

The Victory Summit® Virtual Event: YOPD

Hindsight is 20/20

Recorded on June 26, 2021

Davis Phinney Foundation

Melani Dizon (Director of Education and Research, Davis Phinney Foundation):
I'm excited to introduce Pam Quinn, she is going to be talking about hindsight is 20/20, thoughts from an old young onset.

Pam danced professionally for 20 years and has had Parkinson's for over 25 her personal experience of Parkinson's along with her keen knowledge of the body allow her to analyze movement problems and create solutions to help manage them, among many other things. Pam developed PD movement lab, a functional dance class for people with Parkinson's which she teaches regularly in New York, and at conferences around the world so we are so grateful to have you here today, so Pam I'm gonna let you take it away.

Pamela Quinn (Founder, PD Movement Lab):

Okay, thank you ma'am. And thank you, Amy, and Davis for your perceptive words were right on target. And I have a little quote that I use, keep a smile on dealing smile and mast face, and this this this. So you can use that.

I'd like to thank the Foundation for inviting me to share my thoughts and experience with all of you. I've always thought that Davis Phinney Foundation is a great organization, and I'm honored to be here.

I'm going to begin by showing a video of a dance I made a number of years ago. It's called Welcome to our World. And you need to make sure your volume is all the way up when we play. Okay, let's take a look at that.

{Video Transcript, Pamela Quinn speaking}

My first son was in first grade, he came home one day and said mommy said you're gonna die soon. I said, we're all gonna die, sometime but I'm not gonna die soon. He had only known me with my Parkinson's. How I moved was normal to him. He had never seen me as a professional dancer.

It angered me that his sense of security my world was being affected by this disease. It was a beautiful spring day. I was walking up out of the subway and a man's eyes locked onto me, he said I'm going to heal you. He was wearing a big black cape he said I'm gonna heal you and he



found me down the street, and he did kind of heal me because he made me walk a whole lot faster and once I got away from him I thought maybe he's an angel in disguise.

My second son, Liam, was two when the World Trade Center was attacked. I was pushing him in a stroller up the West Side Highway. There were throngs of people, they were hysterical, they were calling on phones, they were shaking. Everyone was shaky.

I felt guilty for taking pleasure in that moment. I didn't tell anyone because it felt disrespectful. Parkinson's is full of surprises. And contradictions. Sometimes we can't move. And other times, we can't stop ourselves from moving. We're like athletes because we nurture our bodies, we could cajole them, we work them every day, and how we feel about ourselves at any particular moment is directly related to how our body functions. I've had this disease for over 15 years. I hate it. And I'm thankful for it. I hate the fact that it's robbed me of my body, of my dreams for my future, of things I can do with my kids. I'm grateful for the patience it's taught me, the compassion, perseverance of spirit.

Welcome to our world.

Pamela Quinn:

None of us chose to become a member of this group. We may not appreciate the assumption that we would even want to be extended a welcome. But despite our anger, bitterness, shock or deep sadness that result from becoming a person with Parkinson's, there are some profound and good experiences that accompany it.

I am deeply moved by the joy, and determination I experience from my students who take my PD movement lab class. All the while dealing with adversity, and sometimes great difficulty and I, myself, understand like I never have before the power of helping others.

And this nature's not completely charitable because helping others is also about helping myself. It's the best antidepressant around. Would I wish this disease on anyone I know? Never.

But all we can do at this point is take what we have and make it into something worthwhile and hope that that process will bring relief to those who suffer, and a renewed sense of purpose to ourselves.

And is it the last World Parkinson Congress in Kyoto. I passed room that had vibrant energy coming out through its door. The room was full of people with young onset PD. They were a talkative vicious group. I realized that that instant that I had aged out. I was no longer part of that group.

And at that moment I thought we need each other. The younger set could learn from us, older young onsets, how we had managed with families in work, how we dealt with having to trash our long-held dreams for our future.

How and from whom did we hide our disease? And what advice did we have about financial planning, etc? And in exchange our weary efforts could sure use a dose of their youthful energy and fresh determination they displayed to further our cause.

And I also thought, if I had to relive my PD, all over again, what I change, and what would I keep? The posing of that question and its answer is going to be the focus of my talk today and then we will move together.

The we have a title slide. All right, the title slide, it says, "Hindsight is 20/20: Thoughts from an Old Young Onset and what to keep and what to throw."

First thing I would keep is my faith, and my own perceptions. In the beginning, I knew nothing about the disease. In many ways, this was a godsend, it gave me the freedom tonight easy and presumptions presumptuously think that maybe, just maybe I could beat this condition such delusion was good.

It fosters creative thinking and approaches to the challenges I faced. I was not afraid to try things, anything that came to mind. And upon diagnosis to my surprise, by doctors advised me to limit my movement. This was the pervasive and accepted as to exercise at that time.

The fear was that strenuous or complex movement will lead to a fall. But it didn't appreciate the level of physical training, I had as a professional dancer. My knowledge of the body was extensive, and I knew I was at my strongest when I was training hard and really, I questioned their advice. And my suspicions were further aroused by the fact that there was no physical training whatsoever as part of my first doctor visit, because they call themselves movement disorder specialist. I naturally assume that they would offer me some advice that I haven't moved.

So when they offered no training. I was surprised crestfallen, and curious and suspect. I resolved myself that I would follow my own instincts regarding movement, and I would do it made sense to me, which in this case with to do just the opposite of what they recommended.

I would embrace movement and engage myself and whatever ways. My body's into me. I would experiment to find what movement forms helped me the most. When I started to limp, I used my dance training to understand what was going on and topically and tried to find ways to coax my body toward normalcy.

There was also a certain shame factor that inspired me to correct myself. I just wanted to be normal. And on top of that, I wanted a second child. So improving my physical stuff with medication was out of the question.

I was determined to find nonchemical ways to help myself move. And I did.

But the main point and tell you this is not to encourage you to ignore your doctor's advice, but to encourage you to question whatever doesn't make sense to you and to pursue those questions.

I love my doctor and thoroughly dependent on her knowledge of disease, and the drugs that are available to me, but I'm also glad I followed my own instincts in regard to physical activity.

Science eventually caught up with me.

Second, I didn't keep analyzing and thinking about my medication. A few years into taking my meds, I asked my doctor, how can I get the most out of the medicine I take? I couldn't believe I hadn't asked her that sooner.

She said, if you can tolerate it, take your meds on an empty stomach with a full glass of water and wait about 30 minutes before you eat. This was an important question both being able to function as soon as possible. And for keeping my dosage as low as possible by getting the most of the meds, I was taking, subjects also introduced me to the relationship between eating and medicating, and the relationship between constipation, and the effects of medication. Basically, you can't absorb the meds, effectively, human levodopa is our main chemical. I'm surprised that more research hasn't occurred that would let us know more about optimal use and absorption.

There's a second part to this medication section as well. That is increasing my dosage in small increments and the makers of the medicine manufacturer. I cut my Sinemet into corners when I need to increase my dosage. Why increase by 100%, 120% when 5% will work.

As I broke my pills into approximate corners. I had to wonder if the chemical substance in the tube was evenly distributed. Manufacturing these methods in smaller increments would be a big help to us early onset, and it would be something easily accomplished. In addition, it might deter, postpone dyskinesia as much as possible.

I understand about the relationship of Sinemet and dyskinesia, it's that it's not a cause and effect relationship, but they are connected. Beyond medication for longer at higher doses, basically more likely to develop it. But that doesn't necessarily mean that this is something you will experience. It does mean however you want to be careful and specific in order to find the right dose.



You take what you need to exercise vigorously is exercise, the only known preventive measure we have the same time you don't want to overload your system, finding the right balance require where you're tweaking and collaboration with your doctor.

I faced this issue a few years ago and changed my medication to positively effect with my doctors helping lesson.

Let me show this video. There's purposely no sound here. {Shows a video of Pamela with dyskinetic movements}

See the movement? So, I had been on retiree for about a year. And I suspect that that was covered in making me disconnect, because that's the only change I had in my drug regimen. I asked my doctor if there's any problem with me going back on Sinemet.

She said there wasn't, and she made the intelligent suggestion to taper off my drug dosage in the afternoon. Because artificial dopamine tends to build up over the course of the day. So, I only took half a Sinemet from investors may this adjustment and my dyskinesia mostly disappeared.

My friend, Josh Coats, a prominent neurologist from Columbia Medical Center, talks about the sensitivity and complexity of the energetic system, which is one reason why it's so difficult to understand and emulate. By contrast, the drugs we take function in a growth manner. So, that medication can be emphasized and variable costs, individuals are analysis of how drugs are affecting our bodies, is a very important part, getting the most out of our treatment.

Third, this means being specific and detailed with my descriptions of how I'm doing, listening to a doctor's advice, questioning what doesn't make sense and approach in that relationship as a true collaboration. If your doctor isn't willing to do that, look elsewhere, get a second opinion.

So those are some practices, I would keep.

What would I change? The first change would be to strike a better balance between physical challenge and safety on behavior, I regret not having not finding the right balance between physical challenge and personal safety. I love moving, combined with my lack of heat and awareness to warnings that signal that particular threat of moving in a certain way, by running backwards, caused me to permanently injure myself.

I overestimated my physical prowess and overstepped my physical limits. I broke my wrist, elbow both badly, and will not have normal uses them, the rest of my life.

If I had been sufficiently observant, I could have avoided these two breaks. Denial, and ego worked together to blind me in a major way.

Second, I would change the time I waited before going on Sinemet. If I could go back in time, I would go on this drug sooner than I did. It's an amazing drug, and it allows us to exercise, which is the only known preventive measure we have initiates manage sensitivity and a willingness to endure some of the difficulties of being in an off phase and taking the drug earlier is well worth potential downside that may accompany it.

I missed out on doing some activities with my kids, which I was too embarrassed to them, because my physical state.

Third change. Don't put off experiences you're saving for retirement. You will never be as good as you are at this very moment, seize the opportunity. Take that rafting trip you've always dreamt about, don't put things off do them I can travel. So a shame and live your life force change how long it took me to go public with this disease.

I was reticent to share my diagnosis. I didn't tell anyone except my husband. This can be isolating, very alone, is I process. This new reality. If I had to do it over, I would shorten the time in telling people my news. I could have developed friendships sooner. I wouldn't be so alone and dealing with the trauma of the diagnosis.

So, these are my main achievements and regrets. I hope you can benefit from parts of my approach. I will keep and seriously consider what I would do differently to bring my talk, out of the past, into the present and the end video I made my students that our covert experience. I hope you relate to it. It's called Boston. Let's take a look. And then we will move together.

{Shows video}

Pamela Quinn:

All right, now we're going to move together. I need you to be a firm chair, preferably without arms, so you have moved to the side to move your body. If there's anything I do that hurts, back off. If you have balance problems when we stand up, you can hold on to the back of your chair.

These are all exercises that are made specifically to address PD symptoms, mainly rigidity, amplitude of movement, lack of extension. I'm not going to have you learn the sequence, you can just follow me, the moves and the tempo are slow enough to do that.

{Pamela leads a dance}



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.