



The Victory Summit® Virtual Event: YOPD

How to Live Well with YOPD

Recorded on June 26, 2021

Davis Phinney Foundation

Amy Montemarano (Davis Phinney Foundation Ambassador):

So, I am excited now to introduce our last panelist of the day. This is Amy Carlson, and she's been living with Parkinson's disease 2012. She says that PD has changed her life but maybe not in the way that people would expect. She believes that Parkinson's saved her life changing her ways that she never would have anticipated, which is exactly the theme for today. For her, life has become slower, more deliberate, and more immediate. And she finds joy and simple experiences and has come to realize that everyone has their own unique journey in life. And the challenge is to find the meaning in your own.

Thank you so much for joining us today.

Amy Carlson (Davis Phinney Foundation Ambassador):

Thank you, Amy. That sounded really fun. I wonder who wrote that. Typically, I start talking about my situation whenever I talk to people with Parkinson's and to do a little bit of talk about my Parkinson's resume.

And that is that I tend to talk about, just give you a sense of where I'm at, with my disease like Amy M. said, I was diagnosed in 2012. I was 44 years old at the time. I'm now 53, so we're, you know year nine if you're keeping track and I think an ant just bit me. Anyway, I take a certain amount of drugs like most people with Parkinson's and since everybody always wants to know what drugs you're taking, I take Azelect or Rasagiline, was actually every day.

I also take an agonist still I'm taking eight milligrams of were Ropinirol right now. And I take carbidopa levodopa. Let's see. Six during the day like every two and a half hours, starting at 6:30 in the morning I go then at nine and 11:30 and two and then 4:30 and you know you can do the math, seven and I feel like my Parkinson's is pretty well managed I also exercise a lot, and dance every morning for at least 45 minutes. I do some, some yoga also, and you might know that I host a zoom call called Amy Says Dance.

And that started during covid, and it's become quite addicting but the the thing about it is I find that it's really important to be in community and to, to make sure that I'm not trying to do things in isolation I think that being in community is wildly important for my management, my life, my everything in this disease.

It's just so important to be in community. And so that's, that's a really important thing that I would put out to anybody that focusing on being in community is helpful. Now, I told Mel that what I wanted to talk about today was progression. Because to me progression is a really interesting part of Parkinson's disease. We all talk about progression, and how its measured. Okay, so let's talk about progression for a minute.

And, yes, anyone can join the Amy Says Dance zoom, and we'll talk about that, or somebody will gratefully put up some information about it for me, so that you can get that information.

But progression, right now, if you're on this call, you've probably been diagnosed with some form of Parkinson's disease and possibly you've been diagnosed with YOPD, young onset Parkinson's disease. And so, the first thing I did when I was diagnosed was like What does this mean? You know, how long do I live with this disease? Do I die from Parkinson's disease? How do I know what's going to happen next? And that started the big mysterious adventure of Parkinson's because of course as you start to learn about Parkinson's disease, after diagnosis, there's a couple things that become obvious.

And that is that there isn't a lot of really concrete information about where your life is going after diagnosis. There's a lot of studies out there that you can read them most of them are based on people who have more of a typical experience with Parkinson's so the average age of diagnosis is 65, and so then there's different conversations about how long you would live with Parkinson's disease had you been diagnosed at 65.

But that's not quite the same as it would be if you were diagnosed much earlier. You're going to live, most likely a long time that disease, and so the progressions, the classic, what's that thing called, that scale... the hahn and yahr, it's a subjective measure, just like your diagnosis was subjective it's somebody taking a look at you and saying, oh, you look like you have Parkinson's disease, and then with the hahn and yahr scale they're saying, oh, you look like you have stage two Parkinson's disease, and what exactly is stage two Parkinson's disease, but kind of a nebulous description of some sort of physical movement motor function problems.

The reality with Parkinson's, I think, my experience is, there's a lot more than the motor scale and the biomarkers that they're desperately looking for which you know we hear about all kinds of progress on these biomarkers. And if you think about a biomarker. It's, it's something like, you know, other diseases have biomarkers we don't seem to have one yet.

But, you know, if you have if you've been diagnosed with cancer, you measure your progression of your cancer through these biomarkers, white blood cell count and different other things, tumor sizes, and all kinds of metrics, biological measurements that that tell you how you're progressing and doing with your disease.

And we here live with Parkinson's. We don't have many of those, you know we compare to each other, how much meds are you taking? What's your availability of movement during the day? How much OFF time are you experiencing? I hear about a lot about that now.

But there's other things that are going on besides the motor function. And it's important to think about. There's a psychiatric profile that goes right alongside Parkinson's, and alongside the motor part of Parkinson's.

I experienced depression, at least 10 years before my diagnosis of Parkinson's. And now of course I'm led to wonder, was that actually the first sign of my Parkinson's? The psychiatric components are, you know, many. Anxiety, depression, apathy. Then the fun ones, hallucinations, delusions, psychosis. Yeah.

But these are pieces of this journey that you may walk alongside you may find in your journey. And as we move through the seas we go through some very interesting steps, psychologically.

If anyone here is experienced the loss of a friend, someone who's died in your life, or maybe a tremendous loss of a job or a house or a marriage, you may be familiar with this thing called the stages of grief. And I would suggest that in Parkinson's we go through those stages. Often, over and over again as we experienced new losses in our life based on the disease. And it's hard.

One of the things that I think is really important to understand about somebody with Parkinson's disease is they get kind of good at this. Accepting losses, they're going to have to get good at it because we get a lot of practice.

So how do you live well with Parkinson's disease? When you're looking at all this. It's a difficult question to get at. And I would suggest flipping the question on its ear. How do I die well with Parkinson's?

We don't talk about dying very much in the world, we certainly don't talk about it much in the United States, it's not considered a measure of success, I don't think. But really and truly isn't everyone's life progressing from birth to death.

So, when you talk about measuring the progression of my Parkinson's disease, how is that different from measuring the progression of my life from birth to death? I was much more flexible when I was born. Pretty much.

So because I might have trouble now sticking my toes in my mouth like I was able to do when I was a baby, do normal people, do typical people who don't have Parkinson's do they grieve that loss?

I don't know, do we really want to consider that the progression of Parkinson's disease

doesn't matter, this is really funny, my husband is right now trying to put his toes in his mouth and he's rolling around in the grass. I wish you could see, he is on the other side of the camera, you would love it.

Anyway, how do you measure progression in your life? How do you measure progression in Parkinson's? I talk a lot about having a plan for wellness. And all of that comes down to one thing and that is what is your definition of wellness? What is your definition of wellness? And what is your definition of living well or dying well at all?

One thing that I know for certain that Parkinson's taught me is how important the present is right now. This minute right now and I know people talk about that all the time. This minute. This moment.

I choose to have a great quality of life, as much as I can. So, I know that I'm supposed to exercise and move, and any of you who know me at all know that my favorite movement is dance.

I love to dance. And thank God for Parkinson's disease, because it allows me and forces me to spend an hour a day dancing or so. It's the perfect excuse to dance, every single day. I did not do that before I was diagnosed with Parkinson's. In fact, I didn't even do it until I was like five years in.

I had to be convinced that it was important for me to spend time, exercising every day. And now I get to dance, every day. And because I dance every day, I've explored tons of different types of music. And I love learning about new forms of music and new forms of dancing. It's so exciting. It's so exciting.

And then, I've learned some other things. Some of the losses have meant that I have had to recreate my life a little bit. I have to think about how I can live well, and the decisions, while they seem like difficult decisions, each one as brought me more and more joy.

Recently I decided I could no longer handle the house, we had three-bedroom house with, you know that our kids had gone through high school in and and it was a bit of a chore, there was a lot of gardens to it, and it was beautiful and I loved it, it was mine. It was ours. But it was beginning to be very, very, very difficult for me to live there, and feel happy and well, because I constantly was surrounded by all the places where I was failing to keep it up the way it should be kept up, and I just couldn't do it. So, we sold it. And that was a hard decision.

And I'm going to turn my camera around and show you what we replaced it with. That's our sprinter camper van. If you can't find your phone in that van, you're in deep trouble. Now I couldn't find it in my house, heavens no, I couldn't find my phone. I couldn't find my glasses. I couldn't find my meds.



But in that van, it's pretty small. I can find anything in there eventually. There's only so many places it can be. And you know what, the van has brought me here to Acadia National Park all the way from Los Angeles.

It was a hard decision to leave my house earlier than I ever thought I would leave a house to turn that decision on its ear and find a way to live well. This is an opportunity not many people get to have. I know that that sounds crazy.

One of my favorite memories of going to school when I was a kid was learning about the explorers. William Clark and Lewis, Meriwether Lewis right. I loved the idea of going off into terra incognita and discovering new things.

Now I don't get to do that I'm not going into terra incognita as far as Earth goes, people have been to Acadia before me. But I get to live in a brain that's different than other people. I get to live in a brain that has Parkinson's disease. I get to see that from the inside. I'm an explorer. And I'm exploring uncharted territory for so many people.

The brain is a vastly amazing piece of machinery an organ, and I get to see it from the inside. And what happens when it takes a journey, that's a little different. I choose that. I choose to look at it that way. And I hope that that might be a way to live well, and to die well with Parkinson's disease.

Want to Watch a Recording of the Webinar?

You can access the recording [here](#).

Want More Practical Articles Like This?

Much more can be found in the Every Victory Counts® manual. It's packed with up-to-date information about everything Parkinson's, plus an expanded worksheets and resources section to help you put what you've learned into action.

[Request Your Manual Now](#)

Thank you to our Peak Partners, Amneal, Adamas, Sunovion, and Kyowa Kirin, for making it possible for us to print, distribute, and ship the Every Victory Counts manual.