

Why Should People with Parkinson's Disease Exercise?

Webcast

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Fay Horak, Ph.D.

Dan Huntington

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Introduction

Andrew Schorr:

Hello. Welcome to "Ask the Experts." I'm Andrew Schorr. This is produced by Patient Power with Oregon Health and Science University every two weeks where we connect you with leading experts and discuss significant health concerns.

On this program we're going to talk about Parkinson's disease, which of course is a progressive movement disorder. It affects about a million and a half people. We're talked in the past about medications that are used, and we've talked about surgical approaches, but we've left out something, and it's something that they're studying very closely at OHSU in the Parkinson's Center of Oregon, and that is exercise.

We're going to learn about the role of exercise today and how that may well be able to help, and you're going to meet someone in a minute who has benefited, and let me introduce you to him, Dan Huntington. Dan lives about 35 miles from Portland across the Columbia River in Washougal, Washington, and Dan is 50 years old, but Dan I understand about five or six years ago you started to notice a tremor in your left hand, right?

Dan's Story

Dan:

Yes that's correct. My hand would shake a little bit, and at first it sort of made me think of somebody with a nervous fidget, but it would come and go. Often it would be more likely to be shaking if I was feeling under stress, and I went to see my GP, my doctor, several times and was assured that it was just something called an essential tremor so...

Andrew Schorr:

You were relatively a young man in your 40s, and we usually think often of Parkinson's. It's not always the case, but the traditional view is it might be in someone older. The good news is I guess you would say you finally found out what it was; not happy to get a diagnosis of Parkinson's, but you were prescribed some medicines that made a difference, and you continue of course to do your real estate work and be an active parent of some two young adult boys, but exercise has come

into it, and that brings us to the program at OHSU. Tell us about that, connecting with OHSU, and seeing where exercise could make a difference.

Dan:

Well first of all I should say I've always been very physically active, and I've been an avid hiker all my life, and I need to exercise very regularly just to stay sane and to sleep well and that kind of thing. It's as important to me as eating, but when I was diagnosed I had done a fair amount of research prior to my diagnosis and kind of figured out what I had, and I had studied and read about the drugs and about the deep brain stimulation and so on, but I had not found out anything about exercise. The second neurologist I went to see talked to me about my choices, and I asked him what the heck do I do now? He said, 'I really suggest you get hold of OHSU, Dr. Nutt at OHSU. They've got a lot of studies ongoing for Parkinson's, and they may be interested in putting you into one of those studies.' I believe I went to some sort of event that they hold every year at what used to be the Red Lion, "Inn at the Key" or something like that on the Oregon side of the Columbia River actually, and met some of the people in a phased program and heard about the exercise, and I immediately thought that really makes sense to me. I'm a complete layman about the brain, but I know that when part of your brain isn't working you can sometimes with physical therapy get another part to substitute, and the concept resonated with me, and so I immediately wanted to be a part of the study.

Andrew Schorr:

We're going to learn more about the study in just a minute from Fay who you just mentioned, Fay Horak, and we're going to learn more about that. Just one reading on you, and you did end up enrolling in a study, and you're one of the first seven patients in a phase-1 study, a single-center study right now funded by a foundation, but we hope it will grow, on movement and people with moderate Parkinson's. How are you doing? You've been doing it for a few months; how's it going?

Dan:

I've been doing it for a year and a half, and I'd say it's going very well. I think that, well first of all when I started I had some symptoms of parkinsonism that I really wasn't aware of; just kind of dragging my foot, and I learned very quickly in the testing that I would have a hard time going through doorways for instance if I had another task at hand, and very quickly the exercises corrected those issues; so I'd say right away there was some sort of corrective benefit from the exercises, and since then for some reason or another, knock on wood, my symptoms seem to be progressing very, very slowly if at all.

Andrew Schorr:

That's great news.

Dan:

I don't know whether I can attribute that to the exercise or not.

Andrew Schorr:

It beats the alternative for sure. Let's meet Dr. Fay Horak and put all this in perspective and learn about what's going on at the Parkinson's Center of Oregon. Now Dr. Fay Horak is a neuroscientist and a physical therapist, and she has lots of titles there. She is a professor in the departments of neurology, physiology, and biomedical engineering at OHSU, but most relevant to this is she is Director of the Balance Disorders Laboratory. Dr. Horak, thanks and help us understand. We've heard about drug therapies and deep brain stimulation as I said at the beginning. What about exercise when we're talking about movement disorders? And then Dan said he's not a scientist and nor am I, and we think well can exercise help the brain remediate itself a little bit? So tell us about this new world of studying exercise and how it could make a difference as we learn more about it.

Dr. Horak:

Yes, there are some very exciting studies in the literature coming out just recently showing that there are three main ways that exercise can help people with Parkinson's disease. First of all it can help by preventing some problems. It can prevent falls. It can help prevent cardiovascular problems that can be associated with Parkinson's disease. It can prevent back pain by increasing and improving your postural stability and flexibility and also can prevent depression.

The second way that exercise can help Parkinson's disease besides prevention is compensation. It can help another part of the brain, as Dan mentioned, take over function for the part that's not working, and in Parkinson's disease it's the basal ganglia is the part of the brain that starts to be affected more and more as the disease progresses, but other parts of the brain like the cerebellum can take over that function. So by continuing to challenge the movement centers of the brain for coordination and movement, you're teaching the brain how to use best what it has left then and then compensation.

There's a third way that exercise can help Parkinson's disease and that's the brand new and exciting ways coming from animal studies, called neuroprotection. There's some evidence from studies with rats and mice that are made to have Parkinson's disease that exercise can actually increase the number of synapses or connections from one neuron to another. In fact, some kinds of exercise like 'Indiana Jones-type' of agility exercises might even be more effective for that plasticity and neuroprotection than strengthening exercises or just plain walking.

Beneficial Exercises for Parkinson's Patients

Andrew Schorr:

Let's find out more about these exercises. Now you don't have Dan running marathons or anything. Help us understand the style of exercise where having trainers work with people in the study. What are they coaching them on? What does it look like?

Dr. Horak:

What we did is we developed an exercise program that was focused on the kinds of mobility problems that would eventually limit mobility as Parkinson's disease progresses. For example, we recommend exercises that help to prevent rigidity and increase trunk flexibility, such as making kayaking movements. We have other exercises that are focused on the problem of slowness of movement such as lunges with big steps in different directions. We also have exercises that are to prevent freezing. Freezing is when a person with Parkinson's disease stops walking and may lose balance when approaching a doorway or a corner and have problems turning. Even though Dan didn't have a lot of that we would still give him exercises to practice skipping into a corner and making a quick turns and going through doorways and through crowded areas so that his brain learns to deal with this even before it's a problem.

Andrew Schorr:

That's fascinating. Dan comment on all this. So it must be, I think if you're an avid hiker and you're an exercise guy, it's kind of fun if you can do these exercises and see that it makes a difference.

Dan:

It is fun, and it also I would say most of the exercises are ones that I never would have done. I'm not an athlete. For example, one of the things that I do is boxing. It never would have occurred to me to do boxing, but in that case it's sort of the repetitive motion that is a challenge for me with my left arm, which is the arm that has the Parkinson's symptoms, and the yoga for instance is something I played with a couple of times but you know I thought all of this is always it feels kind of good but I don't really have the time in my day for it or it can't really be that big a deal. It's not as good as rigorous exercise, but I've enjoyed just learning some of these other maneuvers, and certainly it was nice getting started on things and some of the things I was pretty good at. I felt at the time I was pretty bummed out that I did have Parkinson's disease at this early age, and it was nice to see that I was able to do these things and do them well.

Andrew Schorr:

Let me mention one thing. Now one of the approaches combines some yoga, and I think you've told me when we talked much earlier that even Pilates comes in, and Pilates is a lot of stretching and core strengthening and actually had the chance to do it a little bit during my summer vacation and found that I was not, I do not have

a movement disorder, but I am not, I'm in shape, but I'm not flexible. But what I found in doing this is stress reduction, and I understand that stress can get your tremors going, so have you seen a benefit in just lowering your stress that you think may be helping control the Parkinson's symptoms?

Dan:

I would like to say I have, but I don't think, for me it doesn't manage to lower my stress. I enjoy doing it, and maybe briefly at the end after the wind down period I feel pretty refreshed but when I get back up and at it again I still, you know, if there's a source of stress in my life it's still there.

Andrew Schorr:

Let's face it, you're in the real estate business, and we're not in the best of economic times, so I'm sure it's a challenge.

Let's go back to Dr. Horak. So first of all a little bit about the Parkinson's Center of Oregon. This is not just your neighborhood clinic. This is really a world-renowned place, and this study could make a big difference for people in many places. For people listening who may have a family member affected by Parkinson's disease how can they get involved? Is this study available? Is there another program or other ways that they could connect with these programs that you have there?

Dr. Horak:

Yes. At OHSU there are many research studies going on in Parkinson's disease and in other areas as well, and so they could go on to the website of OHSU and look at what kind of studies are being offered and where we're looking for patients to participate.

Andrew Schorr:

There are more openings in the exercise study?

Dr. Horak:

Yes. There's more than one exercise program actually going on. There's one looking at Pilates and how a Pilates program can improve strength and flexibility. There's another exercise program in which patients go to outpatient physical therapy and we randomize them into two different kinds of exercise programs. One is an aerobic program and one's an agility program because both of them could be useful, and we don't know which is the most helpful yet. After the 6-week physical therapy exercise program, people can then hire specific exercise trainers to continue the program in the community.

Andrew Schorr:

Right and when we think of getting treatment at a place like OHSU you usually think of having a medical procedure or being prescribed some powerful medicine

but here it's really enlisting the patients themselves to do things that actually would seem pretty basic or natural but just with the benefit of education on what can help and how you do it.

Dr. Horak:

It's a big commitment actually to say, 'Yes I promise to exercise three times a week for the next six months' or even three months. It's a big commitment, but people learn new kinds of exercises that they might not think of, and it's really specialized. They don't just do any kind of Pilates or any kind of Tai Chi. We really try to make it focused on the symptoms that we know go along with Parkinson's disease.

Andrew Schorr:

I want to mention a website address. You can go to www.ohsu.edu/pc which stands for the Parkinson's Center of Oregon.

So Dr. Horak, when I think of what you're offering there then you look at sort of a multimodality approach I guess. So somebody might be taking a medication, and I know that Dan is. Some people might have other interventions that are available now, and then they might have this too. It's not a "one size fits all" and I think you were just getting at that.

Dr. Horak:

That's right.

Andrew Schorr:

We wish we could cure Parkinson's, and we can't at this time, and it doesn't seem, we're not clear on exactly how to prevent it. So for people who develop it then, is that really what they should be looking for and what the benefit of a center like yours is that you can look at the whole person and say of these many different approaches and with a multidisciplinary team how do we help this particular patient?

Dr. Horak:

I think it makes a big difference because everybody with Parkinson's disease is a little bit different. Some people have a lot of tremor and some don't. Some have a lot of balance problems, and others don't have those balance problems. So it is important to customize the treatment for the person, and that goes for exercise as well as medication, and that's what a center that sees many, many patients with Parkinson's disease can do.

Andrew Schorr:

Okay, we've gotten in some questions by e-mail, and I want to pose them to you. Samantha from San Jose, California asked, 'Is exercise only beneficial in newly diagnosed Parkinson's patients?'

Dr. Horak:

Definitely not. Exercise with Parkinson's disease in many, many stages; even when you need to use a walker or a cane, even when you already have balance problems; your balance can improve if you exercise, but it has to be done safely, and that's where we really recommend a physical therapist or a certified trainer who has some expertise in Parkinson's disease that can help people find exercises that are challenging but also safe.

Andrew Schorr:

Yes that's a good point. I've done programs on falls in older people, and of course it may be often older people developing Parkinson's disease, Dan's an exception and we'll talk more about that, but at any rate the worst thing you want to do is fall and break a hip, that can be catastrophic. So I think the point that you make on safety is certainly so important.

Here's another question we got from Joann in Portland, and Joann writes in, 'What particular symptoms are relieved by exercise for most Parkinson's patients?'

Dr. Horak:

One thing that can improve with exercise is better posture, better posture alignment to do avoid too much flexion. You could also improve cardiac function so that they have better heart rate with exercise and therefore less fatigue and balance can improve and gait so that they can have longer steps and walk faster with better balance with exercise.

Andrew Schorr:

You mentioned about heart rate. So obviously if somebody becomes sedentary because of a disabling condition, that's not good for their heart.

Dr. Horak:

That's right.

Andrew Schorr:

And blood pressure or whatever, so really it's about helping the person just maintain their health overall.

Dr. Horak:

That's true, but Parkinson's disease does have effects on the heart too.

Andrew Schorr:

Oh it does.

Dr. Horak:

It has effects on what's called the autonomic nervous system, and that also affects heart function, and so it's especially important for people with Parkinson's disease to do aerobic exercise for their heart.

Importance of Seeing a Specialist

Andrew Schorr:

I have a different line of questioning for Dan for a second. Dan, you went several years before you got an accurate diagnosis. You didn't get it from your GP. First you went to neurologist number one, and you weren't sure you were being helped there. You went to neurologist number two, and then that neurologist who was not at OHSU recommended getting OHSU involved as well. So the symptoms can be kind of vague or elusive and in somebody in their 40s it's understandable that somebody might say well it's not Parkinson's; you're not 70 or 80; so what about what you would say to the audience if they're having symptoms in getting to a center where they can truly evaluate it?

Dan:

Well first of all I think in any health issue you need to be your own self advocate, and it's easier now than it's ever been because information is so available on the Internet, and I think that one fault I could have with myself is that I didn't push harder given that I could have accessed more information online when my GP kept saying I had essential tremor, but I did want to believe that's what I had.

The one thing that I would really like to see about Parkinson's made more public or better known is this issue of (the sense of) smell. I was at a Parkinson's support group last year, and there were maybe 25 people in the room, and 15 of us had experienced significant diminution in our ability to recognize different odors, and it would have been helpful to me to know when I lost my sense of smell that that could be an early symptom of Parkinson's. I just thought well that's kind of strange, but you know it's not the end of the world when you lose your sense of smell. Contrary to what some people might think you can still enjoy food if you can't smell it; you can still taste it; but I would have liked to have known and I think it would have been good for my doctor to ask, oh this is interesting, you've got a tremor, can you smell anything?

Andrew Schorr:

Yes, good point. I think that also makes the point of people at least making even for a second opinion contact with a center like the Parkinson's Center of Oregon because Dr. Horak you all with your team there see more patients with Parkinson's and have for many years than anywhere else in the region, right?

Dr. Horak:

That's correct. It is the largest center for Parkinson's disease in the Pacific Northwest.

Andrew Schorr:

Okay so for our listeners think about that. So yes there are things you could look up, and it says well this symptom goes with Parkinson's and that but as Dan said,

he'd never heard of this, but if he'd consulted at that time with doctors and other team members who deal with Parkinson's every day and have for years, obviously they would have been familiar with it. So it's that sort of wisdom I think you get at a specialty center when you have a long-term chronic condition.

Improved Quality of Life Through Exercise

Andrew Schorr:

Now Dr. Horak, so you've been in the thick of it for many years. Are you seeing progress, and how hopeful are you for people living with this then lifelong condition that we can make a dent in it, we'd love a cure, but helping people live better with Parkinson's?

Dr. Horak:

Yes, I have a lot of hope that; exercise itself can make a big difference. In the past when I started in physical therapy, patients with Parkinson's disease weren't even sent to physical therapists because they didn't think they could be helped, but now you see people being very active in sports when they just get the diagnosis and staying active with walking and hiking and other kinds of exercises. I really think that a lot of the things we thought were inevitable like falls and fractures and stiffness, those kinds of things can be prevented, and people can be active and lead healthier, more fulfilling lives for longer.

Andrew Schorr:

That's good news. Dan Huntington, now I don't know, are you still hiking with your brother and your friends, or how active are you now, and what's your vision of the future even with Parkinson's?

Dan:

Right now the only thing that Parkinson's does to me that interferes with anything I do is my left hand is a little bit slow on the keyboard, so when I'm writing something it feels a little bit funny, but it doesn't interfere with anything else in my life, and I'm still physically very active, and I expect to be physically very active for many years to come.

I read an interesting book about people with Parkinson's, and it's been observed sometimes that people who appear crippled with Parkinson's when they actually get up and move they can still sometimes move pretty well, and my own vision I guess of my old age is that I may be compromised by the Parkinson's, but I'll still be very active.

Andrew Schorr:

I think we should point out a couple of things about you, which to me they say it all. First of all, you just recently got married to Kathy for your second marriage, and you two had developed a relationship just before you were diagnosed, and she's watched all this go on, and then you got married, and I think I'm sure you

both are hoping to have an active future, and so I think that's a wonderful image of you two together and I'm sure having a long, happy life. Then the other part of it is I know you have an 18-year-old son and a 20-year-old son. Hopefully someday these guys might get married and give you grandchildren, so you're going to have to be an active guy to keep up with all that, right?

Dan:

I would like to be. You bet.

Andrew Schorr:

Okay, Dan Huntington, I want to wish you all the best and thank you for speaking with us today. Thanks for being involved in that support group too because I think it's important for people to know they're not alone in that just like with me I was diagnosed with leukemia at 46 with a usually an older person's disease, you too were diagnosed earlier, and I think shows that it could happen to anyone but that life can go on. I'm going to give you the "powerful patient" award for speaking out and learning all you can and taking an active role in your care.

Dan:

Thank you.

Andrew Schorr:

Thank you Dan. And Dr. Fay Horak, so you have this wonderful study going on that we can hear is making a difference for Dan and based on years of your experience and research on how exercise can make a difference. I want to wish you and your colleagues at the Parkinson's Center of Oregon all the best in your work, and let's hope for a cure, but sort of that just ever better management, some through exercise, of Parkinson's. Thank you Fay.

Dr. Horak:

Thank you very much.

Andrew Schorr:

We really, really appreciate it. This is what we do every two weeks with OHSU, our "Ask the Experts" program produced by Patient Power. I'm Andrew Schorr. I'm delighted to bring these programs to you and thank OHSU for its sponsorship. We like to think knowledge can be the best medicine of all, so take a listen again to this program, read the transcript as we have it, and know that every two weeks we're connecting you with other inspiring patients like Dan and experts like Dr. Fay Horak from OHSU. Thanks for joining us.

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