



Davis Phinney Foundation
Tips for Living Well with Parkinson's with Dr. Michael Okun
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Dr. Soania Mathur

So good afternoon, everyone, as Mel mentioned, my name is Dr. Soania Mathur, I'm a family physician and a Parkinson's patient. Having lived with this challenge for now, well, over a couple of decades I'm privileged to serve on the board of directors for the Davis Phinney foundation. And I have the pleasure of being your moderator today. Now, although we, as patients wish there was obviously a cure for Parkinson's disease, and although there's a whole community of researchers and clinicians working hard to achieve this, this remains for the time an incurable degenerative illness. So, then what is most important to us as patients? Well, I believe it's quality of life, living well, despite Parkinson's. And that's what we're going to be discussing today with our expert guest, Dr. Michael Okun.

Dr. Okun is a movement disorder specialist who's currently chair of neurology professor and executive director of the Norman Fixel Institute for Neurological Diseases at the University of Florida health college of medicine. He has written many books and is also one of the coauthors of his highly anticipated newest book *Living with Parkinson's Disease, a complete guide for patients and caregivers*, which is available on Amazon and other sources. Welcome Dr. Okun.

Dr. Michael Okun

Oh, it's a pleasure to be here. And I always enjoy spending an hour with you and also say Dr. Mathur for, for those patients and caregivers, not only is she a board member of Davis Phinney, she has a wonderful blog that you should follow and a great Twitter following and, and I've enjoyed reading and hearing your insights. And so, it's great to be with you today.

Dr. Soania Mathur

Thanks so much, Dr. Okun maybe to get the discussion started. Could you explain to us maybe why you were inspired to write this book? Like why do people living with Parkinson's need such a guide?

Dr. Michael Okun

Yeah. So I actually, you know, learn like everyone else over time and, and, you know, as we get a little older and the hair gets a little more gray, we, we begin to, I think maybe get a little bit wiser. And so I think early on in my career, I was very focused and still in very focused on research. But you know, I realized that, you know, when I started writing more patients, more information for patients and more information for families that that, you know, in some large, multiple the amount that what I would write would be read was so much larger than any of the research papers. So, if you take 500 research papers that I've been involved with coauthors, the things that I've written for patients have probably been read thousands, if not even larger multiples than any of those single papers.

And when we did the book 10 secrets to a happier life, we know it wasn't meant to be a runaway, but that Parkinson treatment book, I mean, it just has gone crazy and still even now you know, a lot of people still read this book and, and it really opened my eyes and opened. I think a lot of people's eyes to just this idea that we need to do better and getting facts and tips and how to live with the disease out to patients. And so we wrote that first book, and then of course people said, well, what about what's new? And that was the one of the tips. And so we wrote a book about, about research, but this is kind of the third book in the series, the living with Parkinson's book. And it's really, you know, a, an answer to the community saying, we need better recipes.

We need better. We, we need more on the tips of how we can live with this, you know, disease. And now we believe you, you, you can live a happier life with Parkinson's, we believe you, but how about giving us a little more guidance along the road? And so that's, that's really what this is all about, and it makes little things can make a big difference. And so, so we really want to put something together where we gave away all of our tricks. And so Dr. Milady and doctor with some D at the university of Florida at the fixed home Institute, we, we got together and given away a lot of our secrets. So it was a fun book to write,

Dr. Soania Mathur

And it's a fun book to read. It's really quite exciting. There's a lot of information. I would encourage people to pick it up, but I think it would make a big difference to have just sort of everything in one kind of, you know well presented, well thought of format. So I think it's great. In the first chapter of the book, Dr. Oaken, you talk about the importance of a correct diagnosis and being involved with this community for so many years, I've heard so many people talk about their stories about how difficult it was for them to get a diagnosis of Parkinson's their journey going from patient from doctor to doctor, without any definitive answers. Why does this happen?

Dr. Michael Okun

You know it's, it's quite a curiosity, right? And I think that the way that you address this is, you know, a spot on, you know, like why in the world, are we still talking about getting the right diagnosis? I mean, we seem to need to be, you know, much further down the road, but it turns out that there's a huge shortage of Parkinson's disease specialists. So we train about 40 a year for is okay for the most rapidly expanding neurological disorder on our, we trained 40 a year. And we don't provide any funding in the United States for them, no Medicare funding, nothing. So it's not like you, you meet these kids and train and cardiology and nephrology and internal medicine. You're an internal medicine. And so we don't, we don't actually have a mechanism to mint people. So it ends up being worldwide, not just in the United States.

It ends up being a burden. If you want to call it a burden of the general doctor. So take care of everything, GYN problems take care of, of prostate problems, take care of heart liver lung. And by the way, if they happen to have Parkinson disease, make sure you take care of that too. And this is, you know, pretty much how things have gone. And so what happens is, is that the interaction is pretty abnormal, you know, and I would say suboptimal, and you go to see a doctor and sometimes even a general neurologist who doesn't have a lot of information about Parkinson's disease themselves, because they see a lot of other disorders in their practice and takes a long time to see a Parkinson's patient. And they just get it wrong. Either they get the diagnosis wrong, but they actually deliver the diagnosis wrong.

And they're telling people that this is not a livable disease, and we've just heard this story over and over again on our helplines. And, and the ask the doctor forum that I hadn't been moderating for 14 years until we retired it this year. And it's been it's been a humbling experience. And I can tell you Sonya, that it's something that disappoints me and I just don't want to see any more patients diagnosed and receive those words. You have Parkinson's disease without the empathy, but also without the background, I understand that this is a livable disease and this isn't the end of the road.

Dr. Soania Mathur

So if a patient suspects, either that they have Parkinson's and they haven't received the diagnosis, or the, you know, they're having these sort of vague neurological symptoms, is it important for them to see a specific type of physician, a general neurologist or someone that's even sub-specialized in that

Dr. Michael Okun

You recommend is, you know, obviously in this and this may seem, you know, like everybody should know this, but let me just take a minute and go over it, because I often have now learned as I've aged that never to assume things. And, and, you know, so when it comes to shaking, you

know, in Parkinson and four to five, people may have shaking one out of five may not. When it comes to, you know, symptoms that you think could be attributable to Parkinson's or some neurological disorder, certainly starting with a specialist is a good idea. And it's not to say that generalists aren't good and some generalists can handle it. It's just, if you were going to play percentages, you would see a specialist like a neurologist. And if you have the opportunity to see somebody who may have done either advanced training called a fellowship in Parkinson and movement or dedicate, you know, more than half of their practice to Parkinson disease, there's a large percentage.

You're going to get to the answer. You're going to get better care, and you're going to get, you know, sort of a better, a better strategy, short and long term. So that's what we've been recommending. Although on the other side, I must admit that we're spending a lot of time now thinking about how to develop education programs and partnerships for general internists family practitioners. And we're beginning to try to train that group of individuals to, because they're going to be part of the solution. So we can't just ignore the fact that, you know, we have tremendous numbers of patients that need to get treated. We need to recognize that we need to bring people into the solution. And so, for people suffering now certainly get to the most specialized that you can, as quickly as you can, for a long-term, we need to be thinking of, have a better public health solution

Dr. Soania Mathur

C you use in the book, the acronym, track tremor, rigidity, akinesia bradykinesia, slower movement, and postural instability, or I guess, problems with balance to describe the motor symptoms of the disease. As you mentioned, we don't always have all of those. And there's also some, a group of non-motor symptoms. What are some of the non-motor symptoms briefly that people can get with Parkinson's?

Dr. Michael Okun

Yeah. So we often talk a lot about the motor symptoms. It's kind of like if you go to the dentist, right, they look at your teeth. So if you go to a quote movement disorders, neurologist, they look at your movement. So they look at your, your shuffling and your, and your, your tremors and your movement. But if you sort of look a little below the water line, some people use that old cliché of the iceberg. There are all these symptoms that are not seeing, are not visible to the eye. Many of them are the so called non motor symptoms, which is not the greatest name, right? That means everything besides motor, right? So, it's not like the most creative name, but Parkinson disease as a construct is the most complex disease in clinical medicine, because it has the most number of motor and non-motor symptoms.

It has a response to dopamine. It has all these fluctuations and things that emerge over time with disease progression, people turn on and off. It doesn't happen, you know, in other diseases. Then we put electrodes and brains and pumps and stomachs, and we do all sorts of stuff. We cocktails of medication. So, the non-motor symptoms can include a list of over 20 symptoms, including most prominently, depression, anxiety, sexual dysfunction, apathy, urinary dysfunction. And so there, there's just a tremendous number. And, and I'll just say, you didn't ask, but I'll throw it in that if you look collectively at the studies and the literature, the clear signature pattern is these non-motor symptoms, depression, anxiety, apathy in particular affect quality of life in a Parkinson patient, more than the motor. And if you go to most neurologists or most general practitioners, they only treat the motorcycles. This is a problem. This is a disconnect. And neurologists and general practitioners need to be pushed to not punt away the ball. So if you're not into football, not punt it away. And, but, but actually to, to, to take on those problems and learn how to treat them, because if you treat them, it has a much greater.

Dr. Soania Mathur

Absolutely. I can't agree more with that. As you also say in the book, not everything that quacks like a duck as a tech. And so what are some of the other conditions that have features that look like Parkinson's, but are actually quite different, some of the Parkinsonism types of, of diseases and others.

Dr. Michael Okun

Yeah. So it's an important point that not everything that looks like Parkinson or sounds like Parkinson turns out to be regular Parkinson's. So how do you know if it's regular Parkinson or not? And so we look for symptoms, some people call them red flags, but let's just say clues, you know, and meaning, this is why you don't want to spend five minutes with your doctor if you have these symptoms or your healthcare team, because sometimes it takes a little time to come up with some of these clues. So, so if you're having trouble moving your eyes, particularly up or down, you might have with the famous actor, from Arthur Dudley, Moore, the pianist, you may have progressive supranuclear palsy. If you're falling or having problems with walking or falls early on, you may have one of these disorders. Some people call it PSP or progressive supranuclear palsy.

If you're having trouble with thinking and hallucinations within the first couple of years of your Parkinson, you might have something called Lewy body disease. If you have problems with skilled movements and we had to do skilled movements, we give everything a name and that we built for it as neurologist, you know that as an internist, right? So, something called apraxia problems with skilled movements, or maybe the, and is doing something that we don't want it to do. That's called an alien limb or elevating out of out of a chair. While you're sitting in a chair, you might have a Parkinsonian syndrome called corticobasal degeneration. And probably the most common one that we see confused with Parkinson is called multiple system atrophy. And

that's where you may get dizziness. When you stand up too fast, you can get any of these symptoms with Parkinson's and that's where it gets tricky to separate.

But if you get early and prominent, you know, problems with your blood pressure and dizziness, when you stand up a unsteadiness, when you're walking, you know, early on problems, digesting or absorbing medications, or a lot of problems with urination or emptying your bladder very early on, these may be signs of what are called Parkinsonism. Now this is where people get confused and I've seen some questions lighting up on the, on the on the screen. And so just to explain it, if you have any of these symptoms, then the slowness, the so-called Bradykinesia, shuffling of your steps. People can turn that Parkinsonian. Okay. It doesn't necessarily mean you have Parkinson's disease. When people refer to Parkinson's disease, they are referring usually to a disorder that has a typical, slow progression or slower progression and has a response to dopamine. Okay. And if you see some of these other features, again, some people call them red flags, but let's just call it clues or other symptoms.

You might have something else, or if you're taking the medicine and you're not responding, there might be something else going on. And people have used these terms like secondary Parkinson's, you know, they've used terms like Parkinsonian disorders. They've used terms like Parkinson plus, and imagine how confusing this is as a patient. Like you're trying to read through all this literature, you know, what the heck are they talking about? And so it becomes very confusing for patients. And so what we talk about when we talk about Parkinson's disease, regular garden, variety, Parkinson disease, you know, not everybody has to have tremor, but certainly tremor stiffness, slowness. These are common features. And typically we don't see a lot of walking or falling problems at the time of diagnosis or any of these eye problems, or a lot of these problems with digestion or dizziness. It's not true in every case, but we certainly look for these things and look for the absence of other things.

And we also want to see a response to dopamine, but all these terms are really confusing for patients. Is it important for people to know the difference is the treatment approach different for these other Parkinsonisms or, or other illnesses that sort of seem like they might be Parkinson's disease. It could be very different. And that's a very good point. Although there are some commonalities right to treating slowness. It could be very different. For example, the depression, okay. The depression and the levels of depression and anxiety and apathy may be much higher in patients with Parkinsonian disorders, patients with progressive supranuclear palsy and some of these other things that look like Parkinson's disease may laugh at times when things aren't funny and cry at times when things aren't sad and that may be completely disabling. And we see that much more commonly by a multiple, many times more commonly.

And these disorders, particularly in PSP, if you fall and fracture a hip, because somebody doesn't pick up that you have PSP early, that could totally change your treatment course. And then people have assumed incorrectly that all of these syndromes do not respond dopamine, but it turns out we have many patients with multiple system atrophy or with Lewy body, or with PSP who may have dopamine responses. And so we, they have to come in and they've got to, we've got to examine them, we've got to keep them safe. And we've got to create the right cocktails, both of therapy. And we talk about drugs. And in the book we talk about people like me are drug dealers or MDs. You're a drug dealer to doctor, sorry, but we give all these medicines and prescriptions. So we're the drug dealers, but in a lot of these syndromes, it's much more powerful to have a good interdisciplinary approach and, and to bring in physical occupational and speech and swallow as some primary specialists that can really help to, to treat these patients.

Dr. Soania Mathur

Right? No, absolutely. And we're going to talk more about those being the drug dealer, as well as the team approach in just a few minutes, but I just want to move on a little bit. So once you've received your diagnosis and you started to get your head around the news, you've come to accept the PDs part of your future, which can take some time for some of us to come to that emotional acceptance, it's time to become an active participant in your management. And the one thing I've learned on my own journey with this disease and seeing those of my Parkinson's community is that you can't be a passive bystander and expect to live well with Parkinson's. You have to, at some point take control over those variables that you do have control over. So I'd like to talk to you for the next few minutes about the advice you have about lifestyle changes, exercise and rehab as was nutritional issues. So, I mean, first of all, we all know that we should exercise. It's good for our hearts, our lungs, our bones, our general health, but what does the specific benefits are there for people with Parkinson's disease?

Dr. Michael Okun

Yeah. So this is a, a great question. And so starting with the construct of exercise you know, it sounds a little contrived, right? You know, just exercise and, you know, we all tell people exercise and has health benefits, but I want to stress. And this is something that we talk about in the living with Parkinson's disease book that, you know, from the very beginning in Parkinson disease, from the history of Parkinson disease, we didn't have dopamine. And in many cases, patients were hospitalized or put into asylums, like you saw in in the book awakenings and post flu Parkinson's, and they needed places to live, you know, homes or nursing home facilities. And before dopamine, they would follow the doctors on the rounds and rounds would mean you would round around in the different rooms that the younger doctors don't understand that because it's all different now, but you would put your charts on a rack and you would round we're on electronic medical records.

And so, they would have the patients around with them, okay, push the chart cart, fold towels. Okay. And they realized that this was actually good. The, the patients would do better. The more they exercise. So exercise therapy has been around even before dopamine. And of course, when a powerful drug and the greatest two advances in the field of indapamide and deep brain stimulation, at least in terms of magnitude of change for the Parkinson's patients. And so we now have moved from a construct of just know, exercise has good health benefits to exercise actually can help Parkinson's too. We have now collectively a lot of studies showing that it's, it has positive, very positive benefits, symptomatically both in motor symptoms and a non-motor symptoms. So now every Parkinson's specialist recommends exercise for the patients. And if you read the latest review in JAMA, the journal of American medical association by most Armstrong, and I it's very prominently featured in there.

And even in the last few point we did for JAMA that this is the field has changed, you know, it's rocked. And the thing that people ask us the most about is, okay, well, that's, that's fine. You know, but what exercise do we do? You know, like, what are we supposed to do? I mean, you keep saying, do exercise. And so many of the studies now have shown benefits. You know, Tai Chi was one of the early ones that showed a benefit, surprisingly in a lot of ways, people didn't think that that would be, you know, something that would show benefit because it wasn't as aerobic, as other things, treadmill training some of the stretching and less aerobic you know, lifting of weights and things are shown changes. So now you have a whole generation of young, middle and more senior researchers beginning to look at dose and types of exercise that can be done.

And even one at the Cleveland clinic, Jay operatives, there's an old friend that looks at, at forcing exercise a little bit beyond your, your capacities for cycling and cycling, being a, another, another one and seeing benefits with different exercises. You know, so for example, Christopher Haas has shown some benefit. You can multitask better when you're on an exercise bike than when you're doing other forms of exercise. And so, so we're also learning what might be better for different patients. And so what's most frustrating now for the patients. Isn't so much that we, we tell them, you know, exercise is good. Exercise is like a drug what's frustrating is as they want to know specifically the answer, we're starting to shine some light on that. We do know that if you don't do enough exercise, so probably 30, 40 minutes a day, even if you have the balance problems and you need to do at seated, there are a lot of seated exercises that you can do as well.

You need to really get to 30. Most of the experts are saying, get to at least 30, 40 minutes a day or more, don't be an Olympian and try to do it for multiple hours a day. We have several patients that overdo it and then they get too tired and they can't perform in their regular activities. Getting your heart rate up. This seems to be important and then staying safe without falling. So if you can meet those general criteria, no matter what the Madlib is, and you find something that you

you're interested in and that you will do consistently, I will end by saying the best tip is best kind of exercise as the kind you're willing to do every day. So, yeah.

Dr. Soania Mathur

You talk a little bit about rehab as well, and, and I often tell people that they need to build a Parkinson's team. We need to be sort of not islands under ourselves. We do best when we're surrounded by people that really have our quality of life in mind. And one of those people that is often very beneficial to your team as a physiotherapist, especially when we're talking about exercise should everyone consult physiotherapists before starting an exercise program? Or what role can they play?

Dr. Michael Okun

Oh, this is a great question. So we have tremendously underestimated the role of a physiotherapist. So physiotherapy is, is what it's called outside of the United States by most locales. And then if you're a good testicle, like man, you live in the United States, we're not as equal to school as we used to be at work or certainly egotistical. We call it physical therapist, but either physical therapy or physiotherapy we have completely underestimated the value of this discipline. And in some cases it can be more powerful than the drug dealers and giving us, giving the drugs. And so where we have fallen down is we have assumed that a referral to any physiotherapist or physical therapist is equal. It's not okay. We have assumed that any physical therapy is good and it's not some physical therapy for Parkinson's patients can make patients fall, for example.

And we've assumed that a generalized plan for patients is as good as a specialized plan for an individual patient. And that is false. Okay. So we've, we've made several assumptions now that we're learning are incorrect. And so the role of the physical therapists or physiotherapists in Parkinson disease is to set the plan okay. For the patients. And in fact, the way that most locales United States being one offered therapy is they will give you, you know, like, let's say you have a stroke or neurologic disease, and we'll give you six weeks of therapy and then they'll set you out. And we're learning that that is just not adequate for Parkinson's disease patients. And in fact, what we need is more interval therapy over and continuously. And that those systems in the brain we call the basal ganglia, respond to queuing. And so the role of the physiotherapist is to set the plan for the individual patient, which means just like your drug dealer, neurologist doesn't exam, physiotherapy does their exam.

And that exam is important to setting what's good for each individual patient and in the different settings. And they also spend a lot of time with the patients and they can see them going on and off their meds and their dyskinesia. So they can actually play an important role in coordinating with the other team members to make sure you're getting the right therapies. And so in the best

possible scenario, you go to an experienced physiotherapists first for a full examination, and then they give you the plan and you take that plan locally. So let's say you're going to an expert center like Dr. Boss bloom, and another lens. They'd give you your recommendations and then you'd go out and you see, you know, in an area you will see what is the best possible therapy for you. And then you take that plan back locally, and they actually carry that plan out for you.

And then the physiotherapist can check back in on you. So the idea of a physiotherapist only staying involved for six or eight weeks, and then checking in and out is old school. The new school is let's get a precision therapy, let's check the symptoms. And then even if the physiotherapist gives you the recommendations, maybe they could be done by somebody who's not a physiotherapist. Could it be a physical therapy aid? Could it be a personal trainer? Could it be somebody else? And so we have to think differently about how we're doing things. And we have to think that just because the healthcare system is set up in the wrong way for Parkinson's patients. So we have to help to teach the patients, the families, the persons with Parkinson, a better way to navigate what benefits do hockey does occupational therapy play.

Occupational therapy is really interesting. When we first started, so Kelly foot and I started this center that became the pixel Institute back in 2002, we formed interdisciplinary teams and kind of our dream, like the dream at that time was could we have a team where the patient's assigned and we revolve around the patient. And so we invited in all these therapists, but I must say, like in reflecting back, I didn't really understand the role of the occupational therapy. And I say this with all respect and, you know, Lisa Warren, Heather Simpson push Gardner Smith. Many people I've worked with over the years will hear me say this. And I say this out of complete respect for them because it was complete ignorance on my part. And so if I didn't understand it as the doctor, imagine if a family member or a patient doesn't understand the value and it turns out in the end and, and Kelly foot, and I say this all the time.

And for those of you that don't know, he's our neurosurgeon that we've worked with pretty well known, famous guy in the field and a really nice guy. We always say it turns out the occupational therapist. The one we didn't really know what they did is probably the most important member of the Parkinson team, because you know, whether you're dealing drugs as the doctor, whether you're prescribing physiotherapy, whether you're doing nutrition consult in the end, the patient, or the person with Parkinson has to go back to their home setting and reintegrate back into life. And it is the occupational therapist that assesses your ability to do all these activities of daily living, assesses your ability and helps you to develop the strategies. So you can go back and be successful in your life no matter what anybody else is recommending or are having you do. And there's absolutely nothing more important to the equation, to the healthcare equation that adds value and getting back to your life.

So, an occupational therapist will do a complete evaluation to see how is your dexterity is one arm worse or better than the other? You know, what, what sorts of things should you be doing? What's important to you? What do you need to be doing? Where are you at most risk? They're the ones that really reintegrate you back into life and where we fail the most is physicians talking about physicians. I'll talk about my failures all hour, if you want. But physician failures, where we fail the most is we give out medications, prescribed things, congratulate ourselves, and send the patients and the family members and the persons with Parkinson's home to fail. And the occupational therapist is determined not to let that happen.

Dr. Soania Mathur

Right. And are there any resources where patients can find out people that are specialized allied health professionals that are specialized in Parkinson's or is it a matter of consulting your own physician for referral?

Dr. Michael Okun

So, it's a little bit of both. Unfortunately we haven't evolved as healthcare systems at least universally on the planet to understand an interdisciplinary approach. We haven't gotten there everywhere. There are certain areas like in another ones that are more evolved and in Israel that are more involved, and then you have patchy areas depending on where you live, stay in the United States or in Europe. And so, because of that, you know, it's super important as a, you know, a family member or a person with Parkinson, super important to be aware and understand what the different team members do. And we sort of talk about this and the living with Parkinson book, just understanding, you know, and this idea that we took too many steps forward without explaining things to patients and why they were important. You know, if you don't understand it, you're obviously not going to be able to integrate into it and you won't be able to appreciate the success and the, and the impact that it can have on your life with the impact being the big, the big word.

And so, depending on the health care system, or depending on the position itself to poke you with those resources is sometimes not the best Parkinson foundations. You know, like the Davis Phinney foundation who were on with today are awesome places to get information because they can immediately identify people in different areas. We have a 1-800-HELPLINE that we've used it a number of years of Parkinson's foundation. But the reality is is that these foundation resources are helpful, but the best patients and caregivers are the ones that seek out those opinions. And they don't believe one person or one thing. And they, they look and sometimes there aren't services available. Sometimes there are, and sometimes there are clever ways to get services and we've begun. Now we've made more progress in 10 days at the beginning of the Corona COVID epidemic and telemedicine than we did in 10 years, right?

At least in the United States, Canada has been aware the biggest user of telemedicine in the world. So you all are way ahead of us in Canada. So congratulations. But we caught up in 10 days and we need to keep those services online. And one of the things that we've been focused on is, is pivoting, right? You get to success, you've got to pivot on it. We need to keep it. And we need to be doing those services for physical, occupational speech swallow and finding other creative ways to reach into people's homes and make sure that they're getting care that actually matters.

Dr. Soania Mathur

Right. And, and you mentioned speech, language pathology. I think that's something I'd like to talk about as well, but I want to move on just so we don't lose sight of the other excellent information in the book. So I just want to move on to nutrition. I mean, Parkinson's disease can kind of affect how we move our food from our mouth and through our digestive system. And it results sometimes in difficulty swallowing and indigestion, bloating, and constipation. How do we know when we're having trouble with like dysplasia, for instance, swallowing difficulties? What are the signs that someone should look for and how common is it?

Dr. Michael Okun

Yeah, so this is another highly underappreciated area, you know, so here's another tip. We call them curls when we're teaching our students and patients, here's a curl to take home. One of the most highly underappreciated areas and Parkinson disease is difficult to with swallowing. Okay. And so it's not just speech. We often have those two S's together, speech and swallowing, but swallowing and swallowing problems. People call that dysphagia yet. It's basically having trouble getting things down your throat for a number of different reasons. And if we look at the leading causes of death, not just a Parkinson disease, but in aging and in other degenerative diseases, it's usually linked to a swallowing problem. And when have a swallowing problem, a lot of times the food goes down the long patch, you know, into the lungs instead of into the stomach. And, and we call that aspiration, okay, when that happens and in Parkinson's disease, we often have what's called silent aspiration.

And so what does that mean? That means you're aspirating and you don't know it that's a bad thing, you know? And so if you're not getting screened and not getting checked for aspiration regularly with Parkinson, that could be a problem. We totally underappreciate this. We under appreciate the power of people's ability to cough. And so I often as a clinician, this wasn't something that I learned in day one, but now having taken care of a bunch of Parkinson, patients made a lot of mistakes at a few successes. You know, like, you know, you, you pick up on a few things and you're, you're an internist, right? So you, you pick up on things as you take care of patients. It takes a while to, to experience this, we need to pass this knowledge forward. Having people cough at the bedside and see, is it, is it, can they barely cough or can they give you a good

cough if they can't give you a good cough, they're at higher risk, we need to, we need to be aware of that to prevent aspiration.

And also we need to pay attention to symptoms and tell them, you know, how are they to know if we don't tell them if you're coughing, you know, or clearing your throat a lot while you're eating, that could be the sign, you know, where you could be silently aspirating. So even getting a test every once in a while, every year or two, just to check it out and follow it along a simple swallowing test is what we do as well. And the study super important can save lives. And then I'll just mention, there is a, a device made by Chris Sapienza Danny Martin and Paul Davenport, that's available called an expiratory muscle strength trainer. And they have a level one evidence study published in the journal neurology, a number of years ago, showing that if you blow into this device a few times a day at decreases your aspiration risk and Parkinson's, so we have to communicate these things and we have to encourage our next generation researchers to help us to come up with more innovations to address both speech and swallow.

But swallowing is one of those pearls that people forget too much about absolutely someone access a device like that, that you just described. Oh, I think just like everything, just like our book living with Parkinson, I think everything's on Amazon. Those researchers, Chris happy ends is now the Dean at Jacksonville university. She she's actually just received another promotion to provost she's terrific. And I often joke that her device for it's on Amazon, but for some reason it's not prime, you know, so I don't know why, but so it might take a few days to get there, but, but they're, you know, they're relatively cheap, you know, devices, but you do want to do it under the care of either a physician or a speech, language pathologists all are, are aware of how these devices, cause they have to show you how to use them, what the bell, so everything, unless they're done, you know, unless you do something correctly, you could be undoing something. So just making sure that you're doing it right. It is also important.

Dr. Soania Mathur

Sure. The one other sort of nutritional aspect that you discussed in the book was constipation, creating constipation. Cause that's, you know, often something that really affect quality of life for patients. Could you just very briefly describe some of the things that patients can do to help with that?

Dr. Michael Okun

Yeah, so we have over the years developed sort of a constipation formula, you know, so to speak, but with our own and talking to other people. And I, one of the people I talked to a number of years ago is actually in Canada, Janice, we have Saki and so, you know, a number of us have different combinations and formulas. And so, getting really family members in tune with getting on a good regimen and staying consistent with that regimen is important because

constipation is not only one of the most common symptoms in Parkinson's it's, it's listed under the non-motor. So some people might call it a motor or something, right. Moving through the intestines. But at any rate solicited as a non-motor symptom, it is super common. And when we look at web hits, you know, you know, for what people ask about, you know, like number one, number two is always constipation, constipation, psychosis, some of these things like people are really seeking information.

And so, it's a problem that's been under appreciated may even be the first problem that comes up. And so, so in the book, we have a recipe that we have for, you know, putting, you know, things that you can do in your diet. You know, dietary changes, changes in fiber and things. Exercise helps. Okay. A lot of people don't know that. So that's another aspect to this is that exercise can help. And we also focus on your water content. So, a lot of people are not drinking enough, so drinking can also change the, you know, like how you're going to do with this. And then there are several new drugs that are in trial that we talk about like grilling drugs and other things. But there's also safe drugs. Like there's a drug called Amitiza that that you've probably used more in internal medicine than we have in Parkinson, but a great colleague of mine who I chatted with this morning, Theresa says it, which did a randomized study of muts and in Parkinson disease.

And a lot of times you can't give up, you've got to keep talking to your doctor. It's very disabling and you've got to keep trying things. And sometimes it's multiple things and I have a patient I'm thinking of right now, I've recently been through this with it, you know, they were having years and years and years of problems. And we just kind of started to try stuff, you know? And the first couple of times I saw him in it and we didn't like hit a home run, you know, we didn't get the first base and we had the first base. Then we got the second base. And then by time we got all the way around all the basis, you know, he said, okay, I'm going to stop. No, no, no, no, no, no. We got it now. Is it the, is it this formula now we finally figured it out for him or, you know, or is it, was it one component or another?

So now we got to work backwards and figure that out. So, so, you know, one of the messages, Sonia is it takes work it to treat constipation and Parkinson and sometimes it's easy and sometimes it's hard and sometimes it's a, it's a, it's a mixture of things. But I mean, if you can help somebody with constipation, I mean, this may sound trite, but I think anybody who's here listening today, notice this with Parkinson's, it can rule your life. It can be one of the most powerful symptoms to have. And until you have it, you just don't, you just can't appreciate that. So important pearls.

Dr. Soania Mathur

Unfortunately, as we all know, this disease is progressive one and inevitably our symptoms tend to get worse. Although the rate of that progression may vary of course, from person to person. But one of the biggest decisions we have as patients to make during our journey is whether to start and when to start medications. So, Dr. Oaken, how do we know when it's the right time for certain medications? And I guess for those of us that are already on them, how do we know when it's time to adjust our current regimens?

Dr. Michael Okun

Yeah. So when is enough enough? I think as the question, you know, when is it time to pull the trigger, you know, for patients struggling with this, all, I'll tell you, I even got a message last week and I not uncommonly get this message from experienced neurologist. Okay. Think about that. Let's just pause for a second. So we were saying these patients are confused. They don't know when to start medicines here. We are an experienced neurologist are asking the same question, right? So, you know, if we just have a little bit of perspective, so those of you that are struggling with that question, just keep that in the back of your mind as this is not like a, a simple construct here to decide when to pull the trigger with Parkinson disease.

But let me tell you some of the pearls that we talk about in the book and some of the things that Irene and wisdom and I were the three authors, some of the ways that we've looked at this, that we've found to be useful, one, talk to the patient, talk to the person. Okay. I know that sounds easy, but you've got to establish, you know, not only what it's like and what symptoms they have, but what do they do understand that person? What do they do every day? Not just at work, but at home and other, other areas of their life, what do you do and how is it impacting what you do? And do you realize some people don't realize it actually is profoundly impacting what they do. You must understand the measure of an impact on somebody's role too, or me or whatever it is you have to.

Then once you understand the person, you understand the things that they want to do in their lives. You have to make a determination of how much disability you think, as a treating physician, I'm talking to the physician side and how much disability they think they have, because some people actually don't believe that they have disabilities. So I may look at somebody and say, Oh my God, that's terrible. We should do something about that. And they're like, no problem. You know, this is not a big deal, you know? And some people are like that with tremor. So I have some people with tremors that are really, you know, like very noticeable and they're like, doesn't bother me at all. Doesn't affect me. Doesn't you know, like I don't care what my spouse says. You have to take that information into consideration when making decisions three or C is you, you then have to ask yourself, are they in danger? Because sometimes people don't want medicines, but they are in some danger. And one of your primary jobs is to assess the

safety of, of somebody. And if you believe that they're balanced or walking could be off timeout, time to start medicines. Okay. Just one of the ways we do that, as we sneak up behind people and we give them a tug on their shoulders. Okay. And if they can't balance themselves in a step or two, you know, then that's important. And early on in the disease, people often say, well, that's no good. Cause it doesn't respond to dopamine. That's actually not true. We actually realized particularly early on in the disease, when I see people who are untreated, they can't correct themselves and I treat them and they can correct themselves. I see the patients. And so you miss this in articles, unless she's she hundreds and thousands of patients.

And so we tried to communicate some of these things together. Are people still wanting to drive or not? Are they still wanting to work or not? So understanding the patients and then making a determination disability, both in your eyes and in the eyes of the patient and then third assessing safety. The last thing is just one more thing is just, do you believe that in this individual case that if you don't start medicine, they could get into, into trouble. So this is a discussion, you know, and it's not, not everybody has to have medicines, but a lot of people will read the internet and they'll read things. And I've been part of, I won't say a blue ribbon panel, but several panels looking at Lima, dopa phobia, and other things. And we shouldn't be fearful of the medicines. Like they're, they're not gonna, they're very safe.

They're not, you're not going to, we now know from data from Ghana and Italy and other places that if you start medicines a little earlier, it's not going to impact you getting dyskinesia or other things. There are other factors that impact that. And so that shouldn't be driving your decision making in general, we have enough data to know that, but people get, can get confused if expert neurologists can get confused. And I can't answer that question in one sentence, then you can understand why people get confused on that. So we try to cover that in the world.

Dr. Soania Mathur

No, I, and I agree. And I think part of the onus is on patients as well. I mean, only we know what our quality of life goals are only. We know how the diseases impacting the different areas of our life. And it's up to us also to communicate that to you so that you can make informed decisions with us about our, our ongoing care. And I'm glad you mentioned about the dopamine phobia, the, the medication, cause that's sort of, there were all those two schools of thoughts when I was early on in this disease, whether to start or not to start. And I think that it's sort of been proven now that, that we shouldn't be afraid of starting something like Sinemet, if it improves our quality of

Dr. Michael Okun

Yeah. And there's several studies now, you know, so it's, you know, there were early studies showing if you drop dopamine on a, on a, you know, on cells, in a dish, the cells die. That wasn't

what exactly happened in the brains of people who were living. And then as the stories evolved, we put that to the test and we actually realized that, you know, it doesn't seem to protect you from losing cells to start to open me in any earlier, but it doesn't hurt you either. And so there's been recent studies that have helped us. And so surely no reason to start if there's not some disability or some impact on quality of life or some danger.

Dr. Soania Mathur

I also think that being ed patients being educated about what their treatment options are, is really important. I mean, knowledge is power in this, in managing this disease as well. Can you briefly just talk about the different medications that are available to patients in very general terms?

Dr. Michael Okun

Yeah. So there, there in thinking through how to proceed and Melissa Armstrong has a beautiful table in this article in JAMA that I think is publicly available for download this review article that came out, I think in February of this year. But in thinking through the medicines, it can be very complicated, right? Because you know, there are dozens of different medicines and lots of different approaches and, and the medicine's changed over time. It's dynamic and you're, it's not just the color of medicine or the pill or anything. It's the timing. Okay. So again, we have to talk to people. One of the things we've learned, we've got to talk to people. We got to understand when the symptoms are occurring along that cycle. And so there are a whole bunch of medicines that are dopamine replacement therapies. So, we talk about Sinemet okay.

Sin means without. Emet means vomit. So you have to have two parts, carbidopa, levodopa, so you don't vomit. Right. But there's also Madopar, which is also another formulation in Europe and other regions of the world that, and those are dopamine formulations. Same with Rytary. These are fundamentally dopamine replacements. Then we have pills that are called dopamine agonists. They go to dopamine receptors in the brain and they tickle those receptors. So they have different effects, not as robust as just simply replacing the dopamine. That's not, they're not as robust on some of the benefits like motor, but pretty solid benefits and a different side effect profile. So things like impulse control and dizziness and nausea maybe problems with dizziness when we stand up a little different, a little more hallucinations with the dopamine agonists and with Topiramate. So it can be confusing. When should you use each one of those two?

And then there are drugs that make dopamine a little more available. So there's a called monoamine oxidase inhibitors and dopamine is broken down by an enzyme in the brain called monoamine oxidase. And another one called here's a long one Catechol-O-methyltransferase COMT okay. So if you, if you affect those two enzymes and we have COMT inhibitors, like Tolcapone, which actually doesn't work in the brain, but another one called Opicapone. If you, if you actually like work and look at those specific ones they can make dopamine more available. They have less impact on then the dopamine and dopamine agonists, but they, they can, in some

cases, the COMT is, can extend the life of dopamine. And then the, the B's some people believe, depending on which study you read, there might even be a very tiny, might not be a much, but there might be a tiny protective effect on cells dying with MAOB like Rasagiline and Selegiline.

And then we know for things like COMT inhibitors, they're specific windows. You want to give them because they can drive more dyskinesia in patients. And then as we cycle through the life and Melissa Armstrong does a wonderful job in her article on this, she cycled through, I mean, think of Parkinson as a lifetime disease. And over the life, you have different symptoms and different windows. And then when you hit a certain window, you know, it might be time to drop a certain medicine like a COMT inhibitor that might cause more dyskinesia. It might be time to think about deep brain stimulation or a Duopa pump or Apomorphine or something, or it might be time, you know, where you're getting problems with thinking where you want to drop off some of these medicines. Like Amantadine, that's used a lot for dyskinesia, for example, but it might cause hallucinations later on.

And so, you know, thinking of it in a dynamic terms, timing of pills, lifetime of an individual patient, and each one of these therapies, either in monotherapy by itself or in cocktail may have its place at a certain time in a certain patient. But if you ask somebody at a support group meeting or pretty there's so many pockets of patients are at probably any event that you go to, you're going to see multiple Parkinson patients. Even if it's not a Parkinson event, if you look left or right, everybody's doing something different than they should be. If everybody's doing exactly the same, then there's a problem. They're probably all seeing the same doctor. That's not, that's not the same team. That's not making the change. It should be a very dynamic disease.

Dr. Soania Mathur

And you have a lot of information in your book. You also have lot of information about that. Some how to treat some of the non-motor symptoms, which may not respond to dopamine, but covering, you know, things like drooling and urinary dysfunction and erectile dysfunction, orthostatic hypotension, where your blood pressure drops, fatigue, apathy. I mean, there's a wealth of information, which I can't believe we're almost at the end of our hour. We won't be able to cover, but it's all there and encourage people to pick up the book and read. But I mean this concept of living well with Parkinson's disease while we continue to search for the cure is, is really a powerful one because until there's a cure, it's all about life experiences, all about our quality of life. It's a way we function day to day. And your book really serves as a resource to help guide patients and their loved ones along this journey with Parkinson's. And I thank you for that. If there is one salient lesson that you would like those that are facing the challenge of Parkinson's to know what would that be?

Dr. Michael Okun

I, you know without a doubt, you know, it's that you can live a happy and healthy and good and meaningful life with Parkinson's disease. I mean, if the world, you know, knew that and embraced that, and everybody on this planet, you know, believed that and understood that concept, you know, just having been around Parkinson disease, my whole career. I mean, that would make me so happy because, you know, I feel like so many people get it wrong and they, they lose so much good life because they don't realize you can have a great meaningful life with Parkinson. And many of my patients have told me their lives are actually better after the diagnosis of their Parkinson's than before for various complex reasons. But it does give you that sense of, you know, there there's, there's, there's every chance for meaning and hope with a diagnosis of Parkinson and lots of exciting things going on. So, I'm not only optimistic, but I'm hopeful because I think there's a difference between optimism and hope and I'm very hopeful. That would be the message that I would want to send it to people.

Dr. Soania Mathur

That's great. I mean, knowledge is power and attitude is everything I think, but Dr. Okun, thank you so much for your time, insight and expert advice. It was greatly appreciated. I know there are a lot of questions that we weren't able to get to, but Dr. Okun kindly agreed to answer some of those after the webinar as well. So I hope you found your time with us helpful and educational. We will be sending out a link for the recording of this webinar in the next few days, which you can share with others. So always remember that you may not have control over your diagnosis, but how you face the challenges that this diagnosis brings is really yours to determine as Dr. Okun had mentioned. So focus on optimizing your quality of life, educate yourself, empower yourself. And as Davis Phinney says, celebrate your daily victories and also remembering these turbulence times to stay safe and be smart about things. And thank you everyone for joining us today.

Dr. Michael Okun

And remember the Davis Phinney *Foundation* is a great resource and a great foundation. And Davis always says, you know, make every day, your best day. And so it's, you know, make sure you're utilizing all the great resources that they have. They've helped so many patients, if you get a minute and you like the book, or don't like the book, leave us a review on Amazon. We'd love to hear from you. So thank you for having me, Sonia, thank you so much.

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