



**The Victory Summit® Virtual Event: Care Partners  
Lessons I've Learned**

Recorded on November 13, 2021

Davis Phinney Foundation

Polly Dawkins (Executive Director, Davis Phinney Foundation):

And now I have the wonderful honor of welcoming Connie Carpenter Phinney to the stage. Many of you know Connie from her work with the Davis Phinney Foundation. For those of you who don't know Connie, Connie is an entrepreneur, an artist, an author, a lifelong athlete, and she's also chair of the board of directors of the Davis Phinney Foundation. She's got her master's degree in exercise science, and she has had well over 20 years of experience as a care partner. Today, she is going to be doing a presentation on lessons she's learned. Connie, take it away.

Connie Carpenter Phinney (Board Chair, Davis Phinney Foundation):

Thank you, Polly. Appreciate being here. And I just want to, let's start, and I also appreciate everyone who's sticking around. I know it's not easy, especially if you're somewhere where the weather's really nice, but I promise to tell you a good story. So stay with me here. But before we get started, let's just kind of digest everything that you've learned this morning. We've had some great chats from Amber and Jessica and all of our other caregivers that, you know, just have such a wide range of knowledge. You know, we're not professionals. But we talk like we are, right, this isn't something that we thought we'd be getting our PhD in, in being care partners. But here we are. So let's take a minute, everyone just kind of be here together. Maybe drop your shoulders a little, close your eyes for a second. And let's just take a few breaths together while we're in this space, worrying about our person with Parkinson's and wondering how we are going to take care, how on earth we are going to take care of ourselves. Just let that thought in and let that out. And maybe let's start this conversation with the notion that we're all doing our best.

I want to set that intention right at the top for you to think about how good you are at this job. And it can be a job of being a care partner. And thank you for showing up today. Let's go ahead and open your eyes. Feel better? I hope so. I'm going to also show you a little PowerPoint today, so we can go ahead and put that up. And you know, I, when Polly asked me if I would do this talk, I said, yeah, but I know way too much to condense it to you know, 40 minutes. And I also feel like many of you have heard me talk before. And so to be honest with you, first of all, I'm still learning lessons. So this isn't the final chapter by any means. And you know what else, it's also appropriate if you don't mind, I'm going to give a shout out to Susan Imke. She was actually supposed to give this talk. And I wish she was here today, and she had a fall and had

some health problems and her husband also had Parkinson's and she lost him earlier this year. So Susan, this one's for you. She has been a long-time speaker at our Victory Summits, and is really a wonderful resource. So I'm trying to channel some of you Susan, as we go into this. So again, first of all, thanks for everyone for showing up. I don't usually lead with the fact that I won the Olympics almost 40 years ago in Los Angeles for my sports cycling, but I thought I'd kind of tell a story from that today. It's a little something I don't usually share with the Parkinson's care partner community, but I think it's important because I teach you a little bit about me, might give you a little inspiration and also a lot of food for thought.

So on July 29th, 1984, I won the Olympics by a 50-mile road race. And I like to say I won the Olympics because wow, it sounds like I won everything, not, I won the first race on the first day of competition in Los Angeles. And it was the first-time women's cycling had been included in the Olympics. So let's go ahead and show the first slide. I want to show you how close it was. I am sprinting to the finish line, a pack of six, there were easily half a million people lining a 10 mil course. The women had five laps, the men did 11 or 12. I don't know, Davis is in the other room. So he would be correcting me about now. But the point is we all raced in this beautiful venue in Mission Viejo with all of these screaming, crazy people.

And I beat my teammate to the line, which you can barely see at the bottom of this picture, by an inch. So I could talk to you know, and I do talk to a lot of groups about what it takes to be an Olympian, but that's not what I'm really going to talk to you about here. I'm going to talk to about what an Olympian is thinking about when she wins the race. So the first thing I did was cross the finish line with my arms in the air. I knew I'd won, even though it was close. And I really didn't know it was that close until the next day when I saw it on a, I think I was on Good Morning America or something and I was like, oh, that was close. And and so Davis was right after the finish line.

I was able to give him a big hug. We were married at the time. And the big story was, could the, you know, the married couple, both medal or both win on the same day and the media had, of course decided that we could. The odds were really stuck to against us. No American had won the Olympic road race in any Olympic history. So we were basically you know, kind of between a rock and a hard place. And I'm sorry, Davis, that you had so much pressure, because I got to get mine out of the way. I raced first. He raced after me. And he was right there at the finish line and he had been trying to watch on a tiny little black and white TV or something that was over in the secure team area.

And he actually couldn't tell at the moment had I won, and I literally fell off my bike in his arms saying, I think I won! So that's the first thing I did. The second thing I did after kind of collecting myself, maybe I combed my hair, I was a little sweaty. Maybe I sponged the sweat off, to be honest, I think I changed into a dry stars and stripes suit for the medal ceremony, but the medal



ceremony, wouldn't be for about half an hour after the race. And it was scheduled kind of in that secure area. So I couldn't see any of my family or friends who had come to the race, my brothers, some really good friends, and Davis's parents were there, but my parents stayed home, and I was born and raised in Madison, Wisconsin. And my mom was diagnosed with multiple sclerosis when she was 30 and I was five.

So I don't have a recollection of my mother without, you know, without MS. MS is also a neurological disease. It can be very debilitating. It's different from Parkinson's in many ways. And it's actually there's much better treatment for it now, but in my mother's day basically she put it on the, tried to put it as best she could on the back burner and not talk about it too much. We're different now, you know, she didn't have these kinds of resources. And part of the reason we started the Foundation was that so many Foundations are, you know, cure based looking for the cure. We want the cure, but I heard throughout my lifetime that a cure for MS was around the corner and while treatment is much, much better there is still no cure.

And so, you know, a big part of why we started this Foundation was that Davis was 40 when he was diagnosed, and we knew this would be a very long journey. We didn't really know how unpredictable it would be. And I think that's the thing that we all know now. Many of you listening today have been living with your person with Parkinson's for 10, 20 years, those of you that are signing on new, good for you to have this resource and other care partners that are sharing such important information. So, we feel lucky and blessed that we've been able to start this Foundation and work together. We rode our bikes together, and now we work on supporting the Foundation together. But in that moment, when I finished the road race, and I was in fact Olympic champion, which in all of my career, I had been very successful, but I had never imagined, fully imagined that moment and what it would feel like and what I would want to do next. And let's go ahead and show the next slide, because I want to let you know that what I wanted to do was phone home.

This was actually in the time before cell phones, actually, some people had big clunky cell phones, you know pretty silly, but I didn't have a cell phone. I didn't have any communication after I finished the race and I wanted to phone home and talk to my parents. So I got on a little frantic search for a telephone, and I was assigned, as I finished, there was a little volunteer that was sort of my shadow and to make sure I got to the medal ceremony when I was supposed to be there. And I said, do you know where I can find a phone? We were in the middle of a residential neighborhood so that there weren't any payphones. I didn't have a quarter anyway, but I started searching for a phone and it's kind of, I've written about it.

And I'm going to just read a little bit to you because I want to keep it straight, but it is ironic today when you know, we can't put our phones down that that's the first thing I did was go look for a phone. So when I asked my turquoise clad volunteer escort, phone? Telephone? she just

shook her head. There has to be a phone I thought. Phone? I mimicked. I looked around, I looked at the coaches. I looked at the other volunteers, the course marshals, phone? Everybody just shrugged. They also might've congratulated me, but I wasn't interested in that. I was interested in finding a landline to call home. So what I did was I started walking toward some scaffolding that was right at the finish line and it had some big, the Olympics were televised by ABC that year.

And so big, big signage, lots of cables coming out of this rickety scaffolding. And I was like, I'm going to go ask those guys in the announcing booth if they have a phone. Cause I knew they would be on a break. Our race was finished, and the men's race hadn't started yet. So I climbed up into the scaffolding and there was Al Michaels who's a very famous football announcer actually. And Greg Lamont, who has won the tour de France and Eric Heiden who grew up in my neighborhood. And as you maybe recall, won five gold medals in 1984 speed skating, which was also my first sport. So I knew two out of the three guys pretty well, and I kind of sheepishly poked my head up into the scaffolding where they were sitting and I said, hey, can I use your phone?

And they they were surprised to see me. They all congratulated me and patted me on the back and pointed over in the corner to where the phone was. And so I said, I'll chat later, I really need to call my parents. So they stayed home because it would have been too hard for my mom. And we never envisioned there'd be so many people there at the race course, but it would've been too hard for my mom to watch and move and be there. So this was the first time women's cycling was on television. And it was the first time and the last time my parents would see me race on TV because I actually stopped racing right after that race in fact. So I grabbed, you know, I sit down, my legs are trembling. I'm really thirsty, but I start dialing (608) 249-5822, my home phone number.

And it starts ringing, oh good, they're not on the phone. I thought maybe they'd be on the phone, then it'd be busy. We didn't even have call waiting at that point. So the phone rang and rang and rang, and I'm starting to think the worst. Like they forgot, my dad had a heart attack, what's going on? And I just let the phone ring and I was holding the, you know, the ringing phone up to my ear. And I was just like, rolling my eyes, like come on parents. And and so all of a sudden, just as I thought they'd forgotten, my mother answers the phone, winded, out of breath. And I have to tell you I've never, ever, ever seen or heard my mother out of breath. And so, you know, she just didn't move fast enough with Parkinson's. She had a wobbly gait, shall we say, oh, with MS. Sorry. She had a wobbly gait, and I think you can all relate to that, not being quite as fast. And she, you know, she was a pretty young woman then, but she was early fifties. I'm calling that young. And when she got on the phone and my first words to her as my dad also chimed in on the other line were mom, jeez, where were you?

And I just love that memory because now that I've had my own children, I can appreciate you know, me just kind of, you know, not just giving them the breath to say, you know, well done. And instead I'm like, at least you answered the phone and they said, yeah, we're great. And you know, I let my dad talk, you know, you did it, it was so fun to watch you on TV. How are you? All of these questions. And then I just was like, but where were you? Why did the phone ring so many times? And my mother answered, oh, dear, we were out in the backyard shooting off bottle rockets.

And you know, this was my mom and my dad, my mom in full flight with her disease, my dad, as the most wonderful care partner. And they were making the most, the sweetest lemonade from the lemons that they had been delivered. And that's what my mother always said. I could always feel her smiling through the phone. She had such an upbeat, positive attitude, and it's something that, you know, I've been able to embrace throughout my life and especially in this journey with Parkinson's. And so, you know, I always tell people what did it feel like to win the Olympics? And, you know, in a big way it was relief, but in the other way, it was this deep feeling of joy and a time and a capacity to connect over time, actually, with all of the people who had supported me in such wondrous ways.

And so my first instinct was to connect, and connection is such a big part of living during this time of pandemic and also living with someone with Parkinson's. And so I would ask you just to sort of sit for a second with that crazy little story and think about your team, your connections, and who's important to you. I think it's very important that we acknowledge how many people lift us up and carry us. And if you feel cut off from family and friends, because you don't live in close proximity, there's always the phone and better than that, FaceTime. And there's also new friends. We've found that many of our new friends are actually better at supporting us than our friends that we knew when we were racing. And that's because they've really only known Davis when he's had Parkinson's and he's had it now for 20 plus years.

Team is important. Team is number one, I think really. Let's go ahead and pull up the next slide. So that's what joy looks like, but I was so far from all the spectators. I couldn't see any of my family members that were there. And so in a lot of ways, all I really wanted to do is get off that podium and go, you know, throw myself at the crowd and find my family. Who I wouldn't see until much later. So that's my Olympic experience. And because of that, let's go to the next slide, because of that my tips to you all may be a little different than what you're used to. I want to give a shout out for the first pamphlet we produced for caregivers, which was called *Rewriting the Rule Book*, which you can download online.

And it has a lot of practical tips from me from my caregiving talks I've done at our Victory Summits and what I've learned from myself or from other caregivers. And you've had a lot of that information today as well. And I think you all know, and I'm so proud of this, that we now

have a Every Victory Counts pamphlet, thinner than the EVC for Parkinson's patients, but also wonderful for the care partner community. And I would encourage you to have your person with Parkinson's read this too, just as you can benefit greatly from knowing more about Parkinson's and your person with Parkinson's, you also want to be able to really, you know, stand there fully informed on both sides of the equation, because care partnering is a two-way street. It's not a one-way street. And so communication is key.

I think you've heard that a few times today, but thoughtfulness between the two of you is also really important. And that kind of thoughtfulness and kindness is what will keep both you and your person with Parkinson's happy or happier, I hope. I know it's challenging and we're all in different places in terms of what challenges we're experiencing right now. But I know one thing, when Davis was diagnosed, he was 40 years old, I was like, we're going to be with this for a long time. It is a long journey. And my first little sketch on the far side of the, on the left side of your slide there is how I represent the journey up, down, and all around. But the number one thing as an athlete, an elite athlete, who was an endurance athlete, I want to say, you have to pace yourself.

And so that's not always possible because some of you are really in the thick of it and it feels like it's 24/7. But part of pacing yourself is also figuring out who you need to bring in to help you. That's so important. The really super, secret tip and kind of unknown and unexplored part, of an elite athlete's lifestyle is rest. And too often, especially I think most of you are older and many of you are retired. So you're not trying to work and balance care partnering, but some of you are, and this is where it gets tough, right? Is when you're exhausted and or maybe you the care partner has other health concerns. But your person with Parkinson's concerns are put before yours. What you need to do, it's just like the stewardess tells you on airplane is put your oxygen mask on first. And that number one thing might be just to get more rest and whatever that means to you, whether it means having separate beds, whether it means sleeping in a different room, whether it means just having time to do your yoga practice or meditation practice without interruption.

And to be honest, if you did the last two, the meditation and the yoga with your person with Parkinson's, it would be better for you and for them, but be a little, so the other thing about an elite athlete is that we're very good at knowing when we're too tired or too overworked and we'll rest. And I say, we rest hard. It's Olympic level resting. So when you see those champions at the Olympics, when you saw them last summer, or when you see the winter Olympics, this coming winter, you know what they do better than anything is they rest. So I want you to think about how you can rest more. Olympic athletes are also terrific at asking for help. They have coaches, physical therapists, they have a whole team around them. They have psychologists. And so who do you need to support you? Think about that.

Who do you need to support you? And think about your team, the people that are on your team that maybe aren't serving you as well now. Maybe that's time for them to move off the team and make room for someone else. So think about that from a very selfish standpoint, from your standpoint, you, the care partner, what do you need and who do you need? And line those people up and learn to ask them for help, help in the kitchen, help with groceries, just coming to get your person with Parkinson's and get them out for a walk or a regular exercise class, if that's possible and coming to sit with your person with Parkinson's. So you can go off on your own if you need that kind of support. And I also wrote down seek nourishment. You know, you don't race a two hour race without eating something and nourishing yourself, you know, having good food beforehand, having good food after having good food during, nourishment, what form does it come in for you? I read a lot. I write a lot and I do a lot of art and that's nourishment for me.

That's nourishment for me. What nourishes you? Optimism. I consider myself an incurable optimist, and you may not feel that way, and you don't have to be like full on optimistic about your person with Parkinson's lot in life or your lot in life. But the more you learn to see things through a positive lens, the better it will be for you and your person with Parkinson's. And it's probably meant you've had to slow down, but you also need to understand that, you know, optimism is learned. You can learn it. It's not the same as toxic positivity. Okay. Where you're just going to say, I'm fine. Everything's fine. Nothing's wrong? I'm good. That's not the point. The point is, is to know, to know how you are for sure, but if you're not doing really well, you have to take steps to help yourself.

And it might be a medical intervention. It might be a friend intervention. It might be a weekend away, but as an elite athlete burnout is a constant fear because if we train too much, we get over-trained, and the symptoms of over-training are very similar to the symptoms that you would feel if you felt burned out. The number one thing that happens is you lose your sense of humor. And humor's so important too. I didn't put it on the list today, but I, as everybody knows, if you've heard me talk before I am a big fan of humor. And if you don't tell jokes, you can at least listen to them and maybe keep a little tickle notebook. We had a great talk about that on one of our recent, our mental health webinar Victory Summit, which was really a great idea to just write down jokes, write down funny things, watch, you know, comedy central, get some humor in your life.

But if you really don't find anything funny, then you probably are burned out. You're languishing, not flourishing. And the best thing for that you can do for yourself is to figure out how to flourish, not languish. And many of us feel like we're languishing in this time of the pandemic, it's so difficult to not feel bad. And the great psychologist, Esther Perel, who has a number of podcasts was talking about the time that we're living in, where we all feel because of COVID and especially during the more tightly restricted times in COVID, how we're all feeling

like we're in some enforced presence, you know, the present tense of a present, right? And so she and Davis and I were listening to this in the car, and we literally stopped the recording to say, wow, you know what, enforced presence, that's Parkinson's, because we don't know what it's going to be like tomorrow.

So we just had to focus on right now. And that's a good life lesson for anyone. And for all of us, sure, it's difficult. You don't know if you're going to make it to, you know, your nephew's wedding because A, maybe it's not the right thing to do health wise, B, your person with Parkinson's just might not be able to make it. And so we have to stay flexible. Right. And that's up there too, you know, and I was joking, can you touch your toes? That's not the kind of flexibility of course we're talking about, we're really trying to just keep our minds agile and kind of go with the flow, but also be able to, you know, guard our best interests. We need variety. We need connections. Up top, you'll see, it says, make connections, DIY, do it yourself, or do it together. Do it together, find support and do it together and make it, you know, make your life a little bit easier just by having, you know, that little extra connection.

And it doesn't mean you're not doing that with your person with Parkinson's. Davis and I do most things together and we enjoy our time together, but I know that I have to be careful, and I have to guard his energy more than I have to guard my own. Stay curious. There's nothing better in life than to be curious about something and keep learning. And so when you're listening to a podcast, a lot of times, like some of these podcasts are so good with Brené Brown, or, you know, I listened to Dax Shepherd's podcasts. And that leads me to all kinds of podcasts. And I take notes when I listen to those, you know, I listen to Poetry Unbound. If you love poetry, their channel has this whole series of podcasts that are just exquisite featuring various poets and discussions around poetry, but what makes you happy?

You know, what makes you happy? Find that, you know, happiness and joy, we've discussed that before too. And it's really, you know, you're aiming as a John Paul Lederach said earlier, you're aiming for this moment of awe daily moment of awe, right? Just something that takes your breath away. And I think we all live, everybody lives in a place where there are natural moments of awe every day, most times in our house, it's the sunset. Let's look at the next slide real quick. Davis took this yesterday, yesterday evening. He races out to our deck because the sky is so beautiful and captures that, and that's almost a nightly occurrence for him. And then he likes to fuss around with those images and, you know, it just gives him a lot of pleasure to you know, crop and look at some of these.

So what brings you joy? Is it a photograph? Is it a bike ride? Is it a walk in the park? Is it a nap? All activities around the table. Can you go back one once? Yeah. And so, you know, I'm going to share also the notion to practice gratitude. And I want to add to that journaling, because when you write things down, whether you're taking notes from a podcast or an





interesting documentary, you might be watching or a book you're reading, you're really engaging in something that lifts you out of yourself. And when you practice gratitude, you're acknowledging that you have many things to be grateful for. I'm usually pretty grateful just that I woke up in the morning that it's just starts right there. Thank you. I'm awake. Let's go, let's do this. So, you know, it, you can keep it simple.

It could be a list of names. It could be events that happened in your past or that you hope will happen in the future. The fact that you're still planning your future is something to be grateful for. So just take a look at what all those various you know, factors are, and spend some time with that in a journal. I love to journal. And most of the time I'm doodling like drawing pictures and, you know, just writing. And sometimes, I refer back to them sometimes I don't, but it's just important to write it down and get some of your hard feelings out of the way too, some of the resentment, because that's a natural reaction to being confined by a person with Parkinson's. But it's also important to know that you can write it out. You're gonna put it out there in the world where it's not going to hurt anybody.

And it might make you feel better. I think it will make you feel better. And a lot of my writing I've been doing recently has been about my childhood and I just love sharing it with my three brothers. And I love when they send me thoughts back about things they remembered or how they remembered things. And so you can time travel. You might not want to travel too much right now, but you can always time travel. And I do that a lot with my mind. I've traveled extensively. I've been very fortunate to have done that. And a lot of times I'm just thinking about, you know, the, the Mediterranean Sea, a beautiful place I might've sat and watched little things like that just can turn your mind to more positive feelings. And that's how you learn optimism if you don't already have it, is to daydream back into things that mean something to you. Let's go to the next slide.

So yeah, a few action steps. Put yourself ahead of your person with Parkinson's on a regular basis so that you are healthy mentally and physically for them. Take time to exercise, of course, and keep making connections, keep making connections, even if they're via zoom. I know people say they're having fatigue from zoom. I understand that if you're in the workplace and you're on zoom all day, but it's a great way to connect with people. And I really encourage you to set up regular conversations with people. You know, I used to, my mother used to call her her mother every Sunday. And so then I had to call her every Sunday and you know, just having that schedule is sometimes really, really helpful. I think we've talked about the other points there. Let's go to the last slide. I'm going to try to get back on schedule a little bit here.

I want to acknowledge that some time being a care partner for someone with Parkinson's kind of feels like you're stuck in a dark tunnel. This is a shot I took of Davis riding through a tunnel in Grand Junction. We had gone back to visit and ride our bikes through an area that we raced in



called the Tour of the Moon. It's just got fabulous rock formations. And I think this is kind of a nice metaphor of just kind of coming out into the daylight or coming out into something that you didn't remember was so beautiful. That was our experience there, just coming out of this kind of darkness. And this was, you know, we actually went to get our vaccinations in Grand Junction because the Boulder ones were kind of backed up and I was like, let's go somewhere.

And so we drove out to the Western edge of our state, took a couple of bike rides and hikes, and it was just such a relief, not only to be vaccinated and feel like the world was opening up a little bit again, but also to ride in this familiar place and revisit a memory that we both shared and had really strong memories about. So don't be afraid to do that. You can always do that via your photos, photo albums, but, you know, take the time to remember what is great in your life. And I think it will help you on so many levels, but as a one Olympian to another, because you're all Olympians in the field of caregiving. What I want to leave you with is this, you need to rest, you need to nourish yourself and you need to stay curious. And by staying curious, you'll stay open. And in the words of my wonderful not my wonderful, but a wonderful Zen teacher that I got to spend some time with what we really want is a soft and open front and a strong back.

### **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.