



**The Victory Summit® Virtual Event:
Our Voices, Our Stories: For People with Parkinson's,
By People with Parkinson's
"A Day in My Life"
Davis Phinney Foundation**

Polly Dawkins (Executive Director, Davis Phinney Foundation):

Well now I would like to invite Carol Clupny, Michael S. Fitts, and Karen Frank on the video. Hi Carol.

Carol Clupny (Ambassador, Davis Phinney Foundation):

Good morning.

Polly Dawkins:

Hey Michael. Hi, Karen.

Karen Frank (Ambassador, YOPD Council Member, Davis Phinney Foundation):

Morning.

Polly Dawkins:

Welcome.

Michael S. Fitts (YOPD Council Member, Davis Phinney Foundation):

Good morning, everybody.

Polly Dawkins:

We have invited these esteemed panelists to join us today to talk about a day in the life with Parkinson's, a day in their life. I'm gonna turn the microphone over to you as advocates and folks who are deeply involved in the work of the Parkinson's community and the Davis Phinney Foundation. So, Karen, may I turn this over to you to start?

Karen Frank:

Yes, good morning. My Day. I cannot keep symptoms from coming and going any more than I can keep from breathing in and out, the cycle between doses, the ebb and flow as I unwind from ON to OFF and back again. I take medication, 24 pills a day to be exact, both for my PD and for my mental and physical health. See, I struggle with anxiety and depression. So, I have an effective, albeit elaborate routine. I take my PD meds four times a day, but I take medication 10 times a day. I take meds for my blood pressure, cholesterol, anxiety and depression, neuropathic pain, and sleep. Meds to me are like putting gas in my tank. I still have to drive the car which I do with lifestyle, mindfulness, slow down, listen to the birds, relax and sit in the sunshine. Throughout my day, I practice gratitude and I pray.

I not only talk to God, but I talk to my father. Yes, my father who had PD and died 10 years ago. So often I imagine my father with me, I will ask him a question and I feel the answer in my bones. I also connect with my tribe. I call several friends every day. Other people with Parkinson's. Zoom, FaceTime, messenger, need I say more? Every day I do something for and with my Parkinson's community. I take part in some sort of advocacy work every day. I try to do something for someone else. Sometimes I just listen to someone else for a bit or pray for someone. I call one person from my support group each day to check in. I like to split my exercise into two or three sessions. I use my apple watch to track and share my progress with my accountability partner.

I'm not "pre"fect some days. And I've learned to be okay with that. Sometimes I may not exercise like a pro, but I always, always, always do something physical every day. I walk, get up and down off the floor, move and wiggle around. I stretch with each dose cycle of meds. And according to my dystonia du jour, I flop around on foam roller as if I know what I'm doing and I make it look ungraceful as hell. I made fun of my husband not too long ago for pulling a muscle playing a video game. I have discovered Oculus, a little boxing on the moon to your favorite jams, maybe a stretching class after, beside a mountain lake, dancing at the virtual club to my favorite tunes. This experience does not disappoint. I watch something funny on TV because laughter beckons. I try to find the humor in many things, including my apathy, which has me writing this story while OFF, my back aching, the internal muscles feeling as if they are twisting aimlessly after a soak and some hot water. At the end of my day, I lay in my bed and I meditate. So, for one hour every night I listen to my guided meditation, and I laugh, because I wanted to buy the app called Calm, but in a PD brain fart one day I accidentally, bought Breathe. Turns out Breathe is pretty great.

Polly Dawkins:

Thank you. Karen Took us through a big range of emotions there. Thank you for that. As you are joining in the chat, feel free to react to Karen's message and her day. Anything you'd like to share. We'll read along. Michael. Welcome. Great to see you. Great to see you.

Michael S. Fitts:

Thank you. Good morning.

Polly Dawkins:

Would you like to take over and tell us about a day in your life?

Michael S. Fitts:

Absolutely. So, a day in my life. Dealing with this disease while yet working. The night before, thinking about what I'll all have to do the next day and or next week. I'm sad to say that most of the time, I tend to overthink things. As a result, it challenges me to make decisions and to meet deadlines. Also, it can be a challenge in my relationships. So, the morning of, how am I feeling

that day, as it can change from day to day. I check my emails. I check my calendar to get a better sense of what the day holds. What things are somewhat immediate? As in things that might be time sensitive. I shower, I take my meds, deciding what I'm gonna wear. And so those that know me know that me choosing out my outfit for the day is definitely a challenge.

Sometimes I have challenges, buttoning my buttons on my shirt. Sometimes I have challenges tying my own tie, but I move on. Delays. I sometimes don't get out of the house in a timely manner. I have to build in extra time to allow for things, it's changing clothes, missing buttons, problems with a tie like I mentioned, as well as misplaced keys. And I've discovered there's a time when I need to leave work, I need to leave home, in order to get to work at a certain time because of traffic. On top of that, I'm not a morning person. So, once I arrive, depending on which facility I need to be in, it can be stressful as well. Meetings are the story of my life. I generally need to prep for a meeting. This activity sometimes takes time and effort, especially depending on what role I play. Am I facilitating the meeting, or I do I have a portion to present? Notes also can pose a problem as I have to write them. Sometimes, when I get to my office, I can't even read my own notes. Then I check in with my staff for updates and my other colleagues, it can range from anything about patron complaints, weather issues, even police reports. So, part of my job in general has to do with diversity, equity, inclusion. That takes up a large part of my day as well.

Some of my most significant challenges, loss of executive functioning, anxiety, depression, et cetera, can find myself in being my own worst critic. So how do I cope? Advocacy, really helps me keeping feeling sorry for myself. I have a variety of support systems, could be my family, friends, formal or informal. Also, my spirituality. I tend to pray and meditate during that time as well. That's my day.

Polly Dawkins:

Thank you, Michael. And part of the day is dealing with the technology issues that we all face. People in the chat have suggestions, but it's part of our new world where we're having to figure out all of this on top of showing up. And I appreciate hearing that it's hard to tie a tie and get dressed and you've done that for us. So, thank you for that. Carol. Welcome.

Carol Clupny:

Thank you.

Polly Dawkins:

Tell us about your day.

Carol Clupny:

Well, I'm going to tell you about a day in my life at home. I am somewhere deep and far away. I hear a sound like an alarm. Where is it? I just wanna shut it off. It's 6:30 am. There's someone beside my bed. It's Charlie, my husband. He's talking. "Here are you pills."

And my tongue feels small objects. There's water going past my lips. He strokes my throat to encourage me to swallow. I feel like a dog. At 7:00 AM, I'm struggling with my balance to reach the bathroom. I get turned around and sat down just in time. Oh, gotta get fresh unders and a panty liner out. I look in the mirror, check my appearance. Am I okay for public viewing? I brush my hair, trying to keep the rubber band around my slippery long hair. Just wanna keep it out of my eyes. My arms don't reach. I can't get them around my neck. I make a mental note to teach Charlie how to do my hair. Now to brush my teeth. I can't stand filmy teeth. Darn I didn't plug the toothbrush in last night. I get my cold water in my Mason jar and put the lid on, struggle up the stairs. I have to get these compression socks on before my ankle swell. It's so hard to pull them up. I'm out of breath. 8:00 AM. Amy says dance. Dance as hard as my body allows me. Yoga breathing with Jane. Charlie delivers a cup of coffee. I check in with the other dancers. We talk about our favorite pie.

Back down the stairs, holding onto the handrail. One small step at a time. 9:45 AM. Coffee, eggs, and fried cabbage for breakfast. We discuss our plans for the day. We only have one car. Will one of us walk or take a bike? 10:30. I remember to take my meds with a big glass of water. Spend some time in the bathroom. Sure takes a long time. Is it a constipation? I should do something. There are dishes in the sink, a pile of clothes on the floor, sketchbooks and pencils and paints on the coffee table and on the kitchen table. I wander around the house. I can't focus on getting any one thing done well. Noon. It's lunchtime. I open the fridge. Nothing looks good. Hey, there's a Power Moves virtual class scheduled right now. Oh, well, I can do those things later. I wanna do something more fun. 1:00 PM. I could ride my trike. I could call some friends over to play fiddle tunes, but they never help clean up. And those chairs are so heavy to move around. Drawing and writing supplies are already here. I don't have to go digging for them.

The afternoon session of Rebel Fit Boxing Club with Kimberly Burke, that'd be fun. 3:00 PM. Charlie says, "You didn't take your 2:30 meds." I lay down across my bed and fall asleep. Because of the way I'm positioned, I can't get myself up. I struggle. Charlie says, your dinner is getting cold. A pang of guilt. He had to make my dinner and he says, "Don't worry about the dishes, I will get them." I go upstairs to hang out and check on my Facebook friends and I call somebody and talk. I can't go to sleep until I've had my last medication at 10:30. I sit on the couch and fall asleep anyway. My sketchbook falls out of my lap and thumps on the floor and wakes me up at some point. I take my medication. I fall back asleep on the couch with my shoes on. I wake up in the morning with my favorite blanket tucked round beside me. Charlie did it. The end.

Polly Dawkins:



Thank you, Carol. People are writing in the chat that Charlie sounds like number one, number one, dude.

Carol Clupny:

Yeah, he really is a good guy.

Polly Dawkins:

That's wonderful. The comments people can really relate to all that you three have shared. Any reactions you all have to some of the comments or to each other's stories?

Karen Frank:

Well, I hear some of my story in everyone's story and that is the beauty of it all because I know I'm not alone and I'm in a great community and Carol and Michael and Polly and Davis and all of the ambassadors and everybody here is part of that. And to be a part of that is such a gift.

Carol Clupny:

I echo your comments. We all share so much. I appreciated how you, Karen, presented your day in activities and things that you did to make it through your day and Michael, you always dress for the occasion.

Michael S. Fitts:

Thank you for that. I think it's wonderful. Although there's a common theme, actually, if a person has Parkinson's, you've met one person with Parkinson's, the same thing, but I do see a lot of similarities with our stories and I'm really, really proud to be a part of this community.

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