

Newly Diagnosed with Parkinson's: Now What?

An Interview with Dr. Aaron Haug

Davis Phinney Foundation

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

Soania Mathur, MD (Physician at UnshakeableMD, Parkinson's Advocate, Davis Phinney Foundation Board Member):

Hello everyone. My name is Dr. Soania Mathur. I'm a family physician and someone living with Parkinson's, having been diagnosed about 24 years ago. And I have the privilege of serving on the board of directors for the Davis Phinney Foundation. And I have the pleasure of having this conversation with Dr. Aaron Haug today. Even though it was a couple of decades ago, not just years, I still remember, as I'm sure many of those in our community do. The day that I kind of heard those first four words, you have Parkinson's disease, or maybe it was actually six words. I think you have Parkinson's disease because as a young woman, I certainly didn't fit the norm. And after that initial, so shock settled somewhat, questions started running through my mind. What does the future hold? How long would I be mobile and productive? Would I remain independent?

Would I be there for my children and my family? Would I be a burden? What could I personally do in order to give myself the best chance of optimizing my quality of life? In other words, I've got Parkinson's disease, now what do I do? So, I'm so glad that I'm joined today by Dr. Aaron Haug to discuss what we do or what we can do for ourselves as newly diagnosed individuals. But before we get started Dr. Haug, could you tell me a little bit about yourself and why you actually chose to pursue a career as a movement disorder specialist?

Aaron Haug (Movement Disorder Specialist, HealthONE Neurology Specialists):

Yeah, absolutely. Happy to be here with you today, Sonya. So, I've been happy to work with the Davis Phinney Foundation over the past few years doing a variety of these webinars, and there's a huge amount of information available from the Davis Phinney Foundation. So, keep that in mind. If there are other things we bring up today that you want to learn more about. I've been here in the Denver community in practice for over 10 years now as a neurologist and movement disorder specialist. And part of the reason I chose movement disorders as my subspecialty career is that I like working with people with Parkinson's. And although it's a tough disease, it's a disease that we do have treatments for that can make a big difference in people's quality of life. Right. and so, it's also something that I feel like the more I work with people with Parkinson's, the more I learn these little nuances. And by being a movement disorder specialist, I can help to provide some additional insight into how to live as well as possible for as long as possible.

Soania Mathur:

Well, we're certainly glad you made the choice, you know, the community, thank great movement disorder specialists, that's for sure. Dr. Haug, I kind of alluded to the fact that sometimes it's difficult to make a diagnosis for Parkinson's when I say they thought I had Parkinson's disease. And that's because we really don't have a definitive test for this disease like we do for heart disease or say diabetes. We depend on the skill of physicians examining us and taking our history. And it's, so it's often a clinical, clinical diagnosis. What symptoms do you ask about or wonder about when you try to make a diagnosis of Parkinson's disease?

Aaron Haug:

So, the symptoms that we think about in Parkinson's, whether it's early or more advanced stages of the disease largely fit into two categories, motor symptoms, and non-motor symptoms. and these can be helpful even early on in trying to distinguish, well, are we dealing with Parkinson's or something else? Is it an essential tremor or is it some other neurological condition? Right. And so, the motor symptoms that a person may exhibit, and maybe they'll be more apparent to a family member or more apparent to the doctor even than they are to the patient themselves, come down to tremor and stiffness and slowness. stiffness can also be called rigidity. Slowness can also be called bradykinesia. And so, a person classically may have some tremor, often worse on one side, often present at rest. So, if the arm is just lying there on the armrest or at your side on the couch although about a third of people with Parkinson's don't have tremors, so there's not always that to look for.

Soania Mathur:

Right.

Aaron Haug:

And then the rigidity in bradykinesia, we can sometimes get just by asking questions like, do you notice that if you're washing your hair that one hand is slower than the other? Or if you're wiping a countertop, does it feel like you're in slow motion? Right. But then those are also things that can be apparent on examination, even if a person hasn't noticed those changes, maybe because they've been subtle and sneaking up over the course of, a few years.

Soania Mathur:

Right. I mean, for myself, I remember prior to my diagnosis, having difficulty fumbling for change at the checkout counter and wondering why I couldn't be as quick as the person ahead of me in establishing, you know, the right amount of change. And the other thing I noticed was it was hard to flip pancakes for my kids as well. So, it was a little subtle thing. I noticed that as well you mentioned the non-motor symptoms and we know that there is much more to this

disease than the motor symptoms even though it's called a movement disorder. Could you elaborate a little bit about those?

Aaron Haug:

So non-motor symptoms are they can be wide ranging. And when I talk about non-motor symptoms, because there are a lot of different symptoms that can come up, I like to point out that this is not a checklist. This isn't, everybody's going to get all of these. Right. but more so it's that if you're aware that this is happening and that it might be related to Parkinson's and that there might be treatments available for these non-motor symptoms as well, then that can be helpful to be aware of. And so, it kind of goes from head to toe, it can be things from thinking in-memory changes, a loss of sense of smell, which can also affect the sense of taste. there can be changes in the so-called autonomic nervous system that cause blood pressure fluctuations or blood pressure drops when you stand up or having to urinate more often, not being able to have a bowel movement as often with constipation.

And so, there's a long list of possible non-motor symptoms. And when I'm first meeting someone, I will often ask the question of how's your sense of smell pretty good or not as good as it used to be. How's your gut function? Do you have a bowel movement almost every day or do you have some bothersome constipation? And then another one I haven't mentioned yet is when you're asleep, do you know whether you yell out or punch and kick like you're acting out your dreams? Those three things of smell loss, constipation, and dream and accurate behavior are not universal, but are very common in people with Parkinson's and can be helpful in making the diagnosis of one or more of those are present.

Soania Mathur:

And from what I understand, those can also precede a diagnosis. Is that true that these things can show up years in advance of actually being diagnosed with the disease?

Aaron Haug:

Yeah. To a very surprising degree. That is true. people will sometimes lose their sense of smell years before people will sometimes start acting out their dreams decades before and so, these can be long before the first sign of a tremor or a slow hand.

Soania Mathur:

Does it mean though, that if you are experiencing those, that you will definitely develop Parkinson's disease? So, someone who has issues with acting out their dreams, for instance, does that mean that they will ultimately be progressing to Parkinson's disease?

Aaron Haug:

This varies from one symptom to another. for example, some people lose their sense of smell and never go on to develop Parkinson's probably in a different clinic like at ear, nose, and throat clinic. Most of their patients that lose their sense of smell don't go on to develop Parkinson's. Right. But in the context of the motor changes, it's a different story. now with the dream acting out what's called REM behavior disorder, it is thought that if a person has that, that they are at much higher risk for developing Parkinson's. But if a person starts acting out their dreams in their sixties, are they going to ever develop motor signs of Parkinson's in the next 10, 20, 30 years and get a diagnosis of Parkinson's? Not, not all the time.

Soania Mathur:

Right. So, what's going on in our brains? What's, what's causing these symptoms to occur?

Aaron Haug:

So, the fundamental problem with Parkinson's is that it is a neurological disease of the brain, and particularly the center of the brain. An area called the basal ganglia has special cells that are involved in making dopamine. And for reasons that we don't fully understand, these dopamine-making cells start to die off. And as there is less dopamine, these physical motor symptoms and non-motor symptoms begin to occur. So, it's a loss of these dopamine cells.

Soania Mathur:

And what I was wondering, so in many diseases that, I mean, I'm just wondering about the how, why that loss of dopamine occurs in many diseases. We can kind of describe it as genetics loading the gun and then the environment pulling the trigger. Can the same be said for Parkinson's disease, or do we know why we start to lose these dopamine cells?

Aaron Haug:

That's a big question and it's not fully answered, you know? the question always comes up of how hereditary Parkinson's is. and if we take the million or million and a half people in the United States with Parkinson's, as far as we know currently with the genes that we currently are aware of and contest, we think that only 10 or 15% of cases are clearly hereditary. Okay. Now, what's going on with the other 85 or 90% of people? Is it that they have some gene that we've not yet discovered, or it's some complex thing of a risk factor here in the genes and a risk factor here in the environment add together? I think a lot of that is still an unanswered question, but there are a few dozen genes that have been identified as being very likely or almost certain to cause Parkinson's if you have one of those genes.

But fortunately, most of the time that's not the case. People are often worried about, oh, what does this mean for my kids, for my brothers and sisters? No one else in my family has, has, has had this and because genetic testing can sometimes be expensive, hundreds or more dollars, I

don't routinely test everyone. But if there's not a clear history of, oh, I have it, my brother has it, my dad had it then I would say what we think is that having a first-degree family member with Parkinson's raises your risk some over the age of 61% of the entire population has Parkinson's. Right. And so, if your risk is 1% and you have a first-degree family member, that maybe goes to one and a half percent. So that's how I think of it.

Soania Mathur:

Right. And that's really important to know because and I'm glad you shared that because I think, you know, when I was diagnosed first, I was actually expecting my first child. So that kind of fear of, of what was going to happen for my child actually was something that consumed me a lot. And I think that's a very common fear that those of us with Parkinson's Disease who are also parents face. So, thank you for broaching that subject.

Aaron Haug:

Sonia, I don't know this, and if you don't mind me asking. Yes. Have you been genetically tested? Do you know if you have one of the genes?

Soania Mathur:

Yes, I have been genetically tested and I don't have one of the genes that we know of yet. I mean, okay. As you know the genetics work that's being done is, is ongoing. So, none that we commonly known about, no. Okay. But, you know, that could change obviously. As we know. I just want to go back to the dopamine loss that you described. And that kind of leads me to think about how we treat this disease if we know that there's lack of dopamine that's causing these symptoms because it's, you know, rather frustrating that we currently don't have a cure, obviously, and the challenges that we bring into that, that this disease brings into our lives, they're not controllable. But the management can be there, as you mentioned. It can be medical in nature or other complementary treatments. But just to get us started, maybe Dr. Haug, can you please broadly discuss the medications that we use to treat Parkinson's disease?

Aaron Haug:

Yeah, of course. So low dopamine is the root problem. And so, most of our medicines one way or another are targeted at increasing that dopamine or decreasing some of the other chemicals that work contrary to dopamine. And so, there's seven major categories of medicines for the treatment of the motor symptoms of Parkinson's. And I'll maybe just there's whole webinars out there about this, so don't feel like you have to soak all this information in auditorily if you're a visual learner. But I'll start with the main one, which is carbidopa-levodopa or L-DOPA for short and often known by its old brand name of Sinemet. So, L-DOPA is a small enough molecule to cross the blood-brain barrier and then get turned into more dopamine So, people say, well, can I just take dopamine in a pill?

And the answer is yes. This is the closest thing we have to dopamine in a pill. Right. And so, Carbidopa-levodopa helps to put back some of what's missing. We call it dopamine replacement therapy. The other medicines work on other parts of the dopamine pathway, or I'll just mention a few. So, there's a family called dopamine agonists. These are medicines like Ropinirole and the neutron patch. these are all synthetic dopamine. So, there's dopamine receptors in the brain, and these medicines target and activate those same receptors just without being quote-unquote dopamine per se.

There's a couple of medicines called MAOB inhibitors, COMT inhibitors these kind of act as boosters for the carbidopa-levodopa by slowing down this monoamine oxidase enzyme or this ethyl transferase enzyme. And so, by slowing down the breakdown of dopamine, you end up with more dopamine. And then the couple others are anticholinergic or adenosine receptor antagonist and amantadine. And we could talk more about each of these, but there's also more information about them available through the other Finnie Foundation materials.

Soania Mathur:

Sure. So, what are the, some of the common first, first line medications that someone who is newly diagnosed with Parkinson's can expect to be offered?

Aaron Haug:

That's a good question and kind of dovetails with the question of when we start and the current, the current thought processes, as soon as your motor symptoms are interfering with your life in some way, socially interfering with your hobbies, interfering with your job, it's reasonable and fairly standard now to start medicines as soon as symptoms are interfering with quality of life in some way.

And then there's a number of factors that play into, well, what is the initial drug of choice? and a few different ways that this might go is if someone has very mild symptoms and wants a convenient as possible of a treatment, we might start relining one pill once a day, not very strong, but can have some benefit for tremor, stiffness, and slowness. if someone has more tremor, more stiffness and slowness and maybe needs something a little stronger right out of the gate, the decision is often between levodopa or a dopamine agonist. And what we find is that over the course of a few years, people usually end up on a couple of two or more medicines together. And it's been shown to maybe not make as big of a difference as we once thought it did on what medication is chosen first.

The main fork in the road is, I see it between levodopa and the dopamine agonist. So that levodopa is a little more effective but has some side effects that can pop up after a couple few years. And the dopamine agonists are not quite as effective and don't have quite those same side effects but have different side effects. So, what I mean by that is that levodopa is the gold standard. It's the most effective for tremor, stiffness, slowness but we know that the higher

dose of levodopa you take for more years, the more likely a person is to develop dyskinesias, the wiggly fidgets. Yeah. And motor fluctuations where the meds work and wear off Right. Several times a day. Those two issues are possible, but less likely with the dopamine agonists. But the dopamine agonist can cause impulse control disorders like pathological shopping, spending gambling.

Right. can cause sleep attacks of falling asleep suddenly and can sometimes cause swelling in the legs. And so, there's one train of thought, which is that if a person is younger, like you were when you were diagnosed, maybe avoid levodopa for a while to avoid these complications if possible and start with an agonist. I tend to not do that. I tend to start levodopa on most patients that are having bothersome motor symptoms and as experts can disagree. But my thought process is that in younger patients, especially male patients, we know that those agonist side effects are also more likely. So, the impulse control disorders and I've seen some people have really severe impulse control disorders, like severe gambling problems that came out of nowhere and so, I will use those medicines some, but I will usually start carbidopa-levodopa as kind of the foundational cornerstone of medication treatment for most patients.

Soania Mathur:

Well, that, that's really good to know, Because I know there's still this perpetual belief in the community amongst newly diagnosed patients that if you start levodopa carbidopa too early that it's going to become ineffective. So, kind of get used to the, used to the medication your body gets used to it. Could you just address that concern?

Aaron Haug:

Yeah. It is a widespread concern, and I would say that there's a kernel of truth in there as there often is and kind of myths and misperceptions So, the kernel of truth is that the longer that a person has Parkinson's, the more medicine they need. But it is not the case that Carbidopa-levodopa stops working after some time. And I'm trying to think if I even have a single counterpoint of this. Patients that take carbidopa-levodopa, even if their symptoms worsen as the disease progresses, they always stay on carbidopa-levodopa as part of their treatment regimen. Maybe it needs to be buttressed with other medications, or the dose needs to be higher more often. But it doesn't ever quote-unquote stop working. It's just that as the disease advances, adjustments to the treatment are often necessary.

Soania Mathur:

Right. Now you mentioned this somewhat when you talked about your male patients. You often will start with dopamine replacement as opposed to an agonist or some sort of other medication. And that's important to note because I think we, you know, we all experience this disease very differently. We vary in terms of our symptoms and our progression, our response to treatment, and our prognosis. We're sort of all very unique in how we manifest this disease.

So, are there other variables that you take into consideration when you're in your approach to each patient? Are there certain things that you look out for?

Aaron Haug:

I would say age is probably the single biggest factor. Okay. So, if someone is 60 or 70, kind of an average age of onset for Parkinson's, then it might be a simple playbook. We start with carbidopa-levodopa, and after a few years, if we need more, we just increase it. If someone's 40 or 50, maybe we start with carbidopa-levodopa and keep the dose low, maybe no more than one pill three times a day, and then add other secondary medications to support that dose. And by keeping the dose lower, still try to keep as long as possible of a time window before some of those motor complications develop. If, if someone's older, 80 or 90, carbidopa-levodopa and Line are about the only two medications that I'll consider because some of the other categories, the agonists, the anticholinergics amantadine can have side effects that are much more prevalent in an older patient population.

Soania Mathur:

Right. So, it's not an easy way to manage. There's, there's a lot of variables you have taken into consideration. And that kind of leads me to the question that in terms of medical care, what type of physician should we see for management and follow-up? Can this be managed by a primary care physician, general neurologist, or movement disorder specialist?

Aaron Haug:

Yeah. Yeah, it's a good question. And I think depending on where people find themselves in the country and a big city or a rural setting, the options are going to vary. So, I think that there are and it more than, you know, the label on the door primary care or general neurologist or movement disorder specialist, that probably comes down a lot to the provider's experience and so, there are, I don't doubt primary care doctors that can walk in the room and know someone has new diagnosis Parkinson's because they've seen it many times before. Whereas there may be neurologists that mostly see other conditions and might not be able to tell that it's Parkinson's. And so I think we have to be realistic about what our options are, but if there's a primary care doctor or a general neurologist that seems kind of unsure about the diagnosis, or you get a feeling that maybe they're not as sure as you would like them to be seeing someone, a movement disorder specialist who kind of sees people with Parkinson's all day every day and has really fine-tuned their Spidey sense for what's going on can be helpful maybe just on a one time occasion or if availability permits, then maybe having a movement disorder specialist as your primary person for Parkinson's.

Soania Mathur:

Right. I, you're right. I guess it's very specific in terms of geographic location and disease severity and that sort of thing as well. Those variables must come into play. But we also often talk about this team approach to managing Parkinson's disease. So, movement disorder specialists you say, may be part of that team, and your primary care physician might be part of that team, but who should, who should be on your team? And who leads the team I guess, as well?

Aaron Haug:

Yeah. Good question. I think that you know, for it's good to have at least a primary care doctor and some whether it's that person or a neurologist you know, probably kind of two people in the center. And the reason I say it that way is that if a person is trying to see just me as a movement disorder specialist, and then they have a question about their cholesterol or chest pain or something, I need them to be able to have a primary care doctor to talk to those things about so, you know, with primary care and a Parkinson's provider kind of as the hub of the wheel, I think the spokes that go out, the other team members that can be helpful kind of depend on the situation, the symptoms that a person is dealing with.

Right. So, if there's issues with strength coordination, balance, then a physical therapy consultation that might be from early on, or it might not be until we're some years into things. Right. If there's issues with softer speech or swallowing trouble, then a speech therapist an occupational therapist, often can come up with kind of how to adapt to symptoms and find a workaround. So, things like button hooks or, you know, weighted utensils to overcome some of the effective tremors so PT, OT speech, and then bother bothersome overactive bladder, a urologist might be helpful, adjusting to the diagnosis, a psychologist dealing with anxiety and depression, a psychiatrist. And so those are some of the people that come to my mind first. And not everyone needs to have eight consultations the first time they're diagnosed with Parkinson's. Right. You know, we kind of pick our battles and see what's worth the time and effort of meeting with people. But those are all the, some of the members that a team could eventually consist of.

Soania Mathur:

Right. And that, and that makes good sense. And I think you're right, it depends on the patient and the age and stage of the disease that they're experiencing and the symptoms that they have specifically. But that kind of also brings to mind the responsibility of the patient, our, our responsibility of this patient in order to help with our management. Because as, as you mentioned, and as I mentioned, the diagnosis is not within our control, but the challenges and how we face those challenges really is there are certain variables that we can control, certain lifestyle choices that can be made in order to optimize our quality of life. Regular exercise, a healthy diet, decreasing stress, and building your support network are also very important. It can make a real difference. So, what lifestyle recommendations do you make to your patients in order to optimize their life experience?

Aaron Haug:

Yeah. your question and comment kind of makes me think of the serenity prayer. You know, grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference. Right. I think that that's really kind of at the heart of living well with Parkinson's. And so, the courage to change the things we can, some of those are lifestyle factors. as far as diet goes there's something out there called the mind Diet, M I N D, which stands for, it's kind of a combination of a Mediterranean style and the heart healthy style of eating. And that's probably good. But generally, just a healthy, balanced diet and trying to shoot for a healthy weight or health are important. Probably the single most important factor that people with Parkinson's have their hand on the lever for is their level of physical activity.

And I'll even say that the treatment of Parkinson's is kind of a two-prong attack. Medicines can make it easier for you to move, and then you have to move as much as you can and as well as you can. And so, what does exercise mean? Anything, everything counts, and more is better, basically. And so anything from just walking half an hour every day to doing resistance training, balance training, yoga, tai chi, or more aggressive cardiovascular exercise, you know, a brisk or walk a jog, bicycling, swimming, we know there's research that says that the more you do, especially if it's of a moderately vigorous intensity, that not only does that help people feel better, but it can actually slow the progression of motor symptoms slow the progression of the disease. So as much as I would like to have an exercise pill that I could give to people it's something that I really just try to encourage people that, you know, you'll feel better, you'll stay stronger longer, and it will help, help to slow the progression of the symptoms. So, exercise is crucial.

Soania Mathur:

Yeah. No, I agree with it. I recognize that as well. Now it's I will say it's not an easy thing to have to do, but definitely if I exercise every day, I notice that my symptoms are a lot easier to manage compared to if I don't. Just that mindset trying to get over some of the apathy that we have as a community, sometimes experience, it's a little bit difficult unless you schedule it in, and you have some accountability to somebody that you have to do it. But yes, I do agree that exercise is really, really important. And it's probably the one variable that makes the biggest difference in my life. I do, you know, walking on the treadmill, I also do weights and I do yoga to keep the flexibility and use a BOSU ball for balance. But it's hard. It's hard sometimes. And then that's why there's a lot of great community support out there and classes that you can take online or in person that is really helpful as well. And I'm sure you must also refer patients to those facilities as well.

Aaron Haug:

I do. And your point is well taken, it's important, but it's not easy. Or as they say, sometimes simple but not easy. Right. I know I need to exercise more, but you're forgetting about my sciatica and my neuropathy and right? You know, the things that make it painful to walk. So sometimes finding a, you know, working with a physical therapist or getting creative about, okay, what's the one type of exercise that doesn't make you hurt and how much of that can you do? So, I think that in most communities, you know, here in the Denver community, we have another group called the Parkinson Association of the Rockies. And their website has, here are all the exercise classes, here are all the support groups, and they keep those databases up to date to find something that's as convenient as possible. And that sounds interesting.

Soania Mathur:

And that speaks to the importance of community, as you mentioned. I think that what happens sometimes, and we saw this more during the pandemic for anyone with Parkinson's disease, is that sometimes you get socially isolated, and people don't do well with that. But especially when you're newly diagnosed, you don't really know where to turn or where to meet people that are, may be experiencing the same thing if you are the same impact on their life as, as you were experiencing. So can you speak to that, the importance of remaining social and making those connections

Aaron Haug:

Yeah. I don't know some of this research as well as others do, but I heard a headline or saw a headline that loneliness is as bad for your health as smoking is. And so, you know, we you know, sometimes we kind of poo pooh it, like, oh, just pull yourself up by your bootstraps. But being lonely and isolated has terrible health effects. And so, finding some way to find a group of people that you can relate to and get support from. So as far as, you know, I think about support groups and what you want is to find a group, and this may take some trial-and-error. Because you don't necessarily want to find a complaint group. You want to find a support group. And it, it can go both ways. I think of a patient I had who was probably in their late sixties, who ended up finding a home in a quote unquote young onset Parkinson's disease support group, which classically would mean diagnosis under age 50. But this person was still working full-time and so found that they had more of the struggles that the young onset group did, who are often still trying to balance working maybe a young family. And so sometimes taking a little bit of an alternative approach and maybe trying out, you know, a few in-person groups or zoom groups or Facebook groups. Right. Until you find, you know, a few people that you connect with, that's worth some experimentation, I think.

Soania Mathur:

Yeah, I agree. I mean, I was, I lived just outside of Toronto and in my area, there really was not a group of young onset patients or people living with the disease that I could attend. So, I found most of my support group online through Facebook and that sort of thing. And that also online



kind of brings to mind the fact that there is so much out there for patients to access in terms of Parkinson's disease in information and misinformation. So how do you guide your patients to the appropriate resources because you know, Dr. Google isn't always the best source of information for, for patients.

Aaron Haug:

I think that the best resources are kind of the groups with the best reputation. So, things that are on the Davis Phinney Foundation here in Colorado, [Parkinson rockies.org](http://Parkinsonrockies.org), the American Parkinson Disease Association, which is parkinson.org you know, kind of the groups with the best reputation I think are where you're going to typically find the most reliable information. So, it's about considering the source, you know, if you're hearing about the, you know, the benefits of some injectable vitamin, and by the way we sell that injectable vitamin, then you need to kind of consider that there might be a, some conflict of interest there.

Soania Mathur:

Yes. Yeah. I know that makes sense. There are lots of, unfortunately, even on the Facebook groups or the online groups, that is often people that will post things that are, you know, not true and kind of prey on the desperation sometimes of people with the disease. And you're right. Sometimes if it sounds too good to be true, it probably is, or it's probably something you should run by your medical team.

Aaron Haug:

On that note for those of you that have it or those of you that don't yet have it, the Davis Phinney Foundation has this great book called the Every Victory Counts Manual. And if you have the sixth edition or later, then the very last article in that is written by a great movement disorder specialist, Dr. Benzi Kluger, and it's called the Medical BS detector. except he spells out bs. Yeah. And it's four or five pages of, you know, how can you help to determine for yourself the likelihood that something is legit versus maybe closer to the snake oil part of the spectrum. So that's a good thing to look at or a good reason to get the Every Victory Counts Manual if you don't already have

Soania Mathur:

It. Yeah. I think that's really important as well as keeping up with the research so that, you know, the reality of what's going on. And speaking of research, why is it important in particular for people who are not newly diagnosed to think about participating in research?

Aaron Haug:

Yeah, so clinical research is where we get new treatments from So, I will say in my practice, I'm not involved much in clinical research, but there are people in large communities, you know, there's a couple of centers in Denver that have a lot of clinical research and other major metropolitan areas. We'll typically have a variety of trials either testing a medication maybe that's been used for a different condition like diabetes and oh, there's this suggestion that maybe it's helpful for Parkinson's, so let's study that or some brand new medication. And so, I think that for people that are interested in trying something that's not yet proven to work, but that might you know, the chance of getting some new cutting-edge treatment that turns out to be helpful is potentially helpful to you as an individual and also helpful to the community of people with Parkinson's.

Soania Mathur:

Right.

Aaron Haug:

The best resource for that I think is clinicaltrials.gov, where you can type in Parkinson's, Colorado and it'll pull up what studies are there, what are they recruiting, are they recruiting, and what are they looking at?

Soania Mathur:

Right, exactly. I know that, you know, being in my stage of disease sometimes don't qualify for, for clinical trials unless they're looking for people that have been living with the disease for a while. I do know that a lot of trials, or, or you could correct me, seem to be directed towards newer patients diagnosed because of the fact they're trying to determine whether they can give you anything to sort of prevent progression of the disease. Is that, is that true?

Aaron Haug:

I think that is still a big section of the clinical research is, well, what if we look at people that have had Parkinson's for only a few years, have maybe never taken meds, or have only taken a little bit of meds, and then we give some of them the new thing and some of them we just watch, wait, and see and see if we can tell that there's any disease modifying effect, for example. Right. And so, particularly if someone has a new diagnosis of Parkinson's, but their symptoms aren't that disruptive to their quality of life, that is potentially an ideal time to consider clinical research as opposed to if someone comes in and they have a big tremor and it's affecting their ability to work, they maybe just need to go on medicine that we already know is, has a proven track record. Right. but newly diagnosed and not yet needing any or much treatment, it's a good time to think about clinical research for those that are interested.

Soania Mathur:

Right. I think you're right. I think the fact is that, you know, clinical research into finding better treatments or a cure can't really progress or attain their goal without the participation in patients. And I think that's important to consider for sure. As we're sort of coming towards the end of our time together, I'd like to ask you a question. What is the one piece of advice that you feel is most important for someone who's newly diagnosed who's just been labeled with this disease? What is the most important thing for them to know?

Aaron Haug:

I think the most important thing to know is that this is bad news, but it is news that you can deal with. Right. You know, when I started in my clinical practice about 10 years ago, people would ask, well, what does the future hold? And I would really soft pedal it. I would say, well, it's different for everybody. Let's see what happens over the next few years. And I found over time that that really was ringing hollow with patients and even with me the more often I said it, because there are some averages of how things tend to go. and this is maybe another advantage of meeting once or twice, at least with a neurologist or a movement disorder specialist who sees a lot of Parkinson's. is that, you know, we can do this calculation of, okay, your 62, your symptoms started three years ago, your other health factors or this, I have some idea of what the next five and 10 and 20 years might look like for you.

And we can talk about that. So, but what I found when I was being vague about it was that instead of being helpful, people were sort of worrying that they were going to wake up and be unable to move or that they were going to exponentially worsen over the course of a few months. Right. As opposed to this tends to be, you know, a little bit more of the same symptoms, occasional new symptoms as the years go by, but the rate of it for the vast majority of people is slow and not something that changes abruptly. And so, I think knowing that and knowing that there are various treatments, medicines, and exercises that can help to mitigate the symptoms are probably the main take-home messages that I want people to have after the initial diagnosis.

Soania Mathur:

That's a great messaging to end on for sure. So, thank you so much, Dr. Haug, for the conversation. And I hope that those who are listening in newly diagnosed or not friends, care partners, I hope they found the discussion helpful and educational. Because we don't have a choice in diagnosis, but how we face the challenges that this disease brings is ours to determine. So, I advise everyone to sort of choose to optimize your quality of life, educate yourself, empower yourself, and celebrate your daily victories. I think that's really important.

Aaron Haug:

I totally agree. Thank you very much for having me.



Soania Mathur:

Thank you so much.

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