



Transcript

Welcome and Introductions

Rebecca Gilbert, MD, PhD

[Slide 1] Welcome everyone and thank you so much for joining us today. **[Slide 2]** My name is Rebecca Gilbert, and I am APDA's Vice President and Chief Scientific Officer.

I'm 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 like to thank the Simone Charitable Foundation for funding this important program and acknowledge their appreciation for the critical need to provide educational programs like this one to people impacted by Parkinson's disease.

During this time of uncertainty, we know that you still have concerns regarding your Parkinson's treatment and want to identify ways to continue to live your best life with PD. American Parkinson Disease Association, or APDA for short, 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. APDA distinguishes itself as a national organization working one on one with the Parkinson community to make each day better.

[Slide 3] And now to our program. Our presenter today is Dr. Holly Shill, Director of the Muhammad Ali Parkinson Center and Movement Disorder Program at Barrow Neurological Institute, Dignity Health and St. Joseph's Hospital and Medical Center in Phoenix, Arizona.

Today we are delighted to have Dr. Shill share with us information to help you map out the future of living with Parkinson's disease. After the presentation, we will open the program for questions from both telephone and Web participants. We encourage everyone on the line 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.

It is now my pleasure to turn the presentation over to Dr. Shill.



Presentation

Holly Shill, MD

Thank you, Dr. Gilbert. It's really my pleasure to join you, and I really thank the APDA for giving me this opportunity to speak to you all in this virtual manner. I really appreciate it. I think it's a wonderful way to maintain our connections here during this pandemic. So really appreciate the opportunity.

[Slide 4] So just starting off with some disclosures, just so you all know some of the funding sources that I receive. So, most of the work that I do is research in Parkinson's disease. Most of my funding sources and a lot of the things that I'm talking about have been based on some of the research that we've done over the last 20 years or so of managing Parkinson's disease.

[Slide 5] So what I want to talk to you today about is really just how to live well with Parkinson's disease. What I've learned over the last 20 years, both through just clinical management of patients and their families with Parkinson's, but also what the research is telling us, and how do you take all of this information, all of this data, and put it into your daily lives so that you can have better quality of life with Parkinson's? And we're going to be talking a little bit about sort of palliative care principles, which I'll get into here in a minute, and just how that is really applicable to living with Parkinson's. So, let's get started.

So, just some statistics to start with, and these are some, kind of alarming statistics; and I put them in on purpose to really kind of grab your attention. So, the first idea is that Parkinson's is on the increase. There are, for a variety of reasons, mostly because of the aging of the population, but also because of just better care of other health conditions, we are seeing more people living longer and, therefore, more people getting Parkinson's disease.

So, it is actually starting to outpace Alzheimer's disease; so, it is growing faster than Alzheimer's disease, and so that's kind of an interesting statistic. So, long and short is more people are going to be living with Parkinson's.

Another factor is Parkinson's can play a role in loss of employment. The average age of onset for Parkinson's is in your 60s, in your early 60s, and so that's during people's working careers. And so there may be more people not working and living with Parkinson's, and so how do you maintain that quality of life if you are no longer employed because of Parkinson's? What can you do? How can you make everyday count?

So, another kind of alarming statistic is about half of Parkinson's patients are treated by their probably primary care physicians. Only about half actually make it to a neurologist for more specialty care, and so what that means is that oftentimes people's primary care physicians are trying to manage just about everything else in terms of your overall health, your thyroid condition, your blood pressure, that sort of thing, as well as trying to squeeze in Parkinson's management. And so, I think what that means is patients have to be their own advocates a lot of the times of being really well educated about their disease, knowing what conditions to bring up to their treating physicians, and then also when to ask for specialty care and when it's appropriate for that.



And then some more things related to more advanced stages of Parkinson's is that one thing we have realized is that the mortality rate due to Parkinson's disease, or not necessarily due to Parkinson's, but people living with Parkinson's, is higher than we once thought. So, and again that reflects because of the aging of the population, the better care of things like heart disease and cancer, people are actually living longer and so dying either because of, or with Parkinson's disease is a greater potential. And then this concept of skilled nursing being in the more advanced stages of Parkinson's disease can be as high, almost as high as 50%. So just some statistics to kind of file away as we get started.

[Slide 6] So this concept of palliative care, and this is something that we've been doing really, I think, since the beginning. We started this program in 1997; but I really, in the last several years, maybe two to three years, and we've really decided that we need to focus more on this concept of palliative care principles. So, people think about palliative care as end-stage cancer and that sort of thing. But really, I think it can apply to any of these types of conditions that are chronic health conditions that are having an impact on quality of life.

So, what is palliative care principles? It's really focusing on the person living with the disease rather than the disease itself. So not just looking at you because of your tremor or your shuffling gait or something like that, but rather this is a person who has a tremor that's affecting their ability to work or their ability to play golf or whatever their hobbies are.

So palliative care principles focus on relief of suffering. So, what are the issues? And it may not all be disease related. It may be social issues and that type of thing. So, the quality of life, not the quantity. So palliative care principles often involve the caregiver and the care partner in Parkinson's disease. It's an intensive management of complex symptoms, so it's not just the looking at the movement symptoms of Parkinson's, the tremors, the slowness of movement, that type of thing, but also all of the nonmotor issues that affect people with Parkinson's. And we'll talk about all of these things.

And this idea of using the team approach. So, it's not just your neurologist; it's not just your doctor. But it may involve a social worker. It may involve a Parkinson's nurse. It may involve a chaplain, a counselor, a nutritionist, therapist, physical therapists, occupational therapists, so all those types of things that come into your team that you're building to manage Parkinson's. And so, this idea about palliative care is about living as well as you can for as long as you can. So, the idea of having every day be a good day or as best of a day as possible related to Parkinson's.

[Slide 7] And then talking about when do you think about implementing palliative care? So, I'm actually a big believer in doing it right from the get-go, right from the time of diagnosis to start at least applying those palliative care principles. So, the time of diagnosis where people are all of a sudden struggling. I've got this new diagnosis. I thought I was going to be able to travel the world and have all of these hobbies and things in my retirement career, and now I'm facing Parkinson's. That's a good time to start to think about not just seeing the neurologist but also do I need to talk with a counselor about this impact, a social worker, that type of thing.

And then things like change in level of function. So after maybe a fall with an injury, after an illness, or as Parkinson's progresses with cognitive decline, if that starts to occur. So, assistance with activities



of daily living, so if people are starting to struggle more, doing things on their own and starting to need some help with that.

So psychological issues. Sometimes right at the beginning of Parkinson's, people have considerable depression and anxiety, up to 40-50% of patients. And those are big issues that are sometimes hard to deal with in a single visit with your neurologist. So, thinking about these, kind of outreaching into palliative care principles.

Care partner distress. Are there issues that your spouse or whether it's your adult children or your friend or what have you is facing because of your diagnosis? And then more of an end-stage thing when we would traditionally think about palliative care is people with more advanced disease. And I think that's typically where we think of palliative care. But I would argue that you should be considering these palliative care principles, trying to implement them as best as possible along the whole course of Parkinson's.

[Slide 8] And I'd be kind of remiss if I didn't talk about Parkinson's and COVID because I know many people often have questions about the impact of coronavirus and how it's affecting people with Parkinson's, so I thought I'd spend just a minute talking about that.

So, people often ask, "Are people with Parkinson's at higher risk for getting infected by COVID?" And the answer is "probably not." So, we don't think of Parkinson's as affecting our immune system, so we shouldn't be immunosuppressed with Parkinson's. And we also don't think of Parkinson's as affecting the lungs themselves, and we know COVID is basically a viral pneumonia that affects the lungs. And so, we don't think of people with Parkinson's as being greater risk for it.

However, most people with Parkinson's are in the age group where they might be at a higher risk for having kind of an adverse outcome for Parkinson's. So, is there a risk for adverse outcomes like hospitalization, like requiring ventilators, like mortality with COVID? There may be a little bit of a higher risk. I think any infection can hit people with Parkinson's harder, but overall, we don't think of Parkinson's as one of those main comorbidities that really increases risk. So, really, you're going to be looking at your other health conditions and things to get a sense of your overall risk if you were to contract COVID. So that being said, this is a virus we want to avoid and not get no matter how old we are, no matter what comorbidities we have, that type of thing.

And then that, I think, brings to the social impact of Parkinson's and probably the social impact of COVID overall and probably most of what we are seeing is people aren't getting infected at high rates, but they are certainly suffering from the social impact of the isolation, the inability to get out and exercise, the inability to be as social as we were. And we know those are tremendous things with Parkinson's. We'll talk more about that as we go. And in my mind, this is the major impact of COVID on Parkinson's has been this impact of isolation and really trying to figure out ways to still stay connected with people. And, hopefully, that's what you're doing today by participating in these webinars is kind of learning to stay connected.

[Slide 9] All right, so we're going to talk a little bit more statistics and things, so what do you need to know at the time of diagnosis for Parkinson's? What do I like to leave people with when I first make a diagnosis of Parkinson's?



So first of all, I like to tell people to get educated. So, learn about research, learn about what's going on in Parkinson's. We don't have a cure for Parkinson's, but we are working on it, and I'll show you. The next slide is a little bit of some of the research that we're looking at overall. So, but learn what's going on. Learn if you're a candidate for study.

So, most of the studies done in things to try to slow progression of Parkinson's are done in people who are newly diagnosed, and so that's really an important time to think about research, as well as throughout the entire course of Parkinson's. Get educated. Know what you're dealing with. We'll talk a little bit about some basic concepts of Parkinson's.

At the time of diagnosis, look at the impact of Parkinson's on your work and hobbies. Take a reflection of what you're doing now and see how Parkinson's may impact you today, tomorrow, as well as five or ten years from now. And then the other thing we'll talk about is when to start Parkinson's medications, when is it appropriate, when do we think about changing medications across the course?

[Slide 10] So let's talk a little bit about research because this is the hope. This is our hope for the future, and when we're talking about palliative care, one of the best things that you can keep with you every day is the hope for a better tomorrow. And so, in my mind, that's what research really brings us is that, hey, we're actively working on things. We're actively looking for a cure. We're actively trying to get therapies that are better for people.

So, this is a study of a publication that was done called the Parkinson's Disease Pipeline, just recently published in early 2020, looking at what all is out there. And at the time of the report, there were 145 active Phase I through III clinical trials in Parkinson's. And you can see the breakdown there: 26% were Phase I, which is kind of early phase looking at drug tolerabilities and in humans, that type of thing. So, Phase II studies then start to look at efficacy as well as doses for drugs, and you can see there's 42% of studies are in Phase II. And then Phase III are the studies that are really looking at FDA approval. So, these are the larger studies with often large numbers of patients in them, really saying does this drug work? Does it really help people? And if the study's positive, it will lead to FDA approval.

And then the next breakdown is looking at what were symptom therapies versus disease modifying? So, disease modifying are things that change the outcome or slow the progression of Parkinson's, and you can see almost 40% of therapies in 2020 are looking at disease-modifying therapies. So, there's a lot going on. That's the part of hope that I want you to take with you, that there's a lot going on. So even though we do not have a cure for Parkinson's, we are looking every single day to try to find things, and we are getting smarter about it.

[Slide 11] So here are some of the things on this next slide of disease-modifying trials. I just took a few of the highlights in my mind of some of the things that are really exciting. So, there's these what are called kinase inhibitors. So, we know that there's a genetic mutation called LRRK2 (leucine-rich repeat kinase 2), which increases people's risk for developing Parkinson's disease. And that's not even relevant in people with the LRRK2 mutation but also in just sporadic Parkinson's itself. And so, there's been this development of kinase inhibitors that look to be promising in the early phase studies; and so, we're really excited about that. They're still fairly early in development but are coming along.



So, there's ASO, which is called an antisense oligonucleotide. It's just a little bit of almost like genetic material that binds to that gene to basically inhibit it and some really crafty things that are trying to get at the basic roots of what we think is associated with Parkinson's progression.

So, these immunotherapy studies that are looking at monoclonal antibodies against the protein that accumulates in Parkinson's, so-called alpha-synuclein. Gene therapy studies, I'm looking at inserting little bits of genetic material into different parts of the brain to make your dopamine system work better and to provide growth factors to the brain, so very interesting types of studies.

So, these, what are called GLP-1 agonists that are actually mostly used in diabetes but have been mostly in Europe looking at slowing progression in Parkinson's. There's some studies looking at glucocerebrosidase targeting, which is another genetic abnormality that can be seen in Parkinson's. So, targeting that and then some interesting ideas out there of various fungal extracts, some botanicals targeting the microbiome in Parkinson's. So, there's some interesting studies looking at the gut-brain connection.

So, a lot of things going on, a lot that is, in my mind, very promising. And as you kind of think about palliative care, that idea of these studies going on in the background to give you this hope for the future. So even if you don't qualify for a research study to know that they are going on I think is such a wonderful thing to provide a hope of a better tomorrow.

[Slide 12] So the next thing is just kind of education on Parkinson, so understanding your disease across the spectrum of how it starts from the beginning, 5 years, 10 years, 15 years. What does that look like, that kind of trajectory of Parkinson's? I think it's hard for us as neurologists to predict what's going to happen to patients when we're first meeting them in the clinic. But there are some basic concepts that I want to just make sure that you all understand.

So, the first concept is Parkinson's as motor symptoms. So, when we make our diagnosis of Parkinson's, we think of tremor, rigidity, so that sort of stiffness in the limbs, bradykinesia, which is slowness of movement. So those are our motor symptoms that we lean on to make a diagnosis of Parkinson's disease.

And these are the things that contribute to mobility, so troubles with fine motor skills in your hands, slowness of walking, that type of thing. So, the other important concept with motor symptoms is that this is what we mostly are treating with our medications. And so those motor symptoms will respond to medication, and then over time you can see the slide on the right side, the therapeutic window narrows over time. So, people will start to develop what's called on-off phenomenon where the medications will kick in and work for a while and then wear off. And that can happen with each dose of the medication, particularly the levodopa medication.

So, and then over time, you can actually start to see more levodopa-resistant symptoms over time. So, for instance, people might start to develop some freezing of gait, they might start to develop some postural instabilities that may lead to walking problems, balance problems. And those things we think of as being a little bit more resistant to our medications over time.



So, when we talk about prognosis, you've got somebody sitting in front of you, what can you tell them? Most of these symptoms remain. The motor symptoms will remain stable for about the first five years, and then over time you start to see more of these motor fluctuations and then more of these dopamine resistant-type symptoms, so gait and balance issues, that type of thing over time. So that's kind of from a prognosis of the motor symptoms.

[Slide 13] So next we're going to move to the nonmotor symptoms, and in my mind, this is probably almost equally important because many of these things can drive quality of life to a significant degree. So just when you think you've managed some of these motor symptoms, the nonmotor symptoms can start to be somewhat of an issue for people. So, what we call the tip of the iceberg here, so the tremor and slowness of movement being the iceberg on the top. Those are kind of the things we see when we see the patient. But all of these things lurking under the surface that often drive quality of life, so things like mood. We'll talk a little bit more about that. Sleep, we're going to talk about that. So, constipation, bladder issues, urinary urgency, that type of thing. Blood pressure issues, so sometimes people with Parkinson's, their blood pressures drop. Reduction in sense of smell which can lead to decreased appetite. Cognition, so people with Parkinson's may develop some cognitive issues. Sometimes even at the beginning folks can have some mild cognitive issues, and over time that can be more prominent and bothersome for folks.

So, side effects of medications such as hallucinations and compulsive behaviors can start to drive quality of life over time. So, fortunately, they're not extremely common; but they can be an issue. So, skin issues with Parkinson's disease. So dry skin, scaly skin. So, these things. And then probably last and not at all by the least of things is fatigue. So up to 70% of Parkinson's patients have significant fatigue, which can be a main driver of quality of life for folks. So, you say, "Yeah, my tremor doesn't really bother me, but I just don't have the energy for things."

And I'm going to talk about a few of these, which are, in my mind, the most important things. You know, the ones that I think really if you address can have a tremendous impact on quality of life. So those are the ones that I really want to focus on as we talk.

[Slide 14] So before we do that, I just want to talk a little bit about addressing work and hobbies with Parkinson's. And why do we need to consider this? So, if you think about, I don't know, blood pressure, I mean you could have a blood pressure of 200/120 and be walking around and nobody would ever notice that you're one day away from having a major heart attack or a stroke. Whereas with Parkinson's, it's there every day. It's kind of in your face. You can't ignore it. And so, because of that, I think it has such an impact on people's ability to do the things that they enjoy – so whether that's work or hobbies. And so just going through some of these things.

So, Parkinson's may cause symptoms that are visible. So, if you have a job or a hobby, say you're a salesperson and your hand is trembling, I mean that can be something that might be quite distracting and bothersome in your daily life. So, Parkinson's may cause a change in your voice, so a softening of your voice. If you're a professor at a university, it may be hard to do your lectures. So, Parkinson's may cause difficulty getting your thoughts out. So, getting your words out, getting your ideas out. So, Parkinson's may cause fatigue. So, if you have a job that requires a lot of energy demand, if you're a PE coach or something like that, you can see how that might be a major impact on your ability to do



your job. So same with balance issues and hand coordination. So just depending on what your work is and what your hobbies are, you can see a variety of ways that Parkinson's may have an impact there.

And so, what I want people to do at really almost any stage of Parkinson's is think about what you're doing now and trying to stay successful at doing what you are. If you're still capable and finding joy in what you do, if it's pleasurable to do your job, then by all means keep doing it. If you feel like you're doing a good job, you should keep doing it by all means.

But then I want people to think about kind of a backup plan. So, what is the plan B? What is the plan C? So, what if I can no longer do my job? What am I going to replace that with? So, what if I can no longer golf or have a hobby that's having an impact because of Parkinson's? What am I going to replace that with?

So, people always need a purpose, so you always need something that you can find joy and find pleasure in. So, and it's not always just sitting there watching TV or Netflix. You really do need to find hobbies and things that you enjoy. So, think about those things. Give it a lot of thought. Sometimes it's doing things with other folks with Parkinson's. And whether it's an exercise class or an art class or a dance class or something that is for folks with Parkinson's, there are many opportunities out there that can allow you to stay engaged. So, what I just don't want people to say is, "Oh, I'm retired or disabled from my job, and now I'm just going to sit and watch television." So, I like to think of people picking hobbies now that can be very amenable to having a diagnosis of Parkinson's.

[Slide 15] Next concept is when to start or adjust Parkinson's medication. So just because you have a little bit of tremor or just because you have some slowness of movement, does that mean you need to start medication right away? And really the idea with treatment is what is the person feeling? What are the symptoms? What is it that's bothering them? Not what does the neurologist see? "Oh, hey, I see you've got quite a bit of tremor there," that type of thing. But really, it's asking the patient what is bothering them.

So, when I think about you going to your doctor to talk, it's really, "Oh, my gosh, not that I, yes, I've seen some progression since the last time I was in. This is what I've seen." But, no, rather, "This is what is bothering me. This is what I would like you to address as best as possible. So, this is the thing that's making an impact on my quality of life."

So we want to try to reduce disability, so whether it's people's occupation, their walking, their balance, their chores or things they do around the house, or their self-care things, their activities of daily living, we want to minimize that impact of Parkinson's on that. So, thinking about what you do in your daily life where Parkinson's is making an impact and say, "This is what I want to work on to get it better." So not just the symptom but rather the specific task, the chore, and then let the neurologist then figure out, okay, how best is this to address so that people can maintain that quality of life.

So socially disabling symptoms. If it's a tremor that's really bothersome for people, then trying to address that so that they can be more comfortable going out in public. So, reducing the complications of Parkinson's so if it's something like the medications are starting to have wearing off or starting to trigger involuntary movements, so dyskinesias, so how do we manage those things? Are they having



an impact on the person's quality of life? So not just are they happening, but are they having an impact?

And just remember that almost all of the medications approved to treat Parkinson's work on the motor symptoms of Parkinson's. **[Slide 16]** And then here's just a list of medications. We talk about early treatment. We talk about agonists versus levodopa. The reality is that most people end up on a combination of medications, and what we know is that there's really not a lot of difference after seven to ten years of follow-up in Parkinson's. It doesn't really matter what you start.

And so, what the important thing is, is to pick the medications that you best tolerate and best help your symptoms. So rather than worrying about, oh my gosh, is this going to slow the progression five or ten years from no, No, what you want to worry about is, is what you're feeling like today and how best those therapies are helping you. And that's true whether you're talking about early treatment or advanced treatment.

[Slide 17] So I have a brief slide on here about new Parkinson's medications overall, so here's just a list of them. All of these ones on the top part of the slide are approved for off symptoms in Parkinson's. So that's been a big push lately in Parkinson's management is all these FDA-approved therapies are approved for off symptoms in Parkinson's. So, safinamide is a new MAO inhibitor, opicapone a very new COMT (catechol-O-methyltransferase) inhibitor, and then Inbrija[®], an apomorphine, are these what are called kind of rescue medications that are used for sudden off periods in Parkinson's. The sublingual form was just approved in 2020, and that's what the newest version of this apomorphine is. And then istradefylline is an interesting drug that is a novel mechanism of action, what's called an adenosine 2A receptor antagonist; and so, it reduces off time in Parkinson's.

So, here's some of the new medications. I encourage you to kind of get familiar with them and look and see if they might be something that is useful for you. And then the ones on the bottom, Gocovri[®] and Osmolex[®], are approved for levodopa-induced dyskinesias. So, these are the involuntary movements associated with levodopa use over time. So, after a period of time, maybe up to 50% of people will have dyskinesias; and sometimes that's bothersome enough that it needs treatment. So, there's a lot going on, lots of new improved things.

[Slide 18] So exercise. I think exercise is just about as important as the medications in Parkinson's, if not more important. So, finding a way to exercise. There is tremendous research on the benefits of exercise in Parkinson's, and I'm just highlighting some of the results of some of the studies over the years. We know that it improves muscle strength. We know that it reduces instability. We know that it reduces your fall risk, and we know that it improves your quality of life.

We also know the type of exercise that people need to do. So it usually is a combination of both resistance training as well as aerobic exercise, so things like treadmills, cycling, bicycling, walking, those types of things can be very helpful, as well as Parkinson-specific things like boxing and there's a thing called Power Moves, which is a Parkinson-specific exercise program. Those all are things that have been shown to improve people's function as well as quality of life. So, stretching, I put stretching in here. Stretching actually has not been shown to improve quality of life. So if you think when you get up every day and you do a little bit of stretching and you say, "Wow, I feel a little bit better with that,"



you're actually not necessarily improving your day-to-day quality of life with Parkinson's disease. So, it really needs to be fairly high intensity exercise in order to really make an impact. And this is the one thing that's been shown to help with fatigue in Parkinson's.

[Slide 19] Another important nonmotor symptom with Parkinson's is addressing mood. We know that depression and anxiety can be seen in up to 40 to 50% of patients with Parkinson's. It peaks early in the course of Parkinson's, at the time of diagnosis, and as well as more advanced Parkinson's. And it is an independent predictor of quality of life. Say your mobility is actually pretty good and things, but yet you're depressed, I can tell you, you will suffer a worse quality of life. And so, addressing that, first of all, recognizing it and addressing it is another very important thing you can do to make a day-to-day impact on quality of life. It is very treatable. There are lots of options. SSRIs or selective serotonin reuptake inhibitors, the noradrenergic reuptake inhibitors, as well as tricyclic antidepressants. So, I encourage if depression is part of Parkinson's for you to make sure that you're discussing it with your providers because it is such an important predictor of how people feel on a day-to-day basis.

[Slide 20] So sleep is another one. So, again, if you have to pick symptoms that really can make an impact on your quality of life, addressing sleep is another one. So, most people with Parkinson's don't sleep well. Up to 98% of people report poor sleep, and there are many causes for it. So, it can be physical symptoms. It can be your bladder keeping you up. It can be arthritis pain. It can be your anxiety that's keeping you up all night. You could have sleep apnea. You could have restless leg syndrome. You could have very vivid dreams that are happening at night.

And all of these might have different approaches to treatment, and so trying to identify why you're not sleeping well I think is one of the first things. **[Slide 21]** And then also this concept of good sleep hygiene, and I've got a slide on that here which is everybody should be practicing good sleep hygiene, even if you don't have Parkinson's. So, and here are just some things that I like to recommend to my patients.

So, getting rid of false beliefs. You don't always have to have eight or nine hours of sleep a night. So, you're allowed to have a bad night every now and again. Avoiding stimulants prior to bedtime, avoiding diuretics like alcohol and caffeine, trying to exercise which will help your body be more sleepy at nighttime. So, keeping the room cool and dark. Avoiding stimulating activities right before bedtime like watching the evening news and that type of thing.

And then just be mindful, a lot of the over-the-counter medications might cause confusion; and so, do talk to your doctor about those. It's an important thing to mention. So, practicing good sleep hygiene is another important thing in quality of life.

[Slide 22] So fall risk in Parkinson's. So, don't fall. Really, I mean it. Don't fall. So, we see people with Parkinson's disease can fall. Up to 55% fell in the last year across all stages, and up to 30% of falls can result in a fracture. It is a leading cause of nursing home placement, and I think most causes of falls are preventable. So, I'm always just amazed at how many of my patients say, "Yeah, I fall once or twice a day." And I'm, "Why are you falling? There should be no reason for that." So many ways to address your fall risk.



So, exercising, physical therapy, occupational therapy, addressing cognition. So, some people are falling because they're not paying attention to where they're moving their feet, and that can be an issue. And then using assistive devices where appropriate and working with your physical therapist or your neurologist about what is an appropriate assistive device for you. Addressing bone health so that you're both at lower risk for falling; so, addressing bone health can reduce your risk of falling. But it can also reduce your chance of fracture if you do fall.

If your blood pressure's an issue, if your blood pressure's dropping, so addressing that. When you stand up, if your blood pressure drops, and addressing that is important. So that is a leading cause of nursing home placement is fractures due to falls, and so if you want to stay out of the nursing home, this is a way to do it.

[Slide 23] When do we consider additional caregiving in Parkinson's? So, Parkinson's is a slowly progressive condition, and it's hard to know when is it time, when do you consider, do you need additional help? So, it could be 5, 10, 15 years into diagnosis before people start to need additional caregiving.

And so, what are those clues that say you may need to call on additional help? When is it not enough to just kind of go it alone or go it alone with your spouse? So, things that I kind of say as red flags are things like frequent falls with the injuries as a result of them. If you're calling 911 to have the paramedics come pick you up on a regular basis, then probably time to think about it.

Significant hands-on care, needing additional assistance at night, a presence of cognitive issues that people are starting to develop some cognitive issues. And then needing assistance with medication. So, you're needing help setting up your medications and even administering them. Those are all times when the caregiving needs start to go up with people with Parkinson's, and I think that's a time to start at least talking about getting some additional help.

And lots of options for that, whether that's having somebody come in to just take some of the load off of it, thinking about assisted living or group homes, depending on the demands on sometimes things like assisted living or actually less expensive options than bringing people into the home. And so, starting to think about those things when you start seeing an increase in that kind of hands-on care that you're providing to your loved one.

So, there are often state programs. Arizona has a state Medicaid program that provides for long-term care for folks. Our VA (Veterans Affairs) system does as well, so some of the things that you can consider for additional caregiving.

[Slide 24] I've got this kind of funny slide to talk about the world mortality rate, and we're kind of getting towards the end here as we wrap up. The world mortality rate, and no matter what we do, is 100%. So, as we live, that is one of the kind of last things of life is that we eventually will pass away. And so, I think that's a reality for us, whether we're living with Parkinson's or whether we're just getting older. And so that's kind of a funny slide. And people can stick their head in the sand all they want, but at some point, this is something that we are all going to have to face.



[Slide 25] And so I want to start to finish here with talking about these more sort of advanced stages of aging as well as living with Parkinson's. So, this isn't something that's unique to Parkinson's. It's just aging in general.

But there's some interesting statistics in Parkinson's that say only 9% of people with Parkinson's die in their home versus 17% of the elderly. So, 55% of folks with Parkinson's will die in the hospital setting, and then less than 1% of people with Parkinson's receive hospice services. So, and to me this is sort of tragic. If you actually ask people about these things, most people actually say they want to die in their home, surrounded by their family members. And so, to me it's somewhat tragic that we see these statistics in Parkinson's.

And so, what I encourage you to do is to think about this. Talking with your family, not just talking about CPR in the event that your heart stops or putting on a ventilator, that type of thing, but things like where do you want your care to be? So, do you want people to come into your house? Do you want to think about an assisted living? Think about that now, not 5 or 10 years from now when it now is becoming a more critical issue.

So, who do you want doing your care? So, do you want one of your family members? Do you want to hire somebody to do that? You know, think about those things.

Think about your hospitalization. Under what circumstances do you want to be taken to the hospital, and what circumstances would you prefer not to? So, all of those things, I think, are things you can think about. While you have time to think about them, talk with your family about them so that they know your wishes and so can honor those wishes as you progress not just through Parkinson's but also through life in general.

[Slide 26] And then the last concept is spirituality, so this is another concept of Parkinson's. So, and the basic concept is are you at peace? And if not, why not? So, we can't do anything about the diagnosis of Parkinson's. We can't make it go away yet, and so I think we have to find a way to be okay with that, so to not fight it every day in the sense of sort of denial of illness and that sort of thing. And so, I think about spirituality. It's not just religion but looking for purpose and meaning in life, connecting to self and others, connecting to nature, and connecting, feeling like we have a higher purpose so that every day that we're getting up, we're trying to make something, making our own lives better, making other people's lives better.

There were some interesting studies that say up to 85% of people with Parkinson's are embarrassed by their Parkinson's disease, and I find that just tragic. I think we need to find ways for people to be more at peace living with Parkinson's.

[Slide 27] So I'll leave you with these concepts. So be kind to yourself. Forgive yourself. You're not perfect. It's okay to have bad days. It's okay to be a little bit irritable. So be kind to yourself.

If you're a care partner, find joy in caregiving, not just think about it as a job, but find the joy in being able to be with your loved one and provide that hands-on care. I think that's something, there's something very sort of spiritual about that.



If you're a patient who needs care, allow yourself to be cared for. So, don't fight it. Be someone who is appreciating that care and thankful for the loved ones that are involved in your life. So, find a way to meditate and breathe. There's some interesting studies on mindfulness and just spending 15 minutes a day kind of connecting with yourself, maybe connecting with nature, acknowledging strong emotions, and then reaching out and getting support. Don't feel like you have to go it alone.

And I'm going to leave you with that concept and say thank you, and I will turn it back to Dr. Gilbert for the Question & Answer session. Thank you for your attention.



Question & Answer

Rebecca Gilbert, MD, PhD

[Slide 28] Thank you so much, Dr. Shill, for your very detailed and informative presentation. That was fantastic.

[Slide 29] It's now time for the Question & Answer session. We're going to take our first question from the Web audience. So, we have a question from Michael. It is said that one doesn't die from Parkinson's disease. So, what does a PD-related death mean?

Holly Shill, MD

Yes, it's a really good question. And you're right. It's actually fairly rare that people die from Parkinson's itself, unlike things like ALS (amyotrophic lateral sclerosis) and that type of thing which really can be a direct cause of death. So typical things would be things like pneumonia; that's probably the number one cause of death with Parkinson's disease. And we do typically see that in more kind of frailer individuals that they're at higher risk for developing pneumonia. But that's what we mean by that, and so people will say as a complication of Parkinson's. So, say you fall and have a hip fracture and then really don't recover for that. So, people will say it's a complication of Parkinson's disease but not necessarily Parkinson's disease itself.

Rebecca Gilbert, MD, PhD

Okay, great, thank you. We have another question, this time from William. "Can you comment on the neuroprotective effects of exercise?"

Holly Shill, MD

Yes, very good question. So neuroprotective effects of exercise. So, interestingly, it's been shown in animals that it's neuroprotective. So, if you put a little rodent on a treadmill, you can see that they actually do better with the little animal model of Parkinson's disease.

So, it's really hard to demonstrate it in Parkinson's patients though, so that's the hard thing. So, we know that it works in animals, but we don't know for sure that it works on humans, but we think that it does. And so, there are some interesting imaging studies and things like that that show that exercise might be neuroprotective. We do for sure know though that exercise reduces disability, which I think in an effect is sort of slowing progression or slowing the rate of disability due to Parkinson's. So absolutely exercise is an important thing.

Rebecca Gilbert, MD, PhD

Great, thank you. We have another question about assessing cognition. So, there are some really basic tools that are used in the clinic like a MoCA scale (Montreal Cognitive Assessment). Can you talk a little bit about other tools that can be used to more accurately and more comprehensively assess people's cognition when they have Parkinson's disease?



Holly Shill, MD

Yes, very good. So, yes, you're right. In the clinic, so if you see your neurologist or even a primary care physician, they might do a thing called a MoCA, which is just a brief screening. It's a 30-point scale and just kind of done in the office. It takes about 15 minutes or so, and there's scales that you can look at. So, a certain cutoff for what's called mild cognitive impairment and then another certain cutoff for dementia. So that can be used to screen for cognition. But if you really want to get a more detailed assessment, you will see what's called a neuropsychologist. So that's somebody who actually does detailed testing in cognition. That testing can take up to three to four hours or so to complete, but it's very thorough and really gets at both cognitive abilities as well as issues related to mood, anxiety, that type of thing. So those can be really comprehensive and useful assessments.

Rebecca Gilbert, MD, PhD

Okay, fantastic. Should we take a caller that's coming in through the phone?

Operator

Our first question is from Douglas from Tennessee. Douglas, please state your question. Your line is now live.

Douglas from Tennessee

What is the state of monoclonal antibody research, and are we close to any type of trials on that motive?

Holly Shill, MD

Right, oh, very good question. Thank you, Douglas. So, yeah, so monoclonal antibodies, so those are the type of therapy that directly targets alpha-synuclein protein. And so that's the protein that accumulates in Parkinson's and we think is actually sort of toxic to the neurons in Parkinson's. So, the idea is you have these antibodies that go and kind of clean out the abnormal protein in the brain and then hopefully slow progression.

So right now, those are in mostly Phase II studies. There's a number of companies, I think there are four companies or maybe five that are doing that type of research. And they are about in Phase II studies, so they are moving along, so there'll be a new study starting early next year on the monoclonal antibodies. So, I think it's promising so far, but we have not, and we have not really seen any major safety concerns with doing it. So, I think from that standpoint, they are definitely moving forward and hopefully will end up being something that's useful to actually modify the course of Parkinson's.

Rebecca Gilbert, MD, PhD

Fantastic. So, we have a bunch of questions about pain. Could you address the concept of pain in Parkinson's and how that can be treated?



Holly Shill, MD

Yes, that's a really good question; and it's almost a full topic in and of itself of the causes of pain in Parkinson. It's probably about 10% of people that have significant pain due to Parkinson's. So, some people can have really disabling cramping and pulling in their muscles, a lot of stiffness that really leads to a lot of pain. And so, that type of pain is typically addressed through modifying the Parkinson's therapy itself. And then probably more commonly is just the kind of usual things which is all the arthritis and things, all the wear and tear that we get as we get older. And I think more commonly that's what folks with Parkinson's deal with.

And it's a big deal. People with Parkinson's don't tolerate things like narcotics very well, so trying to treat pain in Parkinson's can be very challenging. So oftentimes we're working with our pain clinics and trying to find things that are nonnarcotic solutions to managing pain. So, it can be a very tricky thing.

Rebecca Gilbert, MD, PhD

Okay, we have a great question from Diane. How can we find a neurologist who has expansive knowledge about PD, medication, side effects, and management?

Holly Shill, MD

Very good. Yeah, very good question. So, I think the APDA should have resources there of finding a doctor that specializes in Parkinson's.

So, most neurologists are going to get training in Parkinson's disease management. So, a neurologist has been trained in Parkinson's management. And then there are also what are called movement disorder specialists, so those are people who have gone on to fellowship training in movement disorders, of which Parkinson's is probably the most common movement disorder that we see. So, you can look for that additional certification as well if you really do want somebody who kind of mostly sees people with Parkinson's.

Rebecca Gilbert, MD, PhD

Okay, fantastic. We have a question here from Steven. What are the most effective and successful ways to become enrolled in a clinical trial?

Holly Shill, MD

Oh, very good. So first I would start by asking your neurologist, and a lot of the clinical trials are done in major city centers; and so, if you live kind of in more rural or remote areas, you may not have immediate access to studies. But most of the city centers will certainly have them. So that's the first start is asking your neurologist and then looking at the kind of major city closest to you that maybe has a Parkinson center. So, they're typically the ones doing research.



And then I also always refer people to the website clinicaltrials.gov, so all one word, clinicaltrials.gov, and that actually has all of the recruiting studies going on. And so, you can search. You can put in the search criteria of Parkinson's, and then you can put in your area, your state where you live and come up with clinical trials that are close to you. So, I encourage people to go on there and kind of play around and look at all the work that's being done in Parkinson's.

Rebecca Gilbert, MD, PhD

Fantastic. We have another question that you addressed a little bit, and maybe you want to flush it out. If you feel regularly fatigued, how much should you exercise? And can you exercise too much?

Holly Shill, MD

That's a good question. So, wow, so fatigue in Parkinson's, yes. So very common and exercise, I think, is the best treatment if you will for fatigue. And the way I think about it is if you want to be tired after your exercise, you want to feel like you did good work, but you also don't want to feel like you're so wiped out that you can't do anything else for the rest of the day, so if your exercise is doing that to you, then I think you're probably doing a little bit too much.

My general recommendation is about 30 minutes of kind of moderate intensity exercise at least four days a week. So that's kind of my general rule for most of my patients. So that being said, if you do some moderate intensity exercise but then go for a walk later in the day, I think that's perfectly acceptable. There are people though that overdo it. You know, they're doing two hours of intensive exercise each day, and that might be too much.

Rebecca Gilbert, MD, PhD

All the balance. I think we have time just for one last question, and this is a general one from Sherrell. If you have bladder problems, should you go to a urologist or can your neurologist treat it; and this is really true for all the nonmotor symptoms. Do you want to go to a specialist, or can your neurologist handle these Parkinson's nonmotor symptoms?

Holly Shill, MD

Yes, great question. I think everybody's different, so for myself as a neurologist that specializes in Parkinson's, I am very comfortable managing just about all of the nonmotor issues. I know the medications and that sort of thing.

But everybody else has their own sort of comfort level. Some people would prefer that you see a specialist. So, what I usually tell people is just start by asking your neurologist or your Parkinson specialist. "Hey, what about my bladder? Can you help me with it?" And if they say no, then, of course, potentially go see a urologist or even seeing, talking with your primary care about things.

So, I like to keep my patients so they're not having a specialist for every single body part, where you have a GI specialist managing your constipation, and a urologist managing your bladder, and that type of thing. So, I think then you're ending up running around to too many doctors. So, if you can talk with your neurologist and see if they're comfortable, I think that's a good start.



Closing Remarks

Rebecca Gilbert, MD, PhD

[Slide 30] Fantastic. Well we have so many more questions; but, unfortunately, we are nearing the end of the hour and so we are going to wrap up here. **[Slide 31]** And I want to again thank you so much to Dr. Shill for joining us today and for the excellent presentation and the excellent question and answer session. And my many thanks to everyone participating in today's telephone and Web education program. And, again, I apologize we couldn't get to all your wonderful questions.

[Slide 32] If you have a question and you'd like to speak with someone from our Scientific & Medical Affairs Department, I encourage you to visit our website at apdaparkinson.org or call 1-800-223-2732 and you can ask your question there.

[Slide 33] If you enjoyed today's webinar, we hope you will consider supporting APDA with a donation because with your help APDA can deliver more programs and services like this one which are needed now more than ever during these challenging times.

I also wanted to emphasize to everyone on the phone that we appreciate your feedback as well, as well as your comments, and we want to make sure that you also complete the program evaluation form.

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 research program and Centers for Advanced Research, please again visit us at our website at apdaparkinson.org. 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. So, everyone have a wonderful day.