



Kessler Foundation Podcast Transcript: Coping with MS during the COVID-19 Pandemic

Recorded April 2020 [Listen to it here.](#)

MICHAELE CLAYBORNE-CROSBY: 00:04

[music] You learn how to adapt and live with a small hint of social isolation. So all of this that's going on is nothing that's odd for us. Because this is kind of like it was already our lifestyle.

WEBER: 00:19

Welcome to another edition of Kessler Foundation series on important topics in the era of COVID-19. I'm Dr. Erica Weber. The Coronavirus pandemic is most certainly affecting those in the disability community. While many of our previous podcasts in this series have been with scientists and experts in the field, today we wanted to host a conversation with individuals who are experts of their own experience. I'm joined today by two of our Kessler Foundation employees, both of whom are diagnosed with multiple sclerosis, so that they can share their experiences regarding the last few weeks amidst the pandemic. Carla Basante works to connect individuals in the community with research opportunities as our research recruitment assistant. And Michaela Clayborne-Crosby works with our development department to organize events that bring awareness to our efforts, potential donors, as our development assistant. Welcome to you both, and thanks so much for agreeing to share your personal experiences with us today.

CARLA BASANTE: 01:17

Thanks, Erica. Good morning.

CLAYBORNE-CROSBY: 01:18

Good morning. Thank you.

WEBER: 01:20

Thanks, ladies. It's good to hear your voices even though we're not in the office. I want to get a sense of how has this been going for you? I'm sure life is looking a little bit different. And with your disabilities, having MS at the same time as dealing with the Coronavirus, it's got to be an extra challenge. So can you give us a bit of a insight into what your day-to-day has been looking like?

CLAYBORNE-CROSBY: 01:46

For me, it'd actually be working from home hasn't been that great of a challenge. It actually is something-- the social isolation has been something that I've been used to since the diagnosis back in 2000. Since that diagnosis, I've had to learn to deal with not always being able to attend different events with family and friends because of different health issues or unexpected health issues. So this feeling of being able to work from home has actually been a blessing for me in disguise.

WEBER: 02:30

Interesting. Because I know it's been, if anything, just a really big change. But it sounds like you're noticing a couple more silver linings at least with regard to your work life.

CLAYBORNE-CROSBY: 02:41

Absolutely. Definitely. Absolutely. Simple things like getting up in the morning to get dressed to go to work. Usually, at times when I was working in the office, which the company I love, getting up to get dressed, take a shower, by the time I would get up, get dressed, after taking a shower, I would be completely exhausted and be ready to get back into bed to go back to sleep.

WEBER: 03:05

Oh, goodness.



Kessler Foundation Podcast Transcript: Coping with MS during the COVID-19 Pandemic

- CLAYBORNE-CROSBY: 03:06 Yes. Fatigue is a big thing for individuals who are living with the diagnosis of multiple sclerosis. And fatigue is something that's often hard to explain to individuals. It just really does weigh you down. It make you feel like you've run a zillion miles just from going to get in the shower and getting out. So when you're living with fatigue, sometimes it takes everything you have and even stuff you don't really have to make it from your bed to your car and then driving to your office, and then working in your office all day. So being able to be here in my house working, whether it be on my couch, working while I stay in the bed with a laptop, that has been a phenomenal, phenomenal blessing for me personally.
- WEBER: 03:56 Well, so being able to at least maybe alter your schedule so that it fits how your symptoms happen to be flaring up that day. If I understand correctly, fatigue isn't really something that you can predict in MS. It kind of seems to come out of nowhere sometimes.
- BASANTE: 04:14 Yes. It comes out of nowhere on a daily basis. Especially at this time with us being overly thinking about our health, with having multiple sclerosis, with having an autoimmune disease, with everything that's going on, and with all the restrictions that are global, national, locally. We're extra hypervigilant in regards to trying to take care of ourselves. And that brings stressors in on itself. But being able to work from home, it kind of helps to regulate that environment as well, because we're able to be productive. And again, like Michelle said, our wonderful organization that has helped to adapt to people working from home at this time has been such a rewarding experience. Like Michelle said, I feel the exact same way. We don't know how we're going to feel-- we don't know how we're going to feel every second of every day and fatigue can hit at any time. And we can say it's the weather, we could say it's this, but having, again, a compromised immune system, we're subjected to so many variables. But working from home with an organization that supports you and is staying up to date in regards to different ways to be productive-- like with Kessler, we are now doing telestudies from home. So I am recruiting people to participate in telestudies. So for me, that just adds another highlight to working from home that I'm able to be productive on that level and have more people participate in studies that I know will benefit them.
- WEBER: 06:14 Right. It almost sounds like you've been able to add a new layer of what your job entails by recruiting for these telestudies. So I imagine that's got to feel good that you're being extra productive at this point.
- BASANTE: 06:28 It feels wonderful. And when I do speak to the people who want to participate, for them, they feel like they're able to be productive in their own life because it's very confusing right now for so many people. And now, they can participate in something that's going to help the disability community now and in the future. So to me, that's just a wonderful opportunity now with my position with working from home during this time.
- WEBER: 06:57 That's absolutely great. I think you're right that people kind of don't know what to do at this point, and they're probably very used to being socially engaged or being able to give back and have their usual routine. So perhaps participating in a telestudy allows people who may be struggling a little bit with their own day-to-day to have more meaning. So that's not only a great way that you've been able to remain



Kessler Foundation Podcast Transcript: Coping with MS during the COVID-19 Pandemic

productive in your job, but also a nice way that the general community who wants to give back in terms of research has been able to get by. And so, you've mentioned you don't really know how you're going to feel all day long. So have you found that you've been able to be more flexible with your work schedule now that you're at home?

CLAYBORNE-CROSBY:
07:47

Definitely something that has been a wonderful benefit because I've learned what I can and can't do since I've been here at home. What I am able to do. Sometimes I need to take that break. Sometimes if I'm having migraine pain, I may need to sleep a little bit longer. Sometimes I need to just rest. Sometimes, our bodies tell us, "You know what? You need to slow down. You need to rest." And I'm able to do just that and then get back up at 2 o'clock and do the work that I wasn't able to do in the morning. Or vice versa. If I'm able to sleep all during the day and be up all night, I can do all the work overnight. Our bodies really do dictate to us what our day is going to be like. And unfortunately, it's not always the nine to five.

WEBER: 08:42

Absolutely. And so you've mentioned that it's been so helpful that Kessler Foundation has been supportive of this. What have you found that companies, besides Kessler Foundation, can do to make sure that this is a viable option for their employees with disabilities?

CLAYBORNE-CROSBY:
09:03

For me, I was always working in the office on a full-time schedule. Having the ability to work from home full-time and go back to the office and get things as I need them has been a blessing. It's like a God-sent for me. Because I don't have to worry about-- because I have an at-risk immune system, going to the office knowing that I don't have to worry about running into anybody else there, getting the things that I need and not having to deal with any stress, just getting what I need and then turning around and coming back here, home, and finishing my work here, that has truly answered so many of my prayers. In addition to still having that connection with my colleagues, I have-- being able, yeah, being to email and if need be, to text-message. We're still very connected. Very connected.

WEBER: 10:06

Yes. And that communication is really, really important at this point, right?

BASANTE: 10:11

It's so wonderful. On Friday, actually we're going to be having a group meeting with our staff. I check in once a week with everyone to let them know exactly what's going on so that communication that the organization, that the Kessler Foundation, is providing, the supporting information that the foundation is giving all of us at this time is wonderful. And they're keeping us updated as to what is transpiring. I think that is very important because, again, it's a very confusing time right now with everyone in the world. But the fact that our organization is letting us know what is happening internally with the foundation I think is wonderful.

WEBER: 10:54

So from what you ladies are saying, it's been really important to be able to stay connected with your organization? I know at least on the research side, we've been staying in touch with our research assistants. I just had a FaceTime with a couple of them before and we've been doing Zoom and phone calls and lots of emails. We have a messaging system that we can sometimes use. So it's really been important. So this way, everyone knows what's going on but then, still feels connected from the perspective of projects, but also just from your colleagues, and having that social support in the workplace that we're so accustomed to. But this really brings up that



Kessler Foundation Podcast Transcript: Coping with MS during the COVID-19 Pandemic

idea of social isolation that when you're quarantined, you're not in the same social circle that you used to be in. And we know that social support when you have MS is really critical in order to being able to ward off things like difficulties with mood or anxiety, and also just being able to get your needs met. So how have you guys been able to manage that social isolation piece and trying to stay connected?

BASANTE: 12:08

I've been in touch with so many people in different areas like my church. My church has a wonderful support chain in regards to anything that's needed at this time with family members. My friends that live here locally. The moms. So we do a video chat in the morning and we send each other jokes and we talk about how bad each other looks. Yeah. The gray hair and all that [laughter]. But who cares? I own it. I'll own it. And then family. Family members that you're able to communicate with either through same FaceTime or other things. That's one way to become social. The thing is, you still have that social isolation. For me in particular, because I am not leaving, as my son says, the perimeter. Because no matter what, my personal body chemistry is susceptible to so many things that for me to take a risk to even go to the store, or anywhere, it's not worth it. I can't take that risk. So I am isolated on my own property. But to do things other than speaking with my friends and family and all that, which I started to tell you guys, I now am starting a 1000-piece puzzle. And I am reading books. And I'm still exercising although I'm adapting. I am trying to fan my vocabulary. Now, as far as learning the language, I'm trying to learn the English language. So I am doing things like that.

BASANTE: 13:52

But it takes-- the social isolation is a different feeling. It's one that you kind of-- you acknowledge it, but you don't engage with it. And that's how I look at it. I know it's there but I am not going to engage with it. Because there's way too many things that I can do while I'm alone. I may not be creative, I may not write a song, I may not do that, but I am determined to finish this 1000-piece puzzle.

WEBER: 14:21

Sounds like you are well on your way.

BASANTE: 14:23

Yeah.

WEBER: 14:25

You've been able to really stay engaged and keep yourself busy, whether that's with new avenues for social outlets. Because I don't know about you guys, but I know that we've had FaceTime and Zoom and all of these platforms before, but I never really thought to use them because my social needs were generally getting met elsewhere. So now, there's all these new avenues that people can use and I wonder how much of that may still continue even after things return a little bit back to normal.

CLAYBORNE-CROSBY:
15:00

I will tell you, the family, my in-laws and my personal family, we've been utilizing the Zoom a lot for family meetings once a week. And my husband and I have decided that after this is done, if we're not going to have the family meetings on Zoom, then we're going to definitely have Sunday dinners and kind of take it back to what's really important. And making sure that we spend time with one another. Because it has definitely brought the family and true friendship closer together. Because I do find myself checking on people. "How are you? Is everything okay? What's going on? How's your mom? How's your dad?" Reaching out, and not just telephone-call reaching out, but seeing people's face.



Kessler Foundation Podcast Transcript: Coping with MS during the COVID-19 Pandemic

- BASANTE: 15:51 Yeah. You could also look at Facebook and other forums that people are communicating on with the social interaction. More people are interacting than ever. I know Mark Zuckerberg is very happy. But it's also that social interaction layer, then you can message, you can also do that [FaceTime?] as well. So there's so many different avenues that people are now learning about and hoping that this is going to continue. Just like the doctor's appointments, telehealth programs that they have now too. There's different support groups out there as well that people can participate in.
- WEBER: 16:35 And I'm glad you brought that up, Carla. I was wondering, how is it then for you just managing your MS symptoms since all these began? How have medical appointments been, and getting medications? All that.
- BASANTE: 16:49 I had an appointment with my neurologist yesterday. And it was wonderful. And I was able to accomplish what was needed with my prescription that I do have to take at this time. And it was fine. And I hope this continues in the future. I really, really do. I understand that there are going to be appointments. We have to have blood work up done. He's going to have to see you physically to see what your [inaudible] looks like, and different things. But for somebody who needs just an appointment where they don't have to see the doctor, I think it's a wonderful thing. So right now, for me personally, it's good, but I can't do a tele physical therapy. So for me, the fact that I can't go to physical therapy as needed, that's probably one of my things that has affected me the most. Nothing set up for physical therapy. But the other doctors' appointments are going well. I really have to admit that I'm very thankful for them.
- CLAYBORNE-CROSBY:
17:56 That's good to hear Carla, because for me, I am-- actually on Monday, I have a schedule for a pain institute doctor's appointment. And they had to cancel it. Because of all of the stuff going on with COVID-19, they're having some difficulty getting in touch with the medical insurance department to pre-approve me going to get the pain shots that I needed. So, unfortunately, there is good sides to it-- because I did with my neurologist, I did have a telehealth appointment with my neurologist and that was fabulous. I am going to get my infusion next Friday. That's wonderful. But on the downside, another office that handles my pain issues couldn't get in touch with my insurance to get me approved to get the trigger point injections that I need to help me with my pain spot. So there is-- it's almost like a balance is kind of needed, so to speak.
- WEBER: 19:04 Right. And you can only imagine right now that insurance companies are just as swamped. So it's understandable, but you still need to get your medical and pain needs [inaudible] that.
- CLAYBORNE-CROSBY:
19:18 Definitely. But, hey, you look at it and for me personally, when you're living with the diagnosis of multiple sclerosis, you kind of-- and it's not really a good thing, but you kind of learn to live with the pain. And you deal with it.
- BASANTE: 19:33 Yeah. There's no doubt-- there's never a day where you're not in pain or weird discomfort, so to say. But having it for over 20-something years, I often say that it's like a sister. Some days she wants to do stuff, other days she's like, "No. I just want to stay on the couch. I don't feel good." And then there's other days where you're like, "Come on. we can do this. We could do this together." I don't hate my MS because it's

Kessler Foundation Podcast Transcript: Coping with MS during the COVID-19 Pandemic

part of who I am. So I have to work with it at all times. But sometimes, it's very difficult to work with it. So that's why I said it's like having a sister at times. Because you want to work together with it. But it has its limits of what you're able to do at the time of a flare or a relapse. So, again, it just-- you have to work with it on a daily basis even though you have no idea what's going to happen.

WEBER: 20:39

Carla, I love that analogy. It's just so well put. And it really hones in on that identity piece and also the struggle, but I think it probably gets you to a better place of acceptance where you're seeing this as something you need to join with in order to move forward rather than rail against, because it's going to be with you regardless.

BASANTE: 21:06

Yeah. I can't hate it because it's part of who I am. So that's what has gotten me through understanding and accepting my diagnosis of multiple sclerosis.

CLAYBORNE-CROSBY:
21:23

Getting to that point, definitely meditation and mindfulness helps you get to that point. Because it's not always easy. Don't get me wrong. It takes years. I too have had this diagnosis for 20-plus years. And it isn't easy in the beginning, but everything that everyone is going through now with this [inaudible] place and everything, it kind of becomes natural for us. Because when you're diagnosed and when you're no longer able to do the physical things that you used to be able to do before you lost eyesight or before you had a problem with walking, or before you had a [inaudible] ailment that was brought upon you because of the diagnosis of multiple sclerosis, you learned how to live with a small hint of social isolation. So all of this that's going on is nothing that's odd for us. Because this is kind of like was already our lifestyle. We already kind of have become masters of how to live with this type of lifestyle. Because this is almost like our norm. So this is odd for everybody else, yes, but for us, this is our norm. This is our everyday living.

BASANTE: 22:48

Absolutely. I mean, I lost the ability to drive long distances. And I would drive all the way down to Cape May, LBI, upto Connecticut. I love to drive. I no longer drive long distances because I know what may happen with having MS, with having different issues that may happen between [inaudible] my legs, I opted not to drive long distances anymore. So like Michelle was just saying, it is part of our life. It's being isolated but not being able to drive because of an illness, that's a whole different ballpark. That's only tapping into meditating and mindfulness. I'm such a proponent on that. It's a mind and body. So if your body is fighting against itself, the mind can help regulate it. Although we know [inaudible] with MS, we don't know what they're going to hit or what nerves they're going to affect. But I'm inclined as far as mindfulness with calmness and just really being in the moment. I think that's a wonderful thing. And it's moments like that, being able to channel that strength that has gotten me through losing the ability to drive long distances. But it is such a form of isolation to a certain degree that I never expected. But it's my life, so I accept it.

WEBER: 24:26

So you've both spoken about the importance of mindfulness and meditation and finding ways that keep your life as low-stressed as possible, keeping your mood calm and stable. Are you finding that that has been able to get you through this challenge right now, the pandemic? And is this something that you would recommend to other people whether or not they have MS or a different disability?

BASANTE: 24:56

Absolutely.

Kessler Foundation Podcast Transcript: Coping with MS during the COVID-19 Pandemic

CLAYBORNE-CROSBY:
24:58

I'm trying to get my son who is in college and has to finish this semester at home. So he has such stress and frustration because now he's living at home with his mom. So it's a whole new world for him. And I keep saying, "Please, you need to meditate. You need--" I send him links. Sometimes I don't even say it. I just randomly will send him links. And the other day, he admitted he did it. And I am like, "It will help you to get to a better homeostasis." Oh, without a doubt. Without a doubt. When I was first diagnosed, the first thing that the neurologist said to me-- I was still working in corporate America. And the first thing he said was, "Michelle, I know that you're making a lot of money and I know money is great. However, stress is a silent killer. You need to get out of corporate America." And I was like, "Oh. Oh." Because I was young. I was in my 20s. And I was 25 when I was diagnosed. And I was in corporate America doing my thing, thought that I was living the good life, making tons of money. However, he was right. Stress, truly, is a silent killer. I got all super involved with yoga, the shock recleansing, the meditation. Oh, my goodness. Yes. Because people don't even realize that stress is-- oh, my goodness. It can totally change your world and not for the good. If you can manage the stress that is trying to come and take over your life-- I watch the TV, I watch the news. I call my grandmother, she tells me, "I had a headache, my blood pressure went up because I'm watching this stuff on the television." And I'm like, "Grandma, turn the television off." You know?

BASANTE: 26:54

Yeah. No need. I'm a big proponent on turning the TV off these days. There is no need at this point for certain news stories [inaudible]. That does affect you. But the thing is, the body can't differentiate between good stress and bad stress. The stress that we're feeling right now from confusion, it-- I don't know how to explain it. It's a certain numbness that it brings you. I always have MS symptoms. I always feel pins and needles from my fingertips to my toes. Electric shock going down my back. All of that. But when I mean a numbness, because your body doesn't-- it's like in a constant fight or flight reaction. Because your mind is so confused as to how to process everything. So that's why the mindfulness and the meditation is so key. Because then you can relax your thoughts and that will carry on a reverb into your body. And that's why it's so important. And not just with people who have autoimmune diseases. I think it would benefit everyone, everyone in this world. That's why when I saw how badly my son was stressing out-- plus, he's helping me at home now. He's my caretaker right now. So that's another stress that he was not expecting. So for him to start to adapt the mindfulness, I could see him relaxing better. And I think more people should address that. Because it's not hippy-ish. It's a wonderful health benefit. And that's what they need to say. It's a health benefit.

WEBER: 28:34

It sounds like these things that you've each described that have helped you cope with your MS for all these years are great ways to cope with stress during this pandemic for people with disabilities or just the general population. Because we're all kind of thrown into this world that we don't recognize and our usual coping strategies and supports may really not be as accessible. But something as-- I don't want to say that it's simple and that it's easy, but it's-- you don't need very many resources or space to be able to practice things like mindfulness and meditation. And even just maintaining your mood and your diet, and trying to exercise in any way that you can given our limitations, these sorts of strategies that you've been able to use and perfect over the years are, I'm sure, coming in really handy for you both right now. That they're not



Kessler Foundation Podcast Transcript: Coping with MS during the COVID-19 Pandemic

necessarily new practices that you have to learn amidst all this stress. They're things that you're already very used to doing, and it will serve you really well.

BASANTE: 29:50

Yes. Yes.

WEBER: 29:52

So you've both described a lot of great healthcare strategies that have been very effective for you. What other sorts of resources have you found helpful for living with your MS generally, and things that community can reach out and look for right now when they're most in need.

CLAYBORNE-CROSBY:
30:12

I know that within National Multiple Sclerosis Society, they have the MS navigator that can help you see different things in your area in regards to different groups. I also know that some self-help groups on their own are still continuing to communicate with each other. So if someone has information or any--- I mean, not information, any questions, I think the National MS Society's navigator is a beneficial tool. Most definitely.

WEBER: 30:44

That's a great suggestion and we'll make sure that that gets included in our program notes so you can easily access that. And I believe also probably there are a number of social media, Facebook groups that would be great places to get information and also share what works for you. Because if-- let's say there's been a struggle that you've been experiencing that you were able to find a viable solution to, it'd be great to pass the information on to others who might benefit from it as well.

BASANTE: 31:16

Oh, absolutely. And the MS groups that are on Facebook, I belong to several of them. That's another way to be able to engage in communication with other people while you're in isolation. Because the main thing is, you never want anyone to feel alone. So in regards to reaching out to family and friends or church or groups or social media, know that there always are people there and resources available. But definitely, I think that's a wonderful-- via social media as well.

CLAYBORNE-CROSBY:
31:54

I'm just [inaudible]. I'm thinking about how even though physically you may not be together, next to one another, but even if we are physically near someone and we're wearing a mask, we're still [inaudible]. At this point, I want to remind people that we are all still in this together. We are all still dealing with this. Whether we're diagnosed with lupus or multiple sclerosis or living with autism. No matter what it is. If we're perfectly healthy, if we have sinus issues, whatever the case may be, right now, the whole world is dealing with this COVID-19 issues. So we all have something in common. And knowing that we're together and we are all one and dealing with the same issue can make sure that people know that they're not alone. We are all trying to weather the storm together and if there's anybody who ever, ever feels like they're alone, there are so many telephone numbers out there for depression. Because depression is definitely something that easily slip into in times like these. And I definitely want to make sure that everybody knows that you're not alone. We're dealing with the same thing as everybody else is. And please know that it's just going to get better from here.

WEBER: 33:36

That's a great way to end our time with you ladies. Thank you so much for sharing your experience and your wisdom and staying strong during this time. You give a great face to those living with MS. So we really appreciate your willingness to open up to us and our listeners today. [music] Thank you so much.



Kessler Foundation Podcast Transcript: Coping with MS during the COVID-19 Pandemic

BASANTE: 33:57

Thank you.

CLAYBORNE-CROSBY:
33:59

Thanks, Erica.

ANNOUNCER: 34:01

Tuned into our podcast lately? Join our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. In new episodes, our experts weigh in on the impact of COVID-19 on people living with disabilities. And they talk about how research that changes lives continues at Kessler Foundation. Check back soon to listen to more COVID-19 podcasts on our playlist. The link is in the program [inaudible]. Listen on iTunes, SoundCloud, Spotify or wherever you get your podcasts. This podcast was recorded on Wednesday, April 29th, 2020 remotely, and was edited and produced by Joan Banks-Smith, creative producer for Kessler Foundation.