

Rachel Dolhun:

Hi everyone and thank you so much for joining us. I'm Dr. Rachel Dolhun, Vice President of Medical Communications at The Michael J. Fox Foundation, and I'll be your moderator for today's webinar. Today we're discussing ways to manage stress, anxiety and uncertainty, feelings all of us are experiencing to at least some extent during this time. We're so glad to be able to come together to share our experiences, offer tips we hope will be helpful and to answer your questions.

Being with others and having a sense of community, as we'll talk about, is so important during this time. So even though you can't see us or the other listeners, I want you to know that there are almost 6,000 people who registered for this webinar. That's 6,000 people with Parkinson's, their loved ones, care partners, care providers and researchers who are all here together. Behind the scenes there are five Michael J. Fox Foundation staff members working from their homes who will be answering your questions throughout the hour.

If you have a question, you can type it in the Q and A box near the middle of your screen. We'll get to as many as we can throughout the hour. If you want the slides for download or other helpful information we'll discuss, check the resource list on your screen. We've got a lot to discuss, so let's get started.

A brief overview of our agenda. We'll talk about stress, how to be mindful, ways to manage anxiety and feelings of loneliness, and finding balance during this time. So let me introduce our panelists. Laurie Mischley is a naturopathic physician and Parkinson's disease researcher. Hi Laurie, and thank you for being here.

Laurie Mischley:

Hi, thanks for inviting me.

Rachel Dolhun:

Nataly Kogan is the founder of Happier and author of Happier Now. Welcome Nataly.

Nataly Kogan:

I'm really grateful to be joining all of you. Thank you.

Rachel Dolhun:

And last but not least, we have Dan [Kinel00:02:10] who has been living with Parkinson's since 2013. We're so glad to have you with us, Dan.

Dan Kinel:

I'm honored to be here. Thank you for inviting me.

Rachel Dolhun:

So let's dive in because as you saw, we've got a lot to talk about, and a lot of what I hope will be helpful discussion. Stress and Parkinson's, Laurie, we're all feeling a lot of stress right now, but people with Parkinson's may feel stress in different ways, and as you see on the bottom of the slide there, a Fox Insight survey showed that people with Parkinson's reported more stress and increased symptoms compared to people with Parkinson's. So Laurie, can you tell us a little bit about stress and how it can affect people with Parkinson's?

Laurie Mischley:

Yeah. I think many people with Parkinson's will tell you that their initial symptoms came on during a period of stress, and almost every patient will tell you that their symptoms are worse during periods of stress. We even have rat research that says stress makes motor symptoms worse. But not all stress is bad. You know, I think it's really important to say that stress is just how the body adapts to changes and adjustments in their life. There's good stress and bad stress. Planning a wedding, traveling is stressful, but it's good stress. It's called eustress. There's also distress, which I think a lot of people are kind of trying to navigate right now. There's also physical stress, like you know, going through a surgery, taking a fall, and emotional stress, which you sometimes feel with more rapid heartbeat. You start breathing through the upper part of your chest, your hands and feet get cold. It's hard to focus. So this becomes a really complex issue and each person sort of manifests their stress and handles it differently.

Rachel Dolhun:

I think that's such a good overview, and so important to remember, I think. We see on the screen there exercise, we get so many questions about, "My tremor gets worse when I exercise." You know, that's a great example about a good stress, exercise, bringing out symptoms. But again, we're all experiencing this heightened stress and that bringing out more symptoms. So Dan, can you tell us a little bit about your stress and how that has manifested itself in your Parkinson's maybe even before and during this period of Covid?

Dan Kinel:

Sure. Well, I think having PD and being diagnosed with PD is stressful in and of itself, and then layering on top of that the whole Covid atmosphere and the turbulent times, and the uncertainty of the world around us, in addition to the uncertainty of sort of the world within us in the Parkinson's side of things, is for me at least been sometimes synergistic. It's created more stress, and on top of that the change in our lack of schedules because things are just all different today than they were a month and a half ago [inaudible 00:05:07] As a concrete example, medication schedules. My medication schedule is not as rock-solid as it had been, and it's taken me several weeks to get it back to where it should be because I wouldn't get up at the same time, I wasn't going to bed at the same time. It was just harder to manage. The stresses of living day to day has translated into real world practical problems or issues that most people who don't have PD don't have to worry about.

Rachel Dolhun:

I think that's so important to highlight, and you see the bottom bullet there that that stress itself can make your medication feel like it's not working as well. But not taking your medication on time or on a regular schedule, or getting out of the routine of things can be a stressor in and of itself. So it's really important right now to make sure that you're staying on top of things and being more in a routine and more in a schedule. So let's get to the meat of things.

Dan Kinel:

The bottom bullet, that medications can seem less effective. I know for me at least sometimes when I'm stressed out, that it almost feels like I skip a dose. The impact is much greater than when I'm not stressed out. So being aware and cognizant of that and how you plan your day is important.

Rachel Dolhun:

Definitely.

Laurie Mischley:

This is Laurie. Can I just add to that? I think a lot of patients, that causes more stress when their meds don't work, and during periods of stress I find a lot of people fearing that their disease is progressing because the meds that used to work aren't working so well right now. I think just hearing that stress does change the way you metabolize and utilize your meds, and that it is very common that people will need a little more medication during periods of stress, and when that period of stress is over, you go back to your old dose. This isn't progression, it's just your body coping.

Rachel Dolhun:

That's really important. Speaking of ways to cope and ways to manage, let's get into the meat of it, because stress is all around us and it's different for everyone and there are different ways to manage it. For some people it's exercise. For other people it's journaling, maybe meditating, but being mindful is something that we hear about a lot.

Rachel Dolhun:

In that Fox Insight survey I just mentioned, where people with Parkinson's said they experienced more stress and more symptoms because of their stress, almost 40% of people said they practice mindfulness to manage stress. But Nataly, we hear a lot about it, but oftentimes we don't really know what mindfulness is. So can you tell us a little bit more about some of the definitions for mindfulness and how we can bring mindfulness into our daily lives?

Nataly Kogan:

Absolutely. I just need to say from the outstart that I teach emotional health skills and mindfulness, but I used to be a skeptic of all of this for most of my life because it just was very abstract. And so mindfulness, the way that I think about it, is rooted in awareness, right? We can all relate to the example that I often use of you have your morning coffee, you fill it up, you sit down, and then the next time you look down the cup is empty. You had your coffee but you don't remember having the coffee because it's just automatic. So much of our lives we actually spend in a mindless state, and some of that is incredibly helpful because we need to do some things on automatic. But the challenge comes around the fact that if we are not mindful, if we're not practicing awareness of how we feel, that it actually can lead to us accumulating stress and accumulating anxiety.

Nataly Kogan:

The way that I very simply think about mindfulness is just noticing. It's noticing how you feel. It's pausing several times a day to actually check in with yourself, which not many of us do naturally, to just say, "How am I feeling?" There are a couple of very simple but really important and rooted in research practices that I just want to share about, well how do we actually practice it, and how do we use those practices to boost our wellbeing?

Nataly Kogan:

The first is around acceptance. Acceptance doesn't mean that whatever happens, happens, that we're throwing up our hands in the air. Acceptance is really the skill of learning to see how things are and how we feel with clarity instead of judgment, instead of any kind of harshness, "I shouldn't feel this way," or "This shouldn't be happening." The should is the judgment, and that's where so much of our stress comes from if we get stuck there. So by practicing acceptance and using that first step to just say, "Well, how am I feeling?"

Nataly Kogan:

For so many of us it's really challenging to feel the difficult feelings. It's hard to feel fear, or loss, or sadness. I'm not suggesting these are fun feelings, but research shows that when you allow yourself to feel a difficult feeling without trying to distract yourself, without immediately trying to push it down and not feel it, when you allow yourself to feel it without judgment, with just clarity, you actually get through it in a shorter amount of time and with less intensity. That is because you're not wasting your emotional energy fighting with your feelings. So that's a really powerful practice, the first step of acceptance. The second step is once you are aware-

Rachel Dolhun:

I'll just interrupt you for one second there, and Dan, I'll just bring you in for a moment because I think acceptance is something that people with Parkinson's are probably really accustomed to. We talk about this a lot with the diagnosis, which is really, really tough and hard to acknowledge and accept, and there's a big moment around accepting what that means and what that looks like for the future and the uncertainty of the future. I think there's been a lot of that we've discussed in this moment that we're all living in now of accepting the uncertainty and the fear and the anxiety of where we all are, and so it's sort of bringing that into this moment I think is really powerful.

Dan Kinel:

I agree. I think that one of the hardest parts about the diagnosis is to have the acceptance, and it's not just an acceptance on this particular point in time, it's an ongoing acceptance because symptoms change, your health status change, and it's a progression. It's sort of an ongoing process of continual acceptance, and continual acceptance of differences and changes. I think that being able to do that and cope with that hopefully can help make this community, the PD community more resilient to some of outside stressors, and being mindful and being aware of the fact that you're constantly changing your acceptance yourself, and your disease is constantly changing, will hopefully make it easier for us to think about accepting the outside world and being accepting of the uncertainty of the outside world.

Dan Kinel:

I think that mindfulness ideas are terrific. For me that involves going for a walk in a local park, at socially acceptable distances of course, every day and just being around the springtime flowers and the trees, and just enjoying being in nature, or getting on the phone with friends and chatting for a few minutes. Not about anything earth-shattering or important, but just what's happening day to day. Just sort of being in the moment present and being with other people present in the moment, or by myself present in the moment is incredibly powerful.

Nataly Kogan:

I think actually Dan, you bring up such a great point around going for a walk or chatting with friends, because the other part of acceptance that I think is really important is once you become aware, once you truly become aware of how you feel, how things are, to ask yourself, "What is something that I can do to help me feel a little better," right? That may involve reaching out to a friend, right? I love that you're talking about chatting with friends, or going for a walk, or looking at nature, whatever that is. It doesn't have to be earth-shattering, but taking that one step to say, "Okay, what is something small that I can do to serve myself, to serve this moment, to honor myself?" It's actually really powerful, and I love the example that you shared. When you talked about enjoying nature, enjoying what you're seeing, that's the practice of gratitude.

Nataly Kogan:

There's so much research that shows that when we practice gratitude, which is very simply just zooming in on things in our lives that are good, that are beautiful or kind or connected or loving, especially during a challenge, gratitude becomes a really powerful source of resilience, because all of our brains are much more sensitive to what's wrong naturally. It's part of the way that our brain helps us survive. It's very sensitive to negative stimuli, because usually danger comes with negative stimuli.

Nataly Kogan:

What happens when we're in a challenging situation, which is where we all are right now, is that negativity bias gets even more sensitive. So the brain is looking at all of this uncertainty we're going through and saying, "I think I see danger." Your negativity bias gets even more sensitive so it's easier to feel down. It's easier to read one news article and to feel really, really down. Practicing gratitude is the best antidote, because when amidst the challenge you ask yourself, "Okay, things are challenging. What is something that I am grateful for?" And you answer that question. The more specific you can be with your gratitude, the better. That tells your brain that the challenge, the stress, it's not everything, that there is more in your life that is good. That is an incredibly powerful source of resilience that actually helps the brain not descend into a negativity spiral.

Nataly Kogan:

I love, Dan, when you were talking just the tone of your voice, going for a walk and enjoying nature, you're practicing gratitude. The more that you can be intentional about that during the challenging times, not only do you give yourself these moments of feeling a little uplifted, but you're helping yourself be more resilient, because you're kind of dampening that negativity bias that our brain naturally has.

Dan Kinel:

It's interesting. For me, it's also doing it without pressure. In the Covid environment there's so much outside pressure to learn Mandarin, or be able to learn how to do some new exotic cooking, or use the time for something earth-shattering and different, and transform yourself. For me at least, I just try to get through day by day and hour by hour, and I think the simple things are often the most satisfying, easiest things. They're not daunting. They're not-

Dan:

The simple things are often the most satisfying, the easiest things. They're not daunting. They're not hard to start. Just put one foot in front of the other and go for a walk. Just enjoy being outside. Do things that... I don't feel like everything has to have a deep intense meaning, but just has to bring some gratitude, enjoyment, and pleasant experience and then that's enough for a day.

Rachel:

I love the way you said that, Dan, and I love that you are bringing up the point about not feeling pressure to do some huge new thing, because that's really a part of self care, is to just recognize that we're all going through something incredibly challenging. People have been calling this the new normal. There's nothing normal with what we're going through. It's so hard, and to not expect some impossible new things from ourselves, but as you say, to just focus on practicing that awareness, how we feel, and asking ourselves, "What is something simple that I can do?" The examples you've given, I love that.

Laurie:

I love this idea of-

Rachel:

This is all so helpful and... Laurie?

Laurie:

I was just going to add, I really love this idea of your internal compass, checking in with yourself and not making comparisons to the-

Rachel:

Mm-hmm (affirmative)

Laurie:

... external world. I remember my very first yoga class as a 19 year old. I remember the yoga teacher saying, "If you're looking at the person next to you, you're doing it wrong," and that was a really centered experience.

Rachel:

Yeah, stay on your own mat.

Dan:

I'm laughing because I went to my first yoga class after I was diagnosed with TD and I was astounded that people can move their bodies in any positions, let alone the positions they were moving them into.

Nataly:

But it's such a good experience.

Rachel:

Speaking of yoga and meditation, these are ways to be mindful, but there are so many others. Can you tell us a little bit more about the different ways to practice mindfulness and we're also getting a question, if you can maybe start, and then Nataly, you can add in. What's the difference between mindfulness and meditation?

Laurie:

I'm doing this big huge survey of people with Parkinson's disease, and we're asking questions about people who feel a lot of stress and people who practice stress management. We can see that people who have a lot of stress are progressing faster and people who practice stress management are progressing slower. But we don't know what that means.

Laurie:

I will say that meditation, it is a very active process. You are working. So there is an autonomic nervous system that controls the fight or flight, or rest and digest part of the body, and over the course of a minute, the body is constantly oscillating between these two sides of the teeter totter.

Laurie:

In Parkinson's disease, that's a little out of shape. That doesn't work so well. People tend to get stuck in fight or flight. It's like having your foot on the gas pedal in a car to let up. Meditation is a very active like exercise, rest and digest part of the nervous system. You actually work and focus on doing nothing. If your brain starts to stray you consciously acknowledge it, you don't judge it and you bring your attention back to your breath and so it's different than just relaxing, taking a stroll, unwinding. It's actually like exercise for the calming part of your nervous system [inaudible 00:19:36] to do that. [crosstalk 00:19:43].

Rachel:

Stand by. Sorry, just one second. Dan, I think we're getting some feedback from you so if you can just mute for a second while you're not talking.

Rachel:

I think this is so important to point out here because Laurie, when we were talking about having this call, you said, "I don't know if I'm the person to talk about meditation because I can't meditate". I think people try to force themselves to meditate and for a lot of people it's a great thing but it's not for everyone. It's important to try out number one, different meditation practices.

Rachel:

There are so many different types of meditation. They're not all just sitting there and holding a mantra or trying to focus on your breath. There are different visualization practices or being kind to yourself or thinking about being compassionate. There's many different varieties of practices for meditation, number one.

Rachel:

If meditation isn't for you that's okay too. It's just important to try different things and make sure that you're doing something that works for you as far as mindfulness is concerned. [crosstalk 00:00:20:48].

Nataly:

I just want to add something Rachel that I find so helpful. Dr. Ellen Langer, she's a professor at Harvard, she's really considered kind of the mother of mindfulness and her definition of mindfulness really stuck with me because I'm one of those people who spent most of my life thinking I could never meditate cause that's just sitting cross legged in a dark room for half an hour and no way. My thoughts are all over.

Nataly:

Her definition of mindfulness is noticing new things about the familiar things and that's been really helpful for me so I wanted to share. Even if you just go for a walk like Dan, you were talking about going for a walk. I take a daily walk. One of the things you can do is go for a walk and give yourself a little challenge. I'm going to notice five new things on my walk. They can be, I see a new bird or a new flower or a new person, whatever that is. But in that act of noticing, what that does is it brings us to the present moment and that is really the goal of meditation and the goal of mindfulness is to not run away with wherever thoughts are going, which is usually in the past or the future, but to be in the present moment.

Nataly:

What Dr. Ellen Langer talked about, it has been really helpful for me. I don't sit and meditate in a dark room. I do go for a daily walk and when I do practice noticing or even noticing things she talks about like when your loved one enters the room for the first time, can you notice a couple of new things about them? It can be really small. Mindfulness just helps us to be in the present moment.

Rachel:

Yeah, I think that's really helpful and just being aware of your body and how you're breathing or if your palms are sweaty, your heart is racing or those sorts of things. I think you're looking around yourself exactly like your thing. That's mindfulness. It doesn't have to be a real intense exercise. I will mention too, in the resource list, there are a couple of free online guided meditation practices that are available. But again, there are many, ask your friends, ask other people in the Parkinson's community what works, what doesn't work, and just try a few different ones out to see what works for you. So on that note, I'd like to move on and talk a little bit more about some of the things we started talking about a little bit earlier, some of the ways that you can think about to ease mood changes like anxiety, depression, and feelings of loneliness and isolation that can be particularly amplified during this time.

Rachel:

Now, we talked about mindfulness, which is one good way and meditation, yoga and those sorts of things. But again, stress comes in many different ways and it brings out many different feelings. So I'd like to talk about a couple of the different things on this slide. Dan, you found a couple of ways to do a lot of these things despite the restrictions that are in place right now. We know that maintaining and building connections are so important and keeping active is really important for Parkinson's, for mood, for general wellbeing. Those are two that you really found creative ways to stay in touch with. So can you tell us in particular about your community and about your exercise?

Dan:

Sure. So one of the things that I found incredibly helpful is I have a small group of friends, one person with Parkinson's and a couple people without Parkinson's. We get together a couple of times a week on a Zoom call and just catch up and chat and talk. We actually end each call with a short meditation. Back to the meditation, it's quiet with each other and just sort of be with each other and together in the same space, virtual space I guess. Beyond that talking to friends, making time and as you know, making the deliberate, intentional effort and taking the energy to make the phone call to reach out to someone to see how they're doing and to not just being a recipient of care but to being a thing somebody reaches out and tries to engage with other people is really been a powerful way to, for me at least, to navigate some of the social isolation that comes from just being in your house all the time.

Rachel:

I liked that you said you actually went from once a week to three times a week you knew the community and connection so important during this time.

Dan:

With this particular group of friends, we had gotten together once a week basically for coffee and in person and then about a month and a half ago we decided to get together virtually when all this and social distancing became a new word in our vocabulary and we've since moved to Monday, Wednesday and Friday. The conversations are not always earth shattering or life changing with just get to be with



friends and in the same space and be together. Sometimes it's a half an hour, sometimes an hour and we just catch up.

Dan:

It's really a wonderful way to keep in touch with people and stay social. I think that one of the challenges with PD is that it depends to make your world smaller in many respects. It's hard to be around that. It's hard to get around. It's hard to be understood. When your certain circle is kind of closed in and reaching out and making yourself get out the to the world and being part of a community really is helpful in so many ways

Rachel:

Staying active too, so important but different in this time. A lot of people with Parkinson's find that their group exercise program is their social support and their way to keep them motivated. How have you found creative ways or new ways to stay active during this time Dan?

Dan:

I work out at home a little bit, but frankly I find that kind of boring. I've tried to be outside more and really push myself when I go for my walks and make them longer and longer and really trying to stretch more and be active and outside more. But also in some online classes. It's different. I am the kind of person I like being in a room with other people when I worked out and the Zoom work out with somebody in the screen across you who knows you as the next best thing. It's worth trying. I actually kind of met a couple other people through that process that I hope after this is all behind this in one way, shape or form, I'll get to meet in person. Yeah. I guess I'm not in person, live.

Rachel:

It's so great to hear how people are being creative and being innovative and keeping up their activity around this time. One of the other ways Dan, you talked about this with keeping your connections and sort of the check-ins that you've been doing that has helped you but are also helping others. Nataly, you talked about how helping others is a way to boost your mood but also be kinder to yourself. So I'd like you to expound on that a little bit.

Nataly:

Absolutely. One of the things about kindness is that it's the fastest way to feel a little bit better, is to do something kind for another person. I think we all know that kind of feels really good, but particularly when we are stressed doing something caring kind for someone else that does two things.

Nataly:

First of all, it just makes us feel uplifted. Anytime you do something kind, your brain releases serotonin, which we know makes us feel good. But more importantly, especially given the isolation, many of us are feeling right now, when you do something kind it helps you feel less alone. It helps you feel that you belong, that you have people in your life you care about and that is incredibly powerful. That's something we need as human beings. One of the things that I have found in just talking to folks during this time is how much, and then you mentioned this, how much simple things really matter. So you may not think that checking in on a friend or texting a colleague to just say, "How are you? How are you hanging in there?" You may not think it's anything of a big deal and meaningful, but it's huge because what that tells the other person, if someone is thinking about them, they feel less alone.

Nataly:

I really encourage you to become intentional about your kindness practice. The simplest way to do that is to check in with other people and checking in is one of those things. It's simple to do, but it actually has two components. The first is just to let the person know you'd like to know how they're doing and the second is to listen to what they have to say without if they're worried about something or sad, which many people are right now without trying to fix it or make any suggestions to just be there for them. I think that's one of the biggest kindness gifts we can give to each other.

Nataly:

I just want to share what someone shared with me. It's something she's been doing that I found such a great idea. I'm going to... I've started doing it. She said she looks at her phone contacts once a day and she picks one or two people and she reaches out to them. The woman who was doing this told me she's just connected with some people she hasn't talked to in 10 years and rekindled some old friendships. I think we all have an opportunity right now to reach out more, to check in with people more and by doing that to actually make ourselves feel more connected, which helps us get through this really challenging time.

Rachel:

I love these tangible and actionable practices that you're giving us that are so easy. This takes less than five minutes to do, right? So it's something-

Nataly:

Mm-hmm (affirmative).

Rachel:

...simple that helps others and makes you feel good. So I love these. Laurie, I want to bring you back in with the little box there that says keep up care because that's looked different in this time, but it's so important, especially not just for the regular kind of maintenance of care for Parkinson's, which we talked about with Dan with making sure that you're staying on top of your medication schedule and those sorts of things, but seeing your doctor. What does that look like and how do you make sure that you're seeing doctor for your Parkinson's care or if your anxiety seems to be higher, what kind of tips can you give people there?

Laurie:

Yeah, this is uncharted territory and this is new for a lot of people. Some people are jumping up and down about Medicare has changed their rules and so now they can consult with doctors outside of their state via telemedicine and have access to new providers they didn't have access to a month ago. Other people are freaking out because it's hard to get their battery changed for DVS. Everyone's being affected by this a little bit differently.

Laurie:

I will say, surprisingly, the majority of my patients are actually finding it a little bit easier to connect, to be a little more aware of their diet, their schedules. It's easier to be conscious when there's less stimulus in your environment. There's less moving around. So I think most of my colleagues are all doing telemedicine these days. I think when we started doing it at our clinic my local patients didn't like the

idea they wanted to come in. But now that we've started, they're saying, I'll never come in again. This is great. I can stay in my pajamas and save an hour of traffic and driving.

Nataly:

... my pajamas, and save an hour of traffic and driving. This is fabulous. So I think with this change comes new opportunities. I think we might evolve the way that we do medicine permanently moving forward because of some of these opportunities we're all having.

Laurie:

Absolutely. It's giving us new opportunities, new challenges with it, but a lot to look forward to for the future too, but making sure that we're keeping those lines of communication open. Even if it's through the telephone your doctor is still available, but making sure that you're keeping in touch if things look different.

Laurie:

I don't want to leave this slide without talking about the news, because it's everywhere all the time and it's stressful. So, Nataly and Dan, I want to talk to both of you, but Nataly, I want to start with you, because you talked about how you realized that the news was really stressing you out and it was a bad start to your day. Could you tell us a little bit more about that?

Nataly:

Yes. I realized... Yeah. What I shared was, you know, we live outside of Boston. Our daughter is 15, so we've been on lockdown for about five weeks and she hasn't had school. Earlier this week I came into the kitchen, my husband was there in the morning, and I grabbed my phone. He was sitting there on his phone, and then I realized that this is how we've been starting our morning, because now we don't have to hurry and get breakfast ready and get her to school, so we've just been sitting there and reading the news or social media for the first half hour of the day, and it was making me feel so heavy and so down to start the day. It was actually making it more difficult for me to get through the day.

Nataly:

So I readjusted and I recommitted to starting my mornings in a way that is fueling... You know, the way that we start our days has a huge impact on how the rest of the day goes. If you ever have a bad morning, like get up on the wrong side of the bed, the rest of the day is likely to be pretty crappy, and it's not because there's anything wrong with you. It's because of that negativity bias I talked about. Once you're already stressed or cranky, little things are more annoying and stressful.

Nataly:

So I recommitted to myself, and for the past few days I've been starting my morning by reading a few pages of a book that is interesting or appealing in some way, or some days I've actually watched the TED Talks just on a topic completely unrelated to anything that we're going through.

Nataly:

What I found is I have more energy, I have a different mindset, and so I really encourage you to think about two things. One is just creating a little ritual to help you start your day in a fueling way. It does not have to be long, but just be intentional about it. What are some things you can do in the morning to

help you have a better day? It may be journaling for some people, gratitude practice, a short walk, whatever that is.

Nataly:

And then the second is to just be really mindful about news consumption. There's so much bad news right now, and I'm not sure reading 10 articles gives you any more value or knowledge than reading one. So I just suggest that maybe you limit... I know some folks have done things like they only check news once a day or they only check their local news, or whatever that is. But just to treat your news consumption as something on your to do list, so it's not something you're doing mindlessly all day long. It's something that you say okay, this is when I'm going to do it, now I've done it, I checked it off and I'm done.

Nataly:

I was just going to say it's not just news I think that can be a trigger. I think being mindful extends into being aware of other areas in our life where we find things and people and situations that trigger us, and mindfully avoiding them... I told the story when we were preparing for this call about a woman in town who started practicing biofeedback and I wanted to learn a little bit more about what that was.

Nataly:

So I went to her office and she hooked me up to all these machines that measure heart rate and temperature and respiratory rate, and you can see all of your numbers on the screen in front of you, and I was showing off a little bit. She was saying okay, lower your heart rate by, you know, five beats per minute, increase your blood pressure. And I was 10 years into my yoga practice. I was pretty good at this, and I was kind of getting fancy, lowering my temperature while raising my heart rate.

Nataly:

Then my phone rang and my wires got all crossed, the lines went all over the screen, and I couldn't get control of my autonomic nervous system again, and it was just the ring of a phone that set me off. So just being aware of that, I have kept my phone on vibrate for the last 15 years since I experienced that moment. I saw how my stress... The stress that it created by the ring of a phone for me.

Laurie:

So I think it's not just news, but life that happens and how you moderate that.

Nataly:

Absolutely, and being so aware of what your stressors are. So, Laurie, we're getting a fair number of questions about new or worsening depression or anxiety. What can you tell people about what to do about that?

Laurie:

Well, there are a couple of things, ranging from simple to complex. Dan spoke earlier... He said something about going for a walk, and preferably in nature. It sounds very hippy-esque, but there is this whole field of science emerging from Japan, I think it's called [Japanese 00:37:35] or something like that, but it translates to forest saving.

Laurie:

What we find is we can take people and have them stand in a parking lot for an hour or stand in the middle of a forest for an hour and we can measure inflammation and stress hormones coming down by just standing in a forest, and you don't get that in parking lots.

Laurie:

So it's little things about choosing which environment to surround yourself in that have measurable meaningful impact on your physiology. So it could be as simple as that.

Laurie:

I think there are a ton of foods... There have been two large studies now that show that a Mediterranean diet is as effective as antidepressants for people dealing with chronic depression. I think the science is getting stronger and stronger that a lot of these things, lifestyle modification behaviors, can really translate to meaningful difference in one's quality of life, especially where mood disorders are concerned.

Nataly:

So it's different for different people. It could be, you know, going for walks in nature. It can be your diet. For some people it is medication. It could also be detox therapy. Therapists are very much available, virtually as well, doing a lot of telemedicine now, as you were mentioning.

Nataly:

So I think too the key is making sure that there's an open discussion with your doctor too and your loved ones about what's going on. Another question, Laurie-

Laurie:

And-

Nataly:

Go ahead.

Laurie:

I was just going to say I think that we all handle things like this differently. We're talking about a lot of kind of things that are relaxing, but I actually find that learning Chinese, who mentioned that earlier... But there are things that I could do that give me a sense of control, that when I learn new skills, new tips, new tricks, when I acquire new information it's empowering. It makes me feel like the world might be happening all around me, but there is stuff I can do right here today. There's something for me about education and learning and knowledge that really gives me a sense of power, and that seems to help navigate stressful situation.

Nataly:

Yeah. Focusing on what you can control versus what you can't, I think there is a big, big message there. Maybe a good one for you, Dan, what advice might you offer to help motivate somebody with Parkinson's who was not really active or socially engaged before all this happened?

Dan:

It's interesting you mentioned what you can do. I mean there's lots of things you can do in the Parkinson's community, in your smaller town or city community, in the national community. You can be involved in lots of different things.

Dan:

But in terms of making a difference in the Parkinson's community, feeling engaged and active and feeling like you're making a difference, there's things you can do online, studies, Fox Trial Finder has lots of online studies that you can participate in.

Dan:

You can take those... Participate in those studies from your home and really feel like you're empowered and like you're doing something positive for the PD community.

Dan:

Beyond the PD community, you can volunteer to like... Like someone was saying before, by reaching out and calling people and checking in. Just because you have Parkinson's doesn't mean you can't volunteer and do things for other people and be of service to other people. It's one of the most rewarding things, for me at least, and things that make me feel best about myself.

Dan:

It doesn't have to be anything huge or earth shattering, but just checking with somebody else and seeing how they're doing and seeing if there's anything you can do for them to make their day better. It can be an impressive and powerful and positive experience.

Dan:

The other thing I wanted to mention is the news. That whole conversation reminds me that when I was first diagnosed I obsessively watched the news or read the news on Parkinson's, like six hours a day for days and days and days. My doctor actually kept telling me, "Dan, you're medically prescribed to no more than 10 minutes of news twice a day. This is your medication."

Dan:

I kind of followed that, kind of didn't, but it reminded me that what was happening to me as the whole COVID thing started is that I was obsessively checking the news, and there's no change. It's like, you know, day-to-day in the Parkinson's news world there's no change. Change is slow. It takes time.

Dan:

And the news today is... A lot of it is... Remember, it's designed to make you... To suck you in, to make you worry, to increase anxiety, because that's what makes you watch more. That's what sells commercials. So understanding that and self-limiting your intake is not going to limit the amount of information, it'll just limit the amount of anxiety you take from getting that information.

Laurie:

It's so important, yeah, limiting and making sure that you're in control of when you access the information, how much, how long sorts of things, going to credible sources.

Laurie:

I want to make sure that we spend some time talking about balance and how that balance might be imperfect to right now. It's something that we're all constantly looking for, whether we talk about a work/life balance or an emotional balance. But in this time we're working from different spaces, care partners are often working longer hours, parents are juggling being teachers to their kids while also working full time, and it's gotten to be a lot for a lot of us.

Laurie:

So, Nataly, I want to start with you here and ask you how can we take a step back and slow down and move a little bit more toward an even keel?

Nataly:

You know, one of the things... I actually struggle with the word balance, because I think it's really hard, and for me if I like try to think of balance it inspires his kind of grand notion and then I just get really intimidated, because my life doesn't feel that way.

Nataly:

So one of the ways I encourage you to think about balance is kind of moment-by-moment or hour-by-hour, and it doesn't mean that every hour will be balanced. So there are hours in my day where I'm all work, work, work, and I don't see my daughter, even though she's home from school.

Nataly:

Then what I try to do is when I'm with her I try to be really with her. It really comes back to mindfulness, right? It's just being in the moment you're in. That's a huge source of feeling balanced for me.

Nataly:

When we are multitasking, and by the way it turns out none of us can multitask, we just switch tasks... So when we are multitasking or when we're trying to do a bunch of things all at the same time, that's incredibly stressful for the brain. Actually what helps me stop myself from doing it is it makes us less effective at any of the tasks we're doing.

Nataly:

Each time we switch tasks like that we're actually losing 25% of our effectiveness, which is what I remind myself when I'm tempted to like look at my email as I'm talking to my daughter. So that's my first suggestion, is to just think of how can you be fully present in the moment you're in. So if you have to work, can you like put away other distractions and work? If you're with your kids or a partner or a loved one, can you just be there? That actually helps reduce stress quite a bit.

Nataly:

The other thing I want to highlight is it's incredibly important to take short breaks throughout the day. Even a 10 minute break, so it can be something incredibly simple, just like having your favorite cup of tea or coffee and just not looking at your phone, not multitasking, or reading a few pages out of a book, like I mentioned I'm trying to do that in the morning.

Nataly:

Going out for a 10 minute walk. A 10 minute break during the day really helps the brain get into more of that equanimity balance space. There's a lot of research that shows if you can get a five to 10 minute break outside during the day it boosts your mood right away. It helps reduce stress. And it doesn't have to be sunny. People think it has to be sunny.

Nataly:

I love, Laurie, listening to you talking about forest dating. It's a growing field, but you don't have to be in a forest, just fresh air for five to 10 minutes. So consider scheduling what I call a 10 minute self-reset on your calendar. Mine is... Just so you know, it's at 4:00 p.m. every day, because my energy wanes in the afternoon. It's common for many of us.

Nataly:

But find a time in your day and just yourself a reminder to do self-care reset. And, again, it can be something as simple as a 10 minute break, but when you take that break you help your brain essentially catch up to where you are, to process a little bit, to catch up to your own thoughts. It can be... It seems like not a big deal and so many people I've shared this with are like a 10 minute break? How could it make a big difference? It really makes a really meaningful difference.

Laurie:

I love how you talk about this literal break in the middle of the day or whenever we need it, but you also talked about in essence a bigger break during this time, that we don't have to expect that because it seems like maybe we have more unplanned time we have to clean out our entire basement or whatever. We can really give ourselves a break. Can you talk more about that?

Nataly:

Yes. That's really the practice of self-compassion, right? What is self-compassion? Self-compassion is treating ourselves as we would a friend. I've used this example before. If in the middle of this worldwide pandemic a friend says to you, "Oh, my God, I can't believe I haven't yet cleaned out all our closets," or, "We're in a worldwide pandemic, but I cannot believe I've not started learning a new language, like what's wrong with me," what would you say to that friend?

Nataly:

I don't think any of us would say, "Oh, my God, you're such a slacker. How dare you." We would say something really kind. We would say like, "Well of course you haven't cleaned out your closets. It's a worldwide pandemic. You're juggling so much, you have kids at home," whatever that is.

Nataly:

So I really encourage you to treat yourself with the same compassion and give yourself a break in expectations. Our expectations of what we should be doing, what we should be accomplishing, what we should be getting done need an adjustment right now. We need to, again, recognize all the things we talked about, right? How much stress we're all experiencing right now.

Nataly:

Stress takes energy. Stress takes the energy of your brain, and so we literally have less cognitive capacity right now for new things.



Nataly:

We literally have less cognitive capacity right now for new things. And so, it's just consistent practice of being compassionate towards ourselves in our expectations and I'll share something that ... We do these webinars for our community and I shared this yesterday and it really resonated, so I want to share it here. You know how when you have Chinese fortune cookies and you take out the fortune and you read it, and it's a funny college thing, you add "in bed" at the end just to make it funny. So, when your mind goes to, "Oh my God, I didn't get this thing done." I want you to add, "Amidst a worldwide pandemic." Okay? Like, "Oh, I should really be learning a new language amidst a worldwide pandemic." Or "How come I didn't clean out my closet amidst a worldwide pandemic," it's really been working for me when I get into that over achiever, like, "Oh, all these things I'm not getting done." It really helps me just laugh at myself a little bit and say, "This isn't normal."

Nataly:

And so, I just encourage you to treat yourself as you would a friend and when you find yourself in the "should" space, "I should be doing this, I should be doing this," maybe you can pause and very simply just consider, especially if you're being harsh in that tone of voice towards yourself, can you pause and can you imagine that you're talking to a friend that you love or a loved one or someone you really care about? What would you say to them? And I think in that moment, I hope for you, there's that awareness of just being kind towards your own expectations right now.

Rachel:

Laurie, I don't want to [inaudible 00:49:36] care partners out of this, so is there anything you can add in acknowledging how tough this can be with self-care during this time when care partners might be taxed a little bit more as far as more self-compassion can be added to the mix right now or more mindfulness. What would you say to care partners right now? Laurie?

Laurie:

I don't know who that question was directed to, but I'll say my mantra is, "B-plus is good enough." I don't think any of us need to strive to get an A in our life situation. I think good enough, especially right now, is plenty. And I'll second the compassion thing, I'll second the gratitude thing. I think that it really, for me, comes down to mindset and a perspective shift. We can't change what's happening to us, but we can change how we respond to it.

Laurie:

A couple of years ago I said to somebody that I felt like I was swimming, I was in the ocean and these huge waves just kept coming and pummeling me over and over. And I remember my friend saying, "Sounds like it's time to find a surf board and learn to surf," Right? And that was such a good analogy for me to realize the waves are going to keep coming, the stress of this life, this situation, is still here, but we can change how we handle what's coming at us.

Rachel:

It's all about perspective, isn't it? I want to take us through our last slide and then to some more questions. So, just want to make everyone aware about ways that you can stay connected to our community through all this. So, certainly through these types of educational opportunities, we'll have more coming your way. One on telemedicine, which we talked about in the near future, but also more Facebook Live watch parties, ways for you to tell us that you're staying active, how you're staying active.

And as Dan mentioned, you can also participate in online research from your home. So, Fox Insight is our online observational study where we're learning more about the lived experience of Parkinson's and there will be more studies coming your way there soon.

Rachel:

So, to get to more questions, which have been coming through throughout the hour, Laurie, I'll go back to you. We're getting some questions specifically around symptoms. We talked a little bit at the beginning of the hour about stress. So, tell us a little bit more about how symptoms can worsen with stress. And is that permanent? Is it temporary? Does it indicate that the disease is worsening? How do you manage it?

Laurie:

Yeah. So, without getting into med management stuff, I will say the tremor is almost helpful for some people because you have this external barometer that tells you when you're getting stressed and not. Some people will identify their stress going up because their tremor is telling them so. And so, I think for people who don't have a tremor, it's actually a little harder to be self aware of when your body is responding to stress. I think that the easiest way to identify if any one of us is under stress is you can just sit quietly and put one hand on your upper chest and one hand down by your belly. And if your rest and digest part of your nervous system is dominant, your belly will expand with each breath. If you're in a higher stress state, what will happen is that top part of your chest will go up and down.

Laurie:

And so, you can see if it's your top or your bottom hand that's moving and that will tell you where your nervous system is at. The patient certainly experiences worse motor symptoms, worse tremor and it's very temporary. It is very temporary. I have a lot of patients who say, "I take one pill four times a day, that's great. That works for me except if I'm traveling. When I'm at an airport going through security, I need an extra half tab because the stress of getting my shoes off, getting my stuff on the bed" and it's not just motor, it's all the background noise, the stimulation. Other people take an extra half tab before they go play pickleball with a friend and so it doesn't matter if it's good stress, bad stress, I think many people with Parkinson's have come to understand that when there's a lot of commotion or demands being placed on them, their need for dopamine is greater.

Laurie:

The analogy I'll use is it's like driving a car at a hundred miles an hour. You get worse gas mileage than if you're going 25 miles an hour and then country road. And so, this stressful thing that we're all experiencing right now is high performance. You are asking more of your body and your nervous system. It is only natural that you're going to burn through your dopamine faster. So no, it's not progression. It's just you're asking more of your body and it's not unreasonable to talk to your doc first, but say, "Can I up my meds a little bit in the afternoon? I'm finding my symptoms are worse when X, Y and Z happens." For a lot of people that's very, very helpful and as soon as they get a grip on the situation or the stressor passes, they go back to their old dose. This is not progression. It's temporary.

Rachel:

That's really, really helpful clarification. Thank you so much. Dan, a question for you. A lot of people are experiencing being more tired than usual, sleeping more, sleeping less. Is there anything that you do to help your sleep?

Dan:

Yeah. I think the biggest thing that I should do, that I'm not all as good as I could be about it, is putting the devices away, putting them in a different room and not having the temptation to wake up and I immediately check my email or check the news or do all the things that I've spent the last half an hour telling myself I shouldn't be doing. So, yeah and it's really more of a challenge than it should be. Actually, we had to create a separate drawer in our kitchen where our whole family will literally put their devices in the drawer at night and close the drawer and do that. Sometimes I think we should have a lock on it because it's really tempting. It's like a drug. We're all addicted to it and it takes more energy than I would like to do that.

Dan:

The other thing is trying to maintain a regular schedule. We have two teenaged boys and my wife is home and the tendency is to sleep. We stay up as late as we want and sleep in and schedules are off, nobody's getting ready for work in the morning because we're all working from home or schooling from home. But we're trying more than we have been in the last couple of weeks to just get up when we usually get up and set a time when we get up and when we eat dinner and have lunch and maintain a regular schedule because when we're not on a regular schedule, particularly with Parkinson's and all the medication adjustments and timing issues that are involved in that, things just are harder and so maintaining that schedule has been really helpful as well.

Rachel:

Absolutely.

Laurie:

One thing I'll add about sleep is I think there is a tendency in our culture to grab a bottle of wine or a glass of wine when you start to feel stressed and I don't know that people realize that alcohol will help you fall asleep faster, but it absolutely prevents you from getting into the deeper stages of sleep. And even a glass can really impact one's sleep. You're more likely to wake up in the night, you're less likely to wake rested, you're more likely to have temperature dysregulation through the course of the night. And so, being aware of some of your tools and habits that you think might be serving you, but could actually be hurting in the long run is just something to be aware of.

Speaker 1:

Good point. Nataly.

Dan:

I think that-

Rachel:

We're running out of time, so I want to get to Nataly with one more question. So Nataly, if you're having trouble practicing mindfulness, what else can you try? This person says failing at it is its own kind of stress.

Nataly:

Oh, I hear you. I hear you. Here's the thing. One of the best ways to practice mindfulness is to do something you really enjoy because that's when we actually get to a place because really, again, mindfulness is just being where we are. And so I would ask you to think about what is something you really enjoy doing. A lot of people really love gardening or cooking or writing or painting or whatever that is. Doing something like that is being mindful. And so, for some of us doing something instead of trying to sit and be present or even notice things might actually be more doable.

Nataly:

So, I encourage you to think of something that you really enjoy doing and it doesn't matter what it is. And again, hopefully it's safe to do right now, but when you are doing something and you're just getting lost in it and we all know that feeling. I have a friend who absolutely loves to sing and when she sings, I think something could fall from the ceiling, she wouldn't notice because she's so in it. That's actually, you've probably heard of the state of flow, right? We're in that state of flow when time moves away, we're not really concerned with our thoughts.

Nataly:

So, think of something you really enjoy doing and practice mindfulness by doing it. Something that I do is I love to paint. It's something that I do purely for joy. I've never taken a class. It's not something I do professionally and so when I paint that is one way that I practice mindfulness. It's very active. I'm doing a lot, but in that moment I'm not thinking about my to-do list or something I should have done. I'm just painting. And so, that's actually, I'm really glad for the question because I'm grateful for the opportunity to share that doing something where you are in that moment and really enjoying it is another way to practice mindfulness.

Rachel:

That's so great. I'd love if each of our panelists could leave our audience with one last statement or tip or piece of advice that you think would be helpful. So Dan, I'll start with you.

Dan:

I was just thinking about the previous slide. It said, "Find your imperfect balance," which is, I thought would be great for Parkinson's patients. Many of our balances is not perfect and physically, but I think being okay with everything being a little out of whack emotional and just in the world is okay too. And not to let that get to you, but to try and find that balance and do the best you can with it and with the understanding that the equilibrium will change and that will be okay too.

Rachel:

That's great. And Laurie?

Laurie:

There is a Sanskrit quote that says the best place to meditate is in the mouth of a lion. And I like that. I think it's so easy to come up with all of these excuses why. Well, this is too restless. There's too much going on, I'm too busy. And we have all these external excuses for why we can't tune in and quiet ourselves. And that's exactly when you need to the most. And so, I'll end by the quote, "The best place to meditate is in the mouth of a lion."

Rachel:

Thank you so much. And Nataly?

Nataly:

And I would just remind you of something that my spiritual teacher shared with me when I was in a really difficult, dark place and that is that you are a being and not a doing and there is enough challenges right now without us putting pressure on ourselves to get more done, get this done. And so, if you get caught in that overwhelm cycle, just remind yourself that you are a being and not a doing and that also relates to helping others or connecting with others. Your presence and your care is the biggest gift. And so, that's what I would love to leave you with is just the reminder that you are a being and not a doing.

Rachel:

Thank you all so much for sharing your time and your expertise with us and thank you for being part of our community and for joining us today. We'll be sending a link to the webinar on demand to listen again or to share as you'd like and we really hope you found it helpful. Please mark your calendar for our next webinar, which is on May 21st, where we'll be talking about practical tips and personal viewpoints on being newly diagnosed with Parkinson's. Stay home, stay safe, and stay connected.