Stress and Parkinson’s: Strategies to Manage the Strain (Webinar Audio) Transcript

English (US)

00:00:04.160 — 00:00:13.040 · Michael J. Fox

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00:00:15.040 — 00:00:32.240 · Veronique Enos Kaefer

Welcome to a recap of our latest Third Thursday webinar. Hear directly from expert panelists as they discuss Parkinson's research and answer your questions about living with the disease. Join us live next time by registering for an upcoming webinar at Michael J. Fox. Org.

00:00:41.960 — 00:02:16.250 · Jim McNasby

It's Jim McNabb, the general counsel of Michael J. Fox Foundation and a member of its Patients Council. I was diagnosed with Parkinson's in 2000. Today we're going to be talking about stress and Parkinson's when I make symptoms worse, how it connects to mental health, and what latest research on stress and Parkinson's and how you can eliminate its harmful effects.

So we've got a lot to discuss today. So let me introduce our panelists. First is Becca miller, who's a licensed clinical psychologist and associate professor in the Department of Psychiatry at the Yale School of Medicine. She was diagnosed with Parkinson's in 2013 and is a fellow member of the Michael J.

Fox Foundation's Patients council. Doctor Rick Helmick is a neurologist at Radboud University Medical Center in the Netherlands, and is a principal investigator at the Donner

Center, meaning the System Neurology Group. Your research is stress and Parkinson. And finally, Doctor Hiller, a movement disorder specialist and director of the Northwest Parkinson's Disease Research, Education and Clinical Centers at the VA Portland Health Care System.

She's also an associate professor of Neurology at Oregon Health and Science University. We have a lot to talk about. The first thing is our stress cycle. Amy, let's start with you. Um, experiencing stress is a normal part of life. We all know the feeling of being stressed out. But what happens in the body when someone is experiencing stress?

00:02:16.370 — 00:02:31.850 · Amie Hiller

So there's a lot that happens. It's a complicated cycle with many effects. We can have increase in our heart rate. We can have increase in our cortisol levels. And we in Parkinson's, you may have worsening of some of your symptoms. So there's a number of things.

00:02:31.890 — 00:02:46.610 · Jim McNasby

But I mean is there a difference between good stress. Like a wedding or travel or birth of a new family member? And does it have the same effect that is bad stress. If there is such a thing for someone.

00:02:46.610 — 00:03:34.480 · Amie Hiller

So all stress kind of in the acute phase has kind of similar effects. And we think that's not so bad. That's to be expected. That's a normal response. We should get stressed with things, but what we think of as kind of the bad is if you stay at that high stress level and you can't come back down. So it's that chronic stress that we think is really the problem, the normal kind of up and down, that's not so bad.

And that could happen with good stress, you know, good activities, good things that are happening. But it could also happen with bad things. And then again, kind of the staying stress that could again be from good things or from bad things potentially. And I think it's important to keep in mind that any stress is stress, even when it's a good thing.

So, you know, to just think about how you manage that.

00:03:34.520 — 00:03:51.400 · Becca Miller

Having no stress is not necessarily a good thing, that you want to have a little stress, if which it goes along with good things happening. Right? You want there to be good things in your life that they may cause a little stress, but then you can recover from it fairly easily, whereas chronic stress can cause more problems.

00:03:51.560 — 00:03:56.070 · Jim McNasby

Rick, can you walk us through how it works and how the body returns to baseline.

00:03:56.270 — 00:05:02.490 · Rick Helmich

Yeah. So when people are stressed. But what first happens is that there is a surge of, uh, substance called noradrenaline in the brain. And that acts really fast. So it acts within seconds. And what happens is that it pushes your heart rate up. It makes your pupils go wider. And it also has effects on brain areas that are important for some symptoms of Parkinson's disease, for example the thalamus, which plays a role in tremor.

So those are the acute effects. And then after a few minutes, maybe 10 minutes or 15 minutes, cortisol starts to rise. And that has an effect of say half an hour uh, or an hour. But after that, if stress is gone, that cortisol is back to normal. And in people who experience chronic stress that cortisol doesn't go down again.

It stays up and it might have effects on the brain as well that are not not so good.

00:05:02.530 — 00:05:18.330 · Jim McNasby

Okay. So we talked a little bit about the difference between acute and chronic stress. Hector can I ask you how does chronic stress relate to mental conditions like depression and anxiety. How are they different and where do they overlap?

00:05:18.450 — 00:05:56.360 · Becca Miller

I mean, there are some of the same symptoms like it may affect your sleep. Depression affects sleep. Anxiety can affect sleep, but they're not necessarily the same. So depression is more associated with sadness hopelessness. Anxiety is more agitation, whereas stress can feel like you're kind of more activated.

So they all may benefit from something like psychotherapy, but there are different underlying mechanisms, and something like depression and anxiety can also be often felt together. So there's a lot of overlap. But then there are certain specific differences. But, you know, mental health professional or someone else can really help you tease out.

00:05:56.760 — 00:06:05.280 · Jim McNasby

Can I ask you specifically about your own experience with Parkinson's and how stress manifests itself with your symptoms?

00:06:05.360 — 00:06:32.320 · Becca Miller

I mean, I think it goes either two ways. It can cause me to have more dyskinesia, that it sort of activates that end, or it can cause my medications not to work as well. So it kind of goes both ways. I don't experience tremor, but I've heard from a lot of people how stress really activates their tremor in a lot of ways.

And then there's this kind of cycle of feeling more embarrassed, you know, being more tremulous. And then so it can be a sort of bad cycle in that way.

00:06:32.440 — 00:06:32.959 · Jim McNasby

Yeah, I think

00:06:34.000 — 00:07:16.100 · Jim McNasby

in my own experience, I think of it as kind of a vicious cycle because the stress begets worse symptoms, begets more stress, and you just keep going down. And I find myself becoming clumsy with my speaking, with my gestures, with my tremor, which is really well controlled by DBS that I had, you know, six years ago, but pronounced different.

You know what I'm about to do something like talk to a lot of people on the webinar. Right, exactly. I find myself halting and my symptoms become more so. I try to be aware of that and and not worry about it because, you know, it's not like.

00:07:16.220 — 00:07:18.740 · Becca Miller

The self-consciousness can really kick in.

00:07:18.780 — 00:07:22.980 · Jim McNasby

And it was symptoms or changes do you see in your patients when they're stressed?

00:07:23.100 — 00:07:23.340 · Becca Miller

Yeah.

00:07:23.340 — 00:07:58.570 · Amie Hiller

So some of the things you both already mentioned. So tremor is one that I think for a lot of people really sometimes I call it people's stress limiter. You know, that as soon as their tremor really kicks up it's like, oh okay, I'm stressed. And maybe they don't want to think they are. But you know, that tremor kind of, um, keeps them in check of knowing when they are, um, dyskinesia certainly are one that gets worse.

Freezing of gait is another one where people kind of have their feet get stuck to the floor, and have trouble with walking. Those are kind of the three I would say we think of most commonly as getting worse with stress.

00:07:58.650 — 00:08:05.050 · Jim McNasby

A question from the audience why do my meds seem less effective when I'm stressed?

00:08:05.170 — 00:08:20.970 · Amie Hiller

So it's probably a combination, you know, one if the symptoms are worse, it's going to be harder to manage the symptoms. Right. And then also your metabolism may be going faster when you're stressed and kind of working through those meds, then they may not kind of last as well.

00:08:21.250 — 00:08:28.490 · Becca Miller

Feels like I burn through my dopamine faster when I'm stressed and then more off periods come and wreck.

00:08:28.530 — 00:08:33.289 · Jim McNasby

Why does stress cause these effects in people living with the disease?

00:08:33.409 — 00:10:16.620 · Rick Helmich

That's a great question. So, um, stress has multiple effects on the brain. And what you told us and what Amy told us is also what I see that people experiencing these hyperkinetic movements like tremor or dyskinesia. Those are the clearest or most visible effects of stress on people with Parkinson's.

And that, I think, is caused by these effects of noradrenaline, which acts on motor regions in the brain and in healthy people and everyone. Basically, that also has a role like if you are stressed, you need to act fast. You need to run away or fight or whatever, so that noradrenaline has an effect on activating those motor regions.

And in people with Parkinson's disease, the effect is that things like tremor and dyskinesia as they go up. So that's one thing. And then the other thing is that people with Parkinson's disease experience often that the things that should normally go automatically don't go automatically anymore. So we have to be more consciously think about things that you are doing, and that requires extra effort of several brain regions.

And that is something that we call compensation. So the healthy part of the brain compensates for those difficulties with doing automatic things. And what stress does is it

basically wipes away these compensatory mechanisms. And that is why a lot of other problems in that patients experience become worse when they are stressed.

00:10:16.700 — 00:10:28.220 · Jim McNasby

Okay. Any question for you. How does PTSD or PTSD relate to the history of PTSD? Have an impact on developing Parkinson's?

00:10:28.620 — 00:10:29.660 · Becca Miller

Yeah. So I think some.

00:10:29.660 — 00:11:08.690 · Amie Hiller

Of this is a little bit of a question. So PTSD is post-traumatic stress disorder, certainly something we see commonly within the VA system. And we actually have researchers here who've been looking at this, and it does seem like it's an increased risk factor for developing Parkinson's disease. This was looking at a big data set.

So I think, you know, there's always questions on that type of data. Is it is it fully good data. Also are people who experience PTSD more likely to have had head traumas? You know, there's other things that go along with that. But it does look like there might be a suggestion that PTSD is a is a risk factor for developing Parkinson's, but it's hard to say that for sure.

00:11:09.050 — 00:11:23.770 · Jim McNasby

Okay, Becca, we've been talking a while about physical responses to Parkinson's and stress or stress and Parkinson's, I should say. Um, what about your non motor symptoms? Is there any effect on those?

00:11:24.130 — 00:11:47.120 · Becca Miller

And definitely sleep which is not uncommon for anyone when they're stressed to have more sleep problems. But certainly with Parkinson's I already have trouble staying asleep. So it definitely affects that. And also been like my executive functioning, like being able to plan and carry out things. That kind of feels like when I'm stressed, it's much harder for me to to do things like that.

00:11:47.160 — 00:12:58.380 · Jim McNasby

I'm thinking about my own experience and, uh, and my own experience was at a time in my life where I was very young and ambitious lawyer, and I got this heavy diagnosis when I was 31, and my stress level was off the charts. And I it took me a while to realize that my, my symptoms were in part being worsened by the, you know, the combination of stress and Parkinson's.

And it really, you know, kind of led me to be afraid and led me to think my prognosis or my diagnosis path was going to be much worse than it's actually been. So, um, so I've made some changes over time to reduce that, but that concentration of the two things together is very, uh, you know, is it's very consequential and something that can be difficult to deal with.

Um, a frequent audience question that we're seeing right now is whether or not stress actually causes Parkinson's, as many people are diagnosed, like I was at a particularly stressful point in their life. So what's what's what's the cause and effect relationship?

00:12:58.460 — 00:14:32.810 · Rick Helmich

And that's a great question. So many people indeed experience. And I've also had multiple patients, um, that were diagnosed after a very stressful event. So I had one woman who,

um, developed her first tremor the day after her husband experienced a heart attack, and another patient who developed or noticed her first tremor while she was at her mother's funeral home.

People who experienced their first symptoms, like tremor when they recover from anesthesia after surgery. And these are a lot of stories. And many people tend to think that this event indeed caused Parkinson's. I don't think that is the case. And the reason is that Parkinson's disease already affects the brain 5 to 10 years before the very first symptoms emerge.

So there's a very long period in which Parkinson's disease is already present in the brain, but it doesn't cause symptoms. And that is because these compensatory mechanisms are in place in the brain to prevent these symptoms. And when a very, very stressful event occurs, um, those compensatory mechanisms are transiently wiped away and the Parkinson's disease is unmasked, so it shows itself.

But that doesn't mean that the stress caused it. It just means that it became irritable at that time.

00:14:32.990 — 00:14:46.430 · Jim McNasby

I mean, you went from prodromal to visibly symptomatic. Yeah. Yeah. Right. So we're sticking with you for a second. Is the physical stress of something like a big race or a marathon bad for people with PD?

00:14:46.670 — 00:15:52.420 · Rick Helmich

No, it's certainly not that. So we know that exercise is actually very good for people with Parkinson's. So we get one study here in the Netherlands where people with Parkinson's disease were asked to exercise on a home trainer for 45 minutes, three times a week, for

half a year. And after those six months, the people who did that were not progressing, whereas a control group who did not do that progressed over time.

And we also saw on brain scans that those people who exercise had less loss of gray matter than those who did not exercise. So exercise is actually good. What is now also becoming clear is that there are some people who over exercise, so who exercise so much that they have trouble recovering from that exercise.

But regular exercise, whatever people like could be swimming, it could be running, could do just walking. That is actually good.

00:15:53.100 — 00:16:09.420 · Jim McNasby

That's sort of a form of the good stress that Becky was talking about. Yeah. Another question for you is, um, how do stress and brain fog intersect? You know, there's lots of executive function type issue.

00:16:09.540 — 00:16:47.570 · Rick Helmich

Yeah. So brain fog is is a difficult definition because different people might mean different things when they speak about brain fog. But usually people say that in the context of, uh, fatigue and difficulty to focus or concentrate. And these are symptoms that regularly occur in people with chronic stress.

So. People who have chronic stress. Are experiencing symptoms of anxiety and depression, and also fatigue and difficulties concentrating. So these two are very, very closely connected I think.

00:16:47.690 — 00:16:51.410 · Jim McNasby

And Amy, do you see those kind of issues with your patients?

00:16:51.650 — 00:17:12.650 · Amie Hiller

Definitely. Yeah. And I think you guys both brought that up today. You know, that it's hard to focus and kind of get the words out. And I think even those of us who don't have Parkinson's who have that experience, I think it's intensified. Um, certainly when when someone has Parkinson's and often executive function, it's it's affected by Parkinson's specifically.

00:17:13.050 — 00:17:54.750 · Jim McNasby

And the other thing about stresses is that it can impact your care partner, too. So for all those care partners listening, you know, thank you for all that you do. But I mean, we all recognize that stress affects care partners. You know, I think of my own situation where my partner is putting difficult positions by me because I have, for example, RBD, and he is very stressed out because of that, and with good reason, because no one should have to deal with that.

But it's it's complicated. And you do you hear stories about stress impacting care partners as well as the person living with the disease?

00:17:55.030 — 00:18:46.900 · Amie Hiller

Yeah. And it's not always the partners experiencing it the same way. Right. I think there's some Parkinson's patients who are very stressed, and their care partner might not be so stressed. And then sometimes I see the opposite. I do a palliative care clinic for movement disorders. And we kind of are amazed because it's quite common that we'll have a patient come in with, you know, moderate to advanced disease.

And we ask them about how they're kind of functioning and managing. And their quality of life is quite good, their moods quite good. And then their care partner will be completely stressed and feeling like they're kind of, you know, having to take everything on. So I think it varies by by individual, but certainly it's quite common in care partners that we, we see, um, stress and that they need to get their own help for that.

You know, you can't take care of someone else or help someone else out if you're not taking care of yourself. So that's really critical.

00:18:47.140 — 00:18:51.020 · Jim McNasby

And Becca, does that impact the relationship that you have with your daughter?

00:18:51.220 — 00:19:26.690 · Becca Miller

Yeah, it does certainly. I mean, I think since I've gotten DBS since my deep brain stimulation surgery has been much better, but I think it used to be really a point of stress for us that I wouldn't be able to be reliable enough for her to go take her to a birthday party or something like that. I couldn't, um, the predictability of my symptoms was much less so.

That was really, I think, stressful for both of us. We we talk about the enemy being Parkinson's and kind of gang up on Parkinson's, as opposed to trying to fight with each other. But yeah, it is. It definitely causes stress.

00:19:26.890 — 00:19:39.050 · Jim McNasby

And can you say a little bit more about how to tell if it's stress that someone is experiencing, or whether it's just nervousness or anxiety? Can you help sort through this a little bit?

00:19:39.090 — 00:20:24.350 · Becca Miller

Yeah, it's not always that easy to tell the difference, I think that. Um, I mean, one thing with stress or chronic stress is that you can often identify kind of an event or a situation, whereas anxiety may be seem to come out of nowhere. But I think that, you know, figuring out if it's something that's lasting for a period of time and really affecting your functioning, that it's maybe time to go get some help from a mental health professional who can really help you sort through those things.

I mean, sort of the good news is, is that some of the same things that help with stress and will also help with anxiety or depression. So things like exercise, moving, you know, talk therapy, all those kinds of things. They're all good for those conditions.

00:20:24.550 — 00:20:32.070 · Jim McNasby

Okay. Let's talk a little bit about research and stress. I mean, what makes stress difficult to study?

00:20:32.430 — 00:21:33.620 · Amie Hiller

Um, lots of things. Um, one of it is, um, kind of measuring, you know, what stress people are experiencing, right? Also, we said it's kind of individual that what stresses someone else out. You know, one person out may not stress another person out. Um, the effects may be short lived. It's difficult in Parkinson's in general if we don't have wonderful biomarkers to follow things over time.

So there's lots of complicating factors that make it a difficult area of study. It's not something where, you know, you could you think about like a medication trial, right? And you give someone a placebo and then you give someone else a pill with the the active drug, you can't kind of give someone no stress and give someone else stress.

Straight, right? But, um, I think Brixton made me talk about the work he's doing to try to give people stress reductions and then kind of see what, what the effect is. And I think those things are really promising areas of research.

00:21:33.780 — 00:23:36.870 · Rick Helmich

Yeah. So what you're saying the alias is, is completely true. I completely agree with that. So one of the difficulties with this is indeed that there's no perfect biomarker to measure how much stress someone has in their body. And the other thing being is that it's difficult to put people under stress.

That's not ethical. So what we are doing here is um, is to do the opposite. So to have a, uh, one group of patients who undergo a mindfulness based stress reduction, uh, intervention that lasts eight weeks. It's pretty intense. It's about 2.5 hours per week in a group and one other group that, well, getting the treatment as usual.

And then what we are doing is testing whether the intervention has effects only on the symptoms that people have, like anxiety and depression and also motor symptoms, but also how it affects their brain. So we do imaging before and after, and we see if we follow them up after a year, how long lasting these effects are of that intervention.

And one cool biomarker we are using there is to look at cortisol in hair. So we cut a little bit of people's hair before and after a year. And cortisol builds up in hair. So the degree of how much cortisol you have in your hair tells us something about how stressed you have been over the past few months. Um, so together with also the brain scans, we try to understand how Stress reduction influences the brain and how it influences these chronic cortisol levels in people with Parkinson's.

And of course, we hope that mindfulness not only improves the symptoms of Parkinson's disease, but also that it might have a long lasting beneficial effects on the brain.

00:23:36.950 — 00:24:37.020 · Jim McNasby

Just a quick note. I was talking about my own experience. I used the word the initials RBD just to clarify for the audience what that is is. In short. REM sleep disorder normally is a precursor for Parkinson's, but can be a symptom of Parkinson's, where when you sleep, your body went into an REM sleep paralyzes itself, and when you have RBD, your body loses the ability to paralyze itself.

And so you act out. Your dreams and dreams are often, you know, familiar, often very negative. Like, you know, a shark coming after me. I'm in the water. This kind of thing. And then I acted out. And so I thrash around. And that's embarrassing and painful and can be dangerous for anybody with you. So. And Rick, is the research that you're doing beginning to show how stress affects the dopaminergic system?

00:24:37.260 — 00:26:34.670 · Rick Helmich

Um, yes. At least that's what we're trying. So what we are doing with these MRI scans is also collect data on the integrity of the, of the dopamine cells in the success nigra. We don't have these findings yet. So, um, the last week, the 124th patient and the last patient was included in that study. And we will need some time to to look at the data.

But what we know from other research is what acute stress does. Is it well, squeezes the last drops of dopamine out of the street. And that is because when people are stressed. Like I told you about the noradrenaline, you need to move fast, usually. And dopamine also helps to move flexibly. So in that sense you can understand.

That acute stress increases the opening. And also increases your adrenaline. But in people with Parkinson's disease. The dopamine system is already at their maximum effort of squeezing dopamine out of their system. So what stress does is it overloads the immune system. And that is probably one reason why medication is less effective when you're stressed.

You need more dopamine to cope with the stress and all the symptoms that people have. What we don't understand well enough yet is what the long term effects are of stress on the dopamine system. So if people have long over years, uh, stress, if that has a negative effect on their dopamine cells. There are some animal studies that point in that direction, but there's no evidence at all in humans.

So that is something we need to understand.

00:26:34.910 — 00:26:46.830 · Jim McNasby

So, Amy, what research is going on to validate strategies to reduce the impact of stress? I know measurement is challenging, but what can we look forward to hearing results of that?

00:26:46.910 — 00:27:20.860 · Amie Hiller

Yeah. So I think risk study is, you know, one of the the most exciting thinking about mindfulness, I think. Um, I don't know of all the active studies that are going on because it's often hard to find out about them until until results come along. But I think other things that have been thought about in addition to mindfulness or exercise intervention, um, yoga interventions, management of depression and anxiety symptoms.

Um, all those things are potential, um, things that could benefit stress and have positive effects.

00:27:21.300 — 00:27:29.780 · Jim McNasby

Did you, um, weigh in on that question to you about what strategies are to validating strategies to reduce stress?

00:27:29.860 — 00:28:45.280 · Rick Helmich

I think there are multiple strategies. So like Amy said, exercise, um, can be good. Uh, mindfulness can be good, I think, but it's probably not for everyone. So, um, and then there are also things like social supports and social interactions that are also really important for managing stress. So just to give an example, during the Covid pandemic, which was a very stressful event for for many people, we had a longitudinal cohort of Parkinson's patients that we followed here in the Netherlands, and we also abstained during the pandemic.

So in the first six months to fill out questionnaires on how stressed they were repeatedly, and what we found is that those people who were very stressed were not the ones who had more severe Parkinson's. They were not the ones who had more or less left open. They were the people who experienced less social support from others, and they were people who had more difficulties with cognitive function.

So recognizing these, these things could also help to reduce stress in people.

00:28:45.440 — 00:29:00.880 · Jim McNasby

Thank you. Can I talk to you a little bit about your own experience of managing stress? What works best for you when you're managing or attempting to manage the stress of your job? You're a professor. Yeah, you're a mother. You've got a lot going on.

00:29:01.400 — 00:30:08.050 · Becca Miller

Um, I think one thing that really helps me is just remembering to take things one day at a time, one minute at a time, sometimes just trying to like reorient to that. And I use strategies from cognitive behavioral therapy, like my own training as a therapist, I use for myself, basically, cognitive behavioral therapy strategies, like asking myself, well, what's the worst thing that can happen here?

Kind of trying to reorient to like that it's not as bad. And then also using acceptance and commitment therapy strategies, there's a great book called Get Out of Your Mind and Into Your Life that is like a workbook that people can use that those kinds of techniques and, and strategies helped me a lot. And then I also just, you know, there's always someone awake in the Parkinson's community online.

So any time of day or night, you know, it may be in another country, but there's always someone I can find on Facebook or through chat that will be there that I can kind of, you know, that kind of peer support, just getting support from someone else who's out there and dealing with the same kind of thing.

00:30:08.090 — 00:31:26.880 · Jim McNasby

You know, I myself find that support groups are terrific, you know, because if you can talk about, at least for me, if you can talk and share and share your feelings, it's validating, first of all. But it also just it's like a pressure reliever. It's just it's like somebody dialed down the impact of what's happening, and you feel like you get something off your chest, and there's almost a relief that comes from that, which I think is really terrific.

I'm also a huge proponent of exercise, um, you know, exercise every day. Um, it doesn't have to be something, you know, tremendous. You know, it doesn't have to be a five mile run. You can just be a, you know, a a walk or a dedicated time to stretch or something like that. And I highly recommend that, um, just because it allows you to kind of, you know, if you can put it together with some mindfulness, miss some quiet time and, you know, just say I need 15 minutes from myself right now, that that kind of thing is really important and impactful.

So what do you recommend to your patients who are dealing with stress there? I know exercise is one thing. You talked about a little bit about mindfulness. And you can say worry about that, but are there also medication options available?

00:31:26.960 — 00:31:27.800 · Becca Miller

Yeah. So I think.

00:31:27.800 — 00:33:02.610 · Amie Hiller

For stress itself we don't often think about medications is kind of being the the right way. But if there's stress and anxiety or stress and depression, then as Becca talked about, these often overlap and they often are coexisting. So I think certainly, um, it's worthwhile to talk with your neurology provider, potentially work with a mental health provider to think about medications for managing these things if they're present.

And I think around, um, you know, mindfulness is one particular approach, but the mind body therapies in general often have some. A lot of similar threads there. Um, and you know, I think in, in yoga, the my understanding, I'm not a yoga expert by any stretch, but is that you do the physical, so then you can quiet the mind so that the two kind of work together in tandem.

And I think other forms of meditation also can be something that's helpful. And I think it's also important that people find what works for them. Right. So if, um, there's some people who don't feel comfortable and support groups and if that isn't, you know, it's an anxiety provoking for them to be in a group and, and present things.

So maybe something like an anonymous group chat is a much better, you know, means for, for them to communicate. So I think knowing that there's lots of options out there and trying to find what fits with the person. I think, again, those those connections, be it in your community through a support group or be it other connections that you can make are also really, really critical.

00:33:02.890 — 00:33:22.210 · Jim McNasby

Yeah, encouraging people to explore options that are tailored to their experience is super important, I think. So Rick, we've been talking a bit about movement, yoga and all that. What does exercise and movement do in the body to reduce the effects of stress?

00:33:22.610 — 00:35:17.230 · Rick Helmich

Yeah, that's $1 million question. So I think exercise and things like meditation, they probably work well in Parkinson's disease because they have multiple effects. Um, so Parkinson's disease is a very complex disorder where many different systems are regulated in a different way. Um, so in that sense, it might also be difficult to understand if one single pill would completely solve all of that super complex disorder, we need a complex intervention and exercise and mindfulness based stress reduction are complex interventions.

So they have multiple effects on the body. And one of these effects are for example that exercise and also mindfulness. They reduce the inflammation in your body. So the studies have shown that to regularly exercise or do mindfulness have lower values of substances like CRP or interleukin that are um, well, signal molecules for inflammation.

So that might be one effect. And then there's also studies looking into a substance called hydrazine which is released when people exercise and which also has beneficial effects onto the brain. Um, so it would be great if we really understand what single substance is so important in mediating these beneficial effects of exercise or or other lifestyle interventions, so that we can use that knowledge to create a drug to boost these effects.

When I wonder if it's really that simple because it has so many effects on the body.

00:35:18.150 — 00:35:29.350 · Jim McNasby

Amy, there have been we mentioned mindfulness a couple of times in the answers, but I didn't ask, what does it mean mindfulness? And how can people incorporate it into their lives?

00:35:29.550 — 00:37:09.160 · Amie Hiller

Yeah. So that's another tough question. There's I think there was a time article that came out years ago called The Muddied Meaning of Mindfulness. And because I think it does vary. There's these very structured programs like mindfulness based stress reductions, which I think especially for like a research study, are a great option because they're very regimented.

They follow kind of a typical pathway, and the focus is really getting you to notice when you're feeling stressed and then trying to kind of move away from that so you don't get into this, this chronic stress cycle. And so I think taking courses like that can be super helpful to get you to kind of understand what mindfulness is.

And Jon Kabat-Zinn was one of the big early proponents of mindfulness based stress reduction. And one thing I really like that, he said, was when you're in the shower, just be in the shower. So don't be at work, don't be making dinner, don't be driving the car. You know, just be in the shower and enjoy the moment.

So I think that's kind of the the overall is try to be in the moment, not, you know, thinking about 27 other things because all of that adds so much stress to life. Um, and again, there's these kind of structured programs. And then there's a lot of things that I think there's a lot of things in cognitive behavioral therapy that have similarities and other types of therapies that kind of take things from it.

And I think if people find something that helps them, I don't think it needs to have this name or that name. You know, they can all have some, some positive effects.

00:37:09.160 — 00:38:10.620 · Jim McNasby

That reminds me of some personal experience that I had with when somebody asked me this question is, how do you live your life in the past, present or future? Allocate a percentage. And I at the time I was very young and I my answer was ten, 20, 70 was where I was coming from. I'm doing what I'm doing, but I'm going somewhere.

And now with a little more gray hair driven by the amount of cortisol I have, I know I answered 1080 ten you have a sense of where I've been, but I'm living in the moment. And I was sent to where I wanted, you know, be now or Now but keeping that reasonable. But that but that shift in the data for me was a very interesting exercise and I think is related to mindfulness.

In fact, I want to take advantage of your expertise for once again in psychiatry. When should someone seek professional help for their mental health? When dealing with stress? And what does that look like?

00:38:10.660 — 00:39:30.370 · Becca Miller

I am of the notion that everyone should have a therapist would benefit from a therapist regardless of PD, no PD stress, no stress kind of thing. But I think that, um, you know, it's not as accessible as it should be in our country right now to get mental health care, to get find a therapist. But I think if you if you can and I encourage it to find a therapist who may not specialize in PD, I don't think there are a lot of people who do.

But if you find someone who you like and can build a good relationship with, you can help them to learn more about PD. The relationship with your therapist is the most. Is the number one kind of factor that determines good outcomes? Less so than how they're specifically working, what kind of treatment they're giving you.

But I think also when talking about stress is thinking about like, are there things in your life that you need to change, like quitting the job or changing the or, you know, are you in a relationship that's causing you so much stress that it's not when you want to be in anymore? Like looking at the context to for yourself?

Um, and that may be something that you do with the mental health professional as well, because it can be just a, you know, a big indicator of something going wrong that you can change.

00:39:30.690 — 00:39:47.440 · Jim McNasby

All right. Well, we've got about 10 minutes or 12 minutes left and got a lot of audience questions. So, um, the first one we have quite a few on relate to diet, nutrition and stress. So maybe Rick, you can go first on that.

00:39:47.600 — 00:40:27.440 · Rick Helmich

Yes. There are a lot of neurons also in the gut. So the brain and the gut, they communicate. And um, if people are stressed, that might influence the gut. They might experience constipation and the other way around. There are not a lot of good studies into nutrition and diets and the effects of Parkinson's.

The studies that there are seem to show is that a mediterranean diet. So lots of vegetables, lots of fibers, um, are good for improving your gut health. And that that might also have an effect on stress and motor skills.

00:40:27.760 — 00:41:34.660 · Jim McNasby

Um, a question from the audience. And is there anybody who can weigh in on this one? Traveling abroad is a big issue and always gets my husband stressed. How can we make it

easier for him so I can start on that one, you know, which is, you know, uh, a plane can be an awkward thing to get on and off and try to have an aisle seat.

It's just easier to maneuver for, you know, put the person with Parkinson's there. Um, I try not to have too many pieces of things that I'm carrying with me, like check a bag instead of, uh, carry on, because, you know, if you're not, you should carry the fewest number of things you need to manage. Um, but, you know, if if traveling is a source of stress, then ask yourself if if it's a trip you need to take, you know, and so, uh, you know, sometimes it's unavoidable, but sometimes you can make the choice to find a substitute.

I would say that, um. Does anybody else have a view about traveling in Parkinson's?

00:41:34.740 — 00:42:23.090 · Amie Hiller

Um, I'll often tell people to do a trial run, you know, like, find a hotel that's close by Spy and just do a night in the hotel and see how it goes. Especially like some of the chains, the hotels actually look exactly the same. Another tip I heard from a caregiver, which I thought was amazing, was they were going to a different town, and she got in touch with the local support group and hired a caregiver for a couple of days while they were there.

So they just kind of had an extra buffer, which I thought was such a brilliant idea because I think especially if you're changing time zones where, you know, it's exhausting when you don't have Parkinson's, and then when you've got to take your meds very regularly. And, you know, I think thinking about just kind of having some extra support to make, make the process easier.

Can can be helpful.

00:42:23.450 — 00:43:32.240 · Becca Miller

One of the things that I do is really try and build in extra time and make sure that I am, you know, I start packing pretty early so that it's not so stressful that I'm like thinking it through. And then I just like I'm not building in a really tight schedule, like kind of leaving myself space to recover. And then there's also there's a lanyard and badge you can get called the Hidden Disabilities Sunflower.

But I've heard other people have had good experiences with because sometimes with Parkinson's, we don't always look like there's something going on, but we can really experience some tough times with gait, etc. but this is something you can go online and get HD sunflower.com, but it's a free service or maybe a couple dollars.

They'll send you like a card on a lanyard that you can wear. And this is supposed to be an international symbol of a hidden disability. So they're going to help you kind of help folks at the, you know, at the airport recognize that you may need some extra time getting on the plane, for example. So I've heard I've had friends who've had good luck with that.

00:43:32.440 — 00:43:49.500 · Jim McNasby

That's interesting. And I'm assuming it sounds like a an interesting thing to explore. Um, another question from the audience. What about marijuana use? Does it help with stress or make it worse, or what you're feeling on that? I'll ask Amy first.

00:43:49.780 — 00:44:48.090 · Amie Hiller

Um, so that's another thing where there's just not a lot of research and it's hard to do research. Um, so I think, you know, some of it, the individual, um, certainly I feel like some people who are chronic users can really damage themselves in terms of cognition and can make life just more stressful. Um, and can also kind of get a rebound anxiety.

I think there are some people who've told me, you know, they use small amounts for sleep and find that, um, to be really beneficial. But the the research is really tough, again,

because there's all different kind of formulations and different components and makeup. And then, um, you know, many places, um, it's not legal, or at least it's not federally funded to do research.

I'm not sure within the Netherlands, if there's been more done and there's more information there.

00:44:48.450 — 00:45:00.850 · Jim McNasby

In fact, I'm finding community support that Amy talked about. You know what? And use the buddy network or how do you, uh, you know, how do you find community support?

00:45:01.050 — 00:45:40.710 · Becca Miller

Um, I think there are so many different ways depending on what works for you. I find a lot of my support through Facebook, honestly, like different groups on Facebook and online. Um, there are local area support groups that I know of and attend on occasion, I think. Looking at your local area agency on aging can be helpful.

Um, the buddy network, there's lots online is a huge way of communicating with others, and that you can find people all over the country, all over the world, really. So you can have people in different time zones, which can be helpful in the middle of the night.

00:45:41.550 — 00:46:05.830 · Jim McNasby

So in just a year, you know, I try to use the buddy network as I can. Um, but I, you know, it's a great resource that's offered by the foundation. Um, and, uh, something that, you know, I encourage everyone to use. So time maybe for one more question. Any advice for caregivers and all that? All three of you answer that.

Maybe start with you, Amy.

00:46:05.990 — 00:46:42.820 · Amie Hiller

I think, you know, we talked about Becca, said something about like, think about the things that cause you stress and is there a way to get rid of those? I think for caregivers, that's really huge. You know, are there people that you can hire to do certain things? Are you living in a, you know, very large house with stairs that makes it tough for your partner to to get up and down or, you know, are there ways you can simplify life and make things easier on yourself?

And I think to not feel guilty about those changes, but really take advantage of those changes so that you can kind of get some things off your plate, because oftentimes it gets it overflows.

00:46:42.980 — 00:46:44.100 · Jim McNasby

Back to you.

00:46:44.340 — 00:47:07.260 · Becca Miller

Yeah. I think you can't pour from an empty cup is a pretty nice one, which is so important I think. You know, oftentimes it can feel like the focus is all on the person with PD, but that the, the caregiver needs, you know, to have time for themselves and to really focus on their own mental health and wellness.

And just to take that time is so important.

00:47:07.300 — 00:47:10.180 · Jim McNasby

And, Rick, from you and in wisdom for caregivers.

00:47:10.460 — 00:48:07.170 · Rick Helmich

I think it's really important that well that the system so the, the the caregiver and the patient are both in balance. So I guess my main advice would be to, well, speak to each other about what causes stress, not only in the person living with Parkinson's, but also in the caregiver. friend. We often sometimes have shared sessions where a psychotherapist, for example, speaks to both the caregiver and the patient so that sometimes work and well, shame is often a big thing that that creates this vicious circle.

So sometimes it can also really help to explain to the people around you or even in your restaurants, um, why you're having tremor. Um, and try to break that cycle of shame and stress and more symptoms and ultimately preventing to do stuff.

00:48:07.250 — 00:48:41.590 · Jim McNasby

Okay. Thank you all for those those answers. And I would just conclude by saying to all the caregivers listening, thank you for doing everything that you do, because all of us who have this scourge, you know, depend on you for everything. And so thank you, thank you. So thank you for being part of our community and for joining us today.

Thanks to our expert panelists for your wisdom, for your insight, and for sharing your time and expertise. And we hope you found today's discussion helpful. Thank you and have a great day.

00:48:46.150 — 00:49:01.070 · Veronique Enos Kaefer

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00:49:05.190 — 00:49:14.070 · Michael J. Fox

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