



How Can I Use Parkinson's for Good?
The Importance of Community and Mindset in Living Well with YOPD
with Allan Cole
Davis Phinney Foundation

Jackie Hanson (Program Manager of Audio and Video 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 today. My name is Jackie Hanson and I'm the Program Manager of Video and Audio Production here at the Foundation and I am so glad you're with us! If this is the first time you're listening to this podcast, I'm very grateful you've found us and I want to invite you to reach out anytime, to introduce yourself, to ask questions, to find out what the Foundation's all about. We are happy to connect personally with our community and we love meeting new people. So, email us anytime to blog@dpf.org. Again, that's blog@dpf.org. D P F being short for Davis Phinney Foundation. Also, thank you to all of our seasoned listeners, welcome back. We are also so very grateful you're here as well.

If you missed our episode last week, be sure and check it out. It was an interview with Jessica Shurer who worked for nearly a decade as a social worker for people with Parkinson's and their care partners. In the discussion, Jessica spoke directly to the Parkinson's care giver, really validating the mental health and identity difficulties that come along with that role, and how you can take steps to improve your mental wellbeing as a care partner, and also why you should.

This week, we are moving a slightly direction, that being people diagnosed with young onset Parkinson's. Young onset Parkinson's is vaguely defined depending on where you are in the world, but generally can be defined as being diagnosed at age 55 and under, 60 or under sometimes, 65 and under, really it's about the stage of life that you're in when you receive the diagnosis. There are slightly different things that that person has to deal with such as family and being in a full-time job, and just different types of things, so it really deserves special attention.

Allan is a professor in the Steve Hicks School of Social Work and professor of psychiatry and behavioral sciences at the Dell Medical School. Allan's research and teaching interests include chronic illness, health humanities, and mental health. He is the author or editor of 13 books and the author of dozens of chapters, articles, and reviews in volumes and journals related to the fields of social work, counseling, and the psychology of religion.

Allan was diagnosed with YOPD when he was 48 years old in 2016. As he will share in the following interview, for a long time he lived with the diagnosis alone, sharing it with very few



people in his life and not seeking out community with others with Parkinson's. In the this interview, Allan really shares his journey from diagnosis to where he is now, which is an active member of the Parkinson's community, the Founder of PDWise, and someone who really believes that if shift your perspective and surround yourself with the right community, you can reframe your experience with Parkinson's and use it for good.

Allan Cole, PhD (Professor and Academic Dean, Steve Hicks School of Social Work, University of Texas Austin):

I'm going to talk about my experience with young onset Parkinson's which as Amy said began will soon be five years ago. And in order to do that, I'm going to tell you first what some of the assumptions I'm making are. I'm a social work educator and in social work we talked about the importance, often of sort of knowing what our assumptions are and working with those and making others aware of what our assumptions are, when we're trying to educate or to advocate, raise awareness, whatever the case may be and so I'm going to I'm going to start there.

My first assumption behind everything that I shared today about my own story. And as I invite you to think about your story is that we are more than illness. I know for me, when I was initially diagnosed, my illness consumed me and on my worst days it exhausted who I thought I was. I discovered that isn't the case it's a part of who I am, a very important part of who I am. It certainly has an effect on my life and on the lives of those I love.

But, but at the end of the day I am more than my illness and I would encourage you all to believe that about yourselves too.

I also think it's important to, to name the fact that there is unity in difference and what I mean about that is Dr. Savica has said very wisely and others have said on the, on the panel today and probably will. As much as we are alike in our diagnoses. We are different as well Parkinson's is very heterogeneous and its manifestations and, as Dr. Savica said in the, in the biology and the disease processes behind it.

And so, it's important to name the both and in that for me, I think we are a lot alike and we're also different in our in our stories are going to be different, inevitably, and it's important to honor that. I think it's important that we share our stories, I didn't do a good job of that which I will talk about here in a few minutes for about a year after my diagnosis, but but I know professionally and I teach my students this often that there's great power, both in telling our stories, and also in hearing others tell their stories and so one of the things we know happens when we tell our stories, is that we do what is called in counseling circles, we externalize our, our problems or concerns our experiences in ways that we can examine them or look at them, if you will, from some different angles, perhaps than we have before.



And as we tell our stories we inevitably are working on understanding the matter. They often evolve over time, so that the way we start telling our story, or the way our story sounds when we first tell it. It may sound very different as we've told it for the hundredth or thousandth, or the 10,000 time.

In the same way when we hear other people tell their stories, it helps us to feel like our own experience isn't terribly unique that others can relate to what we're going through. And both of those occasions build community and solidarity, which I'll talk about as well.

Also important for me is the assumption that we is always stronger than I. For about a year I suffered in silence, mostly with my diagnosis I know many, many people who have had similar experiences. I assumed I could and should do this if you will, on my own, of course that nothing could be farther from the truth. but I think it bears mentioning that often that we are stronger together than any of us is by ourselves or alone.

And as Amy I think led off today saying life can can still be really good with Parkinson's so if you're just getting on the Parkinson's road if you're just, you know, if you've just been diagnosed or you're still sort of reeling with that experience.

I want you to know that life can still be good. And in many ways, genuinely, which I'll talk about today. Life can can be better in certain ways, at least that's been the case for me.

So let me start at the beginning. And in order to do that, I'm going to read a brief excerpt from, from my book called counseling persons with Parkinson's disease I am a writer that's one of the things that I do for my Saturday and try to do to contribute to the Parkinson's community and other communities. And I think this will help you sort of understand the beginnings of my story in a succinct way, and and so I will start there.

The chapter is called beginning of chapter one of my book.

"I sit comfortably at the cherry colored wooden desk in my campus office located in the Steve Hicks School of Social Work at the University of Texas at Austin. I can look out of my window and see the university's iconic power and the Darrell K Royal Memorial Stadium, where my favorite team since childhood the Texas Longhorns plays football on Saturdays.

Having lived in Dallas for a few years as a child, pulling for the Dallas Cowboys and Texas Longhorns was my first religion. Rows of coveted books sit on shelves that line the wall behind me, books I began acquiring more than 30 years ago while in college and graduate school.

These books have titles such as the Varieties of Religious Experience, Essays of Ralph Waldo Emerson, the Cambridge Companion to Kierkegaard and Narrative Means to Therapeutic Ends. Together they tell a story of both my professional path, as well as of my existential searches.

As squealing bus breaks announced the arrival of students for early morning classes. I take quick sips of warm coffee between spurts of typing on my computer. My thoughts flow and I'm excited as something new begins to live on the page.

My left hand like my left wrist and forearm has been stiff for months and tries to keep pace with my right hand, more fluid keystrokes. A sudden twitch in my left index finger disrupts my work.

Each time I extend the fingers such as when reaching for the T key it shakes quickly back and forth. You know how a parent shakes a finger when telling her child know or not to do something. This is the kind of movement my finger is making, and I cannot stop it.

It does not move when it rests on the keyboard or desktop but anytime I use it purposefully, such as when typing or pointing at something it swings back and forth like an erratic pendulum on a wall clock.

I chalk it up to having drunk too much coffee and I don't think much more about it. However, that afternoon and keeps twitching and the same thing happens the next morning."

So, the finger twitch led to a conversation with my wife a couple of days later I said you know I have this finger that won't behave, you know, what do you think? And she's always been the partner in our 30 year almost 30 year marriage who worried about health issues for both of us and she said you know you should probably go get that checked out. It's probably nothing but, you know, why don't you go get it checked out so I made an appointment with our primary care physician.

She's been our doctor for coming up on 19 years almost and went in and said to her, you know I'm here for you to tell me I don't have Parkinson's disease or ALS.

I had begun googling symptoms which I don't recommend, but I am a researcher and so I wanted to sort of know what could be going on and so I knew that there was something not right but sort of playfully wanting to dismiss it, I went in and my doctor's playful banter you know which is sort of common in our relationship, quickly changed when she examined me and long story short was, she said, Allan, I'm sorry I can't tell you don't have Parkinson's or ALS.

I want you to see a neurologist and that's where the story began. I was misdiagnosed by a neurologist who was wonderful, but not a movement disorder specialist, finally saw a movement disorder specialist, received the diagnosis on October 26, 2016.

I was 48 years old had two daughters, 10 and eight at the time now they're 15 and 13. And then I began 11 months of suffering in silence.

My wife knew about my diagnosis, my, my physicians knew, two or three very close friends, some of whom are in the medical community knew, but other than that my children didn't know my parents didn't know my colleagues didn't know.

And I started out on this journey, trying to do it on my own, suffering a great deal with fear and anxiety, a lack of knowledge, making all kinds of misassumptions that I'll talk about here too that proved untrue.

And so I say all that to say, if you're struggling with disclosing your, your condition and it's always a personal choice. We have to disclose when it's time to disclose. I wish I had done it sooner because as I've indicated, and will say more about, my life in many ways got better almost immediately once I told people about it.

So let me talk about what I'm what I'm learning in this journey. Again, almost five years ago I've been public now coming up on four years.

And here are some things that I'm learning and I stress learning because I think it's an ongoing educative process, I'm not sure we ever fully exhaust ourselves on this journey but I think we can and do learn lots of things that can help us along the way and really what I've devoted myself to is learning as much as I can from others and then trying to be a conduit means for other people learning from my experience too.

So, the first thing I want to mention and offer for you to think about is the importance of distinguishing between illness and disease.

This is not my distinction I wish it were this comes from a philosopher, British philosopher named Avi Corral. She teaches at the University of Bristol and she herself suffers from a chronic illness a pulmonary condition, but she helped me understand the distinctions between illness and disease and so I want to talk a little bit about that.

When we focus on disease, we tend to look at a person more objectively which is to say we objectify a person, whether we mean to do that or not. And that's because we start to look at a person in terms of his or her, their physical body and it's function, we reduce them or we have the tendency to reduce them to sort of what's going on with them physiologically physically biologically.

And that has its place, but it's also potentially problematic. When we hold this is why it's problematic when we hone in on what's wrong with us, our heart or lungs, our brains other vital organs whatever we linger on how medicine may help them work better and more efficiently well that's what we all want right we want medicine to do its job.



But if we if we linger there exclusively, again, we tend to miss a whole other side of the experience of living with Parkinson's, which I think is best identified as the illness experience and so what is an illness in comparison to a disease? Well, illness in my view, it tends to the subject subjective, or the so what questions of the disease.

And what I mean by that is it attends to the lived experience of disease. Illness is not what is going on within me if you will physiologically as much as it is, what's it like for me by virtue of that disease process.

And I would really encourage you if this hasn't been your experience when you find a doctor or a care team, and it does take a care team in my experience, make really sure that those folks can appreciate the distinction between illness and disease, it's not just semantics in my experience and it's not just sort of, you know, words, but it really these words carry a lot of meaning and the best health care providers in my experience are those who really live fully on the illness side of this sort of comparison, not at the exclusion of disease of course we need people focusing on that, but sort of where the rubber hits the road for all of us is on the illness side.

And one of the things I love about the Davis Phinney foundation is that they spend their time and the resources and their energy around helping people live better with the illness of Parkinson's disease and I think that's a real contribution.

So, in practical terms, viewing Parkinson's principally as an illness helps me hone in on the colors and contours of what my life is live day to day moment to moment that's what I'm getting at.

Another thing that I've learned is that it's really important for me and maybe for you to live in the moment. To live today and not to worry so much into emphasize so much what may be coming in the future, whether we view that positively or negatively many of us view it negatively because we worry about how we're going to be in X number of years and how we're going to look and how we're going to function and what we're going to not be able to do anymore.

All of which may or may not manifest itself in the ways that we fear or imagine by the way, but that robs us of what today may offer and my experience has been that there's a lot in in the moment in the multiple moments of any day and in a single day, that we miss if we're too focused on on the future. I've been really guilty of that most of my life, living too much into the future, having one eye on the horizon if you will have one eye in front of me and Parkinson's has really brought both of my eyes, if you will, to look at what's right in front of me and to really take in the beauty and the joy and the opportunities that come with each of those moments in each and every day that we're alive.



One of my favorite writers, a person by the name of Wendell Berry one of my intellectual heroes, has this line in a book that's titled "What are people for?" that goes like this, "Let tomorrow come tomorrow, not by your will is the house carried through the night." And I say that to myself, often my wife and kids, you know, hear me say it to them and they say it back to me it's really sort of a mantra for us.

Tomorrow will come tomorrow. The future does not exist yet by the way, and so why give so much energy and particularly worry to the future, when it doesn't even exist, let's focus on today and let tomorrow come tomorrow.

Here's some more lessons that I'm learning hopefully really practical ones for you. We have a lot of agency as human beings living with an illness that we may not recognize, or that we may not remember as much as we could. Remember, there's a lot that, that we may not be able to control with respect to Parkinson's, particularly over time. And we can focus on that.

I don't think that's helpful. I think it's better to focus on what we can control, and we can control things like our attitude toward the moments and the days and the multiple days and months and years that we live with this illness, we can control the people that are part of our lives and who are life giving for us as opposed to life taking if you will, we can control the kinds of passions and commitments we make, the ways in which we use our illness and our experience not only to benefit ourselves but to benefit others. We have a lot of agency, a lot more than we probably recognize, and I think it behooves us to to be mindful of that and ask those who are around us and close to us to remind us of that.

Because there's an awful lot we can do to live well with Parkinson's. All of you who are here today, made a choice to do that that's your agency you're here because you know that it will benefit you. And there are lots of those opportunities that sometimes I think we don't recognize as well as we could.

There are a lot of misperceptions about Parkinson's, you probably know that, as well as I do. There's dire need for more education, for more awareness and really since I became public, I've devoted my energy and my passions, to try to change some of those misperceptions and to try to broaden people's awareness and understanding of of this illness and of what people who live with Parkinson's and other kinds of chronic illnesses can do as opposed to what we may not be able to do over time.

I also have learned that consultations are really important. Bringing people with particular kinds of expertise into your life, especially after a diagnosis like Parkinson's and so I reached out to an employment attorney for example, I'm still working, I was diagnosed in my late 40s again, had two young children, that I was raising with my wife and, you know, getting ready to educate and all of that. I wanted to know what my rights were what my protections were what my



employers' obligations were, these vary from state to state and industry to industry to some extent.

The good news is that the law is on our side, on the side of people who live with illnesses and who live over time perhaps with disabilities, I really encourage you to gain some awareness and knowledge of what those particulars are for you and to bring this kind of resource onto your care team, and then the same thing about, about a financial planner, estate planning all of that, we should all be doing this anyway, of course, but sometimes these become more apparent, these needs become more apparent and immediate when a diagnosis is involved.

And then I want to say again that life can still be good, but it can be even better. I've learned that, I'm living that, I tell everyone who reaches out to me that pretty quickly when they've just been diagnosed because I needed somebody to tell me that when I was first diagnosed and I can assure you that it's the case.

Here's some other things that I'm learning that are helpful for me and maybe helpful for you. I'm a doer and so once I became public with my illness I wanted to get involved with, you know, doing some things that try to move the needle to the direction of more support and advocacy and resources, awareness, all of that for people in our community.

And so, you know, here are some organizations that I've gotten involved with, you will know some of these if not all of them you'll have your own organizations but again we are stronger than I, and there's no substitute in my experience for you know really rolling your sleeves up and getting involved to whatever extent you are, you know, desirous of doing that, unable to do that, you know, folks in organizations like the ones that I'm showing here on the slide and many others like them will become your people if you will allow them to be your people and I think you will, I know you will benefit from those opportunities as I have. Community is a big part of the advocacy and awareness commitments for me.

I think that probably most of us in a North American context anyway could benefit from more community involvement and by that, I mean really meaningful community involvement with people that you can be authentic with, and you can trust, and you can live in solidarity with and for me that's been vitally important, I wish I'd done it sooner than I did. But I got started as soon as I could, and I commend those efforts to you as well. Find your people, lean on your people let them lean on you. Dare to be vulnerable with with those people that you trust. And I think that all of that makes for a better longer-term journey on this on this road.

I mentioned purpose and passion I want to say something else about that. There's a great quote that I also, you know, read and repeat to myself often and share with others, it comes from David Brooks, who's a columnist with the New York Times and Brooks writes the following, "we're all fragile when we don't know what our purpose is, when we haven't thrown ourselves with abandon into a social role where we haven't committed ourselves to certain people, when



we feel like a swimmer in an ocean with no edge. People are really tough,” and I would use resilient in that place too, “only after they've taken a leap of faith for some truth or mission or love. Once they've done that, they can withstand a lot.”

And I just think that's really true. And for me, you know, identifying passions and purposes, not only the ones that I had before Parkinson's, but the ones that have developed and are developing since Parkinson's has been really important for building community, for having opportunities to educate and raise awareness, but equally important for doing what I call meaning making or engaging in meaning making.

And I want to say a few words about that for the next few minutes. So, meaning making involves our mindset, you know, what do we think about all kinds of things that inform the way we view the world and our place in it.

And in the meanings that we find in our everyday experiences, the values that we embrace the causes that we adhere to, all of that relates to our mindset and I think you know for me when I received a Parkinson's diagnosis, there were a number of questions that I had to really delve into and answer honestly for myself as a way of beginning to make meaning with my new life, a Parkinson's life if you will and the first question that I really had to wrestle with is, who am I? Who am I now that I have this illness that is going to presumably progress over time, it's going to impact various aspects of my life over many years and my relationships? Who am I going to be and all of that? That was really important for me to spend some time thinking about.

Equally important was the question, who do I want to be? For me, this diagnosis really called upon me to examine my life my values my commitments the priorities that I had operative in my life, and to really sort of interrogate those and ask, who do I want to be and are these the facets of my life that are reflective of who I want to be, and I commend that question to you as well.

What are my values and my priorities, how am I spending my time, all of that.

And then, as I think Mel said or maybe Amy said, attributing this to Mel earlier on in the time together today.

What are my habits and practices in relationship to the mindset that I'm adopting or trying to adopt for myself? I completely agree that you know our thoughts follow our habits and our practices and our actions as much as those follow our thoughts. There's a real reciprocal relationship there so what kinds of habits and practices, do I want to, do I want to adopt for myself or revamp for myself?

So, the questions that involve those sorts of explorations were the following, how do I maintain hope? Am I a hopeful person and if I am or I want to be what kinds of practices and habits, inform my being more hopeful?

The question of hope was one that was important for me.

How can I begin to use Parkinson's for good? Parkinson's is not good. I don't think any of us would say that, but it can prompt good things in our lives, and that's certainly been the case for me, and by virtue of my asking, how can I use this thing that I would never want or sign up for for good has allowed me to find meaning. I hope to contribute to others lives, certainly to meet people who contribute to my life in countless ways for the good.

How can I make something not good do something good in my life and the life of others?

And then again, you know I've mentioned this, how do I spend my time, who do I spend it with, my other resources. All of that is a habit and a practice that relates to the mindsets that we have, which inform the way we make meaning of all kinds of things in this case living with an illness called Parkinson's.

So, here's my unsolicited advice with respect to some things to avoid when you're engaging in this meaning making process.

First of all, living stuck in the past. I think it's easy for us, particularly early on after a diagnosis to sort of think about yesterday. If only we could go back and, you know, life could be simpler and you know I can do all of this, you know, five years ago and maybe almost do it all today, what am I going to be like five years from now? Avoid being stuck in the past live in the present again.

Maybe in the immediate future but I really think living in the present is the key. Don't get fixated on how you used to be.

Maybe you're giving some things up, that you wish you weren't but if you're approaching this the right way, my belief is my experience has been that you're going to gain some things that you didn't envision to. So, not asking how I used to be but how am I now.

Don't focus on what you can no longer do. And again, there's one takeaway I want you to have today, don't suffer in silence, don't go it alone. We is stronger than I.

And again, living too far in the future so, alternatively, here are some things I would encourage you to embrace, and I wish I had embraced them more quickly than I did. Personal agency. I've mentioned that again. Focus on what you can control, influence, shape.



Let go of the things you can't, because you can't, and, you know, using your energy and attempts to change what you can is never a good thing.

Remember that you have some control over your Parkinson's experience but maybe not full control. Focus on what you can control again and let the other stuff go, power of community I've mentioned, the strength of your will, Davis Phinney is the poster person for the strength of the will, you and I know others like that no doubt.

We can do a lot that we don't realize we can do until we have to do it, and reminding yourself and having others remind you that you're a strong person, that you have resilience and you can build it even further over time for me has been part of the meaning making experience.

And then you know for some of us spiritual values and commitments will be, you know, very much a part of this meaning making what is my purpose you know what is true and eternal and lasting and valuable all of that which can relate to our spiritual commitments. I'd encourage you to embrace all of that as you're trying to make meaning in your new your new life.

Here's an exercise that I want to offer you a call it exercising hope I've written about this and it'll say more about that at the end but I do this every day, several times a day. This may not be your thing if it's not, you know, fine. Works for me, but maybe you can use it as an impetus to think of something that does work for you.

But when I wake up in the morning, I begin each day by saying the following words. I'm grateful for another day. I will do my best to make today good. I will focus on my strengths. And I will be hopeful.

I'm grateful for the day I'm going to do my best to make it a good day I'm going to focus on my strengths. I'm going to be hopeful. I say it several times a day so that I hear myself speak these words right sometimes I say these words silently. Sometimes I say them to myself if I'm by myself.

And what I found is that over time and especially if I do this when I'm struggling, I become more proficient with it and I internalize these words, and they start to change my mindset or to help my mindset be pulled back into sort of the frames that are most helpful for me, for living with this illness.

They help me conjure up hope when I am feeling less hopeful so I commend this to you, make it your own. If this isn't your mantra but it's been very helpful to me.

So I want to go back to passion and purpose. A lot of what I do involves education, I'm a professor at UT Austin, an administrator.



I like to write. So I do a lot of writing I have a blog called PD wise, which is just over two years old and it's really a hub for, you know, sharing experiences about life with Parkinson's and I write a lot of the content but but others in the community, write for the blog too. Blogs may not be your thing, but my point is this is my passion and it really serves to connect me with other people in the community who are themselves passionate and helps us to do Parkinson's together.

But finding your purpose and your passion I guess is my takeaway. I have one final thought for you and then I'll stop because I think we have a little bit of time for Q and A, but this is a quote from Epicurious that I also find very meaningful and he wrote, "don't spoil what you have by desiring what you have not. But remember that what you now have was once among the things you only hope for."

And, you know, I had no idea what I would have that's good in my life by virtue of having Parkinson's disease five years ago. But, it's been beautiful in many ways, and I still wish I didn't have it. But I wouldn't give up so much if I didn't have it, that has come to me because I do, and I want you to at least consider that if you're not in that place yet. My hope for you is that you will be sooner rather than later because I think it's true.

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. These things really do help us to increase our opportunity to provide more resources to the Parkinson's community and reach more people to help them live well today with their diagnosis.

Thanks so much to Allan Cole. He is such an impactful member of this community and we are so very grateful to him, as I know others in the community are as well. If you want to learn more about Allan or find any of the links mentioned in today's episode, including the link to Allan's personal website, PDWise, be sure and check out the show notes for the link to the accompanying blog post for this episode.

There, you'll also find links to additional resources on YOPD. We actually have on the Davis Phinney Foundation website a YOPD Topic hub page which conveniently has all of our resources in this specific area in one place. Additionally, this presentation was a part of a larger Victory Summit Event solely focused on YOPD. You'll find the link to the other presentations in this event in the blog post as well.

One last thing, a reminder that this podcast is just one of the many free offerings from the Davis Phinney Foundation. Not only do we have countless additional resources to help you live well with Parkinson's through our blog, YouTube channel, live events, and more, but we also have ambassadors all around the country ready to help you. These are people with Parkinson's, care



partners for people with Parkinson's, and medical professionals, ready to help guide you through the complexities of this diagnosis.

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

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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.