



## Live Well Today Webinar Series

### Understanding Advanced Parkinson's

Davis Phinney Foundation

*Note: This is not a flawless, word-for-word transcript, but it's close.*

Polly Dawkins, MBA (Executive Director, Davis Phinney Foundation):

Welcome everybody. Thank you all for being here and for registering for this webinar on advanced Parkinson's. So, let's get started. Dr. K, welcome back. For those of you who haven't seen one of our interviews with Dr. K, you need to go back into our archives and check it out. We have so much great content that he has done with us. So, to start, for those who haven't gotten to know you in the past, could you tell us who you are, what your specialty is, and where you practice?

Cherian Karunapuzha, MD (Director, Minders Movement Disorder Center):

Happy to. First off, thank you, everyone, for having me as a panelist. It is always wonderful to do one of these sessions. I think the more we understand about this disease from all perspectives, right? From people who have the disease people who help patients with this disease providers, we learn quite a bit from our interactions with you all. I'm a Parkinson's specialist. I work in Oklahoma City. I'm the director of the Minders Movement Disorder Center. We have a comprehensive movement disorder center here which takes a more holistic approach to treating Parkinson's. We like to incorporate physical therapy, speech therapy, neuropsychology evaluations, and community exercise sessions. We incorporate all elements when it comes to taking care of a complicated disease like Parkinson's.

Polly Dawkins:

Would you say that that's a palliative care approach?

Cherian Karunapuzha:

Palliative is the connotation of palliative; the word itself makes it so that most people do not want to hear that word. But in essence, that is exactly what we're trying to do, not just improve one facet of the disease. It's the overall aspect of how the patient lives on a day-to-day basis. So, quality of life is an important measure for us.

Polly Dawkins:

Yeah.



Cherian Karunapuzha:

When we treat our patients.

Polly Dawkins:

And how did you choose this field to get into when you were going to medical school?

Cherian Karunapuzha:

Neurology has always been very, very fascinating to me. Also, I mean, we've had family members who've had pretty complicated or severe neurological dysfunction, including movement disorders.

But as a child, I've always, you know, when we visit family back in India, it was always hard for me to kind of comprehend why is it that this person cannot get enough care. I mean, we live in a very modern society with extremely Westernized medicine, but yet, why not? And so that's kind of where I went with movement disorder. So, Parkinson's specialty is one of those few fields where I think we have a lot to offer if we are aggressive. And the key is, I think that's where we're changing as well as a whole community of providers within the neurology spaces, the aggressive way of managing Parkinson's. And so, I felt like that was a field where I could really shine and do a lot of things, which I love to do.

Polly Dawkins:

Wonderful. Well, thank you for choosing that field and for sharing your extensive knowledge with us. When you think about your practice, can you tell us what percentage of your time you are teaching? What percentage are you seeing patients, and are you doing any research?

Cherian Karunapuzha:

We do all three. We are primarily an extremely busy clinic or a center. We have almost 4,000 patients.

Polly Dawkins:

Wow.

Cherian Karunapuzha:

And we manage this as a team. We have multiple providers. We do research, especially for more rare disease states other than Parkinson's. Currently, we are also a surgical site, which means we do deep brain stimulation and advanced injections. So, botulinum injections are

offered for Parkinson's patients. So, and of course, teaching. I teach, probably; I would say a quarter of my time in a week is spent teaching.

Polly Dawkins:

Great. Well, let's dive into the topic that we're here to talk about today. Thank you for helping us understand where you're coming from and your deep experience and passion for this community. So, the topic we are here today to talk about is really understanding advanced Parkinson's. As we dive into that, can you help us sort of define or understand what is the term advanced Parkinson's? What does that mean to you as a clinician and to our audience?

Cherian Karunapuzha:

Advanced Parkinson's disease is such a controversial term, and the reason I say it's controversial is nobody can come up with a consensus on what that means, both from a clinician standpoint as well as from the standpoint of the patient and their families because there are so many elements to it. We are understanding more and more of this disease, and we've come to understand that there are a wide variety of flavors of Parkinson's.

Some progress at extremely slow paces; even after 20 years, they look extremely mild, and some progress at a much faster pace. Some progress non-physically, and the physical aspects are not too bad. So, if I had to break it down, advancement in Parkinson's disease comes from, let's say, a physical perspective, whereby the medicines that you take do not consistently last from one dose to the next.

You start to appreciate dips from one dose to the next. You have a bearing off of your physical symptoms to where you return back to your baseline. And this happens multiple times throughout the day. And we call this motor fluctuations.

Initially, Parkinson's patients don't have this. They take the medicine; their brain is able to reuse the medicine again and again and again, even without us telling them otherwise. And so even if you, let's say, skip a dose or miss a dose, the previous dose seems to carry forward and cover up for the lack of a dose. So, the smoothness is what is lost.

And this starts as early as five to six years into your disease when we start to deal with fluctuations. So, that's one aspect. The second aspect is non-motor symptoms. Non-motor symptoms are defined as all these other circuits in your brain, which has not got to do with the physical aspects like all your automatic aspects of your body. We call this the autonomic nerves, your bowel movements, your bladder, your blood pressure, your secretions. Two, your mood. So, depression, anxiety, irritability, apathy, three, you're thinking, four, your sleep. These are all aspects which start to deteriorate and very randomly for each patient. So, one person might have the worst constipation possible, and the next person doesn't have that issue. That person has a whole lot of problems sleeping. So, you start to get to a stage where your non-motor

symptoms are becoming intrusive to your lifestyle. Either to your work, your social engagements, your personal day-to-day hobbies, or day-to-day living. These things start to become very intrusive. So, when you have intrusive non-motor symptoms, again, we would like to use the verbiage advanced.

The third scenario, of course, is looking at it from the standpoint of disease duration. Again, a lot of us, from a clinical perspective or research perspective, look at the disease duration, the number of years you've experienced a disease. And so, if you've gone like ten plus years with the disease, then we start to use the verbiage, advanced Parkinson's disease. Again, this goes back and forth on the timeline, but this is one of the traditional ways in which we consider advanced. And then, finally, one of those non-motor symptoms takes a much bigger toll as the years go by, which is cognition.

Polly Dawkins:

Yeah.

Cherian Karunapuzha:

Thinking. This means that eventually, if you live long enough with the disease, most Parkinson's patients can get dementia or Parkinson's disease, dementia. So, when you start to get into dementia with Parkinson's, there, too, we use the verbiage advancement. So, physical non-physical aspects, which are your non-motor symptoms, start to get intrusive. Third, the disease duration. Fourth, once dementia starts to kick in, now we can break advanced Parkinson's disease into several segments: advancement in motor advancement in non-motor, and also to the end stage, where we like to use the verbiage palliated stage of the disease, where that's typically where you have so much of multiple different systems being affected. And the motor symptoms are not very well controlled at all with our standard medications. That's sort of the stage where we invoke the term palliative Parkinson's.

Polly Dawkins:

Thank you for that primer. That's helpful. When I know the term dementia, the fourth thing that you talked about is that dementia is frightening that word to many people. Can you describe a little bit about percentages and what dementia really means when it, when you're talking about advancing Parkinson's,

Cherian Karunapuzha:

There are always some elements of cognitive dysfunction, even when you first start the disease; that's not what we define as dementia. So, a lot of people are inadvertently, you know, afraid to bring this up because it might be like they're endorsing that they've taken a milestone or a step forward, searching for your words as you speak. You can't; that fluency is not there. The

flow is not there. You pause a lot in your conversations. You walk into a room, you forget why you went in there, and you start to think, what was it that I wanted to do? Multitasking starts to get a little bit trickier. These are many times seen very early in the disease. And it's got to do with dopamine dysfunction in your brain overall. So, you will notice this as many times the medicine surges into your system.

Your fluency picks up as the medicine drops, the fluency drops. This is not what we are calling dementia, but this person will experience early middle, and that's okay. By true Parkinsonian or Parkinson's disease, dementia, I'm defining it as multiple daytime confusion. Like you have confusion spells through the day, multiple times you are falling asleep through the day. When you're waking up from your sleep, you tend to be disoriented. You're not fully aware of, is it morning, is it afternoon? Are we going to Dr. K's clinic? No, that's tomorrow. So, you have to be reoriented. And almost always, with this cognitive decline, you get the classic hallucinations, which usually are vicious, but other forms can happen. Paranoia or delusions kick in along with this. And a lot of acting out, or REM behavior disorder, acting out in your sleep starts to happen at this stage. Typically, if, let's say, a person's getting this in their sixties or seventies, I'm expecting Parkinson's disease dementia to be in the 13, 14, 15, or even later down the road. So, it's a very long disease. And we're talking about the lag end of the disease where we're starting to catch this flavor of dementia. So, let's say somebody's getting it in their thirties or forties. Remember, for younger patients who get Parkinson's, the same 15, 20-year disease is now stretched to 30 40-year disease.

Like all those milestones are stretched there, too. At that lag end of that 30, 40 years. Yes, that will happen on average, but it is not something you have to think about in the same timeline. Like, you know, that other person who got it in their seventies after like 13, 14 years developed dementia. So, I'm going to get it at that same pace. Not at all.

Polly Dawkins:

Okay.

Cherian Karunapuzha:

Now, there is a subset of Parkinson's disease, which tends to advance faster into cognitive decline. These are usually older individuals with what we call a kinetic, rigid, or very stiff balance dysfunction. And so, with postural instability, these individuals typically tend to get non-motor symptoms at a much more aggressive pace.

Polly Dawkins:

Does it suggest that everybody who gets Parkinson's will eventually move into a state of having dementia? Or is that just, again, something because it's a progressive disease?

Cherian Karunapuzha:

Right. So, the question is, what is your natural lifespan? If you are lucky enough to live into your eighties, nineties, and live with this disease long enough, it's eventually going to take a toll on the cognitive circuits. However, as with most of us, we lose warranty on some other organ way before we hit 15, 20 years with Parkinson's.

Polly Dawkins:

So

Cherian Karunapuzha:

We die of natural causes way before we ever get to the end stage. So, I tell patients, you know, brand new to the diagnosis that doesn't worry about what is at the end. Live your moments day to day. That is, it's way, it's way more satisfying to live like that because, more often than not, we never get to those stages.

Polly Dawkins:

Okay. That's great.

Cherian Karunapuzha:

It's such a slow disease.

Polly Dawkins:

So, as we're talking about today and thinking about our audiences all over the board in terms of where they are and their Parkinson's journey, if you will. And so, what advice do you have for folks who are saying, well, where am I today? And what should I be looking out for if I'm a care partner, what should I be looking out for? And what do I, what do I have to do to help my person?

Cherian Karunapuzha:

The first aspect, which, you know, care partners have to learn, is to understand this concept of motor fluctuations. Meaning this individual will not be having smoothness through their day. And many times, they're not cognizant that they are dipping. So, it is many times the, you know, the onus is on the care partner to detect that. Like, this person is not really lasting from one dose to the next. That he or she is shuffling more towards the end, or the tremors coming back a little bit more towards the end, or his speech patterns are changing. So, understanding motor fluctuations and an extremely simple and easy way to achieve this is keeping a simple diary whereby you jot down every r how the person's looking like is this person in his own state,

which we define as most of your physical symptoms are melted away to where a sense of normalcy has returned to that body part.

There is no tremor. It's not stiff; it's not stuck. And the person's ability to activate the body parts almost normally and go about their business off is the whole return of those symptoms whereby you are getting back to your baseline without any dopamine left in your gas tank. You are slow, you're stiff, you're trembling, you're shuffling. You have a lack of expressions on your face. So, basically, jotting down is at 7:00 AM, woke up feeling off eight o'clock on, nine o'clock on like this. If you start jotting down through the whole day, within two to three weeks of doing this, you start to see trends for yourself, almost always, like from 11 to 12 o'clock in the afternoon. I seem to be off. There seems to be a stretch at six to eight o'clock at night, where I tend to be dyskinetic with too many movements.

So, these are trends that we start to see, which helps you identify these gaps in your day. Number one. Two, it helps providers like me get a better understanding of your day and tweak your medicines appropriately for that. It doesn't mean you have to live with this. Do you see why it's so important? Because if you're not cognizant of these dips and you come in, and you state that things are relatively fine or you're having too many dips in the day, but you can't discern the difference, you just come in and state that I'm not doing well. What do you mean you're not doing well? Are you? Is the medicine not kicking in? Is it kicking in and wearing off too quickly? If they don't have answers for us, it's very hard for us to tweak the medicine regimen or add a second medicine or a third medicine to make their physical state better.

So, the first step is getting a good sense of gauging how this person is fluctuating or not fluctuating in a day. Two, start to account for those non-motor symptoms. Be aware of whether this person is getting up often to go pee. Is bladder a problem? Is this person evacuating their bowels for four days, or five days? So, constipation, are they starting to get moody? You understand their personality better than any of us. So, are they starting to get apathetic, not motivated to go exercise? Any of those elements? Keeping an understanding of what non-motor symptoms are, and if they're starting to get intrusive to this person's lifestyle.

These are all elements. If you can keep it for yourself and let us know on the visits, we'll be able to address it. If you don't tell us about it or we don't proactively ask about it, this goes missed completely, and it might be taking a significant toll on this person's life. The non-motor aspects of the disease.

Polly Dawkins:

You only have one or two opportunities to see your clinician, or you don't have somebody as experienced as you are, a specialist like you. What, how do you recommend that we navigate this? As you know, people living with Parkinson's care partners make the most of the, and

Cherian Karunapuzha:

I'll be the first to admit always like there are never enough appointments or slots in a day to see all our patients. I mean, I wish there were a gazillion Parkinson's specialists, and we all had just a hundred patients to take care of. We would have enough time for each and every patient. The way we structure this in our clinic is at least patients need to be seen three times a year minimum, if not four or more, based as on whether they get procedures, et cetera. So, three to four visits a year is what we're looking at from a neurological perspective. Now, you may or may not have access to a Parkinson's specialist, meaning they have done extra years of training or fellowship for just Parkinson's. Regardless of if your access to neurological care is three to four times a year, that's very good for advanced Parkinson's.

Cherian Karunapuzha:

This means if you're starting to have motor fluctuations, if you're starting to have non-motor symptoms, or if you're aging into your disease, you're like 10-plus years into your disease, or you're starting to hit dementia; these are times where we need at least three or four a year. If your access to a Parkinson's specialist is not zero, but it's limited at least once a year, they need to have seen you made an evaluation to guide your local neurologist. And these are the things they need to be focusing on. And the reason they do at least once a year is because their ability to offer extra advanced options for treatment is also there. And so, which the general neurologist may not be having, for example, they offer an option for deep brain stimulation for a pump. So, more advanced care options need to be addressed at least yearly as you start to progress with Parkinson's.

Polly Dawkins:

That's a good segue into talking about treatments and therapies for Parkinson's as Parkinson's advances. Can you tell us about some protocols that are out there, therapies that are out there, and things that people might ask their doctors about if they're concerned that their Parkinson's is advancing, and they may only be on Sinemet?

Cherian Karunapuzha:

So, when you start to fluctuate with your motor symptoms throughout the day, carbidopa levodopa, meaning an oral Levodopa formulation, may not be enough by itself. We need to start adding other medications to enhance the impact of this main levodopa medication. So, if you had to think of levodopa as your main gasoline, you want to add fuel additives to make the gasoline burn a little bit better and longer. This is where, many times, your neurologist will decide on a second or third medicine based on your situation. So, for example, if you have dyskinesia, which is the over movements, the dancing-like movements, there are specific medicines we would add just to shave that off. If you have multiple dips in a day, they have medicines that enhance the life of dopamine or levodopa in the system. So, these are some of the early interventions where we start to add multiple meds.



So, this concept that I can fix all my problems with one pill, it has to move to where strategic or judicious use of multiple medications to achieve the best chemical balance in your brain. That philosophy starts to take more of a forefront. And as a person living with this disease and as a caregiver, that needs to be a mindset shift, which needs to happen because we'll see a lot of folks who are very resistant to L Doc. Is that going to be an add-on to my, is many reasons, right? So, financially, of course, this is always a concern. So, we always try to work with our patients to give them the best access to patient assistance programs. And number two, always offer generics, if and when possible, to even out their day. But it's not just finances; it's sometimes it's like, man, I have to take one more pill.

I'm taking one pill for my diabetes, for my cholesterol, for my this. Now, I'm taking two pills for just one disease. How come you don't have just one pill for this one disease? My cardiologist has only one medicine for my cholesterol. So, the helping them understand that, like why we have to add this. I wish levodopa was all we needed, but that's just not how our brain works. And also, as you progress into the non-motor state of the disease, we start to have advanced medication options for constipation, for bladder, for your mood, for any hallucinations, for sleep, for acting out in your sleep or thinking. So, again, we're adding and adding and adding, again, different sets of medicines that do different chemical balancing in your brain compared to what we do with levodopa and dopamine.

So, understanding that, hey, I'm going to be navigating into a space where multiple meds will be used and accepting that that's a very good first step. The second thing is surgical options, as we talked about with pumps and brain stimulators, an advanced option. Third is using injections like botulinum injections to help with extreme tightness in a body part, like your foot's twisting in your toes or curling in your neck, kind of twisted or tight. So, where you kind of look to one blind spot, the other blind spot's easy to look at. These are things that can be corrected with botulinum injections. You have too much drooling. We inject your salivary glands and cut down the drooling significantly. These are options that we can offer as well. Then comes physical therapy and speech therapy.

Physical therapy and speech therapy need to be reassessed and reevaluated once every year. Minimum. As you start to get into your sixth, seventh, or eighth year of your disease. Why we're trying to nip in the bud some of the major issues that happen as Parkinson's patient's progress, the poor bad ones, which get you into the hospital, falls, pneumonias, or infections, usually from aspiration because your throat muscles are weak. And three hallucinations. So, falls. How do we prevent it? We have to be appropriately dosed. If I'm not taking enough dopamine, my dopamine's not enough in my brain, I'm going to be slow, or I'll be fizzling off much faster. And during those moments, I'm shuffling, tripping, falling. So, appropriate dosing. Two, am I strengthening my cores and the big muscles that connect my limbs to my trunk? Because the more strengthened your core muscles are, you're not stooping forward.

You're able to use your tight muscles to pull or bring back that stoop to a more neutral position where the top part of your body is, and the weight of it is transferred directly to your pelvis and to your legs. If you're stooping forward, all that top weight is being propelled forward. So, you tend to stumble and fall when you strengthen the muscles that connect your limbs to your trunk. These are the same muscles you use when you stretch out and spread your legs. When you take a trip, reach out with your arm to stabilize yourself. If they're not strong enough, you're not going to be fast enough to recover when you trip or fall. So, physical therapy becomes really useful. Speech therapy because your volume starts to take a dip. That's the first sign of what's coming next, which is swallowing issues. The same set of muscles.

So, the initial warning sign is that your voice is dipping. So, suppose care partners are able to detect this like they have to. In that case, people are constantly asking this person to speak louder on the phone, or you're constantly repeating questions to this individual; that's when you start to realize this person's not speaking loud enough. They're trailing off towards the end of their sentence. That's when we are supposed to catch them and do speech therapy. Not after their voice has gone down. They're choking on food, clearing their throat excessively that's already passed to the point where they're having swallow issues and probably having aspiration. Because we want to keep those throat muscles strong enough to where you're not accidentally aspirating your rule in the middle of the night when you're sleeping with silent aspirations. Two, when we are eating, drinking, you know, accidentally, some of it is trickling down the wrong pipe. These are things we are trying to prevent because all of that carries bacteria from your throat to your lungs. And we get multiple cases of pneumonia. So, PT and speech therapy. So, even if you don't have access to movement specialists, request that from your neurologist proactively: hey doc, you know, he's not had physical therapy since March of last year. Can we have a repeat assessment and see if there is something we can tweak or improve? Because not all these meds, right? You have your muscles to help you compensate.

It's very useful to have actively seek out the second. The third step is to actively seek out community engagement, where people are congregating together to learn about the disease exercise together. So, usually, support groups. Why is this so useful? First off, whatever you learn with your physical speech therapist is what you're re-engaging in doing on a group basis. So, most of us, including myself, once we're done with therapy, we forget about doing these exercises. These are supposed to be sustained throughout the year. To having a group and being engaged in that helps us sustain this unless we are that strong in our willpower. And we're able to do this consistently at home. Two, you are able to get a lot of answers to your questions with this communal engagement. Hey, you know, he's having this problem with this. Oh, this is what I did. And you know, I made this concoction with prune juice, and it helped him poop. Perfect. So, you get a lot of back-and-forth answering of questions and understanding of the disease from engaging with each other. So, that should be a perfect time for you to always is a perfect time to be engaged with our community. But this would be a great avenue for support and help to all parties involved.

Polly Dawkins:

And doesn't that also help with the social isolation and loneliness that so many of us are?

Cherian Karunapuzha:

Yes, very much so. Especially with the pandemic. We saw this, right? So, we have data on the other big disease, which happens as we age Alzheimer's. Social isolation has a significant impact on cognitive progression. Like so means your decline cognitively enhances it dramatically. If you are socially isolated without any engagement, your cognitive decline is enhanced significantly if you can't hear. So, this is what we tell proactively to everyone. If you have hearing issues, make sure you're wearing hearing aids because That helps quite a bit. So, these are things we're kind of stealing from the Alzheimer's space and incorporating in the Parkinson's space. But we saw this dramatically with the pandemic. A lot of our patients felt like they were going downhill because there was no engagement. They're sitting at home; they're going to be physically declined because they're not moving, they're not active.

Two, because of the small circle of people they get to be involved with cognitively, too. Things start to go downhill. And then the social isolation, without any mention, psychiatric psychological impact, the anxiety, the depression, it hits harder. So, when you're out there with our community, you don't feel that because you feel like as there are a whole army of people around you who are either going through what you're going through, there are help support all of that. So, from a psychological framework standpoint, too, you're in a much better space when you have a group of people to work with on a weekly basis.

Polly Dawkins:

You mentioned the three things that end people end up in the hospital for, and you touched on falls and

Cherian Karunapuzha:

Infections, aspiration like aspiration, pneumonia, bronchitis.

Polly Dawkins:

And the third you mentioned was studies have told me a little bit more about the hallucinations part and what we should be aware of.

Cherian Karunapuzha:

Nobody suddenly starts to hallucinate the real crazy stuff. That's just not how it works. Just like nobody suddenly becomes full-scale Parkinson's, right? I mean, they start off with a little tremor in that one pinky, and then it starts to increase gradually. It's the same way with

hallucinations. They're extremely subtle and almost misleading because you assume it's something else. It's usually visual, where people start to feel vague shadow-like movements along the edges of their vision. Especially in dim lighting, like towards the end of the day, in the evening when they're watching TV, they feel like something moved. It's almost like a car went by the, you know, on the side window, you saw a car going, or did the doctor just run across? Or the feeling like people is standing behind you adjacent to you. These are some of the stuffs which starts to happen inconsistently and then become more and more consistent throughout the day. Usually, evenings are the times when this is most active.

Other forms of hallucinations can happen, too, like hearing. And again, it's very subtle stuff like your name being called vaguely music or insects buzzing, vague visual distortions of lines on the floor kind of moving. These are the subtle ways in which it manifests. It takes two, three years from that point to evolve into something more vivid or well-formed to where you're almost catching somebody there. So, our aim is to be cognizant of the start of these symptoms so that we know when to intervene. We do not want to intervene when, all of a sudden, the hallucinations are really bad, and the person has to be hospitalized. So, that's our aim, right? We're trying to prevent the hospitalization. So, this meaning we have to catch this at least two, to three years before, keep tabs, and also choose wisely the set of medications I'm needing for their bladder or for their physical performance.

Because some of those medicines can activate or trigger the hallucinations. So, if you're not aware of this, we might accidentally trigger or bloom it out more than what is intended by choosing the wrong set of medicines. So, this is why it's so important to keep tabs on this and acknowledge them. There is no shame in mentioning that you are seeing this. Nobody is going to judge you in our space. Like, oh man, you are hallucinating. There is always a bad connotation when it comes to hallucinations. Like you don't want to admit to somebody that I'm seeing things, hearing things because of the social taboos associated with psychosis, but this helps us tremendously to prevent some of those bad outcomes in the future, and it's very useful for us to catch it. Some of the things which predispose an individual to this, of course, are age, the number of years with the disease; the longer you run with the disease, the higher the likelihood of these things happening.

If dementia is dying to set in, and three, if one of your sensory systems has already been damaged, those sensory systems are more susceptible to these tricks, these illusions, these subtle hallucinations. So, if you have vision problems, you have retina problems, cataract problems, you wear thick glasses, you're more predisposed to those visual distortions. First, if you have hearing issues, you're going to be more predisposed to some of those auditory hallucinations. You have neuropathy in your fingers and tips. The sensory stuff, like ants crawling on you. You're going to feel that more. That's just the nature of how the disease picks on those sensory systems that are already damaged.

Polly Dawkins:

So, you've mentioned the things you can do the, for those three hospitalization risks. So, you mentioned physical therapy because I see some questions in the chat. Physical therapy for falls, prevent falls, speech therapy and

Cherian Karunapuzha:

Gait retraining. I, I want to just state falls and gait retraining. Because A lot of patients, once they've taken two, three falls become extremely cautious and they use, keep their arms apart, legs a little bit wider based and take very short steps. Kind like you're walking on ice just to prevent that one more fall. And so, you start to develop a cautious gait pattern. So, we help them get retrained into a more appropriate gait. And also gait training. Retraining involves many times using an assisted device. So, when the therapist assesses the patient and they see that this person has a separate balance problem along with their shuffling, they have to recommend the most appropriate assisted device. Like is it going to be a cane with four prongs? Is it going to be a walker with breaks, without breaks, whatever it is. And then train them to how appropriately to use it.

because What happens is most of us will inherit the walker from my grandma, my mom, and now I'm using it. It might not be appropriate for you. You don't know how to use it, right? You are just carrying and walking with it. There are so many people that we see who use their assistive devices wrongly. So, that's why gate retraining and core strengthening weekly, I'd love to say daily but daily exercises, simple regimens which improve your course. Like our therapists like to say, if you can just stand up 10 times every hour on the hour clock times 10 o'clock, you get up 10 times, ideally without using your hands. But if you have balance issues, push off with your hand. And now 11 o'clock, again, same thing. Go back to doing what you were after, standing up 10 times. This activates your thighs, your buttocks, and your lower back within two, three weeks of doing this for as long as you can remember through the day.

If you did this, you would notice that you're more taught in your trunk, lower trunk, and you're more upright. You're not so astute. Simple exercise. Don't get overly complicated. Don't try to do one-hour sessions. Do very simplistic ways. Do I like to tell folks who've never exercised for the last 20 years. Start off with five minutes of exercise. Don't even break a sweat. Five minutes. That is all I want from you. Just go do whatever it is that you're doing. Lightweights something, five minutes and then go back to drinking your coffee. Watch tv. I don't care. After three months, make it 10 minutes.

So, it'll start to feel like it's a joke. it feels easy on my system. Don't start off with 30-minute one-hour sessions because you're going to burn out. So, this is very, very important. Daily or weekly exercising either as part of a group community or by yourself. Therapy assessment at least once a year. Then you have the speech component. Again, the same thing. Speech therapist assesses you once a year at least to make sure you're not swallowing problems or the volume issue. Practice those exercises daily to weekly. Weekly as part of your community engagement daily would be, it's hard, right? I mean, how do we do these volume exercises in

your home? Especially if other people are staying there. It sounds like you're screaming. I tell folks, incorporate that your daily life, if you drive to buy groceries, sing loudly to nobody's hearing you. Nobody cares how you sing, but just sing loudly as to the music or to, if you read your scriptures every day, pick a word to read out aloud like you're practicing your enunciations your volume with just one words. Or if you have a book or a magazine that you read, just one paragraph. Read it out loud. And then the rest, you're good. So, just slowly incorporate daily routines. Those sustain long.

Polly Dawkins:

And then noticing and talking about hallucinations is the third thing. Early. Somebody asks it's good to catch a third. Somebody asks, why would somebody need to be hospitalized for hallucinations?

Cherian Karunapuzha:

Because let's say when it starts for what would flare up. Hallucinations inadvertently taking too much of levodopa or dopamine. There are certain Parkinson's medicines which activated non-Parkinson's meds too, like bladder medications. They can activate hallucinations. So, when we give too much of a medication, or number two infections, anytime you get an infection, especially UTIs, urinary tract infections, it'll precipitate or activate your hallucinations. Three, any disturbances in salt levels. Like, so you're dehydrated, it says hot sunny day, you sweat it a lot, lost a lot of salt. These are all situations where you can activate your hallucinations. And then finally, any procedure which involves an anesthesia. If we didn't know you were having subtle hallucinations, and then you go in for a day surgery procedure that gets prolonged into a hospital visit. You were supposed to go in for one hour procedure, come anesthesia wears off, you're supposed to go home, but you're not going home because the anesthesia activated the hallucinations.

Now you're real goofy. So, these sort of scenarios all of a sudden makes you subtle hallucinations or maybe just the person oddly standing there is what you see that morphs into real severe hallucinations where you are not you are completely believing that this is real to you. You are confused. You are stuck in your head that these hallucinations happening. You start to get paranoid about your own care partners and other people around you that they're plotting things against you. Things get pretty bad to where we have to stabilize the person in-house in a hospital setting give them strong IV meds many times. Or, I mean, muscle injection medications to suppress those hallucinations. And when we use those sorts of strong medicines, the downside just from a chemistry standpoint in your brain is that those strong antipsychotics will many times slow or clamp down your motor system. You become very slow and stuck so you can move while you're stuck. So, when you do two, three days of strong medications where you're stuck and slow sitting in a bed, your muscles deconditioned dramatically.

For any reason. If you're lying in a bed for three, four days, if you don't use your muscles, they decondition. So, if you have a hospitalization, which is happening because you're confused or having severe hallucinations, the medicines that we use to clamp you down many times will slow your system down. You're lying in a bed, you will decondition. And what happens when you come out? It's like you took a stepwise decline. You were here. It's not even a gradual, it's like five days later now you're here, you're more stooped and you are more stuck, you're more tremulous. And that happens because of that lack of mobility when you're hospitalized. So, we want to prevent that.

Polly Dawkins:

Absolutely.

Cherian Karunapuzha:

It might take stepwise declines. Because if you have several of these attacks, you had a pneumonia for which you had to get admitted, you fell and busted your kneecap and you had to be hospitalized. You had a hallucination with the surgery for your kneecap fracture, whatever it was, that leads to another prolonged stay three that stays in a year. You take three steps down what's supposed to be a 15, 20-year disease. Now we are contracting it.

We are getting to the more advanced stages, faster than what was intended. And it takes much more time for us to pull back up. So, prevent it. That's the point. It's like an oil change. You're doing it so that your car doesn't break down. You don't do it after the car breaks down.

Polly Dawkins:

Boy, that's such an important, that's such an important missive. Sorry, I got a little, little feedback there. Sorry about that. Got another question in. The chat here about if a person, Peter asks if a person with Parkinson's has really advanced quiet, quite drastically, when do you consider hospice or when do you consider a more aggressive approach of, he talks about de-prescribing and really changing their life.

Cherian Karunapuzha:

When you reach the stage where, from a care partner standpoint, let's say when you reach the stage where managing all aspects of this person's life is getting harder because there are too many motor complications, meaning the person's getting to stick too slow, random disruptions to their physical performance, needing much more support with transitions, meaning they have so much balance issues that they need help with. They are transitioning to dining room, going to the bathroom, taking a bath. So, the physical aspects are getting hot or the non-motor aspects are starting to get hot. Patients having to go to the bathroom to pee very often in the middle of the night. Constipation issues to where we have to manually design impact the

constipated stool thinking decline to where a patient has a lot of confusion or hallucinations. So, any sort of these scenarios where it is taking a toll on the care partner to manage all aspects by themselves is where you start to ask for assistance. If you are financially well off to have sitters at home who can help you, aids who can help you, that is great. If not, hospice is a great option whereby you get all this extra support coming in from a palliative standpoint.

Before we even get to the stage, we have to plan our transition of our care team too. So, what used to be a neurologist or neurologist with a Parkinson's specialist or a Parkinson's specialist team taking care of you, we usually tell folks, make sure you have primary care. Because many times an engaged neurologist or a Parkinson's specialist ends up taking care of your constipation, your blood pressure, your bladder, your sleep. We almost look like the primary care, but I'm not the primary care.

I'm not your internist. That's another person who has many times access to the hospital. So, meaning they can admit you to the hospital. So, these are important elements to have in your team. So, having primary care, ideally geriatric medicine. So, geriatricians are an important step to take. So, it might be hard for you to break away from your primary care doctor who you've seen for 20 years. But the geriatric medicine specialists, they are internists who handle patients with brain disorders like Parkinson's, Alzheimer's. They have a much, they have more training in that.

So, our clinics or centers have resources like social work, psychologists, psychiatrists to incorporate care teams kind of. So, you start to become more accepting that you will need multiple people to manage this Parkinson's. You will need gastroenterologist. Sometimes you might need a urologist for your bladder problems. You might need an orthopedic for your hip and knee problems. You need a neurologist, you need a geriatrician, a psychiatrist. So, or a geriatric psychiatrist, usually part of a geriatrics team. Why is that so useful? Because remember number three, cause of admissions to hospitalists, hallucinations. If you had a psychiatrist on board or a geriatric psychiatrist on board, they have hospital privileges. They're the same docs who are going to admit you and take care of your care. The transitional care is so easy, it's the same person admitting you to, they might have a psych floor where they manage patients with hallucinations or cognitive disturbances.

So those are all important elements. So, having multiple providers for those sorts of care early enough so that when you step into this zone, you have already the backup that you need. Because a lot of our patients, many times join our systems in the last minute, like they moved states to be closer to their children because they're advancing in their disease or being taken care of by another practice set up. We get patients who are slightly unprepared and they're the ones who have the extreme frustrations towards the end to the last stages of the disease because they're extremely un they're overwhelmed by, okay I'm not getting all the support I can get from my primary care. Because That's not their role. They, you need to have a





psychiatrist, you need to have that gastroenterologist. These are all elements that have to come in together.

Polly Dawkins:

We could talk for hours. There are so much great content that you know and can teach us. I wonder, as we think about wrapping this conversation up and knowing there'll be many conversations after this, is there anything that you were hoping that we would touch on today that we haven't yet touched on?

Cherian Karunapuzha:

I think we've done very well in covering all the aspects when it comes to advanced care. I think some take-home messaging for, you know, both folks with Parkinson's as well as care partners would be to be more cognizant, more aware of these nuances.

As they start to happen. And diaries are an extremely simple way of assessing this from a physical perspective. Even doing two- or three-weeks log and before your visit with your doctor, if you could do just that much, that gives us so much information about how you're currently doing, it gives us a more realistic perspective. And then being aware of the non-motor aspects and what those are. And so many books are available, including Davis Phinney makes a great manual on Parkinson's that touches on all those topics. So, being well-read about the topic is very useful because when they start to happen, you know, aha, this is that and this, and it's starting to happen, and this is something I need to address on this visit with my neurologist. And they may not be comfortable handling that non-motor aspect. They might at least push you in the right direction to a gastroenterologist or a urologist. So, keeping weekly logs, at least for two or three weeks before your visits, is very important. And being cognizant of your non-motor symptoms and being three proactive about asking for physical and speech therapy at least once a year because it might not be running in the provider's head that when was the last time this person had it. So, these three things are something you can proactively do to get better outcomes with your own health.

Polly Dawkins:

And may I add a fourth one that you've mentioned is to look at your care team and perhaps see if you need to add other medications.

Cherian Karunapuzha:

Don't, don't be shy to add. Yeah, don't be shy. I mean, there are a lot of folks in rural settings where there is no access is limited, but at least having someone in the city who you've seen at least once, yeah. To, you know, keep a point of contact if things go downhill on that aspect, there is somebody to contact.



Polly Dawkins:

Wonderful. We're at the end of our hour. So, appreciate you and your knowledge and your passion for this top these topics and our community. And thank you all for logging in and being here today. We will send a recording, we'll send links, we'll send logs of all of the resources we've talked about today, and we hope you have a wonderful weekend. Thank you again. And be well.

Cherian Karunapuzha:

Thank you everyone. Stay safe.

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