



**How to Live Well with Parkinson's through Dance and Creative Expression
The Victory Summit Boise Event Session**

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Davis Phinney Foundation

Melani Dizon (Director of Education and Research, Davis Phinney Foundation):

Okay. So right now we have Amy Carlson. She's going to talk to us about how to live well with Parkinson's through dance and creative expression. And the only thing I'm going to say about Amy right now is she's one of our Davis Phinney Foundation Ambassadors. And you're just about to learn all the other things about her. So I'm just going to let her take it away. I can't wait to hear you, Amy.

Amy Carlson (Davis Phinney Foundation Ambassador):

Hi, I'm Amy Carlson, and I'm here to talk about creativity and Parkinson's. And the thing is first off, creativity and Parkinson's is a thing. It's studied. It's both anecdotally talked about—I know many examples, myself, of people who experienced an increase in creativity once they were diagnosed with Parkinson's. And there's a lot of arguments about what causes this, but hey, symptom or side effect, I don't care. I'm excited to have something positive going on with this whole Parkinson's thing. So I'm pretty much an embracer of creativity in Parkinson's. Is embracer a word? I'm not sure. Anyway. So in order for me to really talk about this in my life, I'm going to have to take you back a little bit about to who I was pre-diagnosis. So we're going to go back about 10 years ago, cause I was diagnosed—I'm getting close to my ninth anniversary. And we're going to go back to about 10 years ago.

And 10 years ago, I was not the person I am right now. I was somebody who was very focused, very organized, very much a planner and a scheduler. I was a construction project manager, so I probably looked a little bit more like this. And when I was doing that job, I would carry a Franklin planner. I don't know if any of you remember this, but this is that calendar system that everyone seemed to love. And I had one. And let me tell you, I wish I could show this to you, but it's so light because I wrote in pencil because I didn't like to scratch things out. I really liked to make sure that everything was neat and tiny. So it's all in pencil. So you can't see it very well. But let me tell you, there's spreadsheets in this thing. This is from 1996, I think four/seven. Everything is very organized.

There're spreadsheets in here. There's a list of all of my husband's sizes of clothes in case I went shopping for clothes for him. This is a very organized way of documenting my life. And that was how I was at that time. And one of the things I did was as a construction project manager, I scheduled things. And at one time I actually scheduled a project that was 200 years long. It was the decommissioning of a nuclear power plant.

So that's pretty much who I was at that time. After I was diagnosed with Parkinson's, I continued that person for a while. I lived in denial land. I don't know if you've been there, but I certainly have, and I just continued to decide that everything was going to be fine and my life was going to continue the same way it was.

And that's when the creativity came in and tapped me on the shoulder. I was working for the sales department in my company. Everybody takes a turn in sales because we believe that operations and sales go hand in hand. So me and my Franklin planner, I was working on a sales project that would take about a year to assemble, and that project would eventually turn out a proposal, a written proposal that would be about this thick. It would look about that deep. Not only would the written proposal be proposed, but also a presentation would be put together.

And for the presentations, we would have a whole team of people who would go and talk to a bunch of judges. And because there was a whole team of people and because those judges were sitting all day listening to one team after another tell them how great they are, every team would produce a placement and the placement would sit in front of the judge and it would have the pictures of the people on it and maybe a bio and maybe some of our main points.

And I was busy on a Sunday, little casual overtime, putting together my placement for the team that was going in front of this airport proposal that we were working on. And because I have Parkinson's, I fell asleep in the middle of that and I had a dream. I had a dream that the proposal was so bad and the presentation was so bad that the people sitting behind the desks actually took their placements and folded them up into paper airplanes and were shooting them around the room and ignoring our presentation. I woke up with that dream and I knew what I had to do. I had to turn the placement into a paper airplane.

So I designed a quick draft and I took it, I went and I called my sales manager on Monday morning and I said, "We got to go to lunch. I have an idea and it's going to take me a while to explain it." And I explained the paper airplane to him over lunch. And he said, "Amy, that's ridiculous. Get back to the office, get back to work."

I thought it was a great idea. It was very creative, very different, completely different than the way I usually think. Two days later he came to my office. He said that paper airplane thing, work with Arnold, go draft.

Eventually the paper airplane placement was put into place. And each fold told the story of our project and the pictures of the people on it. And it folded up into a paper plane that artistic designer walked the group through. And at the end of the presentation, none of them threw their paper airplanes, except for our team, because all of the people on the board wanted to keep their paper.

We did not win that project, but in the talk-backs afterwards, the people from the airport selection committee told us that it was this example of the creativity that our team would bring to the project. And while they really liked that we didn't win. They really, really liked the airplane and how it demonstrated creativity. And I thought to myself, I don't even know where that came from. I mean, I know it came from a dream, but where the heck did that come? That's the first hint that I had that creativity was something that was new and it was burgeoning in this whole diagnosis of Parkinson's.

So the next thing that happened was I was getting worse. Okay. My Parkinson's was becoming more and more invasive and making it difficult for me to be the construction program manager. And so I started to explore different ways to exercise because I had been told over and over again that exercise was the key component.

I'm a water skier, I'm a snow skier. I'm a couch potato. My exercise regimen was not very well thought out. And my doctor kept saying, "Try something novel, something you've never done before, something where you can learn. That's the key." So I try to Zumba class. This was a complete disaster. I'm 40-year-old Amy diagnosed with Parkinson's, not being managed very well. There's a bunch of 20-year-olds in the class. I'm trying to keep up. My right hand is doing this great thing. My left hand is doing this stiff and awkward thing, and it was horrible. And I ended up in the car and tears, and that was the end of dance for Parkinson's.

For me, few years later, I walked into the Lineage Dance Company at Pasadena, which runs the Dance for PD program. It was totally different. There were no 20-year-olds, first of all. And second of all, everyone looked a lot like me. And however we moved was however we moved. And so for the first time I really embraced dancing. This is the first time in my life I've ever spent any time learning how to dance. I'm close to 50 years old and I'm saying, okay, if this will help, this will help.

And so things began to change with me. I couldn't work my job anymore. And eventually I had to leave my job and I became, well, not a different person because I'm still the same person, but I started to embrace different things in my life. Things that would help me become more adjusted to having Parkinson's in my life. And one of the things I embraced heavily was dance because my doctor kept saying that novel means to be learning all the time—learned movement, not just running on a treadmill. Which by the way, I did try running for a long time, I was eventually able to run, which was kind of amazing, but you know, my legs would go numb and it seemed like it was very repetitive to me.

And I just didn't feel like I was exploring what I really wanted to do. So I started to dance. And a few things happened when I started to dance. One is I became in tune with my body and what it was doing. Proprioception was something I gained access to. I started to learn where my body was in space. I started to tune in to what my fingertips were doing, to what my face was doing, to what my body was doing. And I gained some amazing flexibility. I had never been able to touch

the floor with my feet flat on the floor and my hands. And now I can with my legs perfectly straight. I never done that in my entire life. Maybe when I was like a newborn baby, but that was something I gained after Parkinson's, and it was the creativity of dance that made it attractive to me because the fun thing about modern dance, which is what we focus on at our particular studio, is that any movement you make works, there are no rules. Like there are maybe ballet or Zumba or some other kinds of dance. Modern is just about exploring the body and using it functionally correctly.

So I really enjoyed learning how to dance and I continue to enjoy learning how to use my imagination. There was so much I could explore in dance. And let me tell you, eventually it got to the point where I would be dancing here at the studio, and I will forget for a little while that I had Parkinson's. And while I was here, I met a number of other people with strokes, with Alzheimer's, with Parkinson's, with neuropathy, and we became a community and we support each other and we still do via Zoom and other things. And we enjoy exploring creativity together.

So I identified for myself that this made me feel good. I identified for myself that this was something I wanted in my life. And I was obsessed with how I dancing was great for Parkinson's. It was perfect. And I would tell anybody about it. And I was always telling the artistic director about it. And she asked me if I would be in a show that they were doing, the show was called "A Brain in Motion." And I didn't know really what she meant because I'm thinking like, recital, but that's not exactly how it came down in the end.

I told her so much about Parkinson's, and one day she interviewed me about Parkinson's and dance and I didn't realize it, but she actually wrote the script from things I had said. And the script for my part of that show with my dance partner, Erica Lynn Priolo, was directly from that interview. And it was me telling my story of diagnosis, coming to find dance. And it was much more about how Parkinson's impacted my life, how I hit my hand when I was in meetings, how my hand would do its own thing. And our family called it, "me holding the pizza box."

And I poured my story out into this performance. And when I was done, people came up to me and they said, "Thank you for sharing your story. I've never been able to talk about my story. It's felt so good to hear your words echoing my story." And I knew then that I had identified something very important. And that was that I needed to tell my story because it helped me process the feelings of having Parkinson's. And more than that, it helped other people. And that gave my life meaning the ability to process my feelings of how do I dance when I'm disconnected and I'm fighting with my body. How do I dance when my body feels like concrete? And I just can't seem to go as fast as I would like to.

Creativity, creative expression can allow you a place to explore your story. Remember that Franklin planner? I gave it up for an art journal. And my art journal is the place where I explore my feelings about Parkinson's. And sometimes they're bright and vibrant, and sometimes they're maybe not as bright and vibrant, but every is different. And it helps me explore where I am and what I'm doing.

Allow yourself to use Parkinson's as an excuse, if you need to, or permission, if you need it to. Do different things, do things that are unusual for you. Look into your life and see, is there a place where suddenly I was thinking differently to me, it makes total perfect sense? That you might think differently about the world now? Because your brain is much different than it was. And it continues to change faster than most people's change. And the way to combat the destruction of Parkinson's is to build new neural pathways. The brain is designed to learn, and more than that, it is designed to learn how to move. So find a movement, find an expression, find a way to learn something new. So you can build new neural pathways and expand your brain while it is changing.

I always want to remember and remind people that there's nothing really wrong with your body. It's all in your head. The problems that you have in movement are mostly in your hand. So if you've never been a dancer, it's not because your body doesn't want to be a dancer. Your body is still capable of moving and learning how to move, tuning into the differences. And whether that's dancing or whether it's picking up a paintbrush and learning how to make your hands, make movements that make marks, whether that's acting. Have you ever tried Shakespeare? I have. It's kind of fun. It's a little bit intimidating, but hey, you've got Parkinson's. You don't have time to worry about what other people think. What you have time for is making your body your first and only priority. So allow for that.

And this is what I bring out. My favorite piece of headwear. My Tiara. I am a princess of Parkinson's in some regards, in that I allow myself to make room for Parkinson's in my life. And if that means I'm no longer practicing as a construction manager, but I'm constructing a life as a dancer, I have room for that in my life now.

And Parkinson's, whether it's the excuse or the reason or the devil that I dance with, it opened that up for me. And I wouldn't change anything. People always ask me about that. Would you change anything? And I said, if I could have a cure, not a cure, but a place to stay right here right now, I'd be fine, but I wouldn't want to go back to life without Parkinson's because this walk around with creativity has opened up a whole new world for me. I haven't told you half the stories I wanted to tell you about creativity and what I've done in my life. Since the diagnosis of Parkinson's, I've been creative, but mostly in everywhere.

I want you to feel it's okay to make changes in your life. And creativity can help you. If picking up a paintbrush for the first time is intimidating. I'm giving you permission right now to go do it. If you haven't played with crayons in a long time, get, get out the crayons. Just try. If you are afraid that you're going to fail, here's the big excuse, the perfectly excuse—I've got Parkinson's. It's the excuse for everything. I can't go to that PTA slash church council slash whatever meeting, because I have Parkinson's and I need to take this boxing class. I have Parkinson's and I need to take Dance for PD. I have Parkinson's and I need to...

Thank you.



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