



PT and Parkinson's with Lee Dibble, Terry Ellis, and Gammon Earhart

Recording on October 26, 2020

Davis Phinney Foundation

Melani Dizon (Director of Education, Davis Phinney Foundation):

Hello and welcome everybody. My name is Melani Dizon. I'm the Director of Education at the Davis Phinney Foundation. And today we are here to talk about physical therapy and Parkinson's. I'm super excited to have our three panelists with us—Lee Dibble, Gammon Earhart, and Terry Ellis. These three have been with the Foundation for a very long time, actually. And they started when we funded some of their early research, called the CHOP PD study that charted the progression of disability and Parkinson's, and it found that individuals who do not engage in physical activity in the first two years following a Parkinson's diagnosis actually have a steeper decline in quality of life than those who do exercise or engage in some sort of physical activity. And we're going to talk a little bit about that research study and a whole lot more in just a second.

Lee Dibble received a BS degree in animal physiology from UC Davis and an MS degree in physical therapy from Duke University. He received his PhD in exercise and sports science with a focus on motor learning and motor control in 2001. And he's been a certified athletic trainer since 1989 and a licensed physical therapist since 1991. He has worked at the Duke University Sports Medicine Center and a student sports injury clinic, as an athletic trainer for the United States Soccer Federation, as an athletic trainer and physical therapist for the 2002 Winter Olympics in Salt Lake City, and as a physical therapist at the University of Utah Sports Medicine Center. His research focuses on exercise and motor learning countermeasures to combat postural instability and balance disorders. Since 2016, Lee has served as a professor in the department of physical therapy and athletic training at the University of Utah. You can see his little icon, his little logo at the top of his screen.

Terry Ellis is an associate professor at Boston University College of Health and Rehabilitation Sciences: Sargent College in the department of physical therapy and athletic training. Her research focuses on investigating the impact of exercise and rehabilitation on the progression of disability in individuals with Parkinson's. She's also the director of the Center for Neuro Rehabilitation at Boston University, where she conducts research and provides clinical consultations and education to healthcare professionals and to persons with neurological disorders. In addition, she directs the American Parkinson's Disease Association, National Rehabilitation Resource Center housed at Boston University. She has a PhD in behavioral neurosciences from Boston University School of Medicine and is a board certified specialist in neurologic physical therapy.



And finally we have Gammon Earhart. She's a physical therapist and neuroscientist after graduating from Oxford. She attended Arcadia University and earned her bachelor of arts in psychobiology and a master of science in physical therapy. Upon completion of her physical therapy training, she enrolled in the movement science PhD program at Washington University in St. Louis. She studied nervous system control of movement focusing on how the spinal cord and brain control walking. She earned her PhD in 2000 and then pursued a postdoctoral fellowship at Oregon Health and Science University as a post-doctoral fellow. She studied how people adapt their walking patterns to meet environmental challenges and how damage to the brain or inner ear impacts ability to adapt walking patterns. She directs two research laboratories, the local motor control laboratory and the physical activity research center. Her work focuses primarily on Parkinson's and ranges from basic neuroimaging studies aimed at understanding neural control of movement to clinical trials that compare the effect of different forms of exercise on physical function and Parkinson's progression.

So in the event that you were wondering if we had experts in this field to talk about all of these things, now, you know, you definitely have the right three people. So I'm very excited to talk to all of you today. And I know our community is.

What I'd love to do first, Lee, is to go back to the research and the CHOP PD study. First, can you talk about what the study was, what you were hoping to find, and then where we are now in terms of what we know about Parkinson's and physical therapy?

Lee Dibble, PT, PhD, ATC (University of Utah):

Sure. Thank you for inviting us. We feel honored to be part of the webinar. So when we first began talking to the Davis Phinney Foundation, I think in (Gammon and Terry, you can correct me if I'm wrong), 2009-ish maybe, about the CHOP PD study, we were, as physical therapists, we joked that we had a biased view of exercise. We felt like it was of benefit, but we felt like there wasn't a good natural history study of how people progressed and potentially accumulated more disability. And we wanted to be able to document that, to lay the groundwork for subsequent exercise trials that would show that that exercise and physical activity did something different than just doing no activity. And I think that we were able to provide a nice documentation of that kind of, that progression of disability. And some of the most exciting things, I think, that came out of that study were some of the stuff that Terry led, looking at kind of a sense of a person's self-efficacy or belief that the physical activity and exercise would help them, and that predicted whether or not they would exercise and if they would improve; potentially have some improvement from that exercise, and then also some technical measurements of people's walking ability in the community.

To me, those are two of the most exciting things that came out of that trial. And I think it served as a nice foundation for the subsequent studies that I've done, that Gammon has

done, that Terry has done. And others also. I don't know, Terry and Gammon, if you have anything to add to that.

Terry Ellis, PT, PhD, NCS (Boston University College of Health and Rehabilitation Sciences: Sargent College):

I mean, I think that study was-- it really, like you just said, it provided some nice foundational work in which we've all built off of over time and, you know. Subsequently many, many more exercise trials have been done showing the true benefits of exercise in mitigating symptoms and improving function in people with Parkinson's disease. So I think that was some of the early work that sort provided the groundwork for subsequent studies that have been done. Where we know now that exercise is very beneficial and now we're sort of digging down to the nuances more about really trying to understand what's happening in the brain, understanding the mechanisms by which exercise works. And you know, when a lot of people with Parkinson's have questions about which kind of exercise and how much exercise and all those kinds of things that I'm sure we'll get to later today.

Melani Dizon:

Absolutely. So I want to do just a quick poll to kind of see who's listening and what their experience has been. So this is for people with Parkinson's; the question is, *How long did you have a diagnosis of Parkinson's before you began working with a physical therapist?* And there's a variety of different, it's a multiple choice. You can choose one thing. Just want to see if for some people, was it the first thing that they did? And for some people, they still haven't done it yet. So just want to get a sense of who we're listening to, or who's listening to the webinar. And then we can tailor some of the questions for that. Just give it about 10 more seconds and then I'll share, share the results of the poll.

Lee Dibble:

I just wanted to add one last thing with regards to the CHOP PD study. That was a study that we felt like was really kind of important to do. And it was not something that a national federal funding agency would have funded. So we feel very fortunate that the Davis Phinney Foundation and the Parkinson's Disease Foundation at that point invested in that project. So we owe a debt of gratitude for that.

Melani Dizon:

Well, we owe a debt of gratitude to you for sure. And that's a big part of our mission here, teaching people they can do. So that was a big, big result for us as well.

So about 12% of the people said the PT was one of the first people they called. So congrats to you and whoever your doctors were that decided that was a great suggestion to give you. Some people, actually 23%, have never met with a physical therapist since their diagnosis, which I think is quite common. And then I would say the

majority of other ones are sort of spread out between those other three. So we will talk a lot about why it's important to work with a physical therapist. So Gammon, what is, why is it so important for someone to see a physical therapist soon after diagnosis?

Gammon Earhart, PT, PhD, FAPTA (Washington University School of Medicine):

I think the sooner somebody can see a physical therapist the better, because it allows a relationship to be established and sort of an initial assessment to be performed to determine whether or not the person is currently exercising, what sort of concerns they're facing in terms of their movement, as well as things not related to movement that might be impacting them, maybe things related to mood, or, you know, difficulty doing certain daily life activities, those types of things, and then figuring out what physical therapy approaches are optimal for that person at that time and starting those early. Because one of the things that we found in the CHOP study was that a very sensitive measure of how well somebody was doing was how much walking they continued to do. In fact, that measure was more sensitive than some of the things that would typically be sort of gold standards to measure how somebody is doing.

So I think that just speaks volumes to the importance of movement, and even if you're very early on and you really don't feel like you've had much difficulty, there's still a role for a physical therapist in determining sort of a regular exercise routine to maintain current level of function. So I think starting exercise is one of the key elements in living well with Parkinson's right from the get-go. It can really help to set the stage and prevent subsequent declines, or at least delay them.

Melani Dizon:

Right. Terry, can you speak a little bit about what a Parkinson's assessment might look like for somebody who's newly diagnosed that comes in to see a PT?

Terry Ellis:

I think, if people think about when you go to the neurologist, the neurologist does a lot of these tests, like this and like this, that, and they're looking at things like slowness and stiffness and tremor, and what a physical therapist does is spend more time. We might look at that also, but spend more time looking at walking, walking speed, for example, walking endurance, things like balance, you know, how well somebody can balance under different conditions -- when they reach forward, or when somebody nudges them, for example. We look more at activities of daily living. We have all kinds of questionnaires in which we look at how people are functioning in their everyday life. We look at quality of life across different domains. And so these are things that a neurologist, you know, may not have the time for. And doesn't specifically focus on.

And I think what physical therapists do is take a step back and look at someone's overall function. How are they doing in everyday life? I think one way to think about it:



we all, all three of us, talk about what we call a secondary prevention model or a dental model. You know, I think people, we call it a dental model because people understand and can resonate with what you do with a dentist. You know, with a dentist, you go. You always go to the dentist, you go for a baseline. You go when you're healthy, you go and everything is good. And you know, they do a nice cleaning and they do some x-rays. They figure out if you have any problems and, you know, the best thing that can happen is the dentist says, you look great. Everything's all set, right. No problems.

But then you go back to the dentist in six months, right? Whether you have a problem or not, or a year, or whatever it is, and you have these regular follow-ups, you know, kind of like you go back to the neurologist every six months or so for a medication adjustment. And they do the same tests. Well, when you go back to a physical therapist, they do the same test, the walking, the balance, the quality of life, right. And then, you know, like Gammon was saying, we can determine, based on the data we collected with the Davis Phinney Foundation, we can determine, did the change that occurred over six months, was that just a little bit, is that expected? Is that a lot? Right? And by collecting that very standardized data every six months or so, we know how people are doing, and then we can develop an exercise program tailored to that person's needs. The exercise program is personalized based on the problems that that patient is challenged by. And then we continue to monitor that over the course of the disease. You know, we see people over the course of their lifetime, every six months or annually or so, so that we understand what's going on and we can make the best difference.

Melani Dizon:

Great. I love that dental analogy. We frequently have people in the chat ask, "Why would I, if I'm exercising, why do I need a PT?" And I think that we can go back to that dental analogy. I'm sure all of us have had that experience of, we think everything's fine. Like our teeth, we're fine. But we go into the dentist and they're like, "Oh, there's a cavity forming, or there's this." Even if you don't feel it, it's there. And so the reason why we have a PT is because those tests, those assessments, are going to get to somewhere that we can't get to on our own. And they're going to help us help you over time say, "Oh, well, I need to fill the cavity." Okay. Now we need to walk. Work a little bit on core strengths because of such and such. Right. So I really love that idea.

And also in terms of, I think one of the things that people worry about is if I go to see a PT, I can't, I can't go to a PT three times a week, I'm too busy. I have this, I'm working, I'm doing all of those kinds of things. And you brought up, maybe you go every six months, maybe you go every year, and the PT is going to work with you. They're not going to say, "Oh, you've got to come three times a week." If you don't need it, that that's not what their goal is. So thank you for sharing that. I think that's relieving to

people who are, haven't seen a PT, but want to.

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Lee Dibble:

Just from a collaboration standpoint, I think that we all have collaborations with community programs and we're advocates for some community programs in conjunction with the physical therapy visit, if that works better for people. And, and also certainly within the United States, sometimes the PT ends up being the first person that that a patient might be referred to, but the patient's needs extend beyond or different than what we can provide care for. So we have strong working relationships with occupational therapists that might be able to help an individual on more specific aspects, or speech and language pathologists. So I wouldn't want to say that PT is the be-all, end-all. I think we have a lot to offer individuals early after diagnosis and through the disorder, but also kind of interprofessional practice with other individuals that would optimize the care and the ability of the person with Parkinson's disease to optimize their function.

Melani Dizon:

Great. Thank you. And I think that, you know, somebody had said, "Why a PT over a personal trainer?" And I think we've acknowledged that, you know, a PT, especially a Parkinson's PT, and we'll talk a little bit about what the difference is, they're gonna see something that a personal trainer just wasn't, has not been trained to see. They look at things in a very different way. They've had much deeper training. And so that's one of the differences. And somebody actually said, perfect example of why not using a physical therapist, but using a trainer is detrimental when your PDs gets worse. A PT is just gonna know more about the disease.

Let's talk a little bit about a Parkinson's PT versus a, just straight up PT. So what should somebody look for in somebody who's a Parkinson's PT? What is the extra training they have received that makes it better? And then also if somebody can't access somebody who is a Parkinson's PT, what are the really important questions that they ask that person to see if they're going to be able to help them?

Lee Dibble:

Gammon, you want to take that one?

Gammon Earhart:

Yeah, I'll start off. I'd say, so, every physical therapist will know a little bit about Parkinson's just from the basic schooling that they have in order to be a physical therapist. So I would say anyone is better than no one, if you're not seeing a physical therapist at all. But that being said, there are people who have additional training specifically in neurologic physical therapy, and those people will hold a certification as a certified neurologic physical therapists through our bodies--you know, they take an exam that's regulated federally. And so it's an additional credential that people will have,

and you can search for people who have that particular specialist certification. And then even within that group, there are people who are more specialized and know even more about Parkinson's specifically, not just neurological disorders in general, and Terry actually runs a training program that she can speak to about that additional level of training that some people seek and how to find those people.

Terry Ellis:

Yeah, I think people understand this a little better with doctors, you know, people understand that doctors specialize and have subspecialties, and actually physical therapists, we sort of, our training kind of mirrors that in some ways. You know, people know that physicians can do a residency program and a fellowship program and become board certified. And so one of the programs I direct is a residency program in which we train people to become, to develop expertise in treating people with Parkinson's and other neurological conditions. So they specialize in neurology, you know, just like a physician will specialize in neurology. So those people have had additional training and are more well-versed in the literature and are better able to help somebody with Parkinson's disease at sort of a higher level.

Melani Dizon:

Great, thank you. What role should aerobics, strength, and balance training play when it comes to living well with Parkinson's? And I think in particular, people want to hear about, you know, the intensity piece, how important is that to mitigating Parkinson's symptoms. Lee?

Lee Dibble:

I can go ahead and start, and then we'll all have something to say about this. I think one of the weaknesses I would find in the current kind of exercise studies is that by research design standpoint, we put everybody into a group regardless of their types of symptoms, and they get a particular intervention, and that's kind of the straightforward research design, to kind of keep it valid. But in clinical practice, everybody has a different kind of brand of Parkinson's disease, and they don't have all the same needs.

So I think that's one of the tie-backs to the previous conversation we were having about what a physical therapist can do, is they could look at an individual and say, "Oh, well, you appear to have some slowness of movement or Bradykinesia. That might be a product of some muscle weakness. You would respond most robustly to strength training, and we should put you on a strength training program." Whereas another person might have some fatigue that might respond more to aerobic conditioning and that person might do better with a biking or a walking program or something that would improve their cardio respiratory endurance. And then another person might have some balance problems and they might need something different or might have pain and rigidity, and they might need a more flexibility or yoga type program. So I think it's difficult to say, "This type of exercise is most beneficial."

Melani Dizon:

Great. Anyone else want to chime in on that one?

Terry Ellis:

You know, there's a lot of press or attention on a high intensity exercise. And you know, there are some, there's been some suggestion that aerobics exercise, the kinds of exercise that gets your heart rate up there you know, fast walking or cycling, stationary cycling for example. And there was a study that came out a couple of years ago, run by Margaret Shenkman and Daniel Corcos. And they compared a high intensity to a moderate intensity, to a sort of a usual care. And the outcome that they looked at was this outcome with the slowness and the stiffness of movement that, that test that you do every time you go to the neurologist.

And what they found in that study, there was some suggestion that only the high intensity group showed a significant benefit over the usual care group. Even though the moderate intensity group improved, it wasn't as much improvement over the usual care group. So because of this suggestion, that maybe high intensity is really important, now there's a big study going on all around the country. And Lee and I and Gammon are all involved in this. Daniel Corcos is the PI, the principal investigator out of Northwestern, and we're trying to figure out, okay, now we have to do a bigger study, several hundred people are going to be in this study, and we're going to compare that high intensity to that moderate intensity aerobic exercise to really try to better understand, you know, what's happening. We don't fully understand if it's, you know, does it just mitigate the symptoms, you know, kind of alleviate the symptoms, sort of like what the medication does, or is there something more to it? Does it actually slow down the progression of the disease?

And that's really hard to figure out. It's really hard to figure out, because I'm sure a lot of people on this webinar have heard about biomarkers and, you know, it's really hard to measure the changes in the brain, let's say, that are indicative of slowing the disease progression. We just don't have a really good measure of that. But, you know, in this particular study, they're going to try to look at other brain measures to try to get some idea of what's happening in the brain, as well as what happens on this kind of a test and what happens with walking, for example, that'll also be part of it. So it's exciting. Stay tuned.

Melani Dizon:

Yeah, I think it's exciting that they are looking at things like walking. I think sometimes our community gets intimidated when they see a study that says, you know, it has to be 85% or this RPM and that RPM, and they feel like that's inaccessible to them. They haven't been exercising. And so I think that's great that they're starting to look at other

other factors as well, that are going to help people. And I think across the board, our community is they feel better when they move. The caveat to that is pain, the pain that comes along with having Parkinson's, and for some people, the pain that results from deciding to take on an exercise program when maybe they didn't spend their life as exercisers. And so Gammon, can you speak a little bit about how physical therapy can help reduce pain, improve overall mobility, and what are the sort of triggers or clues to help people determine this is a good pain or this is a pain that I should, make me stop doing this physical activity and seeking help somewhere?

Gammon Earhart:

Yeah, I think that's tricky because it's different for every individual, but I would say in general that what physical therapists can do is help to understand what the likely contributors are to the pain. So is it that somebody has arthritis and the structure of their joint has changed in such a way that maybe you should consider an alternative exercise and not continue with something that's loading that joint repeatedly? Or is it something about the particular pattern of movement that the person is using? And if they could use a different strategy or a different pattern and learn to move in a different way that they could perform that exercise with less pain and less stress on the structures. I think, too, recognizing that the pain that comes like muscle soreness, for example, after exercise should subside. "No, once you've done exercise, it's normal for a tap soreness, but it should subside over time. And that if it's something that's persisting and not going away, even when you lighten up on the exercise, that that's not a good sign and probably something that you want to check in about." So those would be my thoughts. Terry and Lee, you have something else?

Lee Dibble:

One other thing that I know that we ended up looking at is trying to talk to the individual person with Parkinson's disease and see what that kind of time-based behavior is for their pain. Does it correspond at all to their medications? Because if it's related to that rigidity, then it may subside a little bit when they're when their medications are at their best effect. And then we can try to do some things to reduce as best we can the rigidity or work with their referring provider to see if we can, they can extend the medication effect and reduce the pain associated with rigidity as a Parkinson's symptom.

Melani Dizon:

Great. Yeah. And I think that, you know, when you're diagnosed with Parkinson's, it feels like, this, it's always what I have. Parkinson's, that's the thing that I am living with. But we all come to, we probably will all come to a physical therapist or a doctor with other things going on. And so part of it is like Lee said with the medication: is it rigidity? Is that why the pain is? Trying to figure out what is the Parkinson's, what might be something

else that could be treated. And another way that would then allow you to do what you need to do to treat your Parkinson's. And so that's why it's super important to have a sort of an integrative team that's going to be able to address those issues.

One of the issues that people write in a lot about is back pain. And they're wondering if there is any link between Parkinson's and back issues, maybe degenerative disc disease or things like that. It's a very frequent question we get, and we also know that back pain is very common for people as they age. And so what have you seen in your practices around back pain and Parkinson's, and because it is something that can also can really inhibit people or make them not do anything, what are some things that you encourage people to do when they have really severe back pain?

Terry Ellis:

So I can speak to that a little bit. It's very tricky. First of all, I would agree that a lot of people with Parkinson's disease have back pain, and so having someone, a physical therapist with expertise in orthopedics or in the spine, is also really helpful to be able to sort this thing out, figuring out what is the source of the back pain. Oftentimes there is another source that is related to some mechanical problem or some joint problem, but it can be made worse or exacerbated by the Parkinson's disease, by the slowness and the stiffness. And sometimes the approach you would take to treating that back pain is different in the absence of Parkinson's disease. And sometimes some of the things you would give someone to do for that back problem might, you know, help somebody who doesn't have Parkinson's disease, but actually could make it worse in the context of Parkinson's. And so sometimes when we see something, when we see people with back pain, we can understand how what they're doing is actually kind of making it worse because the Parkinson's isn't being considered. So some of the treatments have to go down a slightly different path in order to really get at the problem in the context of Parkinson's, which may be making it worse.

Melani Dizon:

Great. And I would assume that the same would be true for neck pain.

Terry Ellis:

Absolutely. The whole spine. I mean, if you think, I think people understand that, you know, people with Parkinson's disease are kind of, can be stiff and have a lot of stiffness. That stiffness tends to be the greatest in the spine, right? People might notice that they don't, you know, they don't turn and rotate as easily as they used to. For example, a lot of stiffness with turning and moving difficulty, moving in bed, you know, not turning your head as much. And that means there's more stiffness in that spine. And so that then can exacerbate a problem that's already there.

Melani Dizon:

Okay. So, I think we definitely have some questions on what to do if you have back issues. And I think that the key really is to see your own physical therapist, because they're going to be able to look at your whole record, look at maybe x-rays or MRIs or anything else that's going on with you in addition to your Parkinson's, and then develop a very specific individualized therapy for you. Somebody had mentioned, and we actually heard this a long time ago, about back braces for people with Parkinson's. Is that something that you all ever recommend? Is it something that you work with?

Terry Ellis:

I mean, I know you know, typically if you have, if you think about this, somebody is really stiff and not moving enough--a back brace makes somebody move less and holds somebody still. And that's generally the opposite of the approach we want to take. We want to try to get people moving and moving better. Now I'm answering this in a very generalized way. Of course, you know, it depends on the individual circumstances and the type of back problem, but in general, we don't recommend back braces for people with Parkinson's who have back pain.

Melani Dizon:

Okay, great. We have a lot of questions and we're going to get to them for sure. I just want to address a couple more of the, the broader picture. What would you say, Gammon, and I think you alluded to this a little bit earlier, but what sort of experiences are you, do you see from people with Parkinson's around non-motor symptoms and the benefit of PT and exercise for those?

Gammon Earhart:

So there can be a number of non-motor symptoms associated with Parkinson's. I think a lot of people kind of overlook them, you know, you people call Parkinson's a movement disorder, and so movement is front and center, but there definitely can be changes in mood. So maybe depression or anxiety, sort of, apathy. There could be changes in cognitive function. So thinking processes can change. There can be changes in bowel functions, things like constipation, for example. So I guess you could consider that a motor symptom though, arguably. So there is exercise, I would say some evidence of, for exercise benefits in Parkinson's, to specifically address things like mood and thinking, and a lot of evidence from other groups of people as well who've been studied more extensively over time. So definitely, you know, just the changes that come with exercise are not strictly related to movement, but can also impact these non-motor aspects.

Melani Dizon:

Great. Let's see. How much improvement would you say that someone can expect from

working with the PT? How can you measure it? As somebody who's asking about, you know, what are sort of the preferred outcome measures, and I think you addressed the different things that you talk about, but how can somebody know, *This is working. This is worth my time. This is something I need to keep doing.* Lee or Terry, you want to jump in?

Lee Dibble:

Sure. I can start. And I think-- we're physical therapists, and as Terry was saying earlier, the neurologist's job is to focus on the kind of severity of the disease. One of our primary roles is to be concerned about quality of life. And I think that may be one of the primary outcome measures; if it's meaningful to the person and they feel like they're getting benefit from it, then that's probably the most important outcome. We could measure something in the clinic -- balance or gait speed, walking speed, something like that, and we could see an improvement, but if the person doesn't feel like it's meaningful in their everyday life, then I'm not sure it's that important. So we would, we'd probably advocate for having conversation, or certainly we do with our PTs and our PT students, to tell them, "Find out what the goals of the individual person are, and then create the program designed around those individual goals."

I brought up two things that we think are important. And another one came up earlier: pain, certainly, but balance and walking ability. I think that those are kind of more kind of activity or movement and mobility related issues, but again quality of life. And how those would improve quality of life and mobility in the community would probably be the most important outcomes. I don't know if that answers your question though.

Melani Dizon:

Yeah, that's great. Thanks. let's see. So we have a bunch of questions. I'm gonna run through some of them. I know that we've definitely addressed many of them throughout. Let's see. Somebody said, what is the name of the study? And it's called the CHOP PD. It's just capital C H O P PD. And if you go to our website and you click on it and you just hit search CHOP study, that will come up. That's funded research, and you'll get to see that. And then all the articles that are related to that Jay Alberts, yes. The research on cycling and PD: we have a lot on our site about that. You can definitely look at that.

Somebody said, "Why PT as opposed to personal training, rock steady boxing, walking, and biking?" And it's not one or the other; it's using them in conjunction. So, you know, like, like they just said depending upon what's going on with you, if you have a certain issue, they might say, "Hey, boxing is totally fine for you," where they might say, "Actually swimming might be better because for whatever reason," so it's not one or the other. It's having them work together,

Several people have asked about where to find Parkinson's PT in their area. Actually,



we will send you the link for sure on in the show notes, but we also have a site that says, "Where do I find a Parkinson's PT" on our website. If you search that, you will find the post. And then on the information on how to find that a couple of people have asked about well, I'm not going to speak specifically about different exercises again. I think you can definitely talk to your doctor about that.

Some people have said a lot of their access to PTs have been cut because of COVID. And so they haven't been able to see their PT. Do you all have any recommendations for where people can go if they are homebound, they're not leaving their house, their PT doesn't offer Zoom? What are some things that people have been doing to kind of get the help that they need, at least the suggestions for activities and that kind of thing?

Terry Ellis:

You know, now many PTs are providing services through telemedicine and that allows you to go further than just your local area. And so you don't, you know, normally if you're going in person, you'd be looking at something, well, what's close to me, you know, that I can easily get to? But you can widen, you know, you can widen your search to find a physical therapist with expertise in Parkinson's disease who's delivering that care via telemedicine because they could be hundreds of miles away and, and Zoom in and, you know, and help you right in your own home. So we are doing more telemedicine work now than we actually did in person because people are so interested in, you know, coming, you know, just don't want to leave house; it's too risky. And never mind just things like inconvenience and, you know, just the convenience of staying in your home and being able to access that expertise, whether it's a physician or a physical therapist or some other healthcare professional. So I think that telemedicine is an option for many, many people now, whereas that wasn't before. And now insurance companies are covering that at least right now. We are hoping that that lasts and that, you know, they make permanent changes in their reimbursement policies. But right now it's covered with, for many insurance companies. So Medicare and some private ones.

Melani Dizon:

People have asked about, first of all, the name of the study that you are involved with now, the bigger study. Does that have a name right now?

Terry Ellis:

It's a little secret. The acronym is the SPARKS three trial. I need to remember what that all stands for. But people, we're just getting all the regulatory sort of background things you have to do to get a study up and running. That's all going on now. And so the sites around the country are going to start recruiting and enrolling, I would say later this fall or early next year. And so, you know, you can get on that. You can on the Northwestern University's website--I don't actually know if this is live, okay? I think it is. I think it is. If you look up "Sparks three" is the name of it. You can at least get your name on a list,



you know, so that when the time comes to start enrolling that you'll, you know, somebody can call you and do a formal screening to see if you're eligible and all of that. Yeah. So definitely keep keep an eye on that.

Melani Dizon:

We will probably be sharing some information on it too, on our website. It's a pretty giant study and pretty exciting.

Gammon Earhart:

About that study--it's for people who've never taken medicine to treat their Parkinson's. So a lot of people may not be eligible because of that.

Melani Dizon:

Somebody asks about what's going on in the brain. What did you learn about what's going on in the brain through vigorous exercise that could relate to the progression and stopping the progression of Parkinson's early on?

Gammon Earhart:

I would say we don't have great evidence from people because there are a lot of things we can't manipulate and can't measure in people, but there have been a number of animal studies. And those studies show that sometimes the nerve cells make different connections and new connections based on the activity that it has been engaged in. Sometimes the cells produce different chemicals like BDNF, which is a chemical that helps to promote the health of nerve cells. Sometimes new blood vessels are formed in the different areas of the brain to help supply the nutrients to that area, you know, a more substantial way. So there are lots of different things. There also, in some animal models of Parkinson's, seems to be some sparing of nerve cells so that they don't degenerate and die, like they would in the absence of exercise. So there seem to be a lot of different possibilities. And again, I would say that we don't really know for sure what happens in people. It could be any or all of those things. It could also be an increase in the ability of the body to use the dopamine that's available most efficiently, sort of make better use of it than if you didn't exercise. But those are all speculative based on what we've seen in animal models.

Melani Dizon:

Okay. Thanks. Fatigue is a big issue for sure, for people with Parkinson's in general. And then also when you add the exercise onto that. So what are, sort of related to pain, when you have somebody that's complaining of a lot of fatigue, when do you know that, okay, this fatigue is like a different type of fatigue versus like, you can exercise your way out of fatigue? That can happen a lot of times. So what is your advice for people that

come to you and are just, say, "I'm too tired," or "I feel too tired to exercise."

Terry Ellis:

That's a really common question. It's a really good question. So some people feel some combination. "I think the exercise is making me worse," or, you know, making the fatigue worse, or others will say, "I'm not sure, you know, should I be doing more? Should I do less?" And so it's really tricky. This, the studies that have been done on the effects of exercise on fatigue are, there's not that many of them, and they have variable results. So it's sort of gets back to Lee's point. If you kind of have a lot of variability in the people that are in the study, it's hard to really understand it in the depth that we want to understand it. So how we handle this is, when we see somebody in the clinic and we prescribe an exercise program, or if they're already doing one, we kind of more systematically look at the influence of the fatigue on the influence of the exercise, on the fatigue for them.

Like we do things like have them keep a log, you know, when their fatigue is worse and better during the course of the day. When did they exercise? We might be able to improve the fatigue by exercising before it comes on. Let's say, you know, if we know that fatigue is worse during a certain time of day, so it's a very sort of personalized approach figuring out how, you know, when does that person have fatigue? Is it related to their medications? Is it related to a certain time of day? You know, how can we manipulate the exercise to discover, try to understand whether it's making it better or worse, or the same? And maybe we have to do a different type of exercise or a different dose of exercise to try to really get a handle on whether we can improve that fatigue. But it's a very much a trial-and-error, individualized approach for each person.

Lee Dibble:

I think one of the things that we've learned from our our experience with people with multiple sclerosis is that fatigue just doesn't mean one thing. It's not just kind of muscular or metabolic fatigue from, from over-exercising, but there can be kind of neurologic or brain nervous system caused origins of fatigue. So to kind of re-emphasize what Terry said, it's important to understand the nature of an individual's fatigue and where it's coming from to try to address it most positively for that person.

Gammon Earhart:

And just add to that, another strategy is to chunk your exercise. Rather than trying to go at it for 30 minutes at a time, you can do 10 minutes, three times during the day and still get benefits, you know, so that can help. If you are feeling fatigued, you may be able to do more if you do it in smaller chunks.

Melani Dizon:

Great. Thank you. And several people have commented that they do PT via telemedicine, and it's great. And they're having really great results and you don't necessarily have to be in person and even with an assessment, you know, somebody can you know, depending upon where you are, if you are in danger of falling in your home, like you could have somebody with you but you could certainly do some seated exercises and your PT can help you and make sure that you're safe while you're doing those things, but it's definitely worth checking out. It seems like a lot of people have had a lot of success with it. Let's see.

What value is PT when the patient will not practice exercises at home? I think this is a very common question that we get from care partners. And I also get a lot of questions from care partners that say, you know, "My person with Parkinson's has been told, and they still don't want to do it." Any thoughts there?

Lee Dibble:

I do think that there's a problem nationally for people with, and without Parkinson's disease, about being physically active and wanting to exercise. The added layer of challenge for people with Parkinson's is that there's some potentially non-motor symptoms like Gammon talked about like apathy and depression that may be associated with the disease. So it's kind of unrealistic to expect that you should, that the doctors should be able to hand a prescription to the person and say, "Be physically active," and that person's going to be able to sustain that. So I view it as a physical therapist and maybe in partnership with a community program, it's their responsibility to try to provide something that is motivating and enjoyable. And it doesn't feel like the dreaded "E" word, "exercise." Like "I don't want to do that." But that they actually look forward to. So I view that we, that we have to take into account those limitations that may be organic to Parkinson's to try to help in the process.

Melani Dizon:

Great. Terry, were you gonna say something?

Terry Ellis:

Yeah. I mean, just along these lines, I mean, it's hard, you know, it's hard to exercise. It's hard to exercise every day for people who don't have Parkinson's, but you know if

you think about, if you just decide, Oh, you know, you wake up, you wake up in the morning and you say, Oh, you know, I should exercise. Right. You know, you should exercise, but you're like, ah, you know, I'm tired. I don't feel like it. You know? And so kind of one of the things we try to encourage people to do is to schedule it. So you don't like thinking about it so much, you know, you make it a habit and you do it at the certain



same time every day. For example, just like you have a meeting--you have a meeting it's in your calendar, you show up and you do it.

And you know, the more something is a habit, like brushing your teeth, it seems like it's not so effortful. You just do it. It's part of the daily routine. And so thinking about it like that, or every day at this time is what I do, you know? And back to Lee's point, it's gotta be something enjoyable. There's so many options for exercise that's beneficial. That's a good thing. It allows people to choose. And then one of these comments was community exercise programs. I think people will drive an hour and a half to go to an exercise program and drive back because when they get there, it's not so hard. You just go along with whatever the instructor is doing. You just, you just do it, you know, you're going to do it. And then, you know, on the other end of it, you're going to feel good.

I mean, I think that's one reason why boxing is so popular. You go, you go there, you get a lot of encouragement, you get a lot of camaraderie, and it makes it easier. It's not so difficult to do when there's some enjoyment, you know, as part of the process.

And a lot of people mentioned a partner. Yes. If you've got somebody waiting for you, it's really hard not to show up. So exactly. Make it easier, you know, make it somehow easier to fit into your day or, you know, somehow that you don't have to like, think about it, take all those steps, force yourself all by yourself. That's hard. It's hard for everybody.

Melani Dizon:

Right. Gammon, were you going to chime in?

Gammon Earhart:

Yeah, I was just going to say that there are also some online classes that you can join in real time. So I know like the St. Louis APDA has some classes that are broadcast live and they're also recorded. So if it doesn't fit into your day and your schedule, you can consume it at a later time. So I think, you know, taking advantage of technology, and not just classes, but also devices that will track your activity and help you to see: are you meeting your goal for number of steps per day, or number of minutes of activity per day? And things like that. I know I'm very goal oriented. So I like to get the little badge that says I've done it for this many days in a row and those kinds of things. And you can also get the social piece of that as well, by inviting your friends. You have a similar tracking device, and seeing how they're doing and sort of making a little friendly competition.

Terry Ellis:

I think somebody, Mel, somebody just wrote in and said, you know, but what about now with COVID? And these group exercise programs, so obviously that has changed, you

know, right now people are not going to the same classes they were going to before

because of the social distancing requirements, et cetera. But like Gammon said, there's a lot of exercise programs that are available online, either recorded or in real time, and you can still walk outside and you can walk with somebody six feet apart, you know? So there are ways, you know, to get it done. It just requires a little more creativity.

Mel Dizon:

Yeah, absolutely. I was actually talking to Davis Phinney this morning and he had just gotten off a Dance for PD class and he said, "You know, even though I'm not there, this class does the best job of making me feel like I'm in the room." And so part of it is going to be doing a little research and trying out a few things and, you know, maybe the first couple of classes over Zoom you don't like. It doesn't feel like you're connecting in another way. But the third one does. And so be willing to kind of check out what you can do.

Before I get to the sort of the latest research and devices and that kind of thing, how much is too much exercise? How do you know?

Lee Dibble:

I don't know that any of us have, you can tell by the hesitation, have a really definitive answer for that. I can speak to a resistance training type of model, that the intent of resistance training obviously is to increase muscle strength. If somebody is doing weights and they're having increasing muscular pain that's building over time and they're either they're probably decreasing their ability to do the amount of resistance that they have. That's an adverse response. That's not something that they should continue to do without some guidance from someone else. Cause that's moving in the wrong direction and there's potential for tendon injuries and muscular injuries or just overdosing the exercise.

Terry Ellis:

I think that's why it's so important to increase exercise gradually. You don't want to go from, you know, no exercise to, you know, 60 minutes of high intensity exercise, right? That's going to be, you know, that could result in injury. And so just gradually increasing the amount of physical activity and engagement in exercise can prevent some of that. But you know, what's too much for one person might be just right for someone else. So it really comes back to that. You know, it depends on the individual. It depends on all the other medical problems they have or if any, and you know, how the exercise is best tailored. So there's not just a hardcore, "Oh, don't go over this amount." You know, it depends on the person.

And I think the important thing is if you exercise really, really hard, the next day you get up and you are in pain, you can't exercise, you've probably done too much. Yeah. Because Parkinson's is a daily thing that you're dealing with. Right. So all the movements every day is going to add up and it's also going to help you in that moment and hours active. So if you're finding yourself having to skip days, you're better off taking, you know, tapering it back a little bit on those other days. So you don't go too far. 'Cause over time, it's going to be what you can do every single day. That's going to be the most important thing that's going to. Yeah. And, you know, I just want to say something about, you know, obviously doing something every day is great, but if you miss days, you got to take the long view. You know, I mean, this is Parkinson's, this is over years and years, right. And so, you know, there's 365 days in a year. There's multiple years full together. So it's like, if you miss it, you know, a day or two here and there each week, it's okay. Because if you get at the end of that year and you have 365 days and you've exercised half of them, well, great. That's a lot better than nothing. Right. That's going to help the situation.

So do the best you can and don't be too hard on yourself. If you took a day off where you missed a day, or you went on vacation or you were sick or whatever it was, just get back on, you know? The next day is a new day. Just get back on, you know, back on track. And then the outcome will be much better in the long, in the long haul.

Melani Dizon:

Okay. So we are just about out of time. I would love to know from each of you, is there something that you, aside from the SPARKS 3 study, which we've talked about already and we're super excited about anything, that's really, that you're looking forward to in the world of PT and Parkinson's that you want to tell other people about, or anything that I didn't ask that you wanted to talk about real quickly before we leave? Lee, do you want to go first?

Lee Dibble:

I'm going to call out Gammon and Terry. I think the current project that they have going on that is focusing on exercise, but they're focused on trying to maximize that self-efficacy for individuals, finding ways to improve a person's sense of control over the disorder and ability to impact the disorder. And I think that's a really novel and important approach for a variety of chronic conditions. And I think that I'm excited to see what the results of that will be.

Gammon Earhart:

Thank you, Lee. I'm sorry, Terry.

Terry Ellis:

Yeah. I mean, thanks, Lee. That's great. You know, Gammon and I are doing a study in



which word we're trying to help people who are having a hard time exercising enough, who want to be doing more. And so, you know, you can feel free to reach out to us if you're interested in that. But I think what's exciting is that exercise is getting so much attention and there's a lot of studies and a lot of trials going on. And actually Lee is doing a study right now, looking at home cycling. So that's perfect during COVID, you know, where you exercising at home is more the norm. But you know, just like if you think about the way that drug studies operate, you know, in order to really know how to best utilize the drug, you have to know the right dose and the right kind of drug for the right kind of symptom.

And so that's where we're at with exercise. Now, we're really trying to understand like, well, what kind of exercise and what effect does it have on the brain and how much should you do? And it's exciting that we have all these studies going on right now that are helping us understand that more.

Melani Dizon:
Thank you. Gammon?

Gammon Earhart:
I'd say that there are a lot of studies underway, but we already know exercise is helpful. So don't wait for the perfect evidence, get out there and do whatever it is that brings you joy and movement and stick with it.

Melani Dizon;
Great. Thank you. Well, thank you, Lee and Terry and Gammon, so much for this great webinar. I know that our community absolutely loves all things related to PT. So really appreciate you taking the time today. Everybody, we'll send you all of the links and all of the videos and recordings and a whole lot of information about some of the things that they talked about today. We'll send you links so that you can get more information. Thank you, everybody. And we will see you again soon.

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