices like this with, and for our person with Parkinson's affects us. And we need to you know, really assess how we're living. Davis and I downsized pretty early into a single floor condominium with a wonderful view, which is where he takes his sunset shots from. And you know, it's really served us well. It's not for everyone, you know, and I know Amber, the occupational therapist was talking about, you know, trying to get your person with Parkinson's up and down stairs. You know, there's several places in the home that become pretty unhealthy for your person with Parkinson's and stairs can be one of them. And if, especially frequently, and especially if they're running late and they're trying to come down the stairs fast, one time Davis came down the stairs on his back as if he was riding a sled, because he was wearing his some ski boots or something.

And they slipped out and we had a friend waiting at the front door, and I was just like, oh my God. But, you know, he turned it into like a smiling moment as if he'd done it on purpose as if he was the one man, you know, it was a luge run, but, you know, fortunately he didn't get injured, but, you know, that was like, I was just going oh my God, we got to get out of this place cause you know, he'd just run up for something that he'd forgotten. And then, you know, in his hurry and being in boots that he would normally not be wearing in the house fell and, you know, falling is difficult. We talked a little bit earlier today too, about what was one of the topics on the OT, I was thinking, oh, one thing that wasn't included, I wanted to mention was talking about driving. Are any of you concerned about your person with Parkinson's driving?

Yeah, so I just wanted to add that the occupational therapist can also sometimes either direct you to, or help you with an assessment for driving. And yes, the best choice is not to drive, but if they are going to drive, they need to stay in practice driving. And that's another great point that Susan Imke who was meant to be among us today also would talk about with her husband, you know, that when you decide that it's not safe and they drive very, very, very infrequently. You want to remember that they do need to practice. And so infrequently, it's not good. It's better just to not drive at all, if there's a concern. And that's hard, it's really hard. Yeah. And a couple of people are saying their person doesn't drive or decided not to drive. And I think that's, it's a rough one. It's hard with elderly parents, even if they've been healthy their whole life, right, when they should stop driving. And there's nothing worse for your body than a car accident so much better to avoid that if possible.

Jackie Hanson (Education Content Associate, Davis Phinney Foundation):

We had a question, I think, right at the beginning from Alison, she asked, so often when I plan an activity with my husband at the last minute, he doesn't want to participate. How can I best handle these situations?

Connie Carpenter Phinney:

He doesn't want to participate, so you've made a plan and he wants to change the plan basically.

Alison (Audience Member):

Right. I feel like he it might be that he's not feeling well, but I don't take it that way. I take it that he's just doesn't want to do it. And it hurts my feelings. And it, I feel like he's just trying to not go along with what we thought we would do.

Connie Carpenter Phinney:

Yeah. That must be frustrating. And I think, and I think we've all probably experienced that on some level. And I think that's where, and so at the moment that they decide not to go is a hard moment to then have a careful calm conversation around it. Right? And so, you know, let me use it analogy that I would say when my daughter was young and she was in like middle school let's say even grade school, she would ask, she would go to a friend's house for dinner, they'd be playing and would lead to dinner. And then she'd call, and she'd say, can I sleep over? And one of the number one rules in the house was there was no unplanned, there were no unplanned sleepovers. So once we, you know, if she would have asked me a few days before, and I could have talked to the parents and we had it set up, then we might've done that, in this case with you, with Parkinson's.

Can you see the link here? You need to have a rule between you that says you don't get to change the plans, you know, especially about something that's near and dear to me, unless it's an emergency, and I'm only gonna give you like so many, like little cards, like you're gonna make some little cards up, like monopoly, you know, the get out of jail, free card. This could be the, you know, you don't have to go card or I'm going to get someone to come here and stay with you while I go card. But I think that this leads to that bigger question of communication. And then also the bigger question of who's on your team that you can get to support you. And especially if it's an event that's important to you, if it was, you know, your family get together, if it was your friends and you want to still go, you need to be able to have an option right to still go. And that's where you have, that's where you just need this either a bigger team or, you know, some good rules around that, because nobody likes a surprise. And even though we all have to agree that that does happen. I think if you started to have that conversation, when it wasn't go time, it would be most effective. Pat or Gail, do you have anything on that?

Gail Gitin:

It's tough. It's really tough. You know, you plan these things. This is for your mental health, your physical health, and not only don't, you get a chance to go, but then you have more stress because of the situation, it's difficult. Connie, your suggestion is good. I can't imagine other than whatever condition. I mean, if your Parkinson's patient is in pretty good condition, then you just say, here's your dinner, help yourself, I'm going. But that depends on what condition they're in of course.

Pat Donahoo:

Yeah. Yeah. I try to keep an open mind, if she doesn't want to end up not wanting to go to something that we have planned to go, if I don't really care to go, you know, if it doesn't, if it's not gonna affect me either way. I mean, if it's not a planned thing where it's something that I'm really looking forward to, then we can, you know, we talk and everything, but I, like, I was asked if I'm going to Hawaii, I am going to Hawaii, and she is going on a trip of her own to her sister's house. So we've got it all worked out that way, but it could, you know, you never know it could still change, but yeah, keeping an open mind and being willing to give and take and but you do need to take care of yourself and if it's something that's really planned for, for sure, I mean, there's your dinner, I'll be back.

Jackie Hanson:

Richard looks like he has a question. Yeah, Richard.

Richard (Audience Member):

Actually I'd like to make a contribution. Hi, I'm Richard Adler. My friend, Gail, who's been wonderful to me has been keeping me alive for a long time. My wife's in her 17th year, I just said to the chats on a completely different subject. I want to make a contribution. I'm a lawyer for 54 years, former prosecutor, and I specialize in traffic law. I have had many friends and relatives and referrals who ask me, what do I do about somebody who shouldn't be driving? They won't quit. You are playing with fire. Somebody could get killed. Somebody could be maimed, your loved ones could be injured, permanent more permanent ways than, you know. Number one, try to find somebody they trust and make a limited contract with them, maybe for three months, five months where they won't drive. And then it's a renewable contract and have both of you sign it, excuse me, and have both of you sign it so that you're both responsible to each other. And I.



Connie Carpenter Phinney:

Hey Richard?

Richard:

Go ahead Connie, sorry.

Connie Carpenter Phinney:

Yeah. Richard, let me add to that. So interestingly in our case, and I'd just like to share that because I do agree with you that if you feel your person with Parkinson's is unsafe it's a tough call, but you need to help them to stop driving. And I think a contract between you might work, but we also, we paid money to be evaluated, to have Davis evaluated by an occupational therapist who does this for elderly people and people that have challenges like Parkinson's and she and Davis made a contract. And that was that Davis wouldn't drive after dark. And he wouldn't drive in unfamiliar places because she could see where that would cause problems. He doesn't have trouble driving in his town. We live in the town, he was born and raised in, he doesn't have trouble driving to the airport and back because it's a simple, you know, drive. And so that was, to me, was a fantastic suggestion because I think driving an unfamiliar places, is hard for all of us, much less a person with Parkinson's. So, and I was told Richard at one of our talks by someone with similar experience to yours, that having, getting your person tested and an approval for that will actually be a form of defense if your person gets in, you're shaking your head, Richard is that wrong?

Richard:

There are two ways. First of all, I love what you did with, I just learned that my wife through you Connie and a program, is suffering from some dementia after 17 years. Now, she's in a wheelchair for the last two. And I didn't realize that dementia, it's cognitive patterning, but it's also responsiveness to patterns, these could be traffic lights in your scenario, or it could be at home, not even being able to sort sweets and numbers of decks of cards. So the reason I'm mentioning this is if you can find a way there's two ways to do this, number one, you can write to your licensing issue body in the state, usually called the DMV, department of motor vehicles, who in our area, it says Illinois secretary of state, whoever issues the license and write, and ask, say that this person anonymously say this person's unsafe. They'll cancel the license, take the burden off of you to take away your loved ones privileges and have it resolved that way, anonymously. And then a doctor has to write a written approval for that license to get back reviewed by a medical board at the DMV. They have a professional board that does this all the time.

Connie Carpenter Phinney:

I think that's probably state by state right?

Richard:

Every state has this, all 48 states, remarkably. The second thing that you mentioned. My father-in-law took the test. I drove him there cause I didn't feel safe with him driving. This was years ago, we got to the DMV, they took him around, I waited, they came back. I said, how'd you do figuring he failed. And I'm off the hook. He said, I passed. I said, Oh God. Congratulations. Give me the key to the car. Where

did you park? He said, I have no idea. He had no idea where he had just parked his car with the person who tested him, that tells you about cognitive patterning. And he had the beginnings of dementia. I'm sorry. I'll stay out from now.

Connie Carpenter Phinney:

Yeah, let's jump topics. But thank you so much for that because I think it is an important topic and we didn't cover it. We didn't talk about it today. So what else do we have? We have a long, is this a question from Darlene, Jackie?

Jackie Hanson:

Darlene, did you have a question associated with your comment or just contributing?

Darlene (Audience Member):

Yeah. My husband has become, it is a question and it's about me. He doesn't take very much medication, just carbidopa, levodopa, but he's become convinced that his worsening symptoms in the evening come from more and more medication. And so he keeps wanting to reduce his medication and his symptoms keep getting worse and worse. And so I'm watching him suffer. My caregiver burden is increasing, and we've had numerous conversations about this, but he's convinced that his worsening symptoms in the evenings come from his medication, and he wants to reduce it and reduce it and reduce it. He keeps saying, I keep saying, well, are you willing to try whether more medication helps? And he's like, oh, I'll try it maybe sometime, but then he never does. Because it doesn't make sense to him on some level. And I have no idea is this cognitive decline? What's, you know, what's going on here? I don't think that the carbidopa levodopa is causing worsening symptoms. I think it's disease progression.

Connie Carpenter Phinney:

Sure. It could be a combination, but you know, you're not in a position to make that determination, kind of, but you're seeing it right? And so you want to know, is this normal?

Darlene:

Well, here's the caregiver problem too, in his doctor's appointments, he's far more functional than at home. So our doctors follow, our doctor tends is young and tends to follow his lead is what I'm seeing so far. So as a care partner, how do I, I just, I'm at a loss.

Connie Carpenter Phinney:

Okay. Darlene, are you seeing movement disorder specialist?

Darlene:

Yes. Movement disorder specialist.

Connie Carpenter Phinney:



Yeah, that's good. So I think what you want to do is communicate with the doctor's office privately, are you able to do that? Do you have the HIPAA release forms?

Darlene:

I don't know. I have not tried to do that before, so I could try that.

Connie Carpenter Phinney:

Let me make a suggestion. And that is you call the doctor's office and ask them, what do you need from them to sign on? He probably has to sign it too to say that you can speak to the doctor. And I think every caregiver on this chat right here, and I've said it many times should have a HIPAA release form signed for all care for their person with Parkinson's so that you can be an informed member of the team. And doctors do know that people show up in the, in the office, people with Parkinson's doing their best. And very often they ask people to come, you know, make the appointment at a time of day when they're not doing their best. So I would encourage you the next time that you do see your doctor, which I know it always takes months to do this, but schedule it for late in the day.

Darlene:

That would have to be seven or eight o'clock at night, which is not when doctors have appointments, but.

Connie Carpenter Phinney:

Schedule it as late as you can. And maybe ask him to go the appointment unmedicated or ask your doctor to ask him to go to the appointment unmedicated, because they need to see what you're talking about to help you manage it. He's not capable of managing himself. If what your, if he's experiencing worsening symptoms and more discomfort, then he's not going to sleep as well. And, you know, executive function is, you know, decision-making function is highly affected by Parkinson's and by fatigue.

Darlene:

It does seem to be a spiral. Yeah. There's kind of a bit of a spiral going on at this point.

Connie Carpenter Phinney:

Yeah. And it's hard for you and because it's hard for you it needs to be remedied. Okay. And it could be that when you do take more meds, you sometime get more dyskinesia. And that, you know, when you're in more of the on-off cycle variations, Pat or Gail, do you have anything to add to that?

Darlene:

He's had no dyskinesia for several years. He's just, he never takes enough medication to get to that threshold of dyskinesia.

Connie Carpenter Phinney:

How old is he?

Speaker 7:

63. Diagnosed seven years ago. So he's still relatively functional, but you know, it's just, it's tough. Like if he can't button his shirt and he needs me to button his shirt and what he really needs is adjusted medications. I'm just like, how bad does this have to get before he realizes?

Pat Donahoo:

Well, they do have shirts that with magnets on.

Darlene:

Oh yeah. We'll get to those eventually. I'm well aware. I just think we can delay that a few more years.

Pat Donahoo:

I mean, I read your comment a while ago and where I got, where the red flag came up for me was where you say the doctor is somewhat passive and follows his lead and so forth. And I can empathize with that.

Darlene:

I've experienced that in a lot of medical settings, you know, we went to occupational therapist and she's like, show me how you put your jacket on. And he puts it on one sleeve after the other. At home, no, never. And she was like, oh, okay. And you know, not to be pessimistic or anything, but at home it's like, oh my second sleeve, I can't do it, can't do it. And I'm walking over and, you know, helping him. And it's no big deal, but why can he do that in the doctor's office?

Connie Carpenter Phinney:

Okay. Listen up. I hate to say this, but I guess we're at the time where we need to wrap this up. Jackie's saying, yeah, we were just getting to some good questions and I'm sorry about that. But I do think many of you come, yeah, thank you, Darlene, for asking that, that's an important question. And if you, I'd love to hear what happens, I hope you get success with that. Have some success. I know it's hard. And your husband is actually in the age range of someone who, you know, is still experimenting. You know, I mean, we have to honor the person with Parkinson's feeling around taking their medications, but when we can see that it's not working it's very frustrating and there are options and I call it being under-managed when you have, especially if it's a long period of time, so you need, where he's uncomfortable.

So let's hope you can find better management. And I just so appreciate everyone showing up and you know, just being here for us and for your person with Parkinson's, it's so important. There's a couple of things that I was wanting to just close with. And I didn't say earlier, even in mine, I've been listening to a lot of Brené Brown and she talks about, you know, a lot about believing in yourself. And so I hope you can maybe find some of those resources to listen to. Gail always articulates so beautifully how each of us is doing our best. Oh, there you go. Yes. Showing a book, very good. Is that a Brené Brown book? I can't actually see it, but we're doing our best. And if you look for confirmation that you're not good at something, you'll definitely find it. But if you look for confirmation that you're good at something, you'll also definitely find it. So let's go down that road again, that's just this cultivating a little bit more optimism, and that will help you to cultivate joy and then dig into those wonderful moments of awe.



And I think that's where I'd like to leave it today with, with all of you and hope that some of this will trickle out and help you go forward and live a rich life.

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