Community & Goals: Keys To Parkinson's Exercise Success Transcript

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Summit Welcome and Introduction

Hello. I'm Dr. Ken Sharlin Welcome to the Parkinson's Solutions Summit, where during the week long summit, you can enjoy many interviews with experts in the field of Parkinson's disease and it is my hope that you will broaden your knowledge and your way of thinking about solutions and things that you can do to help yourself, your family and your loved ones affected by this disease.

We are about empowerment and resilience and taking charge and not about letting that disease define who you are unless it takes you to a whole other level in terms of thinking about how you can inspire other people.

I am so honored today to welcome Sarah Ingersoll. She is connecting with us from California and University of Southern California. And she's going to tell you a little bit about who she is.

But I watched an interview that she did earlier today, and she's going to really inspire you about exercise and movement and Parkinson's disease. We have a top notch researcher amidst us.

And so without further ado, clinical assistant professor, Department of neurology at the University of Southern California, Sarah Ingersoll. Welcome to the Parkinson's Solutions Summit.

So thank you. Ken and to everyone who's with us, I'm going to start with disclosures as people are always supposed to do, and my disclosure is that I exercise.

So I'm not just telling you from the book. I'm going to tell you that you should exercise and I do it myself. And so you'll notice that we're wearing matching race shirts.

You're not matching on the same thing. I am. That was not by design. You just dressed independently. So I exercise. I recommend that you do it. I think you're generally aware of the idea that is a that's good for you and you should do it.

And how does how do you make that actually happen? And that is really what I have focused on for several years now. I initially, when I got to be old, I thought really, I should do a little exercise and I and I didn't.

Exercise as Core Parkinson's Treatment

And then I joined a team and that was very helpful to me because it's very helpful to have your teammates out there. And you know this you have friends who are nine years old who play soccer, and they wouldn't do it without their teammates and they wouldn't do it with as much energy and fun and enthusiasm without their teammates.

And so that was very inspirational to me, and that is my disclosure to start with. I think that one of the questions that can is going to ask me is what is the literature say about exercise?

And I don't want to assume that you all have not looked at the exercise literature because you have and you all know that you're supposed to exercise.

And the evidence is really very, very strong. It's very strong for people who don't have Parkinson's disease, and it's even stronger for people who do have Parkinson's disease.

And it's been studied a good deal. And there are mouse models and they done all sorts of things. It's good for you. So I think we need to check that box and then move on to the big question of how do you do it?

And I don't know if you've seen the Roz CHAST cartoon, which I could share with Ken later, and it is a terrific

cartoon. It explains what I do in seven words.

It is a cartoon of a middle aged, larger gentleman sitting in a chair. And the title of the cartoon is The Mind Body Problem. And there's a little speech bubble above his head that says get up, and there's a little speech bubble about his above his midsection that says no.

And so it's not just people with Parkinson's disease. It's a lot of people. And we all should get out there. We know that. So what does literature say about getting out there?

I just actually the CDC just published a new set of guidelines for older Americans, which basically says the same stuff that they said for everybody, which is that you should exercise 150 minutes a week.

And really there are no excuses. We don't you know, if you can't do it well, you should try to do it and you should do as much as you can and that kind of stuff.

And we do have chair exercises and things like that. But I often notice that the people who are sitting in chair exercises really should be getting up from that year.

That would be my first opinion. So don't don't be too ready to make excuses for yourself and it helps to. Let's see. The second question that I was going to address, I think was how did how do my views change about exercise?

Once I started working with Parkinson's disease and that needs a little history here. I wasn't always working in neurology, but when I did start working in neurology, I learned they had the usual excuses as these folks with Parkinson's disease and my department of Neurology.

And we so I said, Well, let's start a team just for us. So we started a team and I'm wearing a shirt today, which I will now advertise. We have not changed this shirt.

We've been doing it since 2010. We wear our shirts, we have our cheer. Our cheer is to train focused. We've had pretty much the same coaches. We've had a few coaches over the years and we get together every week and encourage one another.

And that leads me to the one thing that in the new CDC guidelines and other guidelines that have that tell you about some great programs, they don't always tell you the power of getting out there and getting a medal.

And one of the things that we do every year, we train and we have a good time and socialization is part of it. It is it's an important part. But we are training for a goal.

We have a goal race. We do a 5k on Memorial Day. We've been doing the same race for several years now. I don't have the kind of resources that would allow us to do six minute walk tests or any sort of testing of your abilities or whether you get better or whether you get worse.

But we do have tough times and I recommend it very much. I suspect that you've all heard of the Boston Marathon, and the Boston Marathon is pretty expensive and it's very hard to get into and you do not get paid for entering.

All you get is a medal and the bragging rights, of course, and the guy who's put that on for many years wrote a terrific essay called The Power of the Race Medal. Hmm.

So and, you know, here we are wearing our t shirts that we get when we race.

Training Groups and 5K Motivation

And I didn't put on a medal, and neither did our host. But we could have done that. And it's it's very powerful to cross that finish line. And we have a group of people with Parkinson's disease, some of whom need a good deal of help.

We choose a race we can wear. There's no part of time and where you can bring your help. And if you need to, if you need to bring your walking poles, if you really are not able to do it at all.

We have a cheering section where our shirts in the cheering section. So I want to also emphasize that this is an important element of socialization and getting together and cheering for one another and offering that moral support, whether or not you really can do a whole songbook.

And of course, every year some people who swear they can't do a 5k come across the finish line looking just great. So don't write yourself off too, too quickly and then of course they come back because that's the way these things work.

The immunity and connection and purpose and accomplishment. And I can that I can, even in the face of a diagnosis, really, you know, in and of itself is very healing.

Yes. Thank you. Absolutely. Yes. It's wonderful. Do you distinguish, I'm curious, between exercise and movement. For example, we we have exercise prescriptions that are part of our integrative neurology program.

And look, we're human beings and we see, just like you come to the doctor say, well, have you been taking your medicine? Well, you know, sometimes I forget and things like that.

And this is and you know, this is just human nature. Are you doing your exercises? Well, I am walking well, I am gardening. Well, I am mowing the lawn.

What are your thoughts on that? I mean, you know, you know. Well. My thoughts on that. Yes. So my thoughts on that are I believe in exercise prescriptions and that will be my next step.

So I work very closely with the local physical therapy practice. And I they have they've been the biggest source of referrals for the 5K team. We have plenty of people.

We have a great we have a great group. They're just terrific folks and I want them to start writing exercise prescriptions because I think that that will that's a very compelling way to do it for your patients.

We have been less successful with the neurologists recommending the 5K team. They they've gotten better. I mean, I try to send them enough video clips of their patients looking happy that that they will be able to recommend it.

But it is it is a little challenging. So exercise prescriptions are great. So what about what about this movement? What about mowing the grass? All anything is good.

So I'm not a purist when it comes to you've got to do the tango instead of the foxtrot. And there's a lot of that out there. There's a lot of people who want to know for sure if this is the best exercise.

And I can't guarantee that walking is the best exerciser, that running is. And and I belong to some fairly hardcore teams myself. And I don't think it's appropriate to be hardcore about everything to everyone.

And so if you mow the lawn, good for you. But then you should also do it. It's right. It's not either or. And a big part of it, it's an interesting understand it is that you have a training group.

So it's not just the day of the five K. No, no. We that's the goal in the end that you've signed up for the race, but you have a training group, so there's regular connection.

There's regular movement where people are getting together and training for that event. Yes. And I think I sense you can we are both members of the American Academy of Neurology, and I bring a poster pretty much every year to the academy to talk about one or another aspect of training and activity and getting how do you recruit people?

How do you use your team as a recruitment tool for clinical trials of various sorts so that, you know, we we do that kind of we do that also. So we try to make things as scientific as possible.

And and but we have we train all while we don't train it when it's very hot here in Southern California in the summer. So we do take a break in July and August, but we will get back together.

We've been doing this the first year I took a summer break. I thought, Oh, well, they remembered me in September. The answer is yes. They all come back in September.

Everybody knows it's too hot here and other places. It's too cold in Southern California. We're very lucky to be able to exercise out of doors for most of the year.

And as you know, there's kind of an emerging science of the benefits of exercising out of doors. So we try to do that. Yes, as much as possible. Let's go back to Roz CHAST, because we want to make this very practical and I exercise has and I'm going to role play a little bit.

Exercise hasn't been a big part of my life. And now to complicate things further, I have been I have this change in my walking. I'm shuffling. I've had a few falls.

My right side doesn't work as well as my left side. And you're telling me that I should run a5k? Now, obviously we're going to do this. We are going to do this. But how?

What's the first step? What what do I how can I make that transition? I'm if you're I'm sure you're quite familiar with the what with now speaking in academics the trans theoretical model of change and that we're going to go from this very contemplation to contemplation to preparation.

Making Exercise Easy and Accessible

So we're clearly in transitioning from contemplation of preparation because you've got my interest, at least you've got my interest. How do we then go to action?

Yes, I'm going to I'm willing to sign up, but I'm still I'm still back at the cartoon level. You know, And what's what's my app, my first action step beyond signing up.

Well, let me digress back into academia just very briefly to say that The New England Journal of Medicine put it very well when some well-known doctors made the point that it's not just your doctor telling you to exercise, that's just not enough. You.

It's really your environment. And you need to have your environment telling you to do this. So having said that, once I have a name for someone who's gotten to the point you just role play, I say to my contacts in neurology or in physical therapy, I say, Tell them I'd love to talk to them.

And my message, if we're successful in actually connecting and people often tell the doctor or the physical therapist, Oh yes, it sounds great. And then they don't actually think it sounds great.

They just we all have heard that that in the exam room you hear all sorts of stories, but some of the people are actually interested enough to let me call them.

And when I call them, I say, I would love to see you. Here's where you are going to meet me and I'm going to be waiting for you there. And here's exactly what you're going to park and it's going to be.

You do not have to sign up. That's another thing that I will come to you when I talk about our conceptual framework. I think you have to make it easy for people to the extent that people have to go online and have to get a password and have to sign up and have to tell what you know, let alone describe your medication program, anything at all I say is, you come, I'll be there.

I'll meet you if they have a friend. Anybody else that they know doing it, that's that's that's fantastic. And usually they don't. So usually I say, I would love to meet you and let's get together and there's no sign up.

There's no feed. There's a free lunch. We have free lunch. I'll tell you about that. And and only about half of people can can make it. But if you can come, most but not all of the people who come will stay with us.

So the hard thing is just making what you want to do is make an invitation that's compelling, that has as few barriers as possible. And we're not very good at doing that in academia.

You've got to sign up. You've got to we have to have your whole record on file. I ask people to sign a disclaimer, a disclosure when they get there saying that they are doing it at their own risk.

And I've never had anyone say they wouldn't do it, but I don't ask for anything else upfront because that just is a deal breaker. So we've been and we've been doing this since 2010, we're going strong.

I sent you the video of us at our most recent five K. It's all about the environment and making it really easy for people to do it. So it's easiness. So I really hope that there are people in your community who are interested enough in doing this kind of thing that you can make it easy for you.

That's awesome. And we're doing the Pound on the Pavement five K T-shirt. That's our local Parkinson's group of the our annual five K, and it's a lovely event that I've participated in several times.

I would say in general that as you can imagine, it is it is set up as a fundraising event. And what we need to do actually is say, hey, maybe if you have the diagnosis of Parkinson's disease, you can run it for free, right?

You can run it for free. Not only and you can bring your you can bring your caregiver, too, because I really encourage one of the other things that we neglect in health care is that when we send someone, when we write for someone to have a physical therapy appointment, then their caregiver gets to sit in the parking lot and file her nails, whatever.

Another important issue is how do we make this appealing for the caregiver of the friend, your daughter, who's going to bring you? Please encourage them all to come.

Also, free lunch for them, too. We want you know, it's we need to make this appealing and easy. And we often get involved in our own programs and we don't make it appealing and easy. So so so that's that's my message there.

And that goes back to the New England Journal article that said, you have to make it. You have to make the environment welcoming to this, do whatever it is you want people to do.

Yes, My my wife, Valerie, is a health coach and life coach. Really brilliant. But does a lot of good work. But she listens to podcasts and lectures all the time.

And I heard one speaker say that, you know, positions aren't coaches. Typically positions are really consultants because we tell people what to do. And as you say with the New England Journal article, most often we don't respond as human beings to being told what to do.

We respond when it kind of comes from within. It comes from the heart and so you have to have your why, you know, why why should I run at five K? Why is it a good idea when I have Parkinson's?

Shouldn't I be just staying on the couch? So it sounds like by the time folks come to you, they've already been exploring their why? It may not be in complete focus.

They have. Yes. They've already been exploring that reason. Why? It does mean that they that they're physical therapists in their neurologist have started them down the path.

And that's because you are frontline people. I'm I'm not at this point in a position I used to do and have a different role at the university. But for the last several years, my role really has been to work with folks with Parkinson's disease on exercise.

And I want to make a small push here. The Parkinson's Foundation has been in part responsible for funding us, and we are able to hire coaches because we have support both from the Department of Key and from the Parkinson Foundation.

So that's another important message and it's quite inexpensive to run these programs. I have great respect for the boxing programs that are in for folks with Parkinson's disease and for the dance programs, but all of those do require a certain level of equipment and space.

And one of the advantages of having a walking program is our biggest expense.

Measuring Outcomes and Quality of Life

Every year is not for our coaches. It's really to get registrations for our annual five K Gonzales. But still, it's it's something that many of many people should do because it's not a big investment in equipment or space.

How about outcomes? Because ultimately you're I know there's a question that's way to measure long term outcomes and what are we measuring and what can I expect if I have Parkinson's disease and besides a medal, somewhat the medal?

Well, you know, you'll be proud of your medal people. People are almost always proud with their medal and it's it's it's it's worth getting. But outcomes are a tremendously important and difficult issue because and I added that in my question.

That's a question I'm part I hope all of us can wrestle with a little bit because there are innumerable studies on the benefits of exercise that are short term.

So no matter whether I'm teaching the tango or the foxtrot or the rumba, if you do it for six weeks or even six months, I can measure some important changes.

How about six years? You know, I've been doing this since 2010, and you start with the group of people who are in their sixties and seventies and you follow them for more than ten years.

They are basically not going to get better because that's that's not good. The relevant metric for this. So it's you know, exercise is terrific and it's wonderful for you, but it will not make you 25 again.

We have to be realistic about that. And so what will it do for you? What we have sent to the American Academy of Neurology, some stats on what it will do for your mood, whether you think that's a valuable thing, whether and the caregivers also get to weigh in on this.

They love it and they always say, oh, here I get to come, I get to participate and that maybe, maybe is the metric we should be primarily focused on is the benefits for your caregivers and your family.

And you can bring your dog to our thing and as long as it a well-behaved dog, we had a badly behaved dog once, it couldn't come. But you know, we really can accommodate almost anything.

And so the metric is not going to be, yes, I can do you know, yes, I can do a marathon. We have one guy who does America. That's wonderful. He's written a book about it.

My name is John Ball. He's terrific, but he's the only one. And he's actually given these scale back to half marathons now that he's in his seventies.

So the metric has to be how you feel. And that's, I think, my best my best answer at this point where we have a biomarker for how this is affecting some other dimension of your physical fitness, Maybe.

But I think feeling better, as you know, that exercise is an acknowledged treatment for depression. This is for people not with. Parkinson's about it.

Yeah, but there is some data. There is some data on the impact of exercise, for example, on dopamine levels. Yes. Yes. And so. Right. Can you talk a little bit about that?

Yeah. So we do we do know that that it does affect not only chemicals but also connectivity. So exercise is good for brain connectivity and basically so processing speed and things like that are positively impacted by exercise.

And certainly in the short term, we usually conduct those kinds of studies over quite a short term time frame. And it is rare for someone to say, Oh, I am just raring to go now that I've exercised for a couple of weeks.

But the fact that people come back year after year to exercise as a team tells me that they find it a valuable experience. And that is that sort of brings me back to the whole issue of how do you make this easy for people?

But yes, there you can you can measure, measure some. I wouldn't really call them surrogate endpoints for a study. I think we have yes, we can demonstrate things that were short term, but we really I'm interested in long term outcomes.

We always say here that one of the things that I want to see from my patients is that, you know, can they talk about how they're doing today because their quality of life today better than it would be if they weren't doing this?

And it's almost always 99% of the time. Absolutely it is. You know, this approach that we have is called lifestyle medicine. Functional medicine that complements all of the traditional tools in the toolbox.

Isn't curing the disease, but it is allowing for a greater level of function and quality of life than we would see if someone wasn't doing these things.

And that's very rewarding. Yes. Yes. So I am the immediate past treasurer of the Academic Consortium for Integrative Medicine and actually Lifestyle is my greatest interest.

I think that there are other wonderful modalities, but I think that if you get the lifestyle part, well, well-organized and you are getting some you're eating a healthy diet, you're getting some exercise, you're getting sleep, the rest will fall into place as best it can.

And sometimes there's limitations to that. And now that I'm not getting any younger, I am more ready to acknowledge limitations. But we just we do what we can.

Absolutely. There's another common, as you know, probably one of the most common symptoms, non movement symptoms of Parkinson's disease. That is also almost certainly improved with exercise.

There has been some data in other chronic neurological diseases looking at the impact of these lifestyle factors on fatigue. Yes, such a common complaint.

And when we introduce these movement programs and use objective measures of fatigue as objective as we can be with that, they're still generally self administered questionnaires, but fatigue often does improve and that's really important to folks.

I'm glad you brought that up. Yes. That that isn't something that we have surveyed for in the past because we put more of an emphasis on the social component.

And that I think that's very important. Thank you. As have there been some studies have looked at other

biochemical or perhaps things at the cellular level.

Say we talk a lot about, well, what are some of the things that are driving Parkinson's? There's evidence of mitochondrial dysfunction.

Lifestyle Medicine, Fatigue, and Biology

And then we exercise and mitochondrial function improves respiration, improve the ability to produce energy, improves the ability to perhaps balance oxidative stress, improves.

And then and yes, and there are there are a lot of very good animal studies, some of which are actually conducted by a colleague of mine in the same department using rats.

And you can pretty easily demonstrate that there are some mitochondrial benefits. But I want I'm focused mostly on benefits that you would notice. So, you know, having people tell you that your brain imaging is better is is fine If you don't feel better and you can't get out of bed, then I don't care so much about your brain image.

That's because I'm so much on the clinical side. But I respect the people who are on the other side. On the on the science side. Yes. Because we we ultimately, again, have to say why should why should I do this?

Sometimes I and I don't know where this came from, but I heard someone say, I think probably this goes back to my training in neurology that there was an expression at the Massachusetts General Hospital that no one should be allowed to die with their electrolytes out of balance.

Well, of course, yeah, we can all the time. But we have similar we have similar stories about, yes, you don't get to die in my ICU unless you've had certain medical interventions.

Yes. Right. And the reason you could do it is for yourself. You do it for yourself. You don't do it because it's going to help Dr. Sharlin study or it's going to prove that something.

You do it for yourself. That's my that's my that's my approach to individual individuals who I get a chance to talk to and and persuade hopefully to join this team.

So, yes. There is a tremendous enthusiasm in an integrative clinic in which we bring in all the lifestyle factors into the experience of the patient. There's a tremendous interest in diet.

So I first of all, I do want to hear about the lunch. Oh, yes, that's right. Let me talk briefly about lunch. So we serve we don't make a big deal about it.

But one of my colleagues once said, you can skip the stuff about exercise. Just say to the free one. But so we have actually. Over the years. There you go.

Now, over the years, we have developed a free lunch that we now are basically every week and it's a very popular lunch. It is a giant pot of lentil stew and lentils.

The Washington Post just ran a or was some other popular news outlet Why Americans Should Eat More Lentils. First of all, we eat them because they're cheap and they're easy to prepare.

And you can make it enormous that I want those. And I will share my special recipe with you that you can make a big bad lentils, you can schlep it to your park and you can walk in the park.

And when you're done with your walk, you can serve lentils. And I also serve coffee. And if people want to bring other stuff, that's okay. And sometimes they do.

But but the official menu is coffee and lentils. And that's that's my story to tell you. The secret, the secret to making

lentils that everybody loves is to put when you put you put your lentils, you put your bra to put on there.

They're vegan lentils, by the way, because lots of people can eat lots of stuff. I have yet to meet someone who can't eat lentils because they're sensitive to them.

And you put just a little bit of molasses that's a secret in them. And then it just kind of cuts that bitterness. You don't put a lot just a little bit.

Anyhow, lentils are very popular. We have lentils every week. We do not really give a lecture on diet. We just serve lentils. It's just the way it's done.

And then we do a just a little bit of proselytizing for healthy diet, but we mostly lead by example. That's what we try to do. Well, that's wonderful, folks.

Before we started recording this interview, I was telling Sarah Ingersoll about an idol that a woman that we really cherish for her contribution to athleticism among older adults.

And if you haven't heard about her, this is Sister Madonna Buder You know, they say that in the Ironman triathlon they had to make new age group categories for her because she was the oldest competing athlete and she get older a little bit every year.

And then they say, well, we don't have a category for that. And so they have to make a new category for her. But one of her many, many wonderful accomplishments.

And of course, she's an elite athlete, is that she really didn't become an athlete until she was about 60 years old. And so it's so important to know that, you know, you don't have to be the Ironman like she is or the the Iron Nun, as she's sometimes referred to.

But it is you're not too old to start a movement program in your life. That's I didn't really talk too much about that. And I love that. I did not learn to swim until I was 65.

And I had been I and I if I had known we were going to talk about Sister Madonna, I would have chewed up photos of me racking my bike. Next to Sister Madonna at age group nationals and Triathlon, which I did for three years.

I think we were there together. So at any rate, don't worry about being duo. Forget that idea. Just keep going. Just keep going.

Lentil Lunch, Late-Blooming Athletes, and Closing Advice

And folks, when they come to me sometimes, you know, they've read the blogs, they've watched the videos, listen to podcasts, and there are things that are very, you know, trendy ketogenic diet, high intensity interval training, you know, and everybody wants to sort of jump into the formula.

But what we always say is, hey, let's just take a moment and learn about who you are as a person, where you are at this moment in time, and whether or not those tools are presently or eventually perhaps right for you.

They are just tools. But the goal is let's just get one foot in front of the other for now, right? That's it. Yes, that's great. Everyone can accomplish something.

And you know, we can we can hope we can put our sister Madonna posters on our wall right next door, rock and roll posters and everything else but that's just to give us that sort of pie in the sky of anything is possible.

And even with Parkinson's disease, we can bear that in mind. And to make this a little more personal, you sign up for a 5k most 5ks, we'll have a photographer at the finish line, and then you'll have a wonderful picture of you crossing the finish line.

And it's so true and it's so true. And you know, at the Ironman, you may know that it's a tradition actually, not just to stick around and welcome the most elite professional athletes cross the finish line in the midday time.

But that race that starts usually at about 6:00 in the morning goes till midnight the the very same day. And it's a tradition to equally, if not more, welcome the midnight finishers, you know, because they they really are the finishers.

They are the heroes of the race. And you can be the hero of your 5K equally as well. Well, Sarah Ingersoll, it's has been such a pleasure to chat with you today.

Before we wrap up our interview, is there anything you would like some our viewers to to know or if they want to read more or connect with you or your program, your research, can you give them a little bit of information?

Well, yes. I think I sent you the links to the ANN And if anybody feel free, contact me personally. You have my contact information like especially, my email, you email me.

Anybody feel free to email me and we will talk about your specific situations, what you can do to get moving. But I don't want to side of the message, but feel free to contact like.

That would be wonderful. Once again, we really appreciate your willingness to participate in the Parkinson's Solutions Summit. A very, very important message.

You can move. You should move. Sign up for a race, find yourself a group that you resonate with because it's because it has. It is as much about community and connection and purpose and can do.

And by golly, your life is really just beginning. It is not ending with Parkinson's disease. So much left to give and to learn. And and so it's a wonderful message that she is sharing.

Thank you Ken and good luck. Right. Thank you so much.