



Can Do MS Podcast

Coping With COVID-19 Isolation and Unpredictability

Episode 36

Narrator: Hello and Welcome to the UMS Podcast. Today's podcast is Episode 36. We are going to talk about coping with COVID-19 isolation and unpredictability. I would like to welcome our guest today. I am excited to have you both on the podcast. Thank you for joining us. Leading today's conversation. We have psychologists, Ross, Kyle, you guys have heard from before she's been working with UCLA for a number of years as a Senior Programs Consultant. So, Ross. Feel free to take it away.

Roz Kalb, PhD - Psychologist: Hello, everybody. I want to welcome my guests and thank them very much for having this important conversation with me. She is chosen not to share her name because of concerns about disclosing her MS during her ongoing job search, which is very wise first. She and I are going to talk a little anonymously. Could you give us a little background about yourself? How long you had an MS and Where you live and Where you are in your life?

Female Guest: Sure. So, I got diagnosed with MS, 9 years ago now, and I was diagnosed because my symptoms had been relatively persistent, and then became exacerbated with a lot of stress. And so, that is how I ended up going to the emergency room and getting my diagnosis. I live in Colorado, and in the mountains and I'm really active and have a very active lifestyle, and that's always been part of big part of my life and MS has definitely affected that. But I try and think and hope that it will not affect it greatly and do as much as I can, which is how I became involved in can do, Anna.

Roz: Wonderful. Tell us a little bit about your family.

Female Guest: I am married and I recently had a baby and that was interesting being pregnant with MS, and then delivering with them MS, and then the pandemic. So, just a lot of change and a lot of different things and variables over the past year.

Roz: The past year has been very, very stressful for almost and I am hoping that you will describe for everyone, What it is been like giving your circumstances as a mom and as a person living with MS. Who is used to having a very active busy life span?

Female Guest: Yes, I think for me, what has helped my MS most is to maintain a certain activity level, a certain diet, and lifestyle. And when the pandemic hit and then when I was pregnant, a lot of that changed and altered and shifted. And so, it was really challenging for me to Pivot my mindset and to be positive, and maintain my positivity and optimism. I am also just trying to figure out different avenues and order to be active as much as I could with everything with all the other constraints that were happening.

Roz: Friends of your personal safety during COVID and the safety of your family. How did that play out for you and your husband and your baby?

Female Guest: Yes. I found out that I was pregnant about 2 weeks before we all got put into the 2-week. What we thought was going to be the 2-week isolation and I remember being really scared because of the unknown. I think that the unknown is done, is, and has been the scariest part about MS. Really. Some being diagnosed and kind of on an ongoing daily basis. You just never know.

What your next day is going to look like. What your next even minutes are going to look like. Every day is different. How your symptoms are going to affect you and then all of the other confounding variables. And so I think when the pandemic first hit and when we started to get more information about it, I was really scared that because I had this diagnosis, not that I have any corresponding impairments with my lungs or my heart anything. But just because I have a neurologic diagnosis. I really thought that I was going to be, that I could be more impacted because of COVID, and that made me really fearful.

It made my husband really fearful and then knowing that I was really vulnerable. Anyways, because I was pregnant, made us just, it was really scary. Scary few months there and so, we did everything that we could. We isolated really intensely. We ordered all of our groceries. Which we are lucky to be able to do. I know that is a resource that was not available to everybody and there were a lot of times that we would have to wait for longer periods in order to get groceries delivered. Which made our dietary changes. Just need to be different and going out to the store something I enjoyed. It was something that I got to get out of the house, it was something I got to do for myself. I got to look at recipes and so it just made it really different and It was hard, it was really hard.

Roz: How long was it before you got the very reassuring information that you are not more at risk because of having MS.

Female Guest: Yes, I think I talked to my Health Care Professionals about... Gosh. I think it was a few months into it. I think it was like, 3 or 4 months into it when I would talk to them and they said, "You know, there really is not evidence that this will affect you any more than it will affect anybody else. What that effect could be, there is still a lot to understand, and Obviously, So be safe, just like we are asking the rest of the community to do but your Ms does not necessarily put you at a higher risk."

Roz: So, that we are moving into somewhat different things with Coleman, and more and more people are vaccinated. How is your sense of risk in your husband sense of risk shifting, is your behavior changing now as a result?

Female Guest: Yes, I think, at first, we had... We called them our quarant-team and there were 4 people that were just kind of our quarant-team. And we saw them just to maintain some pro-social integrity in our lives and we tried to go on walks and things like that around the neighborhood. As think, that our social network has expanded a little bit.

As of now, we are vaccinated and our child has his immunizations and I was breastfeeding when I got my vaccinations and my hope is that I was able to pass some of those antibodies on to him. This was also really reassuring and scary, and I think that there were a lot of questions about Whether I should proceed or whether I should not breastfeed or whether I should get vaccinated, or whether I should not get back to needed.

Again another conversation for another day but it was it was really interesting to go through that. So yeah now that we are all vaccinated, I think we feel a lot more comfortable regaining and exiting our isolation in our life of quarantine and getting back out there. So we've been doing a lot more hikes, we've been getting out a lot more with our sandwiches has been really rewarding.

I think that's been one of the biggest challenges with covid, is that I am very fearful that our child has not been adequately socialized and he hasn't been able to be held by his grandparents, as much as we would have liked, or seen met all of the family that we would have met if it wasn't for covid. So I think that's definitely different and then in terms of other things in lifestyles like eating and dietary things. We now go out to a restaurant and eat, which is really nice.

We are able to kind of regain the same eating habits as we had pre-COVID. We are going grocery shopping and farmers' markets are starting to open up now. And So, it is just, it is nice to get back to normal. And I think that we feel healthier and safer because of all those things.

Roz: Okay. Well, Thank you very much. Is there anything I have not asked you that you feel is important for others to understand about living with COVID?

Female Guest: I think something that was for me and just because it was so isolating, and I think that a mess can be a really isolating disease. Anyways, just kind of the nature of the disease can be really isolating because No, 2 diagnoses are the same. No, two people are the same and even if somebody appears the same on paper, they are very much not the same in prison clinical presentation. And so I think when you have such an isolating diagnosis.

And then, on top of that are being it, learned living in a very isolated Universe. All of those stressors are just exacerbated and so something that was really important for me is to really lean on my community. I really leaned on the resources. I can do MS, has available online. I

reach out to people who I had met through the programs. That I probably would have not done before just because I have my own social network and I never saw that opportunity.

And it was kind of a blessing of COVID to be able to do that. And I feel really blessed and special to have that community to lean on. And then I think really taking some insight and looking within ourselves to say like where are my vulnerabilities? Where my biggest stressors and what actually really helps me. Things like journaling things like going on a walk and how beneficial that can actually be and weighing the pros and cons of that. Even though it can be really scary to go out in public because of what, you know, the unknown. Weighing the risks and benefits of those activities. And I think that is like the hardest part of all of this.

Narrato: And that is it for today's show. Thank you to both of our speakers. We really appreciate you joining us on the Podcast to share your experiences with us.

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