



**The Victory Summit® Virtual Event: Care Partners
How To Step Away From Parkinson's**
Recorded on November 13, 2021
Davis Phinney Foundation

Polly Dawkins (Executive Director, Davis Phinney Foundation):

Hello folks, as you're joining us. Hi Barb.

Barb Ankenman (Care Partner):

Hi Polly. Hello everyone.

Polly Dawkins:

Welcome back. So today is a panel, a panel of Barb and Polly, and this summer, Barb and I had a lovely chance to meet here. She was in Boulder and we had a chance to meet and over coffee, outdoors and the beautiful Colorado, and we have a chance to talk about her experience as a care partner to her husband, Dale, and really some of the strategies and tips that she and Dale have used and she's used for herself to really not make Parkinson's the center of everything. And we got into deep conversations about volunteerism and other ways to get out into the community. So I thought we wouldn't necessarily recreate that conversation, but we would have a very similar conversation and welcome you all to that. And maybe get ideas that you all could share about things that you do to step away from Parkinson's and not make Parkinson's the center of every single thing that you do. So, to start off, for those of you who may not have heard Barb on the care partner panel, Barb, would you mind introducing yourself? Tell us a little bit about you, maybe about your family, where you live, how long you've been a care partner. And again, if you'd like to be on video in the audience, please feel free to be on the video.

Barb Ankenman:

Okay, well, hello all. My name is Barb Ankenman. I live in the Northern Kentucky area right outside Cincinnati, Ohio, and my husband Dale was diagnosed with Parkinson's almost 20 years ago at the age of 46. And he also had, about five years in, he had DBS surgery. So we have gone through that. And so, likewise, I've been the care partner for 20 years. We really are in this together as I'm sure you all understand throughout it. And you know, I think we've had such a wonderful amount of information already today. What a day? Something we have heard a lot about and Polly was introducing about the need to step away from Parkinson's because you know, I don't know about you, but I feel sometimes it's every minute of the day, every action we take, every decision we make, one way or another seems to revolve around Parkinson's and it's that way for us as caregivers, it's also that way for our partner who has the diagnosis.

And we found, even though that can be a 24/7 role, we do need, we need an identity, a purpose, some relevancies, some accomplishment, that has nothing to do with Parkinson's. We need that for ourselves, and our partners need that also. So I think we're here today to talk about strategies. The one thing that Dale and I have found works for us both individually and also together has been volunteering out in the community. It gives us a chance to focus on other people, interact with other people, focus on maybe challenges and issues that don't have to do with Parkinson's, allows us to give, be relevant and feel good about ourselves as we help others too.

Polly Dawkins:

What are some of the things that you do? Tell us a little bit out of your volunteerism.

Barb Ankenman:

Okay. Something that I do myself is I volunteer at a women's prison and I do a ministry for women's prison and help them as they're in that very, very dark place, find hope for themselves and forgiveness. Forgiveness is a big part of it, just forgiving, not only other people and circumstances that have often caused them to be where they are, but to forgive themselves. It's been very, very worthwhile and eye-opening to me also, because I speak to these women who are literally in a prison, their movements are restricted, they cannot do what they want to do when they want to do it necessarily. And it also made me understand Dale and his Parkinson's as well because someone with Parkinson's and sometimes us as caregivers, we're in a prison also. It's a different prison, but it's a prison where we can't always do and go and be what we want to do and go and be and you're caught up in it. And you do have that feeling of hopelessness. So that's been the great one that I do. And that has taken me out of not only taken me out of Parkinson's, but also at the same time kind of, given me insight into it as well.

Polly Dawkins:

Hmm. That's an interesting analogy. How do you do that Barb and feel comfortable leaving Dale?

Barb Ankenman:

For we're very blessed in that he is still very mobile, still very much able to care for himself for periods of time. So we are able to do that. Sometimes when I've done it will be for a weekend though. Oftentimes I'm just going up there for short periods of time, but sometimes we do what is like a weekend retreat there within the prison. And during that time I'm looking for friends and family who are helping to check in on him, be with him. And they help make that happen there. It's finding those people to support you and what you're doing, and Dale understands how important it is for me. So he supports it. From that standpoint.



Polly Dawkins:

I'm just saying we're welcoming quite a few other people are joining this conversation as you're joining, Barb and I are chatting about ways to step away from Parkinson's. And she's speaking specifically about volunteerism in doing ministry in a women's prison.

Barb Ankenman:

We also have, Dale and I will do, we'll volunteer together at different places, and this has taken a different, it's changed over time as some of his physical abilities have lessened. We used to do a lot of very active ones, but more recently with COVID, we started volunteering at a local food bank where, if you have Kroger's and click lists, you'll understand it, we're loading the food into people's cars, they pull up and there's, you know, very little contact, wear masks, and we're taking the food for them and loading them in the cars, at the same time, able to, Dale will usually tell them a pretty stupid joke and get them laughing and they get a little interaction. We get a little interaction. That has become more difficult as Dale's balance became more challenged.

So we now look at different ways that he and I can do something together and volunteer. We're getting involved with transporting rescue dogs. So oftentimes they need to be taken from out of the shelter and into a foster home. And there may be some traveling involved with that. So we will transport the dogs, rescue dogs. And Dale is also looking at a volunteer opportunity with, he's a veteran with the, oh, I'm drawing a total blank, the O S, at the airport where they have a little welcome area for veterans.

Polly Dawkins:

Ok. Yeah yeah yeah.

Barb Ankenman:

And so he can talk with them, again, getting some social interaction and just getting out of that Parkinson's for a bit.

Polly Dawkins:

So rescue dog transportation, delivering groceries for folks during COVID, volunteering in the women's prison. That's a lot of things you're doing.

Barb Ankenman:

You know, the prison ministry, I mean, that can be as little as an hour a month a few hours a month, it's, you know, little bits and it allows flexibility with the transporting the rescue dogs, you know, they'll put a word out, we need a volunteer for this. And so you can see if that fits

your schedule or how you're doing that day. So you're not totally locked into it, but you're able to take advantage of it.

Polly Dawkins:

Great ideas. I want to open up to those of you in the audience. Does anybody have ideas or things that they are doing or to volunteer or step away from Parkinson's that you want to chat about with us? And as I'm seeing those of you join, I understand that one of our presenters for the breakout session didn't show up. So we will for sure have that session and deliver it some other time. Apologies for that. Feel free to take yourself off mute and put your video on and join in the conversation.

Pat (Audience Member):

Polly?

Polly Dawkins:

Hi, Pat. Welcome.

Pat:

I do volunteer as well. I've volunteer at the local historical museum here, but I had to time my volunteering, we've I talked to my husband about it and we chose a time when he is normally napping. So right after lunch, I get in my car, I drive downtown and I've got a couple of hours when I can be away from the house, know that he's going to be okay. And one of the advantages is that I bring back a different perspective. So it gives us something more to talk about when we're at home, but I wanted to ask Barb. One thing I had to overcome was a feeling of guilt because I was leaving him at home and he didn't have anything to engage in.

Barb Ankenman:

That absolutely is nice, I still get those twinges because you know, I'm out and about talking to people, seeing people. And one, he's just so supportive of me and he understands my need to do that. And that's where you can have some real honest communication between you of what you need to be a better caregiver for them and a better partner for them. But that's also why I've searched for opportunities that we both can do. You know, again, with the like the transporting rescue dogs. If he's not able to drive, I can be the driver. If he's having a tough day speech wise, you don't have to have a conversation with the dog. And we can get out there and still feel both of us in, in for him, particularly that he's doing something with a purpose he's helping out he's being relevant. So I do search for those opportunities that we can do things together. But we do have to consider the physical limitations there.

Polly Dawkins:



And Pat, if you are volunteering when he's resting, how do you ensure that you do as Connie was suggesting earlier that you rest yourself?

Pat:

You know having something to do, well, and I only volunteer two days a week. I'm able to get away. So on those other days, I do sit down, and I have some quiet time for myself during his nap time, if you would. So that's, it's okay. But I love the idea of Barb and trying to find something we could do together. It's just difficult to find those opportunities sometimes and then to convince him that it's a good idea. I am going to look for that. Thank you for that suggestion.

Barb Ankenman:

Yeah. And I think once someone gets out and does it and sees how rewarding it is, it's kind of like exercising at the gym. A lot of times, you just, you really don't want to go, but once you get there, you're glad you came. So hopefully that'll be helpful in getting them there and get a taste of it.

Pat:

Thank you.

Polly Dawkins:

Thanks Pat, for those ideas. Anyone else have ideas of either how to get out into your community, how to get away from Parkinson's or perhaps how to get your person with Parkinson's out from having Parkinson's being focused every day?

Catherine (Audience Member):

I'd like to say something.

Polly Dawkins:

Hi Catherine.

Catherine:

Hi. My husband, COVID really threw a wrench into a lot of different things, physically being present, like volunteering. But what I suggested when COVID started is that my husband call five friends every day, because they were isolated. And I thought that it would enable him to reach out and touch somebody else's life. So it was kind of like his own personal ministry and you know, it's amazing. He really took it to heart and he called, oh my gosh, I can't even tell you people he knew in high school people that, you know were in our wedding. I mean, people that,

you know, we, our son had grown up with in school. I mean, he just connected with all these different people and, you know, it was, it really was a wonderful thing because he would come to the dinner table then and talk about the conversations that he had. And, you know, it was just a real, you know, it was such a wonderful experience, even in the midst of COVID. So there are opportunities even with COVID.

Polly Dawkins:

That's such a lovely idea. Catherine, how, I know so many people talk about sort of overcoming that lack of inertia or that initiative to pick up the phone. Did you and your partner, your husband struggle with that piece of it, or did he immediately take to this idea?

Catherine:

Well, my husband is the more personable of the two of us. So he actually was like all gung ho for this since the very beginning. And, you know, it's really been so interesting because we, he has friends even that have Alzheimer's and he checks in with them all the time. And so, you know, he may be the only call they get, you know, I just think it's really you know, it's helped him and it's helped other people, but he didn't seem to have any reservations about making the phone calls. And maybe it was because, you know, he didn't have a chance to see people on the street like he normally, we used to take a walk all the time down to the avenue and he would, you know, be like the mayor of the town saying hi to everybody. So you know, for him to pick up the phone was not that big of a deal. He just took to it, so.

Polly Dawkins:

That's great. I think that's not everybody's experience. You're lucky that he was able to do that so readily.

Catherine:

Well, then it took the focus off of him and put the focus on somebody else. You know, that's the beauty of volunteering too, is that it takes the focus off of yourself and we all are healthier when we're focused on somebody else rather than ourselves so.

Polly Dawkins:

Exactly. Hi Jeannie Quam, I see you've gone on video and off mute. Welcome.

Jeannie:

Thank you Polly. It's good to see you. So I think Polly, you may know, but the community may not know that my husband loves to play his instruments. And so our community, we live on a lake and so every Friday evening, he goes out and gives a concert on the lake that other members around the lake can hear. And that gives him something to look forward to. And he gets applause and cheers and other things immediately. But then when we have opportunities



to be what I would call face-to-face, there are opportunities for more feedback on how that's going for him and connections, oh, you're the guy that plays the saxophone, you know, that kind of thing. So it gives him a lot of stuff. And as time has gone on, I am involved in making sure that how he proceeds to the lake is safe and things like that.

But then when I'm in the community, then I also get some feedback about what they have enjoyed as far as that goes. And then we, we also both volunteer at our church to play in the band and the community there. So that is a big part and we have felt safe lately to get back involved in our church from that standpoint. So that's really nice as far as some other involvement. So getting involved with people, the other thing is when he has responsibilities and maybe it's not a good driving day for him, I'll go along and then in whatever community we happen to be in for that volunteering position, I'll check in with friends that I haven't seen for a while. And so that gives me some opportunity to do that visit in person like Kathleen was saying, Catherine, sorry, was saying about making the phone calls and checking in with friends.

Polly Dawkins:

Yeah. Somebody is asking the question. Deborah is asking the question in the chat about a really tough topic. I don't know if anybody in the audience or Barb or Catherine or Jeannie have suggestions. She says that her husband is really limited in his ability to even communicate. He's got Parkinson's disease dementia with dementia. He's really hard to understand and to communicate, and she doesn't have family. She doesn't have friends who can help, and she doesn't have a lot of money to hire help. Does anybody have any ideas for Deborah's, how she can get away, how she can help provide extra care and have a little time off, feel free to unmute yourselves or Barb if you've got ideas.

Barb Ankenman:

Yeah, I would search for maybe a senior care association where they may have day care in different senior centers where possibly she can get a respite if they could care for him or send someone in just so you can have lunch with a friend.

Pat:

In our area we have, and I know there are throughout the nation area agency on aging and disabilities, and they often have small grants for respite care, but they do have care, not provide, well, they have care providers, they can share lists of information about, but they have case managers who can help, especially folks who are on limited incomes. So I would really recommend looking into your regional or your local area agency on aging and disability to see what they might be able to help with.

Polly Dawkins:

Thanks for that, Pat.

Iris (Audience Member):

It is the communication that is really a problem for us. Les has adjusted to be having Parkinson's. He's had it for about I suppose, 16 or 17 years. And I just, I'll put myself back on video again. Yes. I can't get back on video, but anyway, our problem is communication because his DBS that he had probably, I don't know, eight or nine years ago, affected his speech. 1% of the people that have DBS or the brain stimulation for those of you who aren't familiar with that term. So he cannot speak clearly. And so I need some help with that because if he could speak clearly, I could understand what he needs when he wants. I'm having to consider putting him in or having him placed in a home after the holidays just because it is so frustrating for me to try to communicate with him. So if there's any ideas of what can happen with the stuttering and fast speech, after that, I would be very grateful.

Jeannie:

Has he had any speech therapy contact or did anybody ever suggest a communication board of some sort that would help with that?

Iris:

He has speech therapy every day and his coordination isn't good enough for a speech board.

Polly Dawkins:

That's challenging.

Barb Ankenman:

Very, very challenging.

Iris:

Now, you're hearing my Alexa and that has helped us greatly in his medication. He takes the carbidopa levodopa every hour cause we're trying to be our own pump. And that, so that's really helped. So that is one tool that we have used and really helps us. We have Alexa that reminds us to take the medication every hour.

Polly Dawkins:

That's a great, we heard her in the background.

Catherine:

Yeah. I just put something into the chat about LSVT loud. Have you heard about that?



Iris:

Oh, yes. We've had that too. We live in a remote part of Iowa. Lamars, Iowa, the ice cream capital of the world, but we do have very good healthcare here. So we've done everything that we can find other than we don't have a local boxing program, but with Iowa State University, we do have a boxing once a week on zoom. Zoom has been wonderful for us. We do yoga twice a week with Peter Lynch. That's a free thing for Parkinson's. So that's the Iowa State. Iowa State has a zoom every day at two with something singing or whatever. So we're doing what we can, I think, but there's, the last six years have been pretty tough.

Polly Dawkins:

Zoom certainly has enabled all of us to tap into resources where we live to access things, especially as we were talking about things that are outside of Parkinson's, but even for your person with Parkinson's accessing classes and therapies that you wouldn't otherwise have, but there are many other church groups that are meeting and singing groups and quilting groups that are meeting on zoom if you have a hobby like that to, if you can't get out of your house, if that's part of the challenge.

Barb Ankenman:

And sometimes if you can't get out of the house, is there something you can do in your house? Can you invite others over, friends over to do a book club, you know, who aren't going to care if the house is neat, or, you know, something like that, but you know, perhaps there's an activity you can engage right there and bring others in.

Polly Dawkins:

That's a good idea.

Catherine:

You know, there was a group that was in the bay area called the hummingbird project and they used to do travel videos. And they could, they went to different countries, and it was to help people that were in Alzheimer's or dementia go back to a place that they, you know, when they traveled, when they were younger. And we went to one with Ireland and another one in Norway and they integrate music, stories, language, and then pictures. And sometimes it just stimulates memories for the person. And it was something that you could just do at your computer.

Polly Dawkins:

Yeah. I've heard about virtual tours of museums that you can do. Barb, you were mentioning when we met this summer that even during, or especially during the last 18 months during COVID time, it's been hard to get out and do some of the volunteerism things that the prison hasn't been necessarily open. You've done some of that on zoom, some of the ministry on



zoom. But I love the idea that, you know, delivering rescue animals and delivering groceries, I think that's such a creative idea of how you can continue to get out together and do things even if your options are fairly limited.

Barb Ankenman:

That was, that helped us get through COVID, that absolutely did. Cause you can do some of those things with very minimal contact and and do it safely, but still get out and about in that way and get some interaction. We at the beginning of COVID, I mean, what, the other thing we did was walk our dog and we've had to be more flexible with that. I mean, it's, as you know, with Parkinson's, things can change very quickly and we're at the start. We could hike with our dog, two or three miles, and now on a good day, a really good day, Dale may be able to do a mile, but more often than not, I'll be walking the dog, but that again, just getting out and walking the dog even just staying in the neighborhood. So I'm not gone from the house. I know he's safe for the next half hour and I can get outside, walk the dog, maybe see some neighbors, and certainly feel the sun and the wind and enjoy the changes in seasons like that.

Polly Dawkins:

Yeah. Hi, Susan, did you have a comment?

Susan:

Yeah. Just to support Barb's volunteerism. I have volunteered for several years with an organization called hospice Niagara. And so I live in Niagara on the lake in Ontario. That's why it's called Niagara. And part of our besides taking care of end-of-life clients, we also do bereavement programs for those who've lost someone that they've loved. And one of those activities is a weekly grief walk. And I volunteer for that and I have found it extremely helpful to be able to listen to other people's problems and be empathetic to them during COVID of course now when the phone starts ringing let me, so part of the problem has been that we haven't been able to do the grief walk, so we've done telephone counseling and I've learned more about people dying of cancer and heart disease and other things than Parkinson's, but it's kind of even though it's somewhat related, it's taking me away from my own and from my husband's actually disease and I have found it very rewarding quite frankly, and comforting.

And so this has kind of gone on to even include some family situations this year. So I've started to become me the counselor and of record, I guess. And what I've noticed is that I've developed a really close relationship with the care partners. And when I kind of send out good messages from the universe to people, I have more care partners on my list than I do people with issues just because I can synthesize more with them. And, and as we all know, most people don't know what you're doing anyway or what it means. And when you are one, you certainly do. So anyway, this has been wonderful. I usually sit in on the monthly meetings and I have found them very interesting because sometimes I'll go and say, oh, do I really need to do it today?



And blah, blah. And then there's that little comment that Gail makes, or Connie and you think, oh, wow. I had a question. I didn't know it, but I've got an answer. Anyway. So thank you for that. And thank you for today.

Polly Dawkins:

Oh yeah. Susan, thanks for your comments. Quick question for you. How did you find the grief walking, that organization and get involved in that?

Susan:

Well, you know, it's interesting when I retired, I started to do a lot of volunteer work. Most of it was for cultural, theater and whatever. And I thought, well, this is great, but you know, other people could do this. And I at the time I thought, well, I'd really like to do something where I could maybe touch people and maybe make a change in somebody's life. Well, little did I know because my husband hadn't been diagnosed that time, that the life for the person I might have been touching was closer to me than I thought. At any rate there was a lot of training involved because you really need to be able to deal with people's you know, whether they're nearing the end of life or they're, they've already gone through that process. But what I really learned was it's more about listening and I don't have to give a whole lot of advice. I just have to be there and maybe ask some questions but try not to say some of the obvious things that are totally meaningless, it's about listening.

Polly Dawkins:

Yeah. It's such a good point.

Barb Ankenman:

It is and as we touch others and help others, it always helps us. Then it brings it right back.

Susan:

It really does.

Polly Dawkins:

Yeah. Thank you. Barb, how did you originally get involved in the ministry, in the women's prison?

Barb Ankenman:

That was through not directly with my church, but through a a group of women I knew through just a religious organization, and I'd heard about it, and I'd thought about it. And I always said, oh, I'll do that sometime. I'll do that sometime. Wasn't sure, I guess I was kind of putting it off,

but then I had a good friend who was doing it and she said, come along with me, try it out. And I was hooked. It's actually an organization that's throughout the country. It's Kairos Center National Prison Ministry. They have it for men and for women and it's throughout our country. And in 14 other countries around the world they've been around.

Polly Dawkins:

Would you be able to put that in the chat? So if others are interested in that work, they could, or it might spur ideas for them about ways they could get involved in something that's completely unrelated to Parkinson's, but super meaningful.

Barb Ankenman:

Absolutely. Will do that now. Thanks.

Polly Dawkins:

And speaking of chat, I'm gonna pop the main zoom link to go back to the main webinar as we close out here in about three, four minutes. Well, probably three minutes. We'll close out. I'll pop that in there. So you can just click on that and go back to the main webinar. And we'll have a really quick wrap up there before we do that, I want to see if there's anybody who has any other comments. I see such lovely conversations, people helping one another in the chat here with ideas on respite care and all but do you all have any ideas or comments for Barb or for each other about ways to step away from your day-to-day role as a care partner and perhaps get away from Parkinson's.

Catherine:

I like to go into nature. You can see by my picture, I go to Fioly which is near close to us. It's a, I've a membership there. And just to kind of go down there and just take a walk. I try and arrange to have somebody with my husband, and then I go just for a couple hours with you know, a girlfriend or our son, or, you know, just something like that and just the whole change of venue. It just, it resets my mental and emotional state. So that I'm that I remember who I am.

Polly Dawkins:

That's so important and the research around nature and nature's impact on us as human beings is so compelling and strong. There's a book written by Florence Williams called *The Nature Fix*. And it's just such an important part of our every day and the other topic of getting yourself into sunlight every day and reset your clock in the morning, your circadian rhythm every day in the beginning of the day, to get that natural light to reset your day, tells your body it's time to have a new day, and perhaps reset your emotional state as well.

Catherine:



That's exactly right.

Polly Dawkins:

As we're wrapping up here, I have gotten a message that the, if you were hoping to see the presentation on "Getting Your Ducks in a Row," the presenter got her time zones mixed up. So currently she's doing that presentation on zoom to know audience, but so that it's recorded, and we will share that with the show notes today or at the end of the session, probably close to two weeks from now we'll send out everything to everybody. Here's the link to, oops, let me see if I can get this link into here. If you'd like to go back to the main session, I'm going to click on this here, put it in the link. Sorry, put a link in the chat for you, bear with me, and we'll just be there with Connie and everybody and wrap up for the day, probably be five minutes. So if you'd like to come back and say goodbye and get some last-minute resources, we will see you there. I'm going to end this zoom by thanking Barbara for sharing her experiences, and at least getting this conversation going. I'm hopeful you've walked away with one or two things that you might try, suggestions that Jeannie or Catherine or Susan or others had, try out some new things, thanks to everyone for giving each other ideas in the chat. Barb much gratitude.

Barb Ankenman:

Thank you for involving me.

Polly Dawkins:

You're welcome. Take care.

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