



**Parkinson's and the Good Life with Dr. Laurie Santos, Davis Phinney,
and Connie Carpenter Phinney**
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Davis Phinney Foundation

Melani Dizon (Director of Education, Davis Phinney Foundation):
Hello and welcome everybody to "Parkinson's and the Good Life with Dr. Laurie Santos." My name is Melani Dizon, and I'm the Director of Education at the Davis Phinney Foundation. And I'm really excited to be here today to talk about the science of happiness. Before we get started, I'm just going to go through a couple of housekeeping. First of all, the agenda: Laurie is going to be with us for the first 30 minutes. And I'm going to ask her a bunch of questions, and we're going to talk about what it means to live with a chronic disease and how it relates to happiness and how we can thrive in this situation.

If you want to learn more about Dr. Laurie Santos, you can go to [happiness lab.fm](http://happinesslab.fm). She's got a great podcast, and you can see all the podcast episodes there and read more about her. Dig in. It's really a really fun podcast to listen to.

So, okay, I'm going to introduce. We only have 30 minutes and we're going to get going. Dr. Laurie Santos is professor of psychology and head of Silliman College at Yale University. She is an expert on human cognition and the cognitive biases that impede our choices. Her course "Psychology and the Good Life" teaches students how the science of psychology can provide important hints about how to make wiser choices and live a life that's happier and more fulfilling. It recently became Yale's most popular course in over 300 years. Laurie, thank you so much for being here today. We're going to jump right in. So what was it about this conversation and this community that made you want to say yes when I invited you?

Dr. Laurie Santos (Professor of psychology and head of Silliman College at Yale University):

Well, I mean, honestly, I know there's so many people in this community who need these sort of actionable tips to feel happier. So that was one reason. But my personal reason is that, you know, I too have a family member who's suffering from Parkinson's. My father-in-law was diagnosed a couple of years ago. And you know, he's been doing well on his journey, but I've watched the way that this disease can make you feel isolated, the way that this disease can kind of change your identity. You know, he was an incredibly active person who was really good with his hands. He was a woodcarver in his spare time, he built ultra light planes. So the disease has really changed the way he kind of interacts and the sort of hobbies that he can have and so on. But I've also



seen through his example the fact that you can get through this disease and be happy and thrive, and so I wanted to talk a little about his experience, but also just about the tips that science gives us for how to feel better.

Melani Dizon:

Thank you. So people living with Parkinson's wake up every day, I say, with good news and bad news. The bad news is that they have Parkinson's, a degenerative disease that's going to impact many, many areas of their life and can impact their quality of life. The good news is that they can live with this for very, very long time. And so, you know, what does the science tell us about happiness and living with a chronic disease?

Dr. Laurie Santos:

Well, I think science gives some really good news here, right? And I think one of the main messages that comes from the research is just this idea that our circumstances, you know, that we're living with a degenerative disease or some other bad circumstance, those things don't necessarily affect their happiness as much as we think. And so we know this from research that's really looked at people who have, say, really fantastic circumstances, right? Like you hit the lottery. Or really awful circumstances. And one study looked at someone who—individuals who had been in a car accident and become paraplegic. You know, so this is a different kind of—not degenerative disease, but now you no longer have the use of your legs. You know, really sudden change in your physical abilities. And what the research shows is that even though when you first, when this change first happened, so the day you win the lottery or the day you're in this accident, your happiness is really deeply affected.

What the research shows is that six months on, one year on, your happiness isn't affected that much. We are experienced—what researchers call hedonic adaptation, which is just a fancy way of saying we get used to stuff. So just even though it might be, kind of not so great as you sort of are slowly watching the disease progress slowly, watching your abilities go away, the data suggests that as something bad new happens, you're going to get used to that too. And so just as you've made do throughout the course of this situation so far, so too you'll be able to do that even in the future, even as things get worse and worse. And I think that's a striking thing. Even as you're, even if you're in a situation where your physical abilities are, have gotten really worse, like objectively things are really bad, subjectively we get used to that stuff too. And so I think there's a real message of hope there, that you don't need to be perfectly physically healthy, have all your abilities to be happy because the mind has this feature where we get used to stuff. It means that even a diagnosis like this can allow you to be happy, even all the stages of this disease.

Melani Dizon:

Right. So then what is going on for people who seem to be able to put on a better face, that seem happy and seem to have a positive outlook and those that each time something kind of gets thrown at them, they're just, just worse and worse? Is that just, no matter what? I mean, forget Parkinson's, that's just life in general? What's going on with that?

Dr. Laurie Santos:

Well, there, I think there are a couple of things that are going on. One is the idea that we often think that happiness is heritable. In other words, there's just, some people are born to be, you know, happy, optimistic. You know, roll with the punches. Some people are just born to be more mopey, more down in the dumps, you know, see the dark side of things. We think that that sort of thing is built in. And the evidence suggests that part of it *is* built in. There is a component of our happiness that tends to be heritable, but it's a much smaller component than we think. It's probably less, around 40% of our happiness, which you might think sounds like a lot, but that means there's a whole lot of your happiness that you can change yourself. It also turns out that the parts of happiness that seem to be heritable are those that—we have some control over what's heritable.

It seems that how easy it is for you to engage with different coping skills—whether you naturally are a grateful person, whether you naturally look to the bright side of things—the good news is even if that's not natural for you, there are techniques you can use to do that, techniques you can use to look on the bright side, to experience more gratitude, to be more social. And this is the message of all the happiness research, which is that we can copy the behaviors of naturally happy people. And that means that not-so-happy people can become happy themselves.

Melani Dizon:

So it's really no different than any other habit. We might not be naturally inclined to exercise or to be able to write or whatever and that we can put habits in place so that it becomes more of a default over time. And we naturally go in that direction.

Dr. Laurie Santos:

That's exactly right. We think happiness is like, we're born that way or it's about our circumstances, but the data suggests that like all other good things, it's just something we need to work at. And as you work at it more and more, just like any other habit, it gets easier over time.

Melani Dizon:

Great. So one of the big things, one of the questions we get a lot, and I would say even more so in this time of COVID is that people living with Parkinson's constantly sort of

have these punches thrown at them. It's one thing after another. A member of our community passed away yesterday. And so a lot of people are rightfully so upset, and they can't make the connections. They can't connect with the family. They can't do all of those things that are not only super important in regular life, but, for people with Parkinson's, that's how they learn to thrive, is through those relationships. And so I think this question may have multiple parts, but how do people continue to kind of roll with all the punches that come their way? And then when things like this—when there are so many unknowns with Parkinson's, people fear, “Is that going to be me?” Maybe the person died young or maybe the person, you know, really struggled. “Is that going to be me? Am I going to turn into that?” There's a lot of that fear of the unknown. And so how do people deal with that? And how does that impact our sorrow, how we feel? Does fear affect our feelings of sorrow? And we're just sort of like borrowing trouble in the future, right?

Dr. Laurie Santos:

Yeah, yeah. Yeah. Well, I'll answer the second one first, which is this idea of, you know, how do basically, I think you could put it, like, “How do we get through negative emotions?” I think Parkinson's brings lots of negative emotions, generally, like uncertainty, frustration, you know, fear of what's going to happen next. And I feel like even people without Parkinson's are suffering from a lot of negative emotions right now during COVID. We're scared about the nature of this disease. We're uncertain about what's going to happen in the future. We're frustrated that we can't do our normal routines, that things are really difficult. And so our instinct, when we experience negative emotions. is to run away from them or to kind of have a stiff upper lip. “Oh, just pretend it's not happening.”

The data suggests that that's not a very good strategy for a couple reasons. One is that we know the only way through emotions is actually *through* them. We've kinda gotta feel them. They don't just tend to go away, but the research suggests that trying to suppress your emotions is really bad. It's actually bad cognitively. So it can lead to memory errors, you know, basically some of the errors, the cognitive errors you're trying to avoid in Parkinson's. You might be bringing those on by sort of suppressing your feelings about Parkinson's.

Melani Dizon:

That's super interesting. I've never heard that before.

Dr. Laurie Santos:

Yeah. It's an interesting fact in its own. But it's also awful for your body. In fact, you can show, there's studies where you get people to try to suppress their negative emotions and you show that they experienced cardiac stress. You're actually hurting your heart

and your cardiac system by trying to do this.

And so that raises a different question of “Okay, I shouldn't suppress my emotions. What should I do?” And the data suggests, ironically, what you should do is try to feel them. Really schedule some time where you can sit with emotions, notice them, and feel them. One of my favorite techniques to do this is a technique that's been popularized by the meditation teacher Tara Brach. It's called, it's a [technique that's called RAIN](#), which is an acronym for Recognize, Allow, Investigate, and Nurture.

And so the first step is, you just need to recognize you're having a negative emotion. And I've seen this in my stepdad. He'll notice a tremor or something that was easy for him to do before that's hard. Holding a spoon or working his iPad, whatever it is. And I think that will come with, you know, that's frustration. That's uncertainty, that's fear of, “Oh gosh, is this getting worse?” That's when you recognize, okay, “What is this emotion?” Call it. It is have a moment where you're like, “Oh, that thing is that's, that's negative.”

Then you do the hard thing, which is to allow which is allow it to be there just as it is. It's not going to go away. You're not happy about it, but it is there. I often use the analogy of like, it's like an annoying neighbor who comes over. You know, pre COVID when they used to show up. You don't really want them there, but you're not going to kick them out. So you just kind of allow them to be there.

Then you investigate. “What does it feel like in your body?” Is your chest getting tighter? Is your brow getting thicker? How does this emotion manifest? Notice the physical signs. I think something—folks with Parkinson's actually notice a lot because you're so trained to pay attention to your body. Do that for your emotions, too.

And then do some nurturing. How would you help a friend or a spouse who going through that emotion? What would you do for a child who is experiencing that? What can you do to nutritiously take care of yourself? The research shows that people who allow their emotions and investigate them and go through it, they kind of get to the other side without all the negative consequences. So the irony is, as those emotions come up, you want to be there and allow them. That sort of answers the first part of your question.

The second part of your question, the first part, was this idea of, well, what are skill sets we can use in this tough time to cope? I think getting through your emotions is one, but there are other coping mechanisms that are really important, even if they're tougher to get right now. We mentioned isolation. All the research shows that social connection can be an incredibly powerful coping skill, right? We all know this, you know, everyone who's in this Parkinson's community knows this. Of course, it's harder to do that now than ever

before. But I think this is a spot where we need to embrace the techniques that we do have access to. Everyone who's logged onto the Zoom call right now knows how to use technology to connect. You can talk to, you know, you can't really talk to me because we're having this panel discussion, but you can talk to someone.

Zoom is a freely available platform that anyone can use for 45 minutes to connect with someone. It's a little bit more work than popping over to see a friend. And it might take a little bit of skill to build up your technology skills to do this. But all of you have been kind of changing your habits throughout this process, this situation that you're facing with Parkinson's. So like just embrace those same skills you learned for that and use it to intentionally connect with people over technology or pick up the phone. You know, if you just really don't want to deal with computers and Zoom, that old phone is still there. You can call a friend. We have to be more intentional about it. But the research suggests that putting in that extra effort will pay back a lot.

I think a final coping skill is really trying to engage with this emotion of gratitude, this positive emotion that we get from counting our blessings. The research shows that the simple act of experiencing gratitude can bump up your well-being. Especially if you do a gratitude practice, it can do that in as little as two weeks. But gratitude also seems to help our cognition. It actually helps us with willpower. People who are more grateful are more likely to save for retirement. They're more likely to eat healthier. It's because it's easier to forgo temptations when you're feeling more grateful. I think gratitude might be an emotion that's helpful to bump up well-being of everyone listening to this, but also the kind of cognitive skills you need to, you know, face a situation like this, where you really have to be paying attention and working hard and sort of building up these new habits.

And gratitude is yours completely for free. All you have to do is just train your attention towards the blessings in life, which, you know, during a year like 2020 can be hard. I think we all want to complain and gripe about what's happening, but the research suggests that shifting to things that give you joy, shifting to things that are just still blessings will really bump things up. And you know, they're all blessings. You know, everyone who's still on this call is above ground today. And that wasn't a given in life, right? I'm sure there are even small pockets of joy. Like, you know, the smell of your coffee in the morning. The smile of a family member or friend. Those things are still there. We just have to train our mindset to see them.

Melani Dizon:

Two things. So on the gratitude piece, I think sometimes people hear it and there's like, "I'm going to do it." And they forget. So one of the things I always recommend is for me, when I'm at a stoplight, anytime there's a red light, I'm just talking about all the things I'm grateful for. My kid does it now. Like, that's just what we do. But also if you're

somebody who's not driving and you're not getting out and about, you can set up a trigger in your house. So every time you go to the bathroom, you say five things that you're grateful for. Just create a trigger for yourself so that you don't go another day without doing it. And it does, it makes a huge difference. Huge difference.

Dr. Laurie Santos:

I heard like brushing your teeth or taking a shower. Those are things you're going to do most days. And you know, that's a great time to do this.

Melani Dizon:

Back a little bit on the "allow" piece. So if we are talking about those, the other three seem very clear. But how are we going to do that? What does it look like to allow something? I mean, what if a neighbor that comes over, I can just say, "Okay, you're here." But if I'm just, in the moment and I'm just feeling super sad and I'm like, "Okay, I'm recognizing this as sadness." How do I just allow it?

Dr. Laurie Santos:

Yeah. It's talked about as sort of non-judgmentally being present with that emotion. I even sometimes say—you know, I experienced this too, frustration, uncertainty, lot of anxiety around COVID, around the election—of using this technique a lot in the last couple of days. I usually just say, "Okay, you know, anxiety, you're cool. Like, you're cool. Let's just hang out for a couple of minutes and let you ride yourself through." And you know, you sound a little cooky when you're talking to your own anxiety, but it sort of works. And then don't try to run away from it. Just try to notice how it feels. Try to be like a curious nerdy scientist as you do the investigation.

The key is that, you know, sometimes when these emotions come up, we just want to run away. And you know, I get, I watch myself get an urgent craving to check social media or just do something that's going to distract myself, eat something. Just don't be with it. Change the subject in my brain. But that doesn't work. So don't change this, don't change the channel in your brain. Just like, hang out with it. Try not to judge it or hate it. Just say "All right, we're just going to be together for a little bit. I don't have to like it, but I have to not run away."

Melani Dizon:

Right. Right. Absolutely. Somebody asked, "Can a worldview that includes religious faith help and being able to be thankful and even joyful in the face of loss and suffering?"

Dr. Laurie Santos:

Yeah, definitely. There's a lot of evidence that that not necessarily religious faith so much, but religious practices definitely boost well-being, and the gratitude piece, I think

is important. Many religious faiths include things like expressing gratitude. You think about saying grace before meals or of Buddhist practices where you really do things like gratitude, meditations. There are a lot of faith-based practices that allow you to embrace things like gratitude.

Many faith-based practices involve social connections. I think that what many of us are experiencing is if you would go to services or go to church groups, and you're not doing that in the same way during COVID, I think that shows the importance of that practice. That social connection was really, really critical. But a lot of religious practices gives you a sense of meaning. That there's something higher than you, that's more important than you. And I think that can also be really powerful for well-being. So I think if you strayed from your spiritual practices, especially the practice part, engaging with gratitude and things like that, go back to those things during tough times. They really can bring you more joy.

Melani Dizon:

Great. Thanks. So the research shows that there's a sweet spot when it comes to stress. There's too much, and obviously it's just too much and it's going to impact your life and maybe your ability to get things done, your work, your relationships, that kind of thing. No stress isn't good either because it's not going to, you know, have forced you or compel you to really do anything. So how do you know when you've kind of crossed that line when it's too much? A lot of people with Parkinson's actually will experience their motor symptoms more if more stress is there. But some people that don't have as many motor symptoms have more depression and anxiety, and especially their anxiety will increase. So how do you know when it's going from good stress to bad stress and what to do about it?

Dr. Laurie Santos:

Yeah. I think you should, need to, again, this is sort of why recognizing and noticing kind of helps. You know, for me personally, I can tell the difference if it's affecting, you know, the normal habits that I had. Like, am I sleeping the same way? Am I getting the normal amount of movement in, or am I kind of canceling that? Am I being short and frustrated with my spouse and my family members? If you're paying attention and mindful, you can kind of get a sense that it's a little bit too much.

But I think on that point, one thing the research really shows is that again, you know, we think of stress as bad, you know, we think of tough situations as bad, but the research suggests that tough situations can often be a blessing in a way that we don't expect.

There's a lot of new research on what scientists called post-traumatic growth. This idea that sometimes we go through a traumatic experience, say a chronic disease or a

diagnosis or something like that, and it actually makes us feel like we've grown. You gained some resilience in life. And I'm sure everyone who has Parkinson's on this call or family members of people with Parkinson's get it. You know, the normal, small stuff. Like you're not going to stress it anymore. You know, if you can make it through Parkinson's, it means the tiny stuff doesn't feel as profound. So you're gaining some strength; you're gaining resilience.

You also get a sense of what really matters in life. I think when you suffer from a chronic disease, you recognize that not everything is a given. It causes you to have gratitude for tiny things.

And I think, you know, again, thinking of my father-in-law's case, I see the gratitude he has for the movements that are still easy. I think he's grateful for them in a way that he probably never was before this disease. And those things are meaningful. Those things actually give you joy. In some ways they're an interesting gift.

And so one thing to remember is even the parts that are stressful, even those things that are frustrating, they can allow you to build resilience. They're giving you a sort of strength that you didn't have before.

One final thing is just to remember that even stressful times are stressful in part because of our mindset towards them. If we're kind of taking like, "Oh, woe is me, Oh, not again, this thing, this horrible challenge, I can't get through it. What a pain." That's a certain mindset that's going to cause us to interact with that stressful circumstance in one way. But it is completely up to us to choose the mindset that we engage with.

On one of my podcast episodes, I interviewed this guy, Bill Irvine, who has a great book called *The Stoic Challenge*. And he kind of brings us back to the ancient Stoics who remind us that you can see challenging situations as a challenge, as a game. Like, game on, right? Like, "Oh, now this motor movement has changed around like, okay, let me play the game where I'm still joyful and I'm still trying to thrive even in the face of this stuff." And so in some ways you can see your chronic disease as sort of, you know, that he jokes about the Stoic—God's kind of leveling you up, right? It's getting harder for you, but can you sort of see it almost like a game and a challenge to make it through, and keep your wits about you in this interesting way.

And so a final thing with stress is to think about the mindset that we have and the mindset that we use to face this stuff. And remember that while the choice about how our disease progresses might not be us, we have complete control over the mindset that we take to address those changes.

Speaker 1 (22:56):

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Melani Dizon:

Right. Great. So in your course “The Science of Well-Being,” and also everybody, you can see that course on [Coursera](#), it's actually free, look for “The Science of Well-Being,” and we will send those notes to you so you can check it out. But you talk about “rewirements,” and every time I trip over that word. What is a “rewirement” and what are some potential rewirements that people with Parkinson's can do to live happier, better lives?

Dr. Laurie Santos:

So rewirement, it was kind of a joke, you know: in academics, we have course requirements, which like your midterm and final. “Rewirements” were activities that I was assigning my students like a course requirement, but they were there to rewire students' brains. To rewire their minds. Happiness habits come a little bit easier. And so rewirement were all kinds of activities that we know empirically can boost up your well-being. And we've talked about a couple. So one is social connection. So tonight, call a friend, call someone you haven't talked to in a long time, make a social connection that is new to you. Another is to experience gratitude. So take, you know, five minutes tonight to scribble down a few things that you're grateful for, or better yet, write a gratitude letter, which is one of our rewirements.

You know, think of someone that you really have been meaning to thank and haven't had a chance to do. That's kind of social connection and gratitude sort of squished into one. Do a random act of kindness. Can you use some free time or, you know, donate some money to a cause you really care about? Phone bank for a good cause right now? How can you use five to 10 minutes to get outside yourself and think about someone else?

The research really shows that when we're faced with stressful events, one of the best things we can do, ironically, is to focus on helping someone else, not helping ourselves. And that kind of convinces us that we have the resilience to get through our own problems.

And then a final requirement is just to take time to savor. To just take time, to notice the joyful things and pay attention, be mindful, be present with them. You'll often, we have joyful things in our life, you know, like a couple ice creams in the afternoon maybe, or, you know, like a funny video on the web or even just like talking to someone close, to our spouse or kids. And we just don't take time to be mindful and present and enjoy the joy that comes with that. So that's the act of savoring, really to try to embrace this.

Melani Dizon:

Yeah. And right now it's, you know, I guess it's maybe the silver lining of the COVID situation is just, we have time. We probably have more time than we've ever had. You know, we've kind of, like many people have gotten rid of commutes and all travel and all of those things that we did. So there's time for all of these things to, to happen. So somebody said, we talked about religious practices and somebody said, "Well, what if you're not religious?" And I think that, you know, there are many, many practices, all of those practices that you just said can be done if you're not a religious person. And there are a lot of mindfulness practices that are secular, that have nothing to do with religion. And so those are also things that people can participate in.

Somebody said, "With the depletion of dopamine, happiness is impacted." Yes. So any suggestions for physical changes to help with that?

Dr. Laurie Santos:

Yeah. Well I think, I mean, again, the course of this disease means you're going to have changes that affect your physical bodies, your movements and those sorts of things. And dopamine and all these other hormones are also rigged up to things like your reward system and so on. So you literally, you know, your brain is kind of changing what you find rewarding. Again, that's not something you have control over, but you do have control over how you "achieve dopamine" in the rest of your life. You know, you can mindfully, as I said, pay attention to this good experience. Say, if you're eating an ice cream cone. You can mindfully shift your attention to your spouse and try to remember what you used to love about him or her, or you can mindfully shift your attention to funny things on the internet. There are certain things you have control over and you can kind of provide that boost of dopamine. Now, is it more challenging for people with Parkinson's than folks without degenerative diseases? Yes. Because you have to be a little bit more intentional, but the good news is that that hard work pays off. And as you do that hard work, it becomes more of a habit, becomes easier over time, as you do more and more.

Melani Dizon:

Right. Somebody said, and I don't know if you get this much, but somebody says, "What if you live alone and you just can't," I mean, we talked about picking up the phone and doing that. But my sense is if the person asked the question, there is not, you know, somebody they can call. What are some things that somebody can really do? Like besides the, you know, writing down gratitude. Although I think that is incredibly powerful. If they live alone, they don't see people, the phone isn't giving them the connection and Zoom isn't giving them connected connection.

Speaker 2 (27:48):

Dr. Laurie Santos:

Yeah. I think that the good thing to remember is that sometimes we, when we're feeling really lonely, we can become really focused inward. We can think like, "Oh, people don't want to talk to us," or there's no kind of connection, but often the data really suggests that it's kind of about you, right? There are probably people in your life who really want to talk to you and feel like you're not caring because you're not making the effort. And so the research suggests that the act of trying to make the effort, even if it's hard at first, even if you have this prediction that it's not going to work, can be really powerful.

So I think if you live alone, two strategies are—one, you know, try to get out and about. COVID limits the extent to which we can do that. But the data suggests even that something like weak ties can be quite powerful. So if you're in a spot where there are things that are open and you can kind of go out and, you know, just see people socially distanced right on the street, that can be really powerful. Strike up that connection with a stranger. Again, our prediction is, "It's not going to help. It's going to be weird." The data suggests not. And the data shows that if you just, again, pick up the phone, contact someone, really try to reach out. It feels like you're putting in energy and it feels like it's not going to work. But the research shows that we have misconceptions there. We think "Oh, that person doesn't want to talk to me." Or that family member doesn't care. Like it's going to be a burden to them. But the research shows that we're usually wrong about that. So try it, you know, see if it works. And often the results will be quite pronounced.

Melani Dizon:

Right. And also one last thing before we go. If you live alone, there is incredible power in sunlight and getting it up in the morning. And if you can get up in the morning and have that sun on you while you're taking a walk around the block, that can be a big thing too. And it doesn't take anybody else's input. It's just you getting out there.

Thank you, Laurie. I am so grateful. I know you have to go. It was so lovely having you. Everybody else, stay on. Davis and Connie are going to join us and we'll answer some questions. Thank you, Laurie. Bye.

Okay, Connie and Davis, I'm going to bring you back on, I'm going to ask you to unmute and then ask to start your video while I check out some of these. Okay. You're here. Yay.

Connie Carpenter Phinney:
She was so great.

Melani Dizon:
I know. I want so much more time.



Davis Phinney:

She was just so succinct with all her points. And I loved some of her quotes, like how you achieve your dopamine.

Melani Dizon:

That was great. So we do have somebody, Leigh's actually responding to some of the questions about the course and where to find the course. So we will do that. Somebody said, "We were not designed to handle things like Parkinson's alone. We need others to help carry the burden, to love and affirm and to speak truth, which is, which should help and growing deeper in the things that matter." It's true. It's really is. And I'm, all of us, right. We're born to be in community in this world. And for you, maybe the community is one other person. That's totally fine. You don't have to be the kind of person that needs 10 people around you to feel connected.

Let's see. Coursera. Yes. "Thank you so much, Dr. Santos. Top of my grateful list today." Excellent. Thank you everybody.

So a couple of people, why don't you just keep asking questions and we'll talk to Davis and Connie about it? I do want to ask you this, Davis and Connie. Somebody said, "My husband forbids us from letting people know what's wrong. He wants to pretend he's normal. So people stay away from him because they're concerned. What would you say about that?"

Connie Carpenter Phinney:

My first thought is normal is overrated. Right? But I also think, wow, that's rough. I mean, the fact that you're asking the question means that it's maybe not the way you feel about it, you know, that you don't—you know, having a chronic illness makes you part of a community for sure, but it also makes you feel kind of isolated. And I think that the more that you maybe detach yourself somewhere isolated, you might feel—but that's an excellent question. And I think one that needs to be resolved at the family level first.

Davis Phinney:

I mean, I can understand. Did you say he was, he was the one? Yes. Yeah. I can understand. Yeah, I did that. You don't want to hear anything but normal, but unfortunately with this disease, the longer you deny it, the worse it'll get to you. And you will have to come to a place where you have to be public about it. There's just not really choice in that. And so I would encourage him to look at it as something that he can embrace and not deny. And in doing that, he'll find himself so much more free than he ever expected that he would.



Connie Carpenter Phinney:

Well. I think we see a friend of ours on here, Jim, saying there's freedom in allowing yourself to be vulnerable and open. And I think that comes with time, too, but that's really a true statement, right? And it's actually the first step. And what Laurie Santos was discussing as the mindfulness approach, the RAIN approach. Number R stands for recognize, you know, and recognize means to acknowledge as well. And you know, there are times when you want to step back from that and not have it be front and center, but the reality is quite often it is. And so I think that whole step, you know, just going back to that recognize, you know, allow, recognize your feelings, recognize what's going on, allow them, take the time, make the space to allow them. Investigate. What's making you feel that way?

And that's maybe the conversation that this couple needed to have around that, you know, "What are you afraid of?" Or what do you lose, if it's, maybe, it's not fear. Maybe it's just feeling that the loss is made greater. Well, "Let's talk about that." And then see what you gained, because that's what she was saying about the stoic, you know, that was such good, you know, all the linking of all these things that there's actually so much power in the transformation from being someone who's diagnosed with something, to being someone who's really living with it and really, you know, making the choice to live well. And she really articulated all of those so well and brought them all together in such a forceful way.

And it's easy to say, "Well, it's easy for her to say that because the data shows you one thing." But the reality is if we sit back and—you know, Davis has had Parkinson's 20 years. I can say, too, that he's a stronger person because he puts it out there and he acknowledges, you know, the, the frailties, but we're all frail as humans. And it's a stepping stone, I think. Really, self-awareness is being able to embrace your challenges.

Davis Phinney:

Well, that's like what she said about his friend. Being afraid to engage with his, one of the ultimate cruelties of his decisions in not being open with this, because if you're losing your friends because you won't admit that you have a problem, then you know, you ended up completely alone and that's just terrible.

Melani Dizon:

Yeah. And also, you know, it made me think about how many stories that we've heard from people who, they were just somewhere strange, somewhere unexpected. And they mentioned it. And all of a sudden they met someone else who said, "Oh, I have Parkinson's," and they struck up a friendship. They were in a support group together. They decided to ride. I feel like there is just so much, and so many connections, we

don't realize that are out there. And by not saying it, you know, you could be missing out on some of the friendships or maybe, maybe your neighbor has it. And they're not saying it either. I mean, there's a lot of connections that are made.

Connie Carpenter Phinney:

Connection and doors that open. I think we're looking at doors opening, not shutting doors, and especially not shutting doors preemptively, because you don't even know what it means. If you haven't really embraced it and can't walk through that door, then maybe you don't even know like how much love is waiting for you and opportunity and all of that. And so that's unfortunate and you know, there's nobody that wants to have Parkinson's. So I think we can also acknowledge that. We can recognize that emotion and we can feel it and we can say it, but that doesn't mean that doesn't make it go away. I think it's important not to suppress the feelings.

I guess if the reason you don't want to have it be, you know, face forward is because it's, so it's such a negative emotion. But as Laurie said straight up, is that some suppressing emotions will only make those symptoms, and particularly cognitive symptoms, which is the thing I think we're most afraid of, cognitive symptoms, worse. We don't want that.

Melani Dizon:

Right. Absolutely. I've got, somebody asks, Davis, do you want to answer that one, "Due to physical limitations, my husband can no longer do the things that bring him happiness. Suggestions?"

Davis Phinney:

Well, I think that Laurie addressed this fairly well in that there's got to be something that you can do that brings you happiness, even if it's a very small thing. It's important to understand that whether it's the ice cream or your dog sitting on your lap, there are many things that can bring you happiness. And if you pay attention to them and give them a way in even if if you ca'tn get out and do the big motion things that you want to.

Melani Dizon:

Right. You guys have talked about this a lot. So I want to really address this. Somebody had asked about if, you know, you, "I fear losing my friends," right? And if you fear, they said, someone said, "If you fear losing your friends due to your illness, those are not the kind of friends you would want in the first place." But I'd love for you to talk a little bit about your story. Because I know that you had said, you know, "We have friends after Davis, after Davis was diagnosed, and before ,and things change." So can you share a

little bit?

Connie Carpenter Phinney:

Yeah, I think a couple of things. There are some great points in the chat on the side. It's hard to not answer you all right away. Believe me, we're holding you in our thoughts and will try and want to get to you. And there's some great points over there. But I do think that we did have friends that knew Davis before diagnosis. And remember he was diagnosed when he was 40. So, you know, his early life friends who saw him as a superhero had a hard time kind of adjusting to what they might've perceived as loss of superhero status. Even though those of us living with Parkinson's know that he's more of a superhero now than he ever was during his athletic career, to which he'll start to cry, so I'll be careful, but I also—you know, it's so true, because it takes so much strength to live with this disease.

And, and someone said, “Well, what about when you're at work?” And granted, when you're at work, you don't want your Parkinson's face forward because you might get passed over for promotion. Because of that, we understand that as well. And many people struggle with that. I understand that 100%, but at the same time, there is this balancing act that you have to navigate. And we did find that people that had met Davis only after he had Parkinson's had an easier time adjusting to the ups and downs of the disease. Whereas some people that knew him from a long time ago, when they see him doing well on a good day, they're like, “Okay, now he's better.” And then they don't understand the bad days. And you know, that's the problem is that these days are—first of all, we don't count on the good days, but we don't count on the bad days either.

And so I acknowledge when she talks about making a choice. I mean, some of us at sometimes might be, “Ah, I can't make a choice in my outlook,” but actually you still have the opportunity to be able to do that because, you know, you can choose your friends, by the way, and the people that aren't supportive and don't seem to understand, and the people that you will drift away from that you don't need to be with because you only need friends that you have a good reciprocal relationship with, you know, and most times, I mean, Davis gives as much as he gets, right. So, you know, it's a give-and-take, and his voice is a real problem for him. So he feels a lot of times he can't communicate. And that's why I jabber so much, but—I know, I can read his mind. But at the same time, you know, it works that way, you know, and there's a challenge. And I do think that picking friends and knowing who you want to be with is really an important step. Choose your friends carefully.

Melani Dizon:

Yeah. Davis, can you speak a little bit to the voice because I know that that is something that you have a struggle like a little bit, and somebody said that when they get tired, you



know, their speech gets slurred and that can impact relationships. What, how do you deal with it? What do you do? What are some practical things that people can do?

Davis Phinney:

Well, I mean, pre COVID, I had a great singing group I'd joined with, and now of course that's not available to me. And so I feel like in this time, my voice is ebbing and flowing maybe a little bit more because I'm just not using it as much. And I noticed that when I was going to classes with my Parkinson's friends, I was talking a lot more throughout the day. When I'm here in the house, it's more quiet here and I have less reason to talk. And so I talk less and that's to my own detriment.

Connie Carpenter Phinney:

Are you talking less because I talk too much?

Melani:

No. Gavin said, and I think this is an excellent point, "Consider that happiness, not necessarily from doing things or getting things, but from removing things." And I think this time has definitely allowed people to say, wow, what's most important? What do I need to keep? And what are a lot of the things that I did or had, or was responsible for pre COVID that I don't want to bring back into my life, that didn't bring me happiness? That did not help me, you know, feel joy and thrive? So that's a great thing to think about.

Any other questions for Davis and Connie? We have them here. We have them for several more minutes. So you can ask them anything you want about happiness.

Connie Carpenter Phinney:

I think we had a couple of thoughts, too. Davis was, you know, we've always been a big proponents of kind of capturing a moment of awe in the day—A-W-E—and just, you know, we've heard from other, you know, friends of ours that are in the Parkinson's community, as well as outside the community that, you know, some of the best joy, the greatest joy that comes is to be able to denote a moment every day of sheer awe. So whether or not you wake up to watch the sun rise or watch the sun set, or watch the birds that have bird feeder— little, little things sometimes can just really make your day.

Davis Phinney:

Yeah. And that's so vital because you can notice those moments, then what happens is that you start seeing more and more things as being joyful and joy-producing, and that how you end up being grateful and positive.

Melani Dizon:

Yes. I have to read a couple of these because these are fabulous. First of all, someone just realized that you are Davis Phinney. "Davis, you are inspiration. Thank you and your wife for all you do. God bless you." Yes. Humor is such an important part. Oh, hi, Angela. And Carl, so good to have you guys here today. Yes. Davis and Connie talked a lot about humor and how, how important it is. "Davis, you have a great wife just in case you didn't know." And then, I love this. "We are the three Stooge-ttes from Saratoga County in upstate New York. We are fortunate to have each other. Parkinson's brought us together there. Strength in numbers." Yes, absolutely. Great. "Have you discovered new sources of happiness that you otherwise might not have found?"

Davis Phinney:

I would say maybe during this time, for me, would have to be the "Zen of vacuuming" and chores. Literally it's been such an interesting transformation because pre COVID, when Connie and I used to speak at our Victory Summits, when Connie would take a trip, she'd call me and say, please vacuum the house. And I feel this tremendous weight or burden come onto my shoulders, but post COVID, I, for whatever reason, changed my whole mind frame on that activity. And so I've turned it into something that's actually kind of fun and it feels good to do.

Connie Carpenter Phinney:

It does feel good. And I think it's important to have little challenges, with Parkinson's, you know, that aren't normal. One of our friends wrote in here and thank you, Larry Zahn, because he brings up chronic grief. I think many of us have lost someone during this last six to eight months. And I know, you know, many very dear to us and not always, you know, because of Parkinson's—because of other things, because of cancer, because of accidents. And I think no time is more difficult than this time of COVID to lose someone. And it makes me curious, thinking about it because we're just so separate, you know. My brother's in the hospital right now and my, his wife, daughter and granddaughter, the only way to visit them was to stand on a parking structure outside the hospital with signs and pompoms.

And I think we've all had this experience during this time where we're so separate. You know, they're in Wisconsin, they're in a red zone. They're not allowed to even go in the hospital, and he's already been in the hospital now since Friday. So this is something that we, you know, we feel so deeply in these times and that I, a hundred percent agree, Larry Zahn and everybody else suffering through grief, that this is a time where, you know, we need to listen to the Laurie Santoses of the world who can show us the data, let us believe that actually we have the power in our minds to overcome. So much of what's been happening in our country, so much has been happening around the world with COVID, and so much is happening just inside of us. Those with Parkinson's, those

without—you know, there's just, it feels almost like too much on a daily basis. And so what can you do about that? And, you know, Mel, a hundred percent, we start with gratitude. We start with still remembering that the sun rises and sets and there's those moments of awe. And, you know, we compartmentalize a little bit, but we also don't suppress, you know, when we're sad, we're going to feel sad. You know, it's just the way it is right now. And it's the way it is for many people with Parkinson's. And I think, man, you guys, you got to, I mean, you, the community, all of us need to work even harder at this happiness lab and this happiness project, because it's what we got as humans. We can do this.

Davis Phinney:

And how we achieve our own dopamine is so important. And you do that through creating good habits, as Laurie said, and gratitude is number one—gratitude and kindness. And I think that kindness doesn't have to actually even be more, anything more than an intentional thought towards someone. If you wake up and you think of two or three intentional thoughts of kindness, even that little thing has an effect on you and it can improve your day and improve your outlook.

Melani Dizon:

Yeah. You reminded me of the loving-kindness meditation. You can look up the “loving kindness meditation.” It is so good. It's short. You give love and kindness to yourself, to somebody else, to somebody that you may not think you would normally give loving kindness to. It is quite, quite powerful to do that.

And so this woman asks a question: “I'm a co-facilitator for a women's group affected by Parkinson's in Spokane. What is one thing I can share with these gals to keep them off the ledge?” One thing I would say is breathe. Take a breath, just take a breath and doing it as a group, even on Zoom, it's pretty amazing. Just that is the most powerful tool that we all have. We're all living. We can all breathe, and it is amazing what it can do for yourself.

Connie Carpenter Phinney:

Very true. And I would say even starting and finishing any of your women's group meetings or any meetings with just pausing for a moment and taking a collective breath. Maybe we can do that to finish out our time here—everyone, we can just take a breath together. And in this time of COVID the breath is even so much more significant. And it just feels that much more important.

Davis and I started practicing yoga just before COVID and the focus on the breath, I think as well as everything that it's done to help us balance and just stretch them out and stretch me out as well, has been incredibly, incredibly you know, powerful for us on



almost a daily basis. So you have to find something that centers you. So let's, wherever you are right now, maybe just sit and make sure your feet are on the floor. And sit up a little, maybe close your eyes and take a breath. Nice inhalation, really feel your lungs. Expand, try to hold it, and let it out just slowly. Let it out and try it again. Lift your chest, take the breath in, and collectively, everybody, let it out.

There's power in that. The simple things.

Melani Dizon:

Absolutely. Thank you. And thank you everybody. And over the next few days, if you need it, you might take breaths.

Connie Carpenter Phinney:

Take a breath. Yeah, absolutely. Thanks so much, Mel. And thank you so much to Laurie Santos for contributing today. For everybody that's asking, you will have access to a transcript and to more information and all the links to her work and our work and just keep supporting us, but more than anything, keep supporting yourself. That's what we're here for today, supporting you. Thank you.

Melani Dizon:

Thank you, everybody. Any questions, just email me at mdizon@dpf.org, and I'll get it. Thank you, everybody.

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