



Coronavirus, MS, and You

How One Couple Is Dealing With COVID-19

Episode 26

Rosalind Kalb, PhD (Roz): I am Roz Kalb. I am a clinical psychologist from Can Do Multiple Sclerosis. I am here today with my really good friends, Ann and Karen, who are going to talk with me today about what it is like to live during the COVID-19 crisis as a couple. I want to start by asking them to introduce themselves just so you know who is who here. So, Ann, can you start?

Ann: Yes, Ann Borsellino. I am the one living with MS. I have been living with it for about 23 years. I am a retired high school social studies teacher as well as the president for nine years of about 500 teachers.

Roz: Oh, wonderful. Karen?

Karen Peterson: I am Karen Peterson, Ann's partner for 31 years. I am presently a high school athletic director with no athletics to direct because of the COVID-19 crisis.

Ann: It does not mean she does not have anything to do though, she is very busy.

Roz: Okay. So, Ann, living outside New York City, you are very close to a COVID hotspot. One of many COVID hotspots now. But, I would like to ask each of you, what has been the most challenging aspect of this crisis for you? Again, we will start with you, Ann. What is the most difficult or challenging?

Ann: Well, I think the most difficult thing for me is that I have been in this house for three weeks. If anyone met me or knew me, I do not sit down for very long. I am on-the-go always. I miss playing golf with my newly-found golf friends who are also retired teachers and nurses. We formed this wonderful circle of friends. I was so looking forward to playing. I was even doing virtual golf in the winter. So, I was ready to go. And then all of a sudden, boom, you have to stay home. It is very stressful to have that happen. I am very disappointed. I read a lot of books now. I do a lot of virtual stuff. Because with iPhones, you can have FaceTime with people. And then, that has been a lot of fun.

Roz: So being inside, being confined, and restricted has been the hardest for you?

Ann: Oh, I hate it. I hate the fact I cannot go shopping. That was my life. I look at the circulars and to see where the deals are. I hit all the different stores for the right deal. Now, I cannot do that anymore. It drives me crazy. Because if you do things online with this Instacart and stuff, you cannot look for the deals. Now, you are paying through the nose. It is like a knife through my heart. What can I tell you?

Roz: Well, we do not want any knives through your heart, you know?

Ann: No, we do not. But, I am very disappointed. The way of life is very different right now.

Roz: Well, I am taking away from that, that you are not going out of the house or to the grocery store. So, I have a sense of Karen, what your answer is going to be, what is the most challenging for you living in a hotspot, and dealing with all of this?

Karen: One might say staying home with Ann. But, since we are stuck together in the house, I am not going to say that.

Ann: Let me tell you something, she is no gem either. So, whatever.

Karen: I think it is sort of has evolved over the last two to three weeks. When it first started, it seemed like something maybe we would get over and it would not last this long or whatever. But, I think reality has set in. It is difficult being home when you are supposed to be at work. And then, trying to figure out how to work from home and that is not typically what you do. That has been a challenge. Finding our space to do things on our own in the confines of the house is a challenge. I think trying to stay active and get some exercise in is a challenge. Anxiety and worrying about things are a challenge. We worry about Ann with MS. We worry about my sibling's compromised, health-wise, and just worried about our friends and our family.

Roz: As a couple, and I am going to start with Karen first on this one. But, how have you made decisions about how to protect yourself and each other during this?

Karen: Well, we were not sure how this virus might affect Ann, and if she was more at risk. So, we made a decision a few weeks ago that I would be the one that would go out. But, the more you read, the more you hear, and you are worried about bringing something home. We have pretty much decided to not go out, only shop when we have to. We are trying these new delivery services that are challenging for people like us and low technological abilities. Yes, that has been the challenge.

Ann: Well, every time she comes back from shopping, we make sure that she wipes everything that comes in out in the garage. She is wiping it all off. And then, I bring it inside after she wipes it. I do not want to get too graphic. But then, you come in and you head right up to the shower. Because the clothes go in the washing machine and she heads up to the shower.

Karen: I also made a decision not to go back to work. I had to go in the other day just to grab some things, wore gloves and masks. I was in and out very quickly. Then, a lot of disinfecting when I came home.

Ann: Yes, and then shower. The clothes in the washing machine. That is what you have to do now. You have to protect yourself.

Roz: So, it sounds like you have done a really good job of balancing, to the extent possible, your commitments at work, Karen. You are trying to keep everybody in the household safe and good. It does not sound as though you have had a lot of disagreements about what the priorities are. I can reassure you on one point, on our COVID tool chest which is posted on the Can Do website we have just posted another conversation like this with the nurse practitioner who talked about the fact that there is no evidence that a person living with MS is at greater risk for catching this. We are all kind of in this together. What we do not know yet is exactly what happens if a person with MS gets COVID. But, there is no evidence today that they get a worst-case or a milder case than anybody else. So, I think some of those worries that you have been juggling, you might be able to tone down a little bit, just know you're probably equally at risk.

Ann: I am out now. But, that is good to know. I am glad that you said that. Because that was one of our fears, my immune system. But, I will head out one of these days. I have enough food in this house right now to last at least a month.

Roz: I'm sure you do. So, like other couples, and you have alluded to this already with your usual humor, but I would like to talk about it just a little bit more. You are spending a lot more time together than you probably ever have before except on vacation. What is that like for each of you? Because we are also trying to help people figure out how to deal with the fact of so much togetherness in whatever size space people have. What has it felt like for you to be together so much? What have you done to keep your wonderful "senses" of humor as you try to navigate this?

Ann: I am going to go first. Because Karen, even though she is working from home, she goes beyond the call of duty. That also brings a lot of stress to her. So, what I tried to do is stay out of her way. Like not to bother her when the door in the office is closed. I leave it alone unless I hear like there is no sound. I had to ask her a question, say, "Hey, Karen, can I ask you a question?" I mean, just try to stay out of her way. Because it does get stressful and she gets a little wired up about it. Then, when we do have words or a little argument, the weather is not cooperating here in New York. But, she will go for a walk and she will say, "Do you want to come with me?" I am like, "No, I think that is something you should do by yourself." She does and she goes out for walks by herself or she gets in her car. I remember one day that we had had a little fight. She just got in a car. She just drove. She came home and everything was great. Because you need to separate yourself. I think sometimes, it is not a vacation, this is so not a vacation. You have to define the lines. If you cross them, let the other person go and be

by themselves for a little while. You cannot be together all the time.

Roz: Karen?

Karen: I bought 120 dollars' worth of organic soil the other day online, waiting for that to be delivered to my garage. Ann mentioned the weather here has not been cooperating. I tend to want to spend more time outside than inside. We just have not been able to do that. So, I am hoping when the weather breaks, that is going to be helpful. I know when we speak with our friends in Florida, they have it a little easier. Because they can be outside. Yesterday, they were sitting on their porch in the evening, out in the sun. We are longing for those days when we can be outside in our backyard and still be alone but create a little bit more distance. My new thing this week was trying to focus on the positives that have come out of this. So, having more time together has allowed us to do some things that we typically do not do. It is just trying to figure out how to make that time a positive time, and not sitting in front of the TV and watching the news for three hours. But, doing something that we typically do not get to do. That is our new goal this week. I have not shared that with Ann yet. But, that is our new goal this week.

Ann: No, I know that.

Roz: Perfect. All of us living through this have a lot of feelings. Our feelings kind of go up and down all over the place. I am assuming that you have kinds of feeling frightened, angry, worried, or sad? Do you share those feelings? And talk about the feelings that you are having in response to it all?

Ann: It is funny when this first happened. I went and gave a book to my cousin. Well, I am very close to her. She is more like a sister. We share books. I went over to her house and I left the book on the porch. She opened up her window and I saw her. I started crying. I mean, this was like, right in the very beginning when all this happened. I was like, I could not believe how emotional I got. And so did she. Then, I got in the car. I had told her I loved her, and I left. I do not know if it was the following day. But, my godchild, my cousin, and her sister came over. I am in the driveway and I am all teary-eyed again. I have not done that since. I am okay now with that. But, the first time that I could not kiss them or just hug them. It was tough. Now, I give everybody virtual hugs. That is what I do.

Roz: When you were feeling that sadness, is that something that you and Karen talked about? Or do you kind of keep it?

Ann: Oh, no. I very rarely keep anything inside.

Karen: Nothing.

Ann: Yes. I came home and I told her how terrible I felt. There is a lot of milestones that were coming this year. My godchild was graduating from high school. She was going to play

softball this year. Because she played soccer. She played basketball. She did play softball too. You know what I am. Because I want you to win and come and see me play. Now, that is not happening. It hurt me so much. Then, she had her graduation. She lost her prom. It makes me sad. I tell Karen about it.

Roz: So, sadness has been the biggest feeling for you. Well, how about you, Karen?

Karen: Probably more anxious about the future. I am supposed to be retiring at the end of August. This is not sort of the way I had pictured my last hooray at work. I work with high school kids mostly. It has been very difficult watching them go through this. But, I have shared a lot of that with Ann. As she mentioned, sometimes I get short. I know it is probably because I keep a lot of that inside. But, I found that's because a lot of times I have tried to protect Ann from stuff. That started when she was first diagnosed with MS. I just used to keep a lot inside. But, we have been sharing a lot of this and how we have been feeling. Probably more than we have shared other stuff.

Ann: Every time she comes out of that office, I asked her, "So, what happened today at work?" And I very rarely would ever do that. Now, I am very interested in what is going on behind that door.

Roz: It sounds like something positive could come out of this for the two of you? If you have got a little more used to sharing feelings back and forth and talking more about what is going on with each of you. Maybe that is something that will outlast this epidemic. Maybe that is a very positive message for other people to look at. As you said, Karen, looking for positives. Maybe we are each experiencing some positives out of this that might stay with us, you think?

Karen: I hope. I think I have seen it mostly with the teenagers that I work with and with Ann's relatives. That population and that age group are not one that typically thinks about family. They kind of live their teenage lives. I have seen a lot more reflection. Kids playing board games with their parents. One kid says, "I think my parents still do not like me. They did not like me before this." But, I tried to encourage her. I think that her parents do like her. I am hoping that there will be positives that come from this. When we lived through 9/11, another New York experience, there were a lot of positives that came out of it. We kind of lost those positives over time. I am hoping that some of these lessons will stick with us as we try to emerge from this.

Ann: Yes. I think it is important that people talk to someone. I mean, luckily, I have Karen and she is in the house. But, if you are by yourself, you need to reach out to a friend or a family member. You got to have somebody to bounce things off of otherwise, you could go crazy.

Karen: Ann has been doing a great job with that. As a retired teacher, she was given a list of retirees from all over the state. She has been reaching out to them. She called the woman that catsits for our cats when we go away. Because she is by herself. Her husband passed away a bunch of years ago. Ann just randomly called her today. We have a friend who recently lost

her dad and Ann has been staying in touch with her every few days. So, that has kind of been her hobby and it is a good one.

Ann: Well, I got to talk to somebody, Roz, you know me. I cannot sit too much.

Roz: Well, I think we feel better when we help other people too. So, I have one last question for you. As a couple, I assume you have different tastes in environmental stimuli. One person likes the TV on. One person likes the TV off. One person who likes to watch the news more. One person likes quiet music or silence. Today, we are sort of overrun with information. How have you two balanced your needs? Are you similar in how much you want to hear or listen to? Or are you very different?

Ann: Oh, boy.

Roz: Sorry.

Ann: We are very different. I have the TV on. She would prefer it off. I do win though, the TV stays on. I watch the news. That is probably one of the good things that we are still working and being behind that door. Because I get control of the television and I get to watch what I want to watch.

Karen: Yes. If I did not have my work, I would probably be . . . We are trying to find things on weekends to do better like clean a closet. Everybody is doing it. We are hoping at the end of this to be the most organized people in the world, which I do not think will happen. But, that is a real stressor. It can be exacerbated by this kind of situation. That is why I am looking forward to going outside. Because there is no TV out there.

Roz: The TV I am assuming right now is more focused on news as opposed to just television shows. Ann, you feel the need to keep up with the news and what is happening and hearing all of it. Karen, you have just told us that you are feeling more anxious. So, my guess is hearing the news over and over again would be very anxiety-provoking for you?

Ann: Well, I just want to be clear. I do not watch it all day. I watch it when I wake up in the morning. And then, I am pretty much reading a book or making the calls to other union people and ask them how they are doing. I watch certain other shows during the day. I like to watch a certain person. I felt like I watch it all day long. But, I have to tell you when Governor Cuomo comes on, I try to listen. Because I like him.

Karen: We will just choose to disagree about how much time the TV is really on and how much news is on. I like to get updates. But, I have to tell you, the updates have been pretty much the same for the last week and pretty grim in this area. But, I am interested in what is going on in the world and here in New York, particularly. I pick and choose times when I am focused on the TV.

Roz: Well, I am hoping that the weather gets better soon. So you can get to that gardening and have your calm space and time when you need it. I appreciate the two of you talking today about all of this. I hope you both stay well. I look forward to talking to you again soon. Thank you.

Karen: Okay. Thanks, Roz. Be safe.

Ann: I hope you stay well. Bye-bye.

Roz: Bye.

Cari Fehler: Thank you, Roz, Ann, and Karen for the engaging discussion. Thanks to our listeners for tuning in to this episode of the Can Do MS podcast. A big thank you to our sponsors, Biogen, Bristol Myers Squibb, EMD Serono, Genentech, and Sanofi Genzyme for making this episode possible. Be sure to check out the other episodes in the Can Do MS podcast series. For additional information on living with MS during the Coronavirus, please visit www.cando, that is, C-A-N-D-O dash M-S .org/coronavirus.

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