



Transcript

Welcome and Introductions

Stephanie Paul

[Slide 1] Welcome everybody and thank you so much for joining us today. **[Slide 2]** My name is Stephanie Paul, and I'm the Vice President of Development & Marketing at the American Parkinson Disease Association or APDA for short.

I am pleased to welcome you to this Web teleconference education program designed for people with Parkinson's disease, care partners, family members, and healthcare providers. I would also like to thank Lundbeck and Joan and Ross Collard for funding this important program and acknowledge their continued appreciation for the critical need to provide educational programs like this one to people impacted by Parkinson's disease.

APDA is the largest grassroots network dedicated to fighting Parkinson's disease and works tirelessly to assist the more than 1 million Americans with Parkinson's disease live the best life in the face of this chronic neurological disorder. Founded in 1961, APDA has raised and invested more than \$170 million dollars to provide outstanding patient services and education programs, elevate public awareness about the disease, and support research designed to unlock the mysteries of Parkinson's that will ultimately put an end to this disease.

APDA distinguishes itself as the national organization working one on one with the Parkinson's community to make each day better. And now to our program.

[Slide 3] Our presenter today is Dr. Terry Ellis who is the Director at the Center for Neurorehabilitation & Director Neurological Physical Therapy Residency Program at Boston University College of Health & Rehabilitation Sciences, Sargent College in Boston, Massachusetts.

Today we are delighted to have Dr. Ellis share with us an overview of staying healthy and keeping fit for people with Parkinson's disease. After the presentation, we will open the program for questions from both telephone and Web participants. And we encourage everyone participating to complete the evaluation after the program because your feedback is instrumental in helping us plan for future educational offerings, including teleconferences like this and other programs.

You may view the materials for today's programs by clicking on the Files button on the lower left-hand corner of your screen.

It is now my pleasure to introduce Dr. Terry Ellis.



Presentation

Terry Ellis, PhD, PT, NCS

Thank you, Stephanie, and thank you to the APDA for inviting me here today. It's an absolute pleasure to be here. I'm excited to talk about exercise and how to stay healthy. It's one of my favorite topics, so let's get right into it.

[Slide 4] So here are my financial disclosures. **[Slide 5]** Okay, so one of the biggest questions we have is what is the impact of exercise on Parkinson's disease? How do we understand what are the real benefits of exercise? How is it affecting the actual disease? And one of the big questions we want to know is does exercise actually slow down the progression of Parkinson's disease? In other words, is it neuroprotective?

[Slide 6] And the reason this is very exciting, because we have lots of data with animal models. So, in this case there have been many studies with mice and rats in which Parkinsonism is induced in these animals; and then the animals are run on a treadmill, for example, just like you see here. And what they've seen, what scientists have seen is that there's an increase in what's called neurotrophic factors or chemicals that promote the survival of neurons in the brain.

So, it seems that in animal models, there is some evidence that exercise may slow down the death of those neurons that are particularly vulnerable in Parkinson's disease. Over here, what we see on the right side is that they've seen in these studies that in animal models that exercise also seems to increase the amount of dopamine available. So right here you see all of this dopamine right here in the synapse; and here is the sort of lack of dopamine in Parkinson's disease. But with exercise, there's an increase in dopamine, like you see up the top here. So, exercise seems to increase the release of dopamine, and then exercise seems to increase this chemical that may promote the survival of those key neurons in the brain.

[Slide 7] But how does this translate to humans? What is the impact of this information on humans with Parkinson's disease? Well, that doesn't mean you necessarily have to run in one of these wheels; but the hard part is that we don't definitively know whether exercise slows the progression of Parkinson's because we don't have a good way, a sensitive enough way to measure those neurons in the brain.

So, in other words, we don't have a way to know explicitly in the human brain if those cells that are affected by Parkinson's disease are, the death of those cells is any slower. However, we have lots of evidence in people with Parkinson's disease showing the benefits of exercise across many different outcomes.

[Slide 8] I'm going to share with you this study that was just recently published, this year, in which these investigators tried to get at this issue, could exercise actually slow down the progression of the disease? And what they did here in this study is they asked people with Parkinson's disease to exercise four days a week here at 60 to 65% heart rate max, so that means sort of a moderate level of exercise. And then there was a group of people that exercised four days a week at a higher intensity exercise, so 80 to 85% heart rate max. And then there was a group that didn't exercise or



that just continued with their usual activities, [Slide 9] and on this slide you can see here the outcome that they used, because we can't measure the brain at a sensitive enough level, the investigators used what's called the Unified Parkinson's Disease Rating Scale, which basically is a measure of Parkinson's motor symptoms.

And what this shows here is this is the highest level of exercise, so the high intensity exercise; and what you see here is according to this scale, it didn't move much. And that's a good thing. It stayed at zero. So, this means it didn't move much or didn't get worse. The symptoms didn't get worse at the highest intensity exercise.

Over here, at the moderate intensity exercise the score went down a bit but less so than the group that didn't exercise at all. So, what this is saying is that both exercise groups had some benefit, and the highest intensity exercise group seemed to have just a slightly stronger benefit compared to the moderate intensity. So, these investigators are going to move forward to a bigger trial with even more people to try to study this at greater lengths.

So, what we know at this point is that both moderate and high intensity exercise is beneficial. And what we're still trying to understand is that what is the impact of the very highest intensity exercise on the progression of Parkinson's disease, and we're still learning more about this. So, the next biggest study will look at this more explicitly. Okay, so let's move on here.

[Slide 10] So the idea is that exercise here at the top, and it can influence brain health on the right, so you see we know that exercise increases blood flow, it increases those neurotrophic factors that we talked about, those important chemicals in the brain. And then on the left, what you see is that exercise actually affects the actual neuron itself. So, the little bumps that are sticking out from that neuron there, there's actually more of those that form under exercise conditions.

So, what that means is that the neurons are better able to communicate with each other; and when they're better able to communicate, when you go down here to the circuitry, you actually get better communication in the circuitry of the brain that then leads to better behavior in things like walking, for example.

[Slide 11] So, what everybody wants to know is then, okay, so exercise is beneficial. We know that exercise reduces disability in people with Parkinson's disease. It improves everyday function. What we don't know explicitly is whether it slows down the progression of the disease because we can't measure that in a sensitive enough way. But what everybody asks is, "Well, what is the best exercise then? What are the key components of exercise for people with Parkinson's?"

[slide 12] And so here in a nutshell, there's not one best exercise. There's actually four important categories of exercise. So, a cardiovascular or an aerobic form of exercise; a strength training exercise or resistance training with weights; balance training, balance exercises are very important; and then stretching exercises to improve flexibility.

So, the recommendation for people with Parkinson's disease is to engage in some of all of these four key areas, and I'm going to talk now about each one in a little bit more detail.



[Slide 13] So to improve aerobic conditioning or aerobic function, cardiovascular fitness, and this can be done in a variety of ways. The good news is that not just one type of aerobic exercise is the best, right? There's choices that you have. So, some people might enjoy walking on a treadmill, for example, or just walking outside. Other people might enjoy riding a stationary bike. Both forms of exercise can increase fitness and are considered aerobic activity.

Some people might find that walking on a treadmill is a good choice because maybe you like that better or because you also, in addition to the aerobic benefit, you're practicing the task of walking. And we know that actually practicing something like walking and specific tasks that people with Parkinson's disease might be challenged by, and we want to focus on improving the task of walking. So, by walking on a treadmill or walking outside, it's sort of a twofer. You're sort of improving the task of walking and getting an aerobic benefit. For people who it's not safe to walk on a treadmill or people that have balance problems or freezing, for example, you can still get a good aerobic benefit by riding a bicycle, for example.

Now in order to get an aerobic benefit, you have to work at least, it has to be at a moderately challenging level. And so, the heart rate needs to be at at least 60 to 65% heart rate max. So that means you take 220, minus your age, and then you take about 60 to 65% of that, and that is the sort of level that you want to exercise at.

An easier way to do it is just that when you exercise at moderate intensity, you should just be a little bit out of breath. You should be able to say a sentence but not say a whole paragraph. It should be sort of moderately difficult. Vigorous exercise, you should be out of breath even with a sentence.

[Slide 14] So here you can see on this slide, this was a study done showing that people with Parkinson's disease that walked three times a day for 45 minutes in the community setting at about a 75% heart rate max, so that's at a moderate intensity, just a little bit out of breath with walking, those people experienced significant improvements in all of these outcomes here. These outcomes have to do with fitness, walking, Parkinson's symptoms, even thinking, cognitive function, fatigue, depression, overall quality of life. So, there's many benefits of exercise.

[Slide 15] So strengthening is another important aspect of exercise. Strengthening is important because it helps with the bradykinesia or the slowness that's associated with Parkinson's disease.

[Slide 16] You can see here this was a study done over a two-year period in which people with Parkinson's disease who participated in a progressive strengthening program a couple of times a week over two years had significant improvements in the motor symptoms of Parkinson's, the speed of movement, the amount of force able to produce. So, we know that strengthening is another important aspect of exercise in Parkinson's because it seems like it helps with moving faster and moving more efficiently, overcoming some of those slowness or bradykinetic symptoms.

[Slide 17] When you ask, "Okay, so what muscles should be targeted for people with Parkinson's disease when you engage in resistance or strength training?" and those muscles that should be targeted are the extensor muscles. If you look here at the picture, on the front and the back of this cartoon here, you see the muscles in the legs, the purple and the blue muscles on the front and the back of the legs are very important. So, the quadriceps in the thighs, the buttocks muscles, and then also the back muscles, in the middle of the back here, the muscles, the postural extensors that help



people stand up. So, it's the extensor muscles that are most important to focus on in Parkinson's disease.

[Slide 18] You can see here the strengthening can be done in a lot of different ways. People can go to the gym and use weights, they can use free weights, or they can use machines, or you can simply use body weight, for example. So, you see here in this picture, this is just a squat or standing up from a chair in which your muscles in your legs, the extensor muscles in the legs are working hard to stand up against gravity. And this is just a Level 1, 2, and 3, are different ways to make the exercise more challenging over time.

When we get to the end, we'll show you a picture of the APDA *Be Active & Beyond* exercise book in which you can see pictures of these exercises; and you can download that for free.

[Slide 19] So here we see the other important element of exercise is range of motion or flexibility exercises. Because of the rigidity associated with Parkinson's disease or the stiffness, it's important to stay limber and loose; and here again, **[Slide 20]** you can see this at the end too in the *Be Active* manual, that there are certain muscles that should be targeted, particularly in people with Parkinson's disease. So, we know that people with Parkinson's might tend to be a little bit more flexed over, the posture is in a little bit more flexion or bent forward. And these particular stretching exercises help people stretch the muscles that allow us to stand up straighter.

[Slide 21] And then another important aspect of exercise for people with Parkinson's disease are balance exercises, and balance can be problematic. It can be challenging for people with Parkinson's disease. And some people with Parkinson's disease may experience falling, so this is something that we want to be very proactive about.

[Slide 22] There's many ways that people can work on balance. For example, Tai Chi. Tai Chi has been shown in this study with 195 people with Parkinson's disease, Tai Chi was shown to improve people's balance and reduce falls even more so than things like stretching, for example.

So, in this study, people with Parkinson's participated twice a week for an hour for a six-month period and showed significant improvements in balance and a reduction in falls.

[Slide 23] And we also know about the benefits of dance for people with Parkinson's disease. Tango has been the most widely studied. In this particular study, there were 62 people with Parkinson's disease; and they participated in a 12-month, community-based Tango class twice a week. And they experienced significant reduction in motor symptoms, improvements in balance, better walking, and better quality of life. So, this is actually a fun way to help improve balance and to reduce falling.

[Slide 24] This was a large study here that was done in Australia, and it involved 231 people with Parkinson's disease. And they compared a group of people that participated in a balance exercise program versus people who didn't participate in the program. The reason I bring this up, this particular study, is at the top here where you can see in the red with the arrow, in this particular group, that particular group had the best benefit. And this particular group had sort of earlier Parkinson's, and they were not falling all that much. So, I think a lot of people think, well, if I'm not falling yet or if I don't have balance problems, then that's not something I need to work on.



Well, that's actually, this study shows differently. So, what this study is showing, that being proactive is better in addressing balance early, even if you're not experienced falling or even if you've just fallen occasionally. The results showed significant improvements in balance and less falling in people that were sort of earlier on in the progression of the disease.

[Slide 25] So what we've learned from all of these studies, all the studies that have been done in exercise, is one of the things I want to talk about with this slide is what are the key elements of exercise? So, we know that aerobic exercise, okay, so getting your heart rate up there, breathing a little bit heavy, is important. And if any exercise turns out to be neuroprotective, it is probably the high intensity aerobic training. So that would be more vigorous exercise, aerobic in nature.

And then we talked about strength training and the importance of overcoming the slowness or the bradykinesia. The balance training is important to improve balance and reduce falls. And the flexibility exercises are very important to decrease rigidity and stiffness. But overall, what we've learned from the animal studies and the human studies is that the exercise needs to be a bit challenging for each individual. It needs to be a little bit more intense than what you can do sort of very easily.

So, in other words, there's not one sort of intensity of exercise that everybody with Parkinson's disease should be doing. It needs to be individualized to the person. So, for one person, lifting a certain amount of weight might be very intense and another amount of weight would be the right intensity for somebody else. So, everybody has to think about this on an individual level, but we do know from both animal studies and human studies that people have to be challenged just beyond their current capabilities. So, the exercise should be a little bit more challenging than what you can easily do.

[Slide 26] And then it's important to know well how much exercise we should all be doing, and here are some recommendations. So, in general, the recommendations, and these are recommendations for sort of the general population, and we have found in Parkinson's many of the same recommendations apply. And so, for aerobic activity or the cardiovascular activity, it's important to do about 150 minutes a week. So that could be either 30 minutes a day, five days a week, or it could be 50 minutes three times a week. It doesn't seem to matter as long as it's about 150 minutes a week. And, again, that can be as simple as walking, as long as the walking is just slightly more challenging than what you can do comfortably.

And then strength training and balance training are things that can be done about two to three days a week. And then the flexibility training is something that can be done every day and is usually best done after you're sort of warmed up and the muscles are loose. So, what I like to tell people is that after you do your aerobic exercise and you're all warmed up, that's a good time to do the stretching.

[Slide 27] So you can see here with this activity pyramid that basically on the very bottom is what we should be doing the most, and that's just general physical activity. It's important to know that not only is planned exercise important, but it's very important just to be physically active during the day.

You can see on the very top here we should be spending the least amount of time sitting, so we want to decrease the amount of sedentary time and increase the amount of just overall physical activity.



And then in the middle here, you see the three to five times a week for aerobic activity and then one layer up there, two to three times a week for the flexibility, balance, and strength training.

[Slide 28] So some people say to me, “Well, how long do I have to keep this exercise up?” Well, it turns out that a short-term bout of exercise is beneficial, but more is needed. We know from the data that if you discontinue training, you lose fitness by approximately 50% within 4 to 12 weeks. **[Slide 29]** So the bottom line is we want to embrace exercise. We want lifelong exercise, and it is worth it. We have so much data in Parkinson's showing that people with Parkinson's disease who exercise do better.

[Slide 30] In this study right here, there were 2,252 people with Parkinson's disease who filled out various questionnaires. And at one point in time, they were asked about their engagement in regular exercise. And so, in this group of over 2,000 people, they were divided into a group of people who exercised more than 150 minutes a week, compared to those who exercised less than that or not at all. And the results of this study showed that people who were at least exercising 150 minutes a week had better quality of life, mobility, physical function, and thinking. Also, they had less disease progression one year later. So, when they looked at them one year later, they were doing better across all of these areas compared to people who weren't exercising.

So then, okay, we all know exercise is great. We know we should be doing it, we have just shared with you the data about how important it is, and exercise should be part of the standard care for people with Parkinson's disease. It reduces disability, improves function and quality of life.

[Slide 31] So what gets in the way? Well, lots of different things could get in the way, and everybody might have various reasons that it's difficult to exercise. But we actually did a study with about 266 people with Parkinson's disease, and we found that not only did some of the things you might think of off the top of your head like not enough time, for example, or maybe fear of falling, those kinds of things might interfere. But also, things like low self-efficacy, which is low confidence. So, people didn't feel confident in their ability to exercise safely, maybe not having enough knowledge about what the best kind of exercises are to do or how much to do or the proper technique, those kinds of things.

We also learned that people had sort of low outcome expectation, which means they weren't really sure how much they were going to benefit from exercise. And I hope by sharing this data so far with you today you've learned that the benefits of exercise for people with Parkinson's disease are substantial.

[Slide 32] So how do you get started and get the most out of your exercise? Well, the first thing you should do is make an appointment with a physical therapist, a physical therapist who is knowledgeable about Parkinson's disease. In order to find somebody who's knowledgeable about Parkinson's, you can ask questions like, “Is there anybody in this physical therapy practice who's board certified in neurology or geriatric physical therapy?” They will tend to be more knowledgeable about Parkinson's disease.

And then they can give expert advice about the exercises that are best for you. We talked about those four buckets of exercise; but depending on your challenges, you might benefit a little bit more



from one than another let's say. And the physical therapist can help tailor that exercise program to help you meet your needs.

The important thing is that it's important to follow up with the physical therapist. Unfortunately, right now, some people with Parkinson's haven't even seen a physical therapist or haven't seen a physical therapist until late, until several years into the disease.

[Slide 33] Well, while that's good, we think we can do better. So here, what you can see in this picture here is that a lot of times there's no rehabilitation intervention early on; and it's not until later that people actually go to a physical therapist. Well, how about if we change that up? **[Slide 34]** Now, based on the evidence, what we know is that it's important to exercise early; and you can see a physical therapist early in order to find out what exercises should you be doing. How do you tailor it to meet your specific needs?

And then just like you go to your neurologist for a medication adjustment every six months, we recommend that you go to your physical therapist every six months for a checkup because one exercise program that you start off doing is not good enough for life. That exercise program, just like your medicines, has to be adjusted in order to get the best benefit. And so, it's important to check in with your physical therapist periodically and say, "Okay, what should I be doing differently? Can I make this more challenging?" or, "This isn't working for me, can I do something differently?" They can help you with that.

[Slide 35] We're also doing studies looking at other ways to reach people like using mobile health technology. In this particular example, we are doing a study right now where we're able to deliver exercises remotely through an app that you could access on your iPad or through your phone. So, this is in progress. We hope that more and more people will have access to that.

[Slide 36] So what are the tips to exercise successfully? Well, first, you should expect improvement. Raise your expectation. Exercise will help you. You will feel better. Choose something you enjoy; you'll be much more likely to stick with it. And then partner up. It's much easier to exercise if you exercise with somebody, maybe somebody else with Parkinson's disease or maybe a family member or a friend. Having an appointment or a schedule can help you stick to it. And then mixing it up, a little variety. We talked about the four important elements of exercise. You can do one form of exercise one day and a different form of exercise the next day.

And then you could think about joining an exercise class, which many of you may be doing already. Tai Chi, yoga, boxing, dance – these things can be beneficial, they can help with socialization and enjoyment, and help you stick to exercise.

[Slide 37] Walking happens to be one of the best forms of exercise. So many of you might be using various forms of activity trackers. These are great ideas. You can wear an activity tracker that tracks your steps that gives you some sort of way to monitor your physical activity.

In people with Parkinson's disease, sometimes the quality of the walking, it can be difficult. The steps can be sort of more shuffling in nature. When you're not thinking about the walking, sometimes the quality of walking can be reduced. So, to improve that, walking with music or a metronome is really



beneficial for people with Parkinson's. It helps you sort of improve the quality and the rhythm of walking so that the speed can be better, and you can actually get an aerobic benefit from walking.

We do recommend that people limit the amount of sitting. So, for every hour of sitting, there should be about five minutes of walking.

One thing to think about is when we talked about 30 minutes of exercise a day, the 30 minutes doesn't necessarily have to be all at once. There's data suggesting that walking for at least 10-minute bouts counts. So, imagine, you could actually walk 10 minutes three times a day and get in your 30 minutes.

[Slide 38] So here's the *Be Active* book I was talking about earlier. We've contributed to the *Be Active* book, and we've put together some exercises, we talk about aerobic exercise in here, and we show you pictures of strengthening and stretching so that you can get started today, and you have something that you can refer to with pictures.

[Slide 39] We also are funded by the APDA, and we have a national exercise helpline, so you can actually call us or email us with your exercise-related questions. We may also be able to help you find a physical therapist in your area. We keep a database of physical therapists around the country, and depending on where you live, we might be able to connect you with a physical therapist who is knowledgeable about Parkinson's disease.

So, at this point, we're going to shift, and I'm going to take some questions. Thank you.

Stephanie Paul

Thank you, Dr. Ellis. That was a very informative presentation today.

Question & Answer

Stephanie Paul

[Slide 40] So it's now time for the Question & Answer Session.

All right, let's get started. We have a question from the Web, and this comes from Deanne, and the question is, "How to keep from losing muscle mass in my arms."

Terry Ellis, PhD, PT, NCS

Okay, well that's where the resistance training or the strength training comes in; and so, the strength training can make the movements faster, but they can also make the muscles stronger. And with enough resistance and enough repetitions, you can also see some hypertrophy or some growth at the muscle level.



Stephanie Paul

Okay, great, thank you. We have another question from Julianne, and that question is, “We know what’s important, but how do we motivate ourselves to do it?”

Terry Ellis, PhD, PT, NCS

There is the big question. What a great question. And so, everybody’s a little bit different in terms of figuring out what motivates them.

So one of the slides that I had at the end talked about ways to just make exercise a part of your life; and so instead of having to make the decision every day to exercise, if you schedule it in ahead of time, either scheduling classes or scheduling an appointment to meet somebody to go for a walk, that can really take the decision-making part out of it so you’re not relying so much on having sufficient motivation in a given moment. But scheduling it in makes it much more likely that you’re going to actually show up and do it successfully.

I think things like wearing an activity tracker can be helpful because you can see your progress each and every day. And there are different activity trackers, but Fitbit, for example, they’ll send you messages and encouraging messages saying, “Great job. You did a great job today. Let’s see if you can do that tomorrow.” Those kinds of things help. But it’s a great question and something we all struggle with, and we’re actually doing some studies in that area now to try to identify ways to help people maintain motivation.

Stephanie Paul

That’s terrific, thank you. Okay, here’s an important question from Richard on the Web, and the question is, “How should medications be timed with exercise?”

Terry Ellis, PhD, PT, NCS

Excellent question. It is best to exercise when you’re in your best “on” state. So, once you’ve taken your medicines, usually it takes, it’s different for different people. But it might take 30 minutes or 45 minutes for those medicines to start working optimally. It’s at that point that you want to engage in exercise because you’re most, you’re sort of at your best and you’re better able to work at a high enough intensity and take advantage of the exercise so that you can have the optimal benefit.

Stephanie Paul

Okay, thank you. Here is a question from Daniel, and the question is “Foot pain from neuropathy is affecting my ability to exercise. Do I do more or less, i.e., walk more in spite of the pain?”

Terry Ellis, PhD, PT, NCS

That’s a perfect reason to go to a physical therapist. In that case, it’s really important that the exercise program is tailored to you. So, for example, if walking is painful, in that situation a stationery bike



might be a better option in order to get an aerobic exercise benefit. But I would highly encourage you to go see a physical therapist and make sure that the specific exercise plan is tailored to your needs.

Stephanie Paul

Okay, thank you. Here's a question from Shabir, and this is a little bit about types of programs. And the question is, "Any thoughts on movement programs such as the Feldenkrais method?"

Terry Ellis, PhD, PT, NCS

Well, the Feldenkrais method hasn't been studied enough in Parkinson's disease; so, we don't have enough data, for example, to say whether that's effective or not. And so, I would say two things. I would encourage you to engage in exercise in which we have a lot of evidence showing the benefits, like these things like aerobic conditioning and strengthening and balance training and stretching. However, what you want to think about if you engage in a type of exercise in which we don't have enough information on, is you just want to make sure that it's safe and that there's no serious adverse events that you're likely to experience, that the instructor is knowledgeable. So, you sort of have to judge whether it's a safe environment and the risks are low.

Stephanie Paul

Okay, here's a question from Yvonne, and her question is "Any suggestion for those with late stage Parkinson's or have more frequent falls to still maintain an overall level of activity?"

Terry Ellis, PhD, PT, NCS

That's a great question. I feel that everybody is capable of exercising, no matter what stage of the disease that you're in. It's just that the exercises have to be tailored to your specific needs. So, if falling and balance is an issue, then probably walking outside or walking on a treadmill may not be an option.

However, there are other things, like cycling on a recumbent bike, for example, in which there's more stability provided, so that the risk of falling and losing your balance is very low; but you can still get an aerobic benefit. But that's another example of really going to see a physical therapist to get an exercise program that's tailored to you, to make sure you're doing the best thing that you can do to address your needs.

Stephanie Paul

And here's a question, Terry, that is similar in terms of being limited. This comes from John. "What types of exercises do you suggest for somebody who's in a wheelchair?"

Terry Ellis, PhD, PT, NCS

Yes, it's a similar thing. I think people in a wheelchair can absolutely participate in exercise, but the exercise is typically done in a sitting position, either in the wheelchair or even lying down, for example. But the specific exercises that you would do, whether it's sitting or lying down, needs to be



tailored to you. It needs to be tailored to you because everybody's different. And I think we all understand that Parkinson's is so variable. Everybody experiences a different array of symptoms to a different degree, and so going to see a physical therapist and saying, "I really want to engage in exercise, and I need to know what is possible that I can do safely?"

Stephanie Paul

Okay, Terry, you said it's important for people to see a physical therapist and make sure they're working with experts. Here's a question from George, and it's similar to this. "Do you have any exercise safety tips for those who are living with Parkinson's disease?"

Terry Ellis, PhD, PT, NCS

Yes, I mean I think it's important to choose exercise that you can do safely. For example, if you have balance problems or fall or freezing, then walking on a treadmill is not a good idea. And so, what's safe for one person may not be safe for another person. So, I think choosing things that you feel confident that you can do, that you feel that you're safe doing. Generally, people who freeze can be very successful at riding a bike; and so that might be a safe and effective form of exercise.

But, and I think people walking, for example, if people notice they're walking, when they go for a walk that the walking tends to degrade over time, that walking with music or a metronome can help people keep taking big steps. And those big steps and that nice rhythm and tempo can help with safer walking.

Stephanie Paul

Okay, that's very helpful. Thank you so much. I believe we have a caller who would like to ask a question. So, if we can go to the phone question please.

Terry Ellis, PhD, PT, NCS

Sure.

Operator

Thank you. Our next call is from Shannon from Pennsylvania. Shannon, please state your question. Your line is now live.

Shannon from Pennsylvania

Hi, what are your thoughts on current trends in dance movement classes for the PD patient?

Terry Ellis, PhD, PT, NCS

Yes, I think dance is very beneficial. I shared with you some of the results of the studies that have been done on Tango. Dance seems to have, sort of broad-spectrum improvements can be experienced. For example, depending on the type of dance, people may or may not have an aerobic



benefit, so it depends on how rigorous the dance is. But dance can improve balance, for example, because you're moving forward, backwards, sideways, changing directions. There's also some evidence that dance, like learning new dance moves might be actually beneficial from a cognitive standpoint, so improving thinking and just that experience of learning a new task is actually good for people with Parkinson's disease.

So, I think dance is a good option for many, and it's fun, more likely to keep people engaged for longer periods of time. I don't think it has to be Tango necessarily, although that's where we have more of our evidence. There are other forms of dance that people may enjoy that may be beneficial as well.

Stephanie Paul

Okay, terrific. So, we talked a lot about the target heart rate. So, there is a question from Francis that says, "How do we calculate what our heart rate is supposed to be?"

Terry Ellis, PhD, PT, NCS

Yes, so heart rate can be, so I'll answer that in two ways. So, generally, you take the number 220 and you subtract your age; and then when you have that number, so 220, if you're 70 years old, you subtract 220, minus 70, and you get 150. And then you would take 60 to 65% of that for moderate exercise or 80 to 85% of 150 for vigorous exercise.

That being said, that can be a little complicated for a couple of reasons. And one is that not everybody can monitor their heart rate easily while they're exercising. And, secondly, some people with Parkinson's disease, the heart rate can be what we call blunted. Some people's heart rate doesn't respond in a sort of typical way. So, it might not always be a good indicator of how hard you're working.

To make it easy, I would recommend two things. If you use a scale of 1 to 10, 10 being very hard exercise, 1 being sitting down doing no exercise, a moderate intensity exercise would be somewhere around a 7. So, if you feel like when you're doing exercise that, oh, the difficulty level is somewhere around a 7, that's about moderate intensity. Or you can use the sort of talk test or breathing test. So, if you can say a sentence but you would have a little bit out of breath talking and saying a whole paragraph, that's also about a 7 or moderate intensity exercise. That's probably the easiest way to gauge the sort of kind of "just right level of intensity" to get at that moderate level.

Stephanie Paul

Terrific. I think we have another caller on the phone, so if you could please go to the phone question.

Operator

Our next call is from Beth from California. Beth, please state your question. Your line is now live.



Beth from California

Are there clinical studies that prove boxing helps minimize the progression of PD?

Terry Ellis, PhD, PT, NCS

There are a couple of small studies that have been done in boxing showing some beneficial effects. So, there's no studies that have been done in humans that definitively show a slowing of the progression of the disease, and that gets back to what we were talking about at the beginning of the talk where we don't have a way to measure it. We cannot measure the number of neurons that are preserved in the brain in humans that are living with Parkinson's disease. However, we have lots of evidence that exercise is beneficial at the behavioral level we call it, or we know that when we measure disability and function and walking and balance, there are substantial improvements with exercise.

So, boxing is an example of something that there's a little bit of aerobic exercise, there's some strengthening, there's some balance training in there, so depending on the particular boxing class you're engaged in, you're probably getting some elements of those three key components of exercise, which is a good thing.

So I think that when people think about participating in exercise classes like boxing and some of the dance classes and Tai Chi, you just want to make sure that you're doing it safely, that the instructor is well informed, that you feel comfortable in the class, that your technique is good, that you're using good quality movements so that you can get the best benefit out of the class.

Stephanie Paul

That's very helpful, Dr. Ellis. So, you've given us some terrific information today. So, if I can just sort of ask you one last question.

Terry Ellis, PhD, PT, NCS

Sure.

Stephanie Paul

If you had three key takeaways that you'd like our listeners to get from this call today, what would those be?

Terry Ellis, PhD, PT, NCS

I think the biggest, the first thing is to embrace exercise. Exercise should be part of the standard care in people with Parkinson's disease. Think about exercise like you think about medicine. You need a daily dose of exercise in order to manage your symptoms associated with Parkinson's disease.

Secondly, I would recommend that people find a physical therapist; and find a physical therapist with expertise in Parkinson's disease because not only do you need a neurologist with expertise in the



pharmacology or the medical management, you need a physical therapist with the expertise in exercise who can help you across a lifetime.

And then third, I would say there's a lot of choices that you can make relative to exercise, so choose something you enjoy, choose something you like, choose something you're most likely to stick to, and then do that at the sort of just right challenge level to make sure that you can get the optimal benefits from your exercise program.

Closing Remarks

Stephanie Paul

[Slide 41] Perfect. That's wonderful. Thank you so much, Dr. Ellis. [Slide 42] And my thanks to everyone for participating in today's telephone and Web education program. I do apologize that we couldn't get to all of the wonderful questions. But if you have a question or would like to speak with someone from our Scientific & Medical Affairs Department, I encourage you to visit our website or call 1-800-223-2732 and you can ask your questions there.

I'd like to thank Dr. Ellis for her presentation. I also want to emphasize to everyone on the phone that we really do appreciate your feedback and comments and want to make sure that you complete the program evaluation form.

APDA is so proud to support those living with Parkinson's disease by helping them live life to the fullest every day. We do this each year by providing more than 1,700 support groups that serve more than 75,000 people with Parkinson's disease and their family members and through running 770+ exercise groups attended by more than 21,000 participants. These exercise programs help improve the symptoms of Parkinson's and lessen the impact of disease.

We also offer educational symposia across the country on living well with the disease. These programs have been attended annually by more than 5,500 people impacted by Parkinson's. We rely on the support of the entire Parkinson's community to accomplish all of this.

To join us in this fight against Parkinson's and to learn more about the support APDA provides across the country through our network of chapters and information and referral centers, as well as our National Research Grant Program and Centers for Advanced Research, please visit us at APDAparkinson.org.

Again, our deep thanks to Dr. Ellis and to all of you for joining us today.

We all agree that being informed about your disease and treatment options is the best way to empower yourself and take control of your care. Have a wonderful day.