



## **When Your Child Has MS**

### **Episode 29**

Krista: Hello, and welcome to the CanDoMS podcast. My name is Krista, and I am a program manager here at CanDoMS. We are excited for today's podcast, which is the second part of our 2020 embracing carers podcast series. Joining us, we have two support partners, Patty and Sarah, who are both mothers to children who are diagnosed with MS. In addition, we also have psychologist, Roz Kalb joining us once again to lead the discussion. Roz, you can go ahead and take it away.

Roz Kalb: Hi, everyone. Welcome to our podcast about parenting a child who has MS. My name is Roz Kalb, I am a clinical psychologist, and I am very pleased to be here with Sarah and Patty, who are going to share some of their experiences of having a child diagnosed with MS. So, Patty, would you go ahead and introduce yourself, please?

Patty: Hi. Yes, my name is Patty, and my child was sixteen when she was diagnosed, she is thirty-one now. She is thriving with MS. And I was single when we went through this process.

Roz: Thank you. Sarah?

Sarah: Hi, my name is Sarah. I have a son Mitchell who was diagnosed when he was twenty years old, a sophomore in college at the time. He is now twenty-four. We were just divorced from his father, but I have recently been remarried. So now I have a partner in crime to help me through the rest of this.

Roz: Okay. Thanks very much. So, Patty, can you tell us a little bit about the early days of Channing's first symptoms and her diagnosis? What was that like?

Patty: Yes. Channing was a very active high school student, officer of everything, cheerleader, dancer, et cetera. I noticed in early December, she took the ACT and she came home and slept eleven hours afterwards. The mental fatigue was something I would never have seen from her, but I thought, "Okay, this is the beginning of the holidays, testing is occurring at school, et cetera." And then in mid-January, she came to me and said, "I woke up this morning, and my right side is a little numb." Well, I blamed it on her going to a tanning bed for the upcoming winter homecoming event. She went on to cheerleading that night, where she fell

during the cheerleading activity, the building of a structure, whatever they call that, because she could not feel her right side, her whole right side had gone numb and it looked she had a stroke. That was the very first onset of symptoms. She was in and out of the hospital four different times, misdiagnosed three times until we finally went to the pediatric center for excellence in Stony Brook, New York, and got a definitive diagnosis. I feel like that was a really close time from onset of symptoms to diagnosis because, through the years, I have heard other stories of taking years and years. We are very grateful.

Roz: Patty, how did the diagnosis that Channing received affect your relationship with her over time? At the beginning, there must have been sort of crisis mode, but then what happened?

Patty: We had the advantage of being super close, to begin with. I had been single since she was in kindergarten, but it does place a different challenge on a relationship between a mother and an older teenage daughter. And we became very close, it kind of brought us closer. Then, as the years went on and she got older as college student, she needed to push her own independent boundaries, and I needed to pull my investment in her life, if you will, back a little bit. It has been kind of an ebb and flow, which has caused some hiccups, but the communication, we have been dedicated to keeping open communication through the years. I have gone from being a mama grizzly to a teacher, a mentor, and a partner through the years. I think she would probably say the same thing.

Roz: Sounds like a very nice journey to take with your child. Was it similar for you, Sarah, or different?

Sarah: I think it was a little different. I mean, when Mitchell was in high school, he did have lots of ear infections and things that affected balance and things like that, that they wrote off as just that sort of an item. I mean, he was a male in his late teens, and that is just not a demographic for MS. Mitchell went off to college, and in his freshman and sophomore year, he did very well. Typical college student, good grades, all of that sort of thing. In the fall semester of his junior year, something just seemed different. He was pretty aloof about what was going on in school and how he was doing. Anybody that knows Mitchell knows that he is a talkative guy and shares things with you, so I thought that was a little odd. He was complaining about being tired a lot, but the thing that really caught me off guard was he was not driving his car very often. He used to drive his car to school, park there, go do things, and he would come home and visit. None of those things seemed to be happening anymore. He would always have an excuse. He would take Uber to go somewhere rather than drive his car, and he would say, "Oh, parking is too hard" or something along those. Always had an excuse. So finally, after a couple of months of this and lots of pestering on my side about why do you have a car if you are taking Uber everywhere, he finally admitted he was not comfortable driving anymore.

Sarah: I was like, what do you mean you are not comfortable driving anymore? He said, "My eyesight is getting worse, I do not think I can see well enough to drive." We continued

through the discussion, and he began to admit some more troubling signs about sleeping excessive amounts, even for a college student, having some balance issues. I strongly encouraged him to set an appointment with his primary care physician that he had locally and his eye doctor, that he also had locally, to get checked out and to make sure that he communicated everything that was going on with him to both of the doctors and not just one, so that they could have a full picture of what they were dealing with.

Sarah: He took my advice, got some appointments schedules, went in. I left for Hawaii with some friends, really not thinking anything was going on, and then I asked his dad to say, well, you might want to go up to Reno and then go in with Mitchell and just kind of see ... make sure that he is sharing everything he needs to share. His dad did that, went into the appointment, and about five days or four days after I got to Hawaii, I got a phone call, and he said, "I am in the emergency room. They think something is wrong with me. They are running all kinds of tests," and he goes, "It is either going to be my NMO," which stands for neuromyelitis optica, I believe it is, which is a condition, that is a neurological condition that leads to blindness or multiple sclerosis, and I was in Hawaii in a little bit in a panic at that point in time.

Roz: Sarah, can you remember back to how you felt? Not just about being in Hawaii, but just how you felt hearing that news about your young son.

Sarah: Yes. I knew a lot about multiple sclerosis at that point in time. Now granted lots have changed in the thirty years since I had worked actively in MS, but I felt a lot of anxiety and a lot of nervousness about what was this going to mean for him long-term. To him, I put up this big strong "You will be fine. We will work through this together. Do not stress out about it. I will be home, and we will talk to doctors and deal with it." But inside, I was very anxious and upset and was prone for the last couple of days in Hawaii of bursting into tears while driving down the road.

Roz: And who was your support system at that time? You were divorced, but you were co-parenting, it sounds like, very effectively. Where did you get the support for the feelings you were having?

Sarah: Well, I have a good support system in my family and in my friends and my relationship so, it really helps.

Roz: Patty, how about you? You did a wonderful job of describing how your relationship has morphed over the years as Channing got older and became an adult. Can you describe, going back, how you felt at those early days when you first found out about the MS?

Patty: Oh, absolutely. I can remember it and recall it on a dime. Well, first, when we got the diagnosis in Stony Brook, and we were getting in the van after the long day of testing, Channing was texting all of her friends and so excited, "I have MS! I have MS!" And I just looked at her, because I was feeling a gut punch, and I looked at her, and I said, "Did you hear

what they said in there?" And she said, "Yeah." and she is texting, and I said, "You know, MS, there is no cure, right?" And she goes, "Yeah, it is okay." She said, "Mom, I am not going to die. At least I know now what I have. Everybody has got something, this is just my something," and that was how she handled it from then on. I kind of followed her lead. I was like, "Okay, here we go."

Patty: When she came back, she went immediately to the MS office and introduced herself and said, "Hi, I am Channing. I have MS. What can I do?" And so, I truly have followed her bravery and her lead, and I am not saying that it was not hard, because she came back and could not feel either one of her feet. She was using a cane, and as a dancer and a cheerleader and all of those things, to have mobility taken away from you in an instant and as it just kept getting worse, that was really hard on her emotionally, but she is bottled sunshine, and she was more concerned about making everyone else feel comfortable with what was going on and having her private moments of grief, but she was bound and determined to make the best of it. Her reaction helped my reaction.

Roz: Yes. So, Patty, Channing was busy being Channing, and I know her, and that is a really good description of the way she deals with the world around her about her MS, but that must have made it hard for you in some ways to feel and talk about your own feelings of concern and worry as a mother. Who was your support during that time?

Patty: Well, I have several friends who work in healthcare, and I was working in pharmaceutical sales at the time. I had a lot of immediate medical support around us. One of Channing's friends was actually a pediatric hematologist-oncologist, and he was a very wonderful support, calming, present, but I have lots of families here, lots of friends who kind of stepped in and gave support. Channing's dad does not live here, but he was also very supportive, her sister, but I think my goal was to just remain calm and educate myself, provide education for Chan, or just give her resources so she could lead up. The society was very helpful in providing that education. I think what I did was I kind of bottled up my emotion. There were a few times I cried. Her first infusion of Solu-Medrol was difficult. A friend came over and helped with that, and just the feeling of helplessness, because you want to take that away from your child, right?

Roz: I have a follow-up question for you, Patty. You mentioned that you have another child.

Patty: Right.

Roz: How did you kind of manage the two sisters and trying to make sure that the older sister did not feel neglected or left out?

Patty: Right. Madeline was about to graduate from college at that point, and so she was very busy, very focused on finding graduate school and doing all those things, but she is also very sensitive to her sister's needs, and just, she is the kindest person on the planet. We just kept her informed. I remember her coming to the hospital one time with her roommate, and I

could see the anxiety on her face. I had to measure the amount of information that I gave her, so it did not interfere with this really stressful time in her life as well. Graduating and figuring everything out, but we are all three very, very close. I kept her informed, and I think that is the best thing for her and let her do what she could do. I did not put any burden on her to make her feel like she needed to be there all the time.

Roz: Now, a question for both of you, and I think I will go to Sarah first, but one of the things that happens with any child growing up is that our relationship as a parent changes over time. It evolves as our children, hopefully, grow up and become more independent and wiser even without our input. How do you feel that your relationship evolved as Mitchell's MS evolved, but also as he went into adulthood?

Sarah: Yes, so, I mean, we always raised Mitchell to be responsible for himself. I mean, that was kind of our goal, and that was not necessarily the approach that a lot of parents in our neighborhood took. My thought was if he has a problem when he leaves the house, he has to be able to solve that problem. If he had a problem at school, he had to talk to the teacher. Nobody would talk to the teacher for him. Does not mean I would not support him; he would come for advice. We would work with him, give him some suggestions, never solve it for him. We continued to do that sort of thing after his diagnosis. I had to press him early on to keep at things that he was doing. Get appointments scheduled.

Sarah: Really focus on his schoolwork, that sort of thing. Eat right, move, do not just sleep twenty hours a day. That was especially hard for him when the fatigue hit, came in and set in, but I never took over the task for him. I might provide additional support, be an advocate for him to push things along, give him resources, like Patty said, provide him the information that he would need, but knew ultimately that if he did not make the decision himself, it was not going to be a lasting decision. He had to want to stay active. He had to want to eat right. He had to set goals, keep lists so that he could remember things, but it was up to him to execute on it.

Roz: Which he has done a wonderful job.

Sarah: Yeah.

Roz: Yeah.

Sarah: Yep.

Roz: How about you, Patty? Channing was younger when this started with a pretty significant crisis, and she has also had some other health issues along the way, so how has your relationship with her evolved?

Patty: Yeah, with regard to her MS, I think it has gone from me feeding her information, to her feeding me. That movement, initially her movement to independence, was kind of

misinterpreted by me as her not needing me anymore. We were able to navigate through that and talk about it. My phrasing and discussions with her have become different. I do not say you should ever. If I think there is something maybe she should consider, I would say, "Hey, have you ever considered ..." or I will just send her a link to something that might be interesting, but I do not monitor her decisions. I would wait for her to tell me what those are. I always went to her doctor's appointments as the note taker. Even when we were in the hospital, I would look at her if the doctor started looking at me to tell me information.

Patty: I was like, "This is her illness. This is her health journey. You talk to her. She is the one who has to live with this." Just like Sarah was saying about Mitchell. When it came time to choose a disease-modifying therapy, sure, I would be there to bounce off, but that was her body. She needed to make the decision on what was best for her. I kind of feel like MS has gone from being a roommate in our lives, to a visitor where we are not in daily contact about it. It is more like, "Oh, yeah, and then there is this MS in our life that we deal with." She still will say, "We got diagnosed", which I think is funny. We were just talking about that recently. I do not correct her, but we have talked about this as her disease, but she knows, and is sensitive to the fact that it changed my life as well.

Roz: It is wonderful to hear you say that, Patty, because we at CanDoMS, we make a big deal about that actually with couples and families. That this is not a "me" disease, it is a "we" disease. It is easier to think about that and talk about it when it relates to spouses or partners, but I think it is a very sensitive young adult who realizes that this has this tremendous impact, not just on him or herself, but on all the people who care. The whole helicopter parent thing, which is such a wonderful image, because I think that is what we do. We move in and hover when we need to and pull back when we do not. Sarah, do you feel that there have been moments when your overall strategy for raising Mitchell really stressed you out? That you just wanted to go in and hover like mad and try to protect him? Or has it pretty much worked for you throughout?

Sarah: Oh, no, there are times, right? There are times where you want to jump in and take charge, especially when they are being particularly aloof, and not engaged in what is going on. At the same time, I think it helps that I am not ten minutes away or half an hour away. It is a thought of getting in the car and driving up there, but I think he has evolved to appreciate me and what I bring to the table for him. And he is much more open probably today than he was even a year ago or two years ago, in terms of communication with me, and getting thoughts on it, and sharing what he is thinking, and asking for advice. I will provide it whenever he asks for it, but I will not do it. So, if he comes to me and says, "Can you call my insurance company and do this?" I am like, "No. You are an adult, you need to call your insurance company and do that yourself." And I go, "But if you call three times and they do not respond to you, let me know and I will see what I can do to escalate or something like that, but I am not going to do it just because you are asking me to right off the bat."

Sarah: Usually he is pretty good about it, it is only when he gets particularly tired or particularly stressed out about something that that happens. And we had that just last month

when he was ... I am not sure why it happens this way, other than the fact that he is on Rituximab, which is still an unapproved therapy. Now, obviously, its sister, Ocrelizumab, is very strongly related to that, but that is the approved version. Because he started with Rituximab before the Ocrelizumab was approved, he still gets that version. He goes to UCSF down in San Francisco to get it. But it is always an insurance hoop that you have to jump through every six months to get it approved.

Sarah: Last month or last cycle, he had a two-month delay in getting his treatment, which is not good at all. But it was in the middle of this COVID situation with people working at home, and communication is not helping quite as well between the staff at the hospital and the insurance company and everything else. Eventually, I made a couple of phone calls during that situation because things just were not getting done and he was trying, for lack of a better word. I think he is generally good, except for when he is overwhelmed by something.

Roz: Now, he is your only child. Are you his primary support person in this regard or in life or does he have another partner on whom he also relies for support?

Sarah: Yes. His father and I both provide support in some way. His father lives a flight away, so it is a little further distance than what I can provide to him in terms of it, but his dad is great. I am not going to say anything about that. He will jump on a plane, even in the middle of COVID, to do what he needs to do if he has to. So, that is good.

Sarah: But he has been in and out of relationships. He is not in a long-term steady relationship at this point, so I do not think he has had that aspect, but I think that is a challenge too for young adults with a chronic condition like MS.

Roz: I think that is right. As a parent myself of grown children and now grandchildren, I am very much aware that I still have an on-call button on my forehead. And the on-call button was pushed a lot when my kids were little. Then, we went through adolescence when they did not even push the on-call button when they should have. Then now as adults, interestingly, they come for support about different things, but the on-call button is still there. Patty, what is your on-call button like? How does Channing let you know when she needs you for something?

Patty: We have established a little code on our phone call. First thing she will say out of her mouth is, "I am just calling to vent, I do not need advice, I just need you to listen." Okay, that sets the tone, or when she calls and says, "I really need you to give me your opinion on this." She is just upfront, from the get-go. I do not jump in with an uninvited opinion. I know what my role is when she calls. Now I am getting texts with, "What do you think about this paint color?" or those kinds of things. I know she knows I am here for her all the time. I think trusting one another is a key, but having those discussions about your expectations and boundaries, it will do wonders for your relationship.

Roz: Yep, super. Sarah, how about you? What is your on-call button like?

Sarah: It is fine. Sometimes Mitchell will call me every day, sometimes he will call me once a week. It just depends on what he is feeling and what he is doing. If I do not hear from him for a week, then I am definitely calling him to find out what is going on because that is pretty unusual for him. Sometimes I will get multiple phone calls in a day because he wants more assistance with something, and he will reach out to me. He has never been shy, other than in the very early phases of his symptoms, where he did not want to tell anybody what was going on.

Sarah: He has never really been shy in telling me what he needs, or asking me for what he needs. I do not feel like he abuses that in any way. I do not feel like he just wants me to do things for him because it is easier. He is pretty good at just telling me what he wants. "Hey, Mom, can you look up this drug? Tell me what you think about it", or something along those lines.

Roz: It sounds as though I have been talking to two amazing parents, who really have worked hard to have strong, close, healthy relationships with their kids. They are lucky to have such smart, engaged, proactive kids who are taking care of themselves in a variety of ways. Those things are not always true in families, and you two have navigated this beautifully. I am wondering if you each have any words of wisdom for other parents. Sarah, you want to go first?

Sarah: Sure. I mean, I think it sounds like it was easy now, but it took us a little while to find our rhythm. I think Patty alluded to that as well, right? For me, it is, listen to your child and ask lots of questions. I think that is an important thing. A lot of times, they will skirt around the real issue. Early on, you have to ask those questions and get them to be comfortable with that. I still go to, other than his primary care, his visits down with his neurologist, I go to every visit, or his father goes to every visit, and we share information around that. I am not afraid to challenge or ask difficult questions of his physicians either, even with Mitchell in the room.

Sarah: It is up to Mitchell at any point in those doctor's appointments, at what point does he want to bring me into the room, if at all? He always pretends to bring me in at some point. Challenge the doctors to treat the whole child, not just the MS. Treat the nutrition, the exercise, the psychological needs. That is so important for these kids because they will not necessarily tell us everything that is going on with them, and they need someone to talk to. Keep an open dialogue with them, ask them what is new in the MS world, and what should they be looking out for. Be flexible. Change is constant. Do not be afraid to try something new. Whether it is a cane. Mitchell had one for a while. He does not use it anymore, but he had one for a while because his balance was so bad, and he did not like to take it to school because he felt that people were looking at him. But the reality was when he did do it, he felt more comfortable moving around because he had it.

Sarah: You have to address those psychological issues around that as well. Get involved with your local community. I had some of the best resources we have had with respect to MS, and



how to move forward, have been through CanDoMS, The National Multiple Sclerosis Society. I have reached out for psychologists, for neurologists, for recommendations, for things. Also, just be informed about what is going on and encourage them to be informed, but be a critical thinker too of the information because there is a lot of bogus information out there too.

Roz: Thanks, Sarah. Patty, advice for parents?

Patty: Well, I just want to reiterate what she said about educating yourself and teaching your child to become an advocate for themselves. I think that is very, very important. Be patient, and loving, and kind, not only to your child, to the care team, but also to yourself. I mean, give yourself some grace as you go along and realize all your emotions are valid and work through those. Let your child know that you are there for them unconditionally. Help them to learn to thrive with MS and never allow them to wallow in self-pity. You can deal with the grief that MS, the life changes that MS has on a daily basis. Sometimes for thirty minutes, sometimes for an hour, maybe you have a day that is bad, but do not allow yourself or your child to stay there, help them to see the silver lining. I think that is our role as parents, too.

Roz: I think that is wonderful advice for parents. I have one follow up question for you, Patty. Channing is this very cheerful, bubbly, happy person who deals with a lot of her feelings and challenges inside herself. I know that from talking to her. Do you ever feel like she is trying to protect you from some of the feelings and challenges that she experiences herself, whether emotionally or physically?

Patty: Yes, definitely. Those calls where she will set the expectation for the call, those calls start with, "I do not want you to worry, dot, dot, dot, but." No, we have talked through the depression, the times of depression and sadness that she has had, but she had a teacher in high school that year that she was diagnosed or going through that process, who saw her limping out to her car and very sad. She took her aside, and she said, "Talk to me, tell me what is going on." She said, "I just want everyone to be okay." And Mrs. Picket said, "But you are not okay." She said, "But I will be okay." She said, "Well, let me tell you this. My daughter has diabetes, and sometimes she gets down. So, we set a certain amount of time that she can have to just grieve, and get mad, and do all the things that she wants to do. But then you accept the reality, and you pick yourself up and dust yourself off, and you go, and you make the best of it."

Patty: That was the conversation that was a game-changer for her. And she still refers to that today, fifteen years later. You never know the power of your words. I have thanked Mrs. Picket countless, countless times.

Roz: I am sure you do. It was very good advice. Well, thank you both so much for taking the time to share your experiences and talk to me. I have always loved working with the two of you, and I look forward to having more conversations in the future. Thank you very much.

Sarah: Well, we appreciate it so much, all the good work you do at CanDoMS. It has been so

valuable to us.

Roz: Thank you.

Patty: Thank you, Roz.

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Krista: This podcast is part of the Embracing Care series, an initiative led by EMD Serono, in collaboration with leading caregiver organizations around the world to increase awareness and action about the often-overlooked needs of caregivers. Be sure to check out Embracing Carers further and visit our website at [cando-ms.org](http://cando-ms.org). Thank you all so much for tuning in and joining us today.

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