



**The Parkinson's Podcast**  
**A Conversation with Dave Iverson on Being a Caregiver**  
Davis Phinney Foundation

Jackie Hanson (Program Manager – Video and Audio Production, Davis Phinney Foundation): Hello everyone and welcome to the Parkinson's Podcast. This podcast is brought to you by the Davis Phinney Foundation and brings you experts from the around the country as well as additional educational and inspirational resources to help you live well today with Parkinson's.

Welcome everyone, we're so glad you're here with us. My name is Jackie Hanson and I'm the Program Manager of Audio and Video Production here at the Foundation and I am glad you're with us today! If this is your first time listening to this podcast, I'm so glad you've found us and hope you find some value in today's conversation. I always at the beginning of the episode encourage our listeners to reach out at anytime to [blog@dpf.org](mailto:blog@dpf.org). We love hearing from people, new listeners, and old listeners alike, so reach out, we'll guide you in the right direction, it's what we love to do. We are also so very grateful you are here and finding value in this podcast.

This week we are doing the second part of our 2-part mini-series specifically geared towards the Parkinson's care partner. Last week, we featured a conversation with a panel of care partners. Some were spouses of people with Parkinson's, some were daughters, sons. Some were caring at a distance and some lived with the person with Parkinson's. The conversation was filled with insight and genuine sharing, so I highly encourage you to check it out.

This week we are featuring a conversation we had recently with author, filmmaker and producer, retired broadcast journalist, Dave Iverson. Dave Iverson recently published a book called *Winter Stars*. This book is all about his journey as the primary caregiver for his mom for ten years. When he first moved in with her to be her caregiver he was 59, and she was 95. In this beautifully vulnerable conversation, he shares what that experience was like, the true value of the caregivers in our society, and much much more.

A quick reminder that this conversation was originally a live virtual event, so you will hear a reference to the audience in the live chat every now and then.

So, with all that, here is David Leventhal who is the moderator for this discussion.

David Leventhal (Board Member, Davis Phinney Foundation; Founder, Dance for PD): Thank you so much to the Davis Phinney Foundation for inviting us to share some time with you today. We're really thrilled and honored to be here. And I always look forward to talking with Dave about anything really. And we have pretty much talked about everything under the sun since we first met more than a decade ago. But I particularly enjoy talking about this wonderful book and Dave, when we started working together on *Capturing Grace*, I remember you talking about that film really being your last film project. I kind of envisioned that you would work on

some kind of book. I thought it would be a book maybe about your journey with Parkinson's because as many of our viewers here know, you have such an incredible story to tell. You have so much knowledge and you speak about your journey so eloquently. And so, I was surprised and pleasantly surprised to learn that your book isn't necessarily about your journey with Parkinson's. It's about your journey as a caregiver for your mom. Parkinson's figures in there, of course, but it's a book about your relationship with your mom and how that relationship changes and evolves as you contend with the challenges of caregiving. I'm curious, what made you choose to write about this topic as opposed to the other one or any other ones that you would be knowledgeable about?

Dave Iverson (Author of *Winter Stars*, Writer, Documentary Film Producer and Director, and Retired Broadcast Journalist):

Yeah. Thank you, David. And thank you Melani and the Davis Phinney Foundation family, and all of you for joining us today. It's really a pleasure to be with everyone. You know, in a way, David, I think it's because it's the better story, you know? I think that I'd had an opportunity to do a couple of films about Parkinson's, one for the Frontline Series and then the one I did with you and Dance for Parkinson's called *Capturing Grace*, which is my all-time favorite film project of all the things I've had the good fortune to be involved with. But this experience which had started by the time I was working on that film of caring for my mom became such an all-encompassing and, in some ways, transformational experience that it kind of, you know, trumped everything else in a way it became the, and any caregiver I think will understand this, it was the guiding principle of my day.

You know, if, I might want to think that I was going to write some other story or do some other thing, but if you're a caregiver and you're fundamentally engaged with that, then that tops everything else. It's sort of the organizing principle that you live your day by. And my mom was an extraordinary person. And so that made it that much better a story because she was a story in her own right. And I think that caregiving is one of those life experiences, Parkinson's is this way too, so many important, I think, life experiences share this, that both challenge you and reward you, that bring you sorrow and sadness, but also beauty and insight and love, you know, and for me, those were all part of this experience and writing it helped me kind of understand it that much better. And for reasons that I'm sure we can talk about, I also felt like it's a story that needed to be told because there's such a need for quality care for our oldest citizens in this country. And right now, we're failing as a country to provide that. So, I wanted to see if I could do something that would help spark that larger conversation as well.

David Leventhal:

You mentioned rewards and challenges, this sorrow, the sadness, and the joy. How did your experience living with Parkinson's change or amplify or frame those rewards and challenges? Because as I said a moment ago, Parkinson's is, it's present in the book because you talk about your experience with it. You talk about your father's experience with it and your brother's experience with it in the book as well. But in this care partner journey, how did Parkinson's

change the spectrum of your experience, both the positive benefits and some of the challenges as well?

Dave Iverson:

Yeah, well, I was diagnosed with Parkinson's when I was approaching 57, I guess, years of age and my mom's need for help came just a few years later when I was 59 and she was 95, she had lived independently for the previous 13 years after my dad had passed away back in 1994. And I was doing incredibly well with my Parkinson's as many of us do early on in Parkinson's. I've continued as you know, to be extraordinarily lucky with the nature of my progression. So, I know it seems like a head scratcher, like, okay, you get a Parkinson's diagnosis and then you decide to move in with your 95-year-old mom. Like what kind of sense does that make?

David Leventhal:

I mean, there's an element of like, what were you thinking?

Dave Iverson:

Yeah. Or not thinking.

David Leventhal:

Right.

Dave Iverson:

Exactly. And that was true, actually. I mean, I wasn't thinking about a lot, and I know we'll talk about all the things that I wasn't thinking about and didn't necessarily anticipate, but it wasn't a key factor because I was doing so well, but also for another couple of reasons, one was that my mom was my first example of what it means to be a caregiver because she'd cared for my dad. My dad had also done well in the first 15 years or so of his time with Parkinson's, but his last six, eight years were really challenging, increasingly so, and my mom was there, you know, every, for every moment for every, you know, day, for every ball game they attended at Stanford University, for all the things that they loved, she was always there.

And she taught me something fundamental, really, about living with Parkinson's, which I was then so much reinforced by in our experience working on *Capturing Grace*. By that I mean, my mom was the first person who showed me that you can't stop moving, you know? You have to, that it's all about staying in motion and adding things to your life. And if it takes longer, that's okay. You just stay in motion. And I knew I couldn't do all that my mom had done, but I felt I could be there, and I could be there for her at least partially in the way she was there for my dad. And the last thing I would say is that, and I think this is true for all of us living with any kind of condition that's you know, that's challenging in some way, be that a neurodegenerative disease or something else is that you still want to feel like you can make a contribution.

And I still felt like I was professionally, but I wanted to personally, my mom and I were super close, and I wanted to feel like, and honestly, I felt good about myself for being able to do this. That sounds a little smug, and it probably is and was, but I felt like I can still be a part of this. And that really mattered to me. And so, in many ways, I guess what I'm trying to say in the end is that this all was aligned for me. My dad's Parkinson's, my mom caring for him, my now caring for my mom. At the same time, I was working on my Frontline film. It felt true to my family history and my family story. And I wanted to be a part of that.

David Leventhal:

Which is a beautiful thing. And a lot of the book captures both the closeness of your relationship with your mom, but also this sense of responsibility and connection that you wanted to not just celebrate but go deeper. You wanted to continue to extend that relationship as long as you could, and really explore what that meant for you and I think what makes the book so compelling is that it wasn't, that wasn't always a positive journey. You mention in the book, you write, you were forced in the process of caregiving, you were forced to contend with attributes of personality that aren't always attractive, that there's a, you know, a logical reason for something doesn't always exist. And that you, there were things in that journey, emotional states that you did not anticipate. Can you talk a little bit about that, about what that was like for you? I always have known you for more than decade as a very even tempered, mild mannered, generous man. And you are, and there are moments in the book where some cracks form and you are vulnerable. As an author, you share that so honestly, and compellingly that it's one of the, I think, one of the greatest strengths of the book. Can you talk about that? Those cracks a little bit and how they developed?

Dave Iverson:

Yeah. Well, I didn't anticipate any of it, you know, I didn't anticipate that I'd be so exhausted by being a caregiver. I didn't anticipate that I'd get frustrated. I didn't anticipate that it would reveal my weaknesses in sort of stunning detail. I didn't anticipate I would get angry and fed up with my mom and my situation. So, I went in, you know, incredibly naive and then those cracks were revealed. I also didn't anticipate David, you said before that, you know, it wasn't surprising in some ways that I did this, my mom and I were close and that I would want to deepen that relationship that much further. I wouldn't say I knew that going in, you know, I thought it would be pretty straightforward. My mom and I got along great. We had similar interests, similar politics, similar sports teams, you know, I thought we would be fine.

I didn't know I would be so challenged. And I also didn't know that my mom and I would grow that much closer, in part through surviving those challenges. But yes, I think you, whatever your Achilles heel is, I think caregiving will reveal it, you know, so be forewarned if you are embarking on this. To be specific, for me, one, as you know, is wanting to be right about things and wanting to be organized and have this careful plan for which everything will go just fine if we just follow my plan. Only that's not how caregiving works. You know, you're not in charge.

Your plan that you carefully created will work until it doesn't, which might be tomorrow, you know? So, all of that provided cracks and forced me to be nimble.

You know, I sometimes have used the comparison and make there, you might offer a dance comparison, but mine was to a jazz musician that it's sort of call and response and improvisation and being nimble enough to go in different directions. I was crappy at that, you know, but I learned to get a little bit better. And I learned that being right in particular is a horrible attribute, especially if you're dealing with someone with dementia who makes less sense, or who gets confused. And I would get frustrated with my mom, and I would explain to her why what she said was not true, but why what I'm about to say is true, and that's almost entirely worthless. It took me a long time to figure that out. And maybe we can discuss that more, but I would just say in sum that, you know, caregiving is like this heat seeking missile that pierces you wherever you're most vulnerable and cracks it wide open. And that can be a good thing. You know, it can be an opportunity for great challenge but also great depth and insight and transformation. And I was lucky enough to experience that.

David Leventhal:

You mentioned that the challenges of, or the challenge of wanting to be right and understanding that right, where it has a bearing on a certain truth, is no longer relevant or even helpful. That truth becomes a very, very subjective element in a relationship when you're dealing with caregiving when you're dealing with dementia. Can you talk about that a little bit and how you navigated stories that would come back to you and having to evaluate where is the truth in that? How do I respond to this when it seems so untrue or out of left field, I'm thinking in particular of the example of your mom being left.

Dave Iverson:

Yeah. Well, you know, I spent my career in journalism as you know and facts matter, and trying to tell the story in a factual way, in a clear way, in the way that's fair and true is crucial. And of course, we now live in a time and in a country where our sense of a common set of facts has been terribly challenged, but I think I want to set all that part of this aside and just think about it in terms of living with someone with dementia, because that old saw that, you know, we're all entitled to our own opinions, but not our own set of facts, I came to believe is not true when you're, when someone has dementia. That in fact, when they some say something that's not true, it's not their opinion. It is actually their set of facts that they are living.

And we in turn have to do our best to understand that, to understand what truth there might be beneath those words that on the surface are not true. The example you mentioned is all about that. It's a story I tell in the book about my mom coming home from work one day, and I should mention that I was incredibly fortunate because I had caregivers there during the day so that I could work. So, I was only on duty from the time I got home from work until the next morning and on the weekend. So, I already had it much better than many, many care providers and I know we'll talk about the women who helped me later on. But I came home from work

one day and my mom was as was often the case, she was still in good shape at this point, 97, still really pretty sharp, 98, something like that. Maybe a bit older, but she was, you know, as usual reading the New York Times and she put it down and she looked at me with this very severe expression and said, "David, you will not believe what happened to me today" in this very dramatic way. And I said, "what?" And she said, "I was left in the bathroom for hours."

And I knew that that couldn't have been true, but I just said, "Well, tell me about that, Mom." And she said, "You know, Mele had brought me into the bathroom. She didn't come back for hours. I didn't know if I would survive." And I didn't want to say right away, well, that couldn't possibly have happened. Although I did say that kind of thing, many times, all I said in this case was, well, let me, let me talk to Mele. And she went fine. I talked to Mele, our care provider, and she said, "David, I just helped your mom into the bathroom. I stepped away for a few minutes. I came back in, and she'd fallen asleep. She was just sitting there dozing. And I decided to just let her doze for a while longer. And then I came back in five or ten minutes and gently woke her up."

Well, to me, the point of this, and it took me a long time to understand this. I didn't understand it in the moment. I just thought, "eh, well, that's what happened" and I went on from there. But what I came to realize in time was that if you look at it from our point of view, she obviously wasn't left for hours and hours. But from my mom's, from Adelaide's point of view, it must have felt something like this: I was helped into the bathroom, and then the next thing I know I'm being awakened, and I haven't, how long has this gone on? I feel like I've been here for hours. Well, that was her truth. You know, that was her truth. And she was living that truth. And I came to understand that better over time when she would say other things like, "I haven't been to church," or, "I went to law school," or whatever it happened to be that wasn't true. And I think one of our greatest challenges when we're living with someone whose cognitive abilities are failing, especially someone like my mom who was a super smart, super able, you know, valedictorian of her college class, all of that, when that person is no longer who she wants to be, that we have to really work hard at placing ourself in their position and understanding this world that they're looking out into that's frightening and to hear what's in their heart.

David Leventhal:

You say one of caregiving's more difficult, but ultimately more rewarding challenges is to recognize the truth that lies below what is said, to try and place yourself inside the other person's reality and then look outward onto what must be an unfamiliar and unsettling new terrain. And I think about this passage and what you just said in a way that places you really as a guide, as a facilitator. You don't necessarily have the map because you're both figuring out that path together and that's a significant change for somebody like you, who is fairly take charge, you know, you want to have control over a situation. Here you are suddenly side by side, looking together at this unfamiliar and unsettling terrain and having to navigate that as a partnership, rather than, you know, I know best, or I see it this way, so it is that way, very, very different from other aspects of your existence. And perhaps even what we think about when

we think about caregiving, where it's like, "well, I'm the capable one. Therefore, I'm going to be doing things in this way." Not so, and I think you were, you mentioned in the book, and we've talked about this a lot, but you were blessed to have incredible professional care providers working with you, Mele, Eileen, can you talk a little bit about some of what they brought to their work and this relationship? And I think also this idea of what motivated them. This was not work they did for a paycheck.

Dave Iverson:

You know, you used the word guide a moment ago. Sinai and Eileen and Mele and Roanet, the four principal caregivers we had over time were, were my guides in so many ways. I don't know if I ever reached guide status with my mom. I think the best I could say I did was to just be present to her and to stay with her, not the Adelaide, the extraordinary person she had always been or who I hoped she might still be, but just her. And so, and I got at my best that far. The women you mentioned were my example. They reminded me that caregiving at its most basic is really elemental. It's all about care and touch. It's combing someone's hair when they need it. It's offering them food, spoon by spoon.

It's keeping them warm and dry. It's looking them in the eye and being present. It's, if that person is being crabby and gruff and unhappy, as my mom could definitely be, it's hearing that, leaving the room, but coming back, ready for another go. And if my mom were to smile when you come back, then to just greet her with a smile late at night once, I asked Sanai, one of our caregivers who was a Tongan American, how she did it, you know, because they were so good, so, at such a high percentage of the time, whereas I would fall on my face or get mad or stomp around like a teenager and leave the room or whatever. And she said, "well, when it's late at night and I'm here with your mom," because in time she took over more of the nights from me, "I just, and there's no one watching. It's just Adelaide and me. No one knows what I'm doing. You know, I could be, you know, playing with my iPhone in the corner. No one would know. I just try to remember that I'm not alone. That Adelaide is here. And for me, God is also here."

And for her, what she was saying, I think, was that it was a partnership, that she was in a sense following her call to be a care provider. And she wasn't alone because she was going to be the best she possibly could be with Adelaide. And she was going to do her best, whether anyone was watching or not. But she was pretty sure that there was someone watching, and I had enormous respect for that. And their truthful devotion to their work was so moving to me and they saved me in such a real way and allowed my mom and me to have our story, you know, and to live that out. Because without them, I wouldn't have made it.

David Leventhal:

And one of the things you do so deftly in the book is to amplify the story of these women, these people who are so close to your mom and very special to you, to amplify their role so that we all understand better the real value of caregivers in our society, right? Care is the work that all other work depends on. And yet, somehow, at the level of policy making, at the level of



budgeting, at the level of legislation, we forget that, we ignore it, right? And your book is, it's not an explicitly political book, but there's a message there in the story of these women that says, we cannot devalue or forget about the importance of this role in our society and the importance of these individuals in the fabric of all of our lives. Can you talk about that a little bit?

Dave Iverson:

They are so crucial to providing quality care for the old in this country, just as skilled childcare providers are critical. That care is the work that all other work depends on is something that Aijen Poo, the head of the National Domestic Workers' Alliance, often reminds people of when she's talking too. And we don't honor that enough in this country. Eileen and Sonai, Mele and Ronette, were all immigrant Americans, all women of color, all women for whom English was a second, sometimes third language, all of them work two jobs to get by. And we don't value that enough.

According to the Brookings Institution in 2019, the average home healthcare worker in this country made \$12 an hour. That's just three years ago, \$12 an hour. I was able to do a lot better than that, for reasons I hope we can discuss later on, mostly through the good fortune of where my parents had purchased a home in the San Francisco Bay Area, but that was just good luck, you know, we have to do better than just have a good luck plan. We have no national elder care plan, none. And we have to do better than that. And I worry desperately that it keeps getting forgotten. You know, even in this latest bill, which is now stripped down even further, we're not even dealing with climate change for God's sake, but what got left off the table, once again, was money for elder care and the original Build Back Better Plan that Congress failed to pass last December, there was \$150 billion in that bill to improve elder care specifically for low-income Americans who don't have the good fortune that I did.

So, it gets left behind, and we have to raise our voices about that. We have to advocate for that. I don't mean just writing letters to Congress. Great. We all need to do that. Make phone calls. We all need to do that, especially in the coming months, but it's also talking to your neighbors and friends. It's the next time you hear someone say, "Well, immigration is fine, but we have to have only skilled immigrants coming to this country." I would just like everyone, if you hear that, to ask that person, "well, what kind of skills do we need? What are you looking for in a skilled immigrant?" Because it isn't just technological skills.

It's the skill to keep someone from getting a bed sore. It's the skill that will turn someone in bed the right way so that they stay comfortable, and their skin is protected. It's the skill to change an adult's diapers, a task that I never mastered very well. It is providing love in the most intimate and constant way imaginable. Those are skills that we need, David. And we just have to do much better. We have to do much better because guess what? Someone turns 65 in this country every eight seconds. That means by this time tomorrow, there are going to be about 11,000 more 65-year-olds than there are right now. So, if you think, if anybody thinks they're



going to avoid this problem, well, guess again. We are all either going to provide care or need care or both. That's just the truth. And if we don't get our act together, then people are not going to have the kind of care my family was fortunate enough to have for my mom.

David Leventhal:

One of the passages that stands out for me in the book is your last Christmas and winter stars. And I was wondering if, before we transition into some questions from our community, whether you would bless us with a short reading of that section.

Dave Iverson:

I'd be happy to, David. Thank you. The book by the way is called *Winter Stars: An Elderly Mother, an Aging Son, and Life's Final Journey*. And this passage tells you something more about that title. This is the last Christmas that I spent with my mom. She was 104 and a half at the time, lived to be 105. And in that last year, she was completely bedridden. She was always restless. My mom was this always a ball of fire, always wanted to go out and do things. She'd been this amazing community, you know volunteer and so much more. And so, she would kick at the bedrails of her bed. We had to pillow them at strategic points. So, she wouldn't bang up her foot too much because she wanted to be on the move. And I was worried that she would never find peace. But on this particular night at Christmas time, everything was different.

When I walked into my mom's bedroom, I knew right away that on this December night, she was in a different place. There wasn't any restlessness, she just seemed quiet and calm. She looked to be remarkably at peace. We just sat there for a long time holding hands and I felt a wave of tenderness come over me. After a while my mom looked at me and said in a voice that was soft and only slightly slurred, "You look wonderful." And I told her that she did too. And then I said, "we make a good pair." And she smiled and said, "what a pair."

We just sat for a while. My hand on top of hers, just sitting together, nothing more. And then she turned her head to me and said, "I feel lucky". She said it with more clarity than anything I'd heard her say in recent months. And I told her that I felt lucky too, lucky for all that she'd added to my life and the lives of those around her and that I would always remember what she taught me. And then she said it again. "I feel lucky." And so, I asked her if she could tell me why. There was a long pause. And then she looked at me with eyes as bright as winter stars and said, "because there's love all around."

On that Christmas night, I felt something I hadn't experienced before, that while my time with my mom was still unfinished, our journey was now complete. We had endured our bursts of anger and frustration, but over time, our deep and abiding connection had always held. We had found a steadying and while the current of time and age had taken us into territory we'd never imagined, we'd kept traveling and that journey had carried us to our truest destination as mother and son. It had brought me to the bedside of someone I loved so that I could hear the deepest of all truths: that love is all around.

David Leventhal:

Such a beautiful passage, not just in the emotions that you're sharing with us and that the relationship, and just the way it's written, the way that you've chosen to share that story. I'm going to let those words hang in the air and sort of envelop us for a moment. I really do want to turn over to questions, although I could keep talking with you for many more hours. I'm not going to be greedy. I'm going to invite our community to share questions. This is such a vibrant, active community. I've had the pleasure of meeting many of you at Foundation events or online. And so, this is your chance to share a thought, ask a question. And I will look out for those questions and share them with Dave. Great question from Wayne. Hi Wayne. Wayne has a question about the role of grief and grieving throughout the process of caregiving. How did you contend with the process of grief? You've talked about Parkinson's as a condition of subtraction over time, but I think the same could be true for dementia and as a care partner, you are there witnessing that. Surely there were elements of grief and loss in that process for you.

Dave Iverson:

You know, I'm thinking about how that last passage I read was that in a way my mom and I were allowed, we were fortunate enough to come full circle. We had always been a pair, you know, we'd always had this special closeness. But caregiving and I think my mom's own despair sometimes at what was happening to her separated us at times. I certainly, you know, I didn't beat myself up for getting angry or losing my temper a whole a lot, but it provided friction and maybe there was grief in that Wayne, I hadn't really thought of that as being a source of grief. Maybe that's some of what was happening. And you know, there were many times when I felt like I just can't do this anymore. I've got to move out. And I never did.

And I think it's because I knew somehow that I wasn't done, I did reach that point about a year and a half before my mom died, where I reduced the amount of time I was at my mom's house to just two nights a week. And maybe that was my way of stepping back so that I could, you know be a son again, not just the care official person, you know, not that it was official, but being in charge of all the care, but it's such, it's a really interesting question, Wayne. And I just, I think I want to just think about that more because honestly there were plenty of times when I hoped it would not last longer, when I was ready for my mom to pass on. It never occurred to me when I moved in with her when I was 59 and she was 95 that we would become, you know, senior citizens together, you know, that we would become social security and Medicare recipients together. And there were certainly times when I thought it's time, only it wasn't. So that was the kind of grief, I guess, that I went through too.

I will just tell you the morning after my mom died, I woke up the next morning and I just started sobbing. And I was so surprised that I did because, you know, we had anticipated this for so long, but I think it's because she was gone, this, you know, fundamental kind of was like the kind of compass of my life was no longer there. And yeah, and all I wanted to do was walk into

my mom's bedroom because I knew Eileen and Sinai had spent the night in my mom's room after my mom had died and she'd been taken to the mortuary. They stayed and slept in that room. And I went back in there and I walked in and they just, they knew what I was feeling. They walked over. And there's a picture actually of the three of us just hugging in that moment that I think my wife, Lynn, took. But thank you for asking.

David Leventhal:

Continuing on from that question, did you feel like writing this book was part of how you process the experience and they were, you know, there's a decade of experiences there that you could carry with you and just sort of keep to yourself, but I guess, did it feel very natural to process through the book or, as Jenna asked, did it really take effort to step far enough out of it to process and talk about it? How was that for you?

Dave Iverson:

Yeah, I mean, yes, for me, writing has always been a way to come to understanding life experience. So, for me, it was a kind of natural way to not only understand my own experience, but hopefully provide the one that would be meaningful to others. The greatest single, the most gratifying thing that anyone says to me after reading it is to say, "it just rang true," you know, and that always is really gratifying to hear. And it didn't require stepping away. In fact, if anything, it required stepping into it that much more and trying to really honor my mom's story but be truthful about it, to be truthful about my strengths, but also, more importantly, my failings, because that's caregiving, it must involve and include both. There's no way I think you can care for a parent or a spouse or a child without both. Greats without great reward, but also without great failing.

And I had to reemerge or emerge again into that, I think to try to write the story truthfully. I kept a diary, a journal, through a lot of my time as a caregiver, which I've done most of my adult life, but that was hugely helpful also in the writing of it because I could, and sometimes be surprised by it. I found entries in my journal where I was getting frustrated like six months in, you know, I thought I'd done fine for years. So, you know, that was both revealing and helpful in being able to tell the story.

David Leventhal:

Susie has a great question. I was going to ask a more general question about, you know, what does this, how does this book matter for people living with Parkinson's? So, there are many answers to that, but Susie asks, what did you learn from this process about receiving care for yourself being on the receiving end of care and contextualizing that within the balance of asserting your own autonomy and accepting support?

Dave Iverson:

Well, you know, I think we can all provide care in the best of circumstances and sometimes in most difficult of circumstances, which is not to say that everyone can, or should do or should

make the choice I did. It happened at a particular moment in my life. I was in my late fifties; my career was well established. I was still working, had a lot of flexibility. I had a significant other in my life, my great love, Lynn, but we were not yet married. My daughter was married and... sustaining in my experience. It has to be... like I was living out what was true to my own family story about living with Parkinson's and making the best of that, because I also had such wonderful support from caregivers, the paid caregivers, also Lynn, and also my two brothers who weren't able to be present and who had their own health challenges but were immensely supportive of me, and my sisters-in-law.

I could do things for myself. I could make a movie with David Leventhal, you know, which is my all-time favorite project in life. That's pretty good support, you know. I could, I took up long distance running because I knew that would be really good for my own life with Parkinson's. And I was able to run in a number of New York city marathons to raise money for Parkinson's research. That was supportive. I had wonderful friends who were with me. I think if there's one thing that's true about Parkinson's and also caregiving is that the more you are engaged, the more you're connected to others, the more you have a sense of community, the stronger you can be. Dance for PD is a beautiful example of that, but there are, of course, so many other things, whether that's forming a bike team or a choir or so many things, but I had people with me. And while there were times, I felt desperately alone, when I allowed myself too just be real, I was not. And so, I think that's the common denominator between both experiences.

David Leventhal:

Did the experience make you think about your own Parkinson's journey in the future in a way? Was that not something you talk a lot about in the book, but, you know, sort of just framing your thoughts and then I'm going to tie it back to one other passage in the book.

Dave Iverson:

Yeah. I mean, I do think about that more now. I need to take some more concrete steps. One of the many things you learn as a caregiver is that even if you have an advanced director, an advanced directive, or even something called a physician's order for life sustaining treatment, there are many, many questions that come up about care that it's important to think through. It's not just whether or not you want to be intubated that can constitute extraordinary care. Sometimes it's just a choice of whether or not you want to give someone an antibiotic who's 104, for a urinary tract infection if there's also a way to keep her comfortable without it. There are just many, many complicated questions. So yes, I've thought about those. And I've thought mostly about what I want to communicate, and I've tried a draft of this, but I need to do better at what quality of life means for me and what kind of care I would like to receive.

You know, that, for me, that means being able to play with my grandkids or be here in Maine where I am today and jump in the ocean when we're done with this conversation. If I can do those things then yeah, you bet, revive me if I fall over. But those are all important to think about. But I think about the frailty of life. I was out cutting some bushes down in the little

clearing in front of my cottage here, and I fell and I'm lucky, that doesn't happen to me very often, but I'm here by myself. Maybe that wasn't a smart thing to do, you know? Maybe I have to start thinking about that more. I'll turn 74 this fall. So yeah, all those things, I think about more.

One last point, if you'd asked me 15 years ago, or 10 years ago even, whether I'd want my daughter to provide care for me, I'd say, of course not, she needs to lead her own life. She needs to, I don't ever want to be a burden. How many times do older folks say that sentence? I don't want to be a burden. Well, I don't want to be a burden, but would I like really good care? You know, I don't think my daughter has dialed in. But my wife, Lynn, and I talk about this all the time, you know, because I, the truth is most of us would like good care. And so, we have to do better at creating a society that will offer us that whether that's from a daughter or spouse or son.

David Leventhal:

I think one of the challenges is, and we talked about this at the very beginning of our conversation is finding that balance along the spectrum of the future and planning and thinking ahead with the right now. How do we deal with things right now? How do we play the scene we're in? So, because I know you talk a lot about addressing things in the present moment and you know, it's not that we don't want to plan, it's not that we don't want to project, but with Parkinson's every day is a different experience and we can't necessarily know what the script is gonna throw our way in the future. So, I was wondering if we could wrap up today with another of my favorite passages from the book, which starts with playing the scene you're in and is part of this special trip that you and your mom took to the beach. Does that sound like a good way to kind of...?

Dave Iverson:

Yeah, no, thank you, David, I think that'd be great. David's referencing a phrase that Michael J. Fox has said often, which is refers to the rule he says he learned as an actor, which is that when you're an actor, you have the script and you know how the script ends, how the movie, show, play, ends, but that when you're an actor, you can't act with that knowledge. You have to just play the scene you're in. And he says, that's what you have to do as an actor. But it's really what you have to do with Parkinson's as well. We know something about how that script tends to go too, right, in Parkinson's, but we can't act with that knowledge in mind. We have to play the scene we're in right now. And I think that applies absolutely and perhaps most perfectly to someone who has dementia, that you have to play that scene with the scene that you're in together with that person. So, this is a story I tell in the book about a trip to the beach my mom and I took very late in her life and my mom, although she was incredibly articulate, had always been a person of prose, by that I mean, she wasn't poetic, she was just kind of all business, but late in life, she became, she would occasionally say these stunningly beautiful things, even very late as she did in this story.

My mom had always loved the ocean. We'd taken the same drive as a family for 60 years over La Honda Road in San Francisco Bay Area and heading towards Highway 1. When I was a kid, we'd always compete to see who would spot the ocean first. But today as the ocean came into view, my mom wasn't able to see it. Her vision was failing. So, I said, "Mom, I've got to keep my eyes on the road. So, you let me know when you see the ocean." And when we got about a hundred feet from the water, she exclaimed, "I see it." And a wide smile creased her face. We were at that point when I wanted us both to savor these moments precisely because I knew they would not last, that moments can't be banked or reclaimed later when you need a good moment credit. And as we drove along the water on this beautiful spring day, I tried to remember to do better, to just play the scene I was in, to take in the joy I saw in her face, precisely because it would only be experienced then. For her, there wouldn't be a later savoring.

I tried to remember that moments are to be treasured because they do not last. Like a cloud pushed by the wind, moments part as they become. As always, we pulled into Pescadero State Beach, our ocean destination for the past 60 years. No one in my family actually knows why this is true, but Pescadero is home. We pulled into the parking lot, just south of the beach because it offers the best view. We sat, and we watched, and we were quiet. As we park there, I happened to notice that the children's book, *The Little Engine that Could*, was on the back seat. I'd recently purchased a copy to read to my three-year-old granddaughter. I don't know why, but I asked my mom if she wanted me to read it to her and she said yes. Maybe she liked the title because, like the little engine, she always thought she could, too, and was deeply annoyed when events transpired to obstruct her daily mission: you get up in the morning and you do what needs to be done, for the good of family and the good of society and you do not stop. For my mom, getting old didn't include giving herself a pass. Accepting limitations was not within her DNA. It was her greatest strength, and now, sometimes the source of her greatest sorrow. But in that moment, I read her a story and together we took in the sound of the words, the wind, and the waves.

Me: It's pretty out here today. Isn't it?

Adelaide: I like what's covering me.

Me: Do you mean the blanket?

Adelaide: I mean the sky.

David Leventhal:

Dave, thank you so much for sharing this beautiful story with us, this incredibly crafted, thoughtful, and timely book. Your wisdom, your grace, your honesty, your vulnerability, and your knowledge come through so clearly in the book and in every conversation we have. And I know I speak on behalf of my friends at the Foundation and everybody watching and listening when I say how grateful we are to you for sharing so much with us. Thank you.

Dave Iverson:



Thank you, David. And thank you. You're an extraordinary man and an extraordinary friend and I'm so grateful to be able to do this with you today and so grateful to Mel and everyone at Davis Phinney Foundation for hosting this conversation. Thanks everyone. And for whoever was sending those little hearts through the screen, that was like really sweet. Thank you.

Jackie Hanson:

Thank you so much for listening to today's episode. If you enjoy this podcast, please consider subscribing, leaving a review or giving us four stars. We ask for this, because these really do help us, they improve our ratings in the podcast charts and help us expose our free resources to even more people in the Parkinson's community. So, if you can do any of those things, we would be very very grateful.

A big thank you to Dave Iverson and David Leventhal for this conversation. They are both highly influential forces in the Parkinson's world, and we appreciate them so very much.

Please remember that this episode and all episodes on the Parkinson's Podcast have an accompanying blog post. The blog post contains a link to the video recording of the conversation, all of the mentioned resources in the episode, as well as additional resources related to the topic.

Last but not least, a reminder that this is just one of the many free offerings from the Davis Phinney Foundation. If you haven't yet, please go and visit our website, [www.dpf.org](http://www.dpf.org). There you'll find so many free resources, our youtube channel videos, our blog, live events, recorded events, and even if you hop on over to our ambassadors tab, you'll see all of our people who have volunteered to be ambassadors from all around the country and they have volunteered because they want to help you. You can reach out to them with any questions you might have. These are people with Parkinson's, care partners to people with Parkinson's, and medical professionals, ready to help guide you through the complexities of this diagnosis.

So thank you everyone so much for being here, and we will see you next week.