

Parents Are Hard To Raise, with Diane Berardi Show Transcript Episode 135

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This week on Parents Are Hard To Raise. Diane discusses Parkinson's disease with two renowned experts from the University of California Irvine, Dr. Neil Hermanowicz of University of California, Irvine And Sarah Jones, director of the Parkinson's and Movement Disorder Alliance here in the US.

Announcer 0:57

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Diane Berardi 1:15

Welcome to Parents Are Hard To Raise, helping families grow older together without losing their minds. I'm elder care expert Diane Berardi.

Diane Berardi 1:24

For over three seasons now I've made it a point to ask you, our Parents Are Hard To Raise worldwide family, for input on what topics you would like to hear covered on the show. And nearing the very top of the list for some time has been Parkinson's disease, which is why I'm so pleased to have with us this week, two of the most preeminent experts on the subject, Dr. Neil Hermanowicz and Sarah Jones.

Diane Berardi 1:50

Dr. Hermanowicz...[laughing] they're laughing at me already because I got your name pronounced right.

Dr. Neil Hermanowicz 1:56

You got it right.

Sarah Jones 1:58
You win the Bet

Diane Berardi 1:58
I do.

Diane Berardi 2:00

Dr. Hermanowicz is a professor of neurology, director of the movement disorders program and Vice Chair of the Department of Neurology at the University of California, Irvine. He earned his medical degree at Temple University School of Medicine, and has spent his time split between patient care, clinical research and education, which is likely why he has been recognized as one of the best doctors in America by US News. Sarah Jones is the chief executive officer of the Parkinson's and movement disorder Alliance based here in the US. Under Sarah's direction, the Alliance just published the findings of an extensive caregivers survey on the negative impact of non-mobility related symptoms on the lives of family caregivers, the findings of which I'm hoping to learn more about. Neil and Sarah, welcome to Parents Are Hard To Raise.

Dr. Neil Hermanowicz 2:56
Thank you very much. Happy to be here.

Sarah Jones 2:58
Thank you.

Unknown Speaker 2:59

So When people hear Parkinson's disease, most are familiar with the physical symptoms, the tremors, the rigidity, the moving slow. But what many people may not be aware of are the many non movement symptoms. Could you describe what some of those are?

Dr. Neil Hermanowicz 3:21

Sure. I'll go first, Sarah and you can great jump in if you like at anytime. So, the the non motor or non mobility symptoms are unfortunately pretty common. And may in fact be some of the earliest symptoms that people experienced. And that's been documented, studied and has given us a window on and looking at how Parkinson's may begin, and some

people how and how it can evolve over time. So some of the earliest non motor symptoms can include sleep disturbance, something called REM sleep behavior disorder where people act out their dreams.

Dr. Neil Hermanowicz 3:54

Normally when we're asleep and dreaming our brains are disconnected from most of our muscles but in people with Parkinson's disease or early Parkinson's, that disconnects which may not work and people will be swinging their arms or screaming and they're asleep for example.

Dr. Neil Hermanowicz 4:09

Other, another non motor symptom could be gastrointestinal dysfunction. People may have constipation or less frequent bowel movements. There's something called gastroparesis.

Dr. Neil Hermanowicz 4:21

Another one which people sometimes describe or when asked is impaired sense of smell. Loss or impair sense of smell, which can proceed the appearance of the motor things that you described by a decade or more.

Dr. Neil Hermanowicz 4:36

So long list of other things that my patients described to me that are well known to people with Parkinson's disease including cognitive changes, memory difficulties, sometimes occasionally, hallucinations, for example, or delusional thoughts, bladder problems bowel problems can also occur, even skin problems. People often don't recognize that that could be common manifestation of Parkinson's as well. Skin rashes and even a nasty skin cancer called malignant melanoma.

Diane Berardi 5:12

So if you know if you're a child of an aging parent, you know, in your, maybe your mom or dad, I guess wake up, you know, swinging their arms or, you know, having these cognitive changes I you wouldn't imagine Parkinson's?

Dr. Neil Hermanowicz 5:32

That's correct.

Dr. Neil Hermanowicz 5:34

That doesn't occur to people and I think it may be bewildering and people think it may be just a normal process. Yeah,

Dr. Neil Hermanowicz 5:42

it is actually it was studied some years ago, initially by a group in Minneapolis, Carlos shake and his colleagues they followed people who made this entity called REM sleep behavior disorder and follow men primarily over time and increase percentage of these people who had this sleep behavior showed signs of Parkinsonism. So I'm not saying that everybody who has it will get Parkinson's disease but it has gotten attention as a possible early indicator that something is brewing.

Unknown Speaker 6:16

This these symptoms, what impact would they have on you know, the poor person and their caregiver?

Unknown Speaker 6:25

That's a good point. Because there have been instances where people they awaken their bed partner, for example, by their, by their motions or by their vocalizing. I've had patients or the spouses of patients tell me and I'm afraid the neighbors are going to call the police because people are screaming in their dreams. And there have been examples of bed partners being injured by the person you're sleeping beside. Somebody swinging a fist and unintentionally punching somebody in the nose. For example, that has been known to occur.

Dr. Neil Hermanowicz 7:06

One of my patients some years ago, took a solo for he took a flight from California to New York City to for family events. And he went by himself, which was probably not a great idea. And on that flight he fell asleep was awakened to find a group of people standing around him as his seat because apparently he had been screaming in his sleep while he was on the plane.

Sarah Jones 7:34

Yeah, and if they don't have if they don't have a movement disorder specialist, a neurologist who has advanced training, in Parkinson disease or movement disorders, this may not even come up in a

conversation with a physician. And it's one of those places that, you know, people are embarrassed to ask questions, they don't understand what's happening. And so, you know, to Dr. Hermanowicz point this is a high Risk place for care partners and spouses but not necessarily something that comes to the surface until, you know, pretty far into the disease which is what's great to have the awareness out there so people can bring it up to their physicians.

Diane Berardi 8:16
Oh, yeah, definitely.

Dr. Neil Hermanowicz 8:17
And moreover it's treatable there are things that can be done to to reduce the likelihood or be completely eliminated are things that are used sometimes even something as simple as melatonin there's a medication called clonazepam, Klonopin, which is often a pretty effective in reducing the sleep emerging behaviors.

Unknown Speaker 8:40
So someone having you know, the symptoms. I would imagine they probably would just go to their regular physician they wouldn't you know...

Dr. Neil Hermanowicz 8:52
Well, that's another good point.

Unknown Speaker 8:55
First I it's hard to find these people who are having this this isolated with called REM sleep behaviors. So they don't usually find their way to me. Every once in a great while they do. And I have such a person in my practice right now, who was referred to me by a sleep specialist which has occurred in the past, also. Recognizing how they've got REM sleep behavior disorder, perhaps they've had a formal sleep study, and it was identified and confirmed that they've got REM sleep behavior disorder. So some physicians and this patient was actually referred by the I believe the director of our sleep program here at the university because she knows that that connection between REM sleep behavior disorder and Parkinson's disease. Now that person who I who was referred to me does not have any motor manifestations of Parkinson's disease, that the

patient is well informed it by reading on the internet, there's a lot of information that one can get access to. Although there are the diagnosis Parkinson's at this time is really largely dependent on motor findings which this person does not have.

Dr. Neil Hermanowicz 10:06

Another interesting point though, so when this patient came to see me, I did a formal test for his sense of smell. As I mentioned, that also can be very early, non motor manifestations of Parkinson's disease. And the formal test, which is called the University of Pennsylvania smell identification test are UPSIT. He did not perform well actually, I think his I recall, he was below the 10th percentile, for somebody of his gender, a man of his age. So there were a couple of things. Now they're raising some concern, but still not a confirmation or consistencies.

Sarah Jones 10:45

But, you know, thinking about raising your, you know, Parents Are Hard To Raise, thinking about parents. I mean, these are the kinds of things that I think for adult children to know to be able to ask those questions. If you just do something that's maybe a little odd like to even recognize it. What What is it Dr. Hermanowicz, about 25% of people don't have any tremor?

Dr. Neil Hermanowicz 11:06

That's right.

Sarah Jones 11:07

Yeah, so it's significant. But if you ask the questions, you know, you might surface the REM sleep disorder or hallucinations or delusions, some of the other things that people just don't talk about before they are there. They're physically risky, and they're also just exhausting for people living with this.

Diane Berardi 11:27

Sure. How aware are physicians about...

Dr. Neil Hermanowicz 11:31

About these connections?

Diane Berardi 11:32

Yeah, about these connections?

Dr. Neil Hermanowicz 11:34

I think it's getting better.

Dr. Neil Hermanowicz 11:37

I think in patients, also they will, they will sometimes bring these things up. Because if there's been some question about what's walking has changed, and maybe they do have a tremor perhaps not. But they're having symptoms of maybe some subtle slowness, then people are on the internet and exploring these things may be going to Sarah site and finally information then. So more and more. Certainly compared to early in my career, which was when I started prior to the existence of the internet and access to all this information, more and more people, patients themselves are becoming aware and I think with them physicians, including primary care physicians as well.

Sarah Jones 12:21

Yep. And, and I think to that point, too people are beginning to understand that there's treatments for it, right. I mean, there's, the treatments are relatively new in the last few years for some of these, some of these complications for Parkinson's and some of the challenging symptoms and it's nice to be able to have people recognize that there is some hope out there and they address some even if there's not a cure for the disease. There are some ways to potentially mitigate some of these symptoms.

Dr. Neil Hermanowicz 12:53

I think Sarah makes a good point because sometimes we know that in the past people would, it's been published has been studied, People would be visiting a variety of doctors for on average, two years with symptoms that they couldn't... that were troubling to them, but they didn't quite understand what they were coming from. But as as the knowledge about early manifestations of Parkinson's and these non motor things are increasingly identified, I think people arriving at an answer, I hope, I suspect they're arriving at an answer to what's going on what it isn't that Parkinson disease earlier than they used to, which is a good thing. I mean, it's not good. It's not happy news to hear that one

has Parkinson's disease, but I'm thinking of a patient who I still see and she was relieved to learn that she had Parkinson's because she thought she had something called ALS or Lou Gehrig's disease which is much worse. So just knowing what it is that one is dealing with can at least bring some peace of mind, although again, it's not a happy diagnosis to hear..

Sarah Jones 13:55
Yeah.

Diane Berardi 13:57
Is the patient aware if they are having delusions or hallucinations?

Dr. Neil Hermanowicz 14:04
Sometimes they are. I've been hearing these kinds of symptoms pretty much throughout my career they've been getting increasing attention in more recent years. They're mentioning that there was a more specific medication developed for exactly for those symptoms.

Dr. Neil Hermanowicz 14:24
When they first occur, people may realize so that that cat that I see in the corner is not actually there or the child that I think is sitting on the sofa doesn't really make sense. So there can be insight, retained and for some time that people realize that that's not really true. Really, people have a sense of there might be somebody standing beside them and they look at as there's nobody there. So, when people are having delusions, I should say hallucinations. hallucinations are usually visual that they may be auditory or other senses involved as well, typically at the onset. They're their visual. People do know, at least for a while, this is not correct. But as time goes by that insight can oftentimes not be present and people start thinking, well, there actually is a stranger in my bathroom at night.

Sarah Jones 15:21
They don't always tell their care partner or their loved ones, either.

Diane Berardi 15:23
Right. I was gonna say they probably don't.

Diane Berardi 15:28

We're going to continue talking with Dr. Neil and Sarah Jones. But first, if you're a woman, or there's a woman in your life, there's something you absolutely need to know.

Diane Berardi 15:48

I want to tell you about my friend Katie. Katie is a nurse and she was attacked on her way home from work. She was totally taken by surprise. And although Katie is only 5 feet tall and 106 pounds she was easily able to drop her 6 foot 4, 250-pound attacker to his knees and get away unharmed.

Katie wasn't just lucky that day. She was prepared.

In her pocketbook, a harmless looking lipstick, which really contained a powerful man stopping aerosol propellant.

It's not like it was in our grandmother's day. Today just going to and from work or to the mall can have tragic consequences. The FBI says a violent crime is committed every 15 seconds in the United States. And a forcible rape happens every five minutes. And chances are when something happens, no one will be around to help.

It looks just like a lipstick. So no one will suspect a thing. Which is important since experts say, getting the jump on your attacker is all about the element of surprise.

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Darkness brings danger. Murderers and rapists use darkness to their advantage. We all know what it's like to be walking at night and hear footsteps coming at us from behind. Who's there? If it's somebody bad, will you be protected? Your life may depend on it.

My friend Katie's close call needs to be a wake up call for all of us. Myself included. Pick up a Lipstick Bodyguard and keep it with you always.

Announcer 17:52

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Announcer 18:12

Want a great new way to listen to the show? Just say, "Alexa. Play, Parents Are Hard To Raise podcast."

Alexa 18:20

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Announcer 18:25

It's as simple as that.

Diane Berardi 18:27

You're right Dolly. There are so many really cool new ways to listen to our show. It's hard to keep track. You can join the one hundred and eighty million listener is on Spotify. You can listen in your car, at the gym, or pretty much anywhere on your smartphone with Apple podcasts and Google podcasts.

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Diane Berardi 19:11

So, Sarah, where can our listeners learn more about this study and the results?

Sarah Jones 19:19

You know, we have, if you visit our website www.PMDAlliance.org, we have a page that has all the information about this study, and a link to the actual research findings, as well as some additional information that people might want to read about to learn more about the different things we've been talking about, whether it's hallucinations or delusions or sleep disorders. And then we also have a link to our YouTube channel which has extensive video. I think we have about 70 educational videos

on there with different physicians like that. Dr. Hermanowicz and Yep, so any of those, and then also, specifically for adult children, we have a private Facebook group, just for adult children of people with Parkinson's and other movement disorders so that they can have conversations about the different challenges they're having, navigating, supporting, you know, the parent who's the care partner as well as the person with the disease.

Diane Berardi 20:26

Right? Okay. That's wonderful. Because I can't even imagine you know, day to day life and the quality of life for the people with the disorder and their caregivers.

Sarah Jones 20:43

Yeah, we like to say, you know, it's really we say it's an equal opportunity disease that everyone in the family has Parkinson's. Nobody really gets to escape it. Everybody just has a different manifestation of it. So if you're this the care partner you're living with it too. It's just a little bit different. And as an adult child, and I think you're, you're navigating that too. My father in law had Parkinson's and, boy, we kept trying to help and support navigating, you know, that journey and understanding what was going on and has a different way that this shows up. I mean, boy, Dr. Hermanowicz, there's got to be, there's dozens of symptoms. And so no two people have exactly the same way that this shows up in life.

Dr. Neil Hermanowicz 21:37

That's one of the challenges of both making diagnosis in the first place because different forms as Sarah mentioned, not everybody has tremor with Parkinson's disease. So it can be tricky, including for people who focus on this. It's not a simple diagnosis, to be confident of, in all cases. And in the course, how it may change over time, and the kind of symptoms that people developed a little can vary greatly from one person to another. As the hallucination example, it's pretty common and there's some studies indicate that 50% of more people Parkinson's may have it at some point, but you know, 50% or so don't. Some people may have other issues like very troubling GI symptoms or problems with your bladder or sleep issues that other people don't go through. So

it does have a wide variety of this presentation of how it can be troubling to people.

Diane Berardi 22:35

I had a client who was diagnosed with Parkinson's disease, but you know, when I think about it, she also had intestinal problems. She had constipation all the time. And she had some cognitive changes. And I remember her caregiver saying to me at one time, she said, she looked at me it was kind of like she was just staring but she wasn't there. And she said to me, you're the devil, you know. And, and... but she was going to all kinds of different doctors, you know. And I don't believe they were kind of connecting some of those symptoms to be part of the Parkinson's disorder.

Dr. Neil Hermanowicz 23:24

I think it wasn't so much recognized some years past but I think increasingly, again, thanks to educational efforts like Sarah's organization, people understand this is not something unusual necessarily with Parkinson's disease. This is something that can occur and as Sarah mentioned, to this day, unfortunately people the person who has Parkinson's disease or care partner, they may not bring it up when they come to see their provider, physician, nurse practitioner, etc. And unfortunately, the physician or their provider may not ask about it. I think that behavior is changing. I certainly hope it that this is because if it's not recognize that can be troubling. In years past I had patients who called the police even not that long ago, somebody just saw recently had a few years ago called the police when his wife was, was gone for a while, thinking that somebody was trying to break in and harm him. So that it's not recognized that dealt with these kinds of symptoms can be very troubling.

Diane Berardi 24:27

Yeah. Well, we reach millions in 169 countries and physicians around the world. We want to make them aware as well as caregivers, and patients themselves. So what's the best way and what kind of support can we give people with Parkinson's and their families?

Dr. Neil Hermanowicz 24:54

Sarah, go ahead.

Sarah Jones 24:55

Well, I you know, I'm thinking about one of the most important things is actually seeing a doctor who has expertise in this. So movement disorder specialist, which is like what Dr. Hermanowicz is, that's a specific practice. And it's actually a neurologist with advanced training and movement disorders. So it's, it's a specialist of a specialist. And, you know, that's something that people don't even know it's out there.

Diane Berardi 25:19

Right. And we have, you know, we're not just in the US, we have 169 countries, so that might be...

Sarah Jones 25:28

And there's movement disorder physicians all over the world. And, you know, actually on our website, we have a link to the movement disorder society which has an up to date listing of all of the movements sort of specialists across the world to address that. And there's something interesting about this disease and I don't know if it's synchronicity or the fact that people tend when they're diagnosed I'm not sure what the reason is, but we find people who will not always seek out the [specialist]. And that's important. Even if it's once a year. We tell people you're not cheating on your doctor to go see a specialist.

Diane Berardi 26:04

Right. Yeah. You find people, people do fear that. Yeah, I don't know what it is.

Sarah Jones 26:12

Yeah. And I think too, sometimes we don't think about, you know, I'm curious what you think about this Dr. Hermanowicz that sometimes adult children or care partners might see something that the person with Parkinson's may or may not see just because of perhaps where they're at in their disease process.

Sarah Jones 26:31

But you can always share that information with a doctor even if they can't reply back to you they least have that information from you. Information can always go the one way. Correct?

Dr. Neil Hermanowicz 26:42

Correct and what as you bring them up, one example of that I almost hate to mention, but it's important one is driving. people with Parkinson's disease has been studied and published in medical journals do have an increased risk of having an accident. And I have very, very few people in my practice people who are coping with Parkinson's disease who themselves and said, You know, I recognize my driving is not what it should be. I'm just going to stop. Family members may recognize that and often do but have some reluctance about intervening in something that's regarded as so important in terms of one's independence and identity. But, it is something that's the kind of information it's another topic. That's, that's not pleasant to touch on. But I do it on a regular basis in my practice, because the stakes are just so high. I mean, even in short trips close to home, people could get into something serious, it could have lasting repercussions. So it's, it's, it's good to have.

Dr. Neil Hermanowicz 27:45

I'm always disappointed it's so one of my patients shows up without anybody with him, a spouse or family member that can help share, you know, the visit. And understand what's being the information that's being exchanged. And it also provides an outside and somebody providing additional information about how things were going.

Diane Berardi 28:05

Yeah, sure.

Dr. Neil Hermanowicz 28:05

I want to go want to go back to one something that Sarah had touched on or that was brought up about in terms of how does one cope with these things that we want to see a movement sort of specialist which they're hard to find in some parts of the world even some parts of California Southern California, it's not easy that access despite the density of physicians here. but I think another way that people learn how to deal with this diagnosis is attending educational programs. I've gone to several that Sarah's organization has sponsored and there was always a good turnout and these are opportunities for people to exchange information who are not just from whoever speaking but also

from one another and you know coping methods or do you do you do do have you experienced this was this happened to you? And also learning about the developments in the field. It's going through these programs and sharing information among other people. I was involved with a program in of all places Iceland, which is my wife's home country. And the turnout was immense. I mean it was there was such an eagerness for knowledge and that relatively small country but it came over very well. And I'm hoping that this continuing in Iceland with the with a specialist were there.

Diane Berardi 29:27

Well, the work you you're both doing, you know, I'm bringing this to light bringing all this information, the studies and again, Sarah, your website, www.PMDAlliance.org.

Diane Berardi 29:44

Thank you so much for listening. Parents Are Hard To Raise family, I love getting your emails and questions so please keep sending them. You can reach me at Diane at ParentsAreHardToRaise.org or just click the green button on our homepage.

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Thank you so much for listening. Till next time, may you forget everything you don't want to remember, And remember everything you don't want to forget.

See you again next week.