



PODCAST

When Your Child Has MS

Episode 118 – Podcast Transcript

[Instrumental music]

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

Patti: Hi. Yes, my name is Patti, and, um, my child was 16 when she was diagnosed. She's 31 now, she's thriving with MS, and, um, I was single when we went through this process.

Roz: Thank you. Pat, uh, Sarah.

Sarah: Hi. My name is Sarah, and I have a son Mitchell, who was diagnosed when he was 20 years old, a sophomore in college at the time. He's now 24.

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

Patti: Yes. Channing was a very active, um, high school student and officer of everything, cheerleader, dancer, et cetera, and I noticed in early December, she took the ACT, and she came home and slept 11 hours afterwards. The mental fatigue was something I had never 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, you know, I woke up this morning and my right side is a little numb. Um, well, I blamed it on, um, her going to a tanning bed for the upcoming winter, the homecoming event, and, um, she went on to cheerlead that night where she fell during the, um, cheerleading activity, the building of a structure, whatever they call that. And, um, because she couldn't feel her right side, her whole right side had gone numb, and it looked like she'd had a stroke. So, that was the very first onset of symptoms and she was in and out of the hospital 4 different times, misdiagnosed 3 times until we finally went to the, um, Pediatric Center for Excellent and Stony Brook, New York and got a definitive diagnosis. I feel like that was really close time from onset of symptoms to diagnosis because, through the years, I've heard other stories of taking years and years, so we're very grateful.

Roz: So, so, Patti, how did the diagnosis, um, that the Channing received affect your relationship with her over time?

Patti: Um, at the beginning there must have been sort of crisis mode.

Roz: But then what happened?

Patti: But we have the advantage of being super close, to begin with. I've been single since she was in kindergarten, but it does place a different challenge on a relationship between a mother and a older teenage daughter and we became very, very close, that kind of brought us closer. And 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. And so it's been kind of an ebb and flow which just caused some hiccups. But the communication, we've been dedicated to keeping open communication through the years. So I've gone from being a mama grizzly to a teacher, a mentor, and a partner through the years and I think she would, would probably say the same thing.

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

Sarah: Um, I think it was a little different. I mean, we, 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 is just that sort of an item. I mean, he was a male in his late teens, and that's just not a demographic for MS. So, he went off to college and his freshman and sophomore year, he did very well. You know, typical college student, good grades, all of that sort of thing, but 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. And anybody that knows Mitchell knows that he's a talkative guy and cherish 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 wasn't driving his car very often. So he used to drive his car to school park there. Go do things, and he'd come home and visit.

And none of those things seem to be happening anymore and he'd always have an excuse. He'd take Uber to go somewhere, rather than drive his car. And he'd say, oh, parking's too hard or something along those, So, always had an excuse. So, finally, after a couple of months of this and lots of pestering on my side, about, you know, why do you have a car if you're taking an Uber everywhere? He finally admitted he wasn't comfortable driving anymore. And I was like, what do you, what do you mean you're not comfortable driving anymore? And he said, my eyesight is getting worse, I can't, I don't think I can see well enough to drive. So we continue through the discussion and he began to admit some more troubling signs about sleeping excessive amounts, even for a college student, um, having some balance issues, and so, I strongly encourage him to set an appointment with his primary care physician that he have locally and his eye doctor 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 1 so that they could have a full picture of what they were dealing with.

So, he took my advice, got some appointments schedules, went in. I left for Hawaii with some friends, really, not thinking anything was, was going on. And, and then I asked his dad to say, well, you might want to go up to Reno and go in with Mitchell and just kind of see, make sure that he's sharing everything he needs to share. So, his dad did that, went into the appointment and about 5 days or 4 days after I got to Hawaii, I got a phone call and he said, I'm in the emergency room, they think something's wrong with me. They're running all kinds of tests and he goes, it's either going to be my NMO, which stands for Neuromyelitis Optica, I believe it is, which is a condition, that's a neurological condition that leads to blindness or Multiple Sclerosis.

Roz: So Sarah, can you remember back to how you felt? Just how you felt hearing the news about your young son?

Sarah: Yeah. You know, I knew a lot about Multiple Sclerosis at that point in time. So, now, granted lots of changed in the 30 years since I had worked actively in MS. So, but I felt a lot of anxiety and a lot of nervousness about, what was this going to mean for him long-term? You know, to him, I put up this big

strong, then, you'll be fine, we'll work through this together, don't stress out about it. You know, I'll be home and we'll talk to doctors and deal with it. But inside, I was very anxious and upset.

Roz: And who was your support system at that time? You were divorced, but you were co-parenting?

Sarah: Yeah.

Roz: It sounds like very effectively. So, where did you get the support for the feelings you were having?

Sarah: Well, my now husband was with me in Hawaii at the time. So that was, he's been a rock, my sister, and my father, and my mother, and I too are all very close. And my father and my sister both live within 30 minutes of Mitchell. It was nice to have somebody that could actually went to over to the hospital and reported back to me as well. So, I have a good support system in my family and in my friends, and my relationship, so it really helps.

Roz: Uh, Patti, how about you? So 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 that, those early days when you first found out about the MS?

Patti: Oh, absolutely. I can remember it and recall it on 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 and because I was feeling like a gut punch. And I looked at her and said, did you hear what, what they said in there? And she said, yeah, and she's texting. And I said, and you know, MS, there's no cure, right? And she goes, yeah, it's okay. She said, Mom, I'm not going to die. At least I know now what I have, everybody's got something, this is just my something. And that was how she's handled it from then on. So I kind of followed her lead, you know, I was like, okay, here we go. So, when she came back, she went immediately to the MS office and introduced herself, and said, hi, I'm Channing, I have MS. What can I do?

Roz: Yeah.

Patti: And so I've truly have qualified her bravery and her lead. And I'm not saying that she, it wasn't hard because she came back and couldn't feel either, 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 to take it away from you and in an instant, and as it just kept getting worse, that was really hard on her, emotionally. But she, she is bottled sunshine and she was more concerned about making everyone else feel comfortable with what was going on and, you know, having her private moments of grief. But she was bound and determined to make the best of it. So her reaction helped my reaction.

Roz: Yeah.

Patti: So.

Roz: So, Patti, Channing was busy being Channing, and I know her, and that's 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?

Patti: I have several friends who work in healthcare and I was working in

pharmaceutical sales to the time. So, I had a lot of immediate medical support around us, but I have lots of family here. Lots of friends too kind of stepped in and gave support. Channing's dad doesn't live to hear but he was also very supportive. I think my goal was to just remain calm and educate, myself, provide education for Chan, or just give her resources. What I did was I kind of bottled up my emotion, there a few times I cried, and just the feeling of helplessness because you want to take that away from your child, right?

Roz: So, now, a question for both of you and I think I'll 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. So, how do you feel that your relationship evolved as Mitchell's MS evolved, but also as he went into adulthood?

Sarah: Yeah. So, I mean, we always raised Mitchell to be responsible for himself. I mean, that was kind of our goal, you know? And that wasn't necessarily the approach that a lot of parents in our neighborhood took. We, my thought was if he has a problem when he leaves the house, he has to be able to solve that problem. So, if he had a problem at school, he had to talk to the teacher. Nobody went in to talk to the teacher for him, right?

Roz: Mm-hmm.

Sarah: Didn't, doesn't mean, I wouldn't support him, he'd come for advice, we work with him, give him some suggestions, never solve it for him and we continue to do that sort of thing after his diagnosis. So, I had to press him early on to keep at things that he was doing, get appointments scheduled, really focused on his schoolwork that sort of thing, eat right, move, don't just sleep 20 hours a day. And that was, especially hard for him when the fatigue kind of 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 Patti said, provide him the information that he would need that new ultimately, that if he didn't make the decision himself, it wasn't going to be a lasting decision. So, he had to want to stay active, he had to want to eat right, he had to set goals, keep less so that he could remember things. It was up to him to execute on it.

Roz: Which he has done a wonderful job.

Sarah: Yeah, absolutely.

Roz: Um, how about you Patti? So, he, he, when Channing was younger, [sound] when this started with a pretty significant crisis, and she's also had some other health issues along the way. So what, how has your relationship with her evolved?

Patti: Yeah, I, with regard to her MS, I think it's gone from me feeding her information to her feeding me. And that, you know, movement, initially, her movement to Independence was kind of misinterpreted by me as her not needing me anymore, you know? And so, we were able to, you know, navigate through that and talk about it and my phrasing and discussions with her has become different. I don't say you should ever, you know, if I think there's something, maybe she should consider, I would say, hey, have you ever considered? Or, you know, I'll just send her a link to something that might be interesting, but I don't monitor her decisions. I wait for her to tell me what those are. And I always went to her doctor's appointments as like the note taker. And even when we were in the hospital, I would look at her if the doctor started looking at me to tell me information.

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, you know, when it came time to choose a disease-modifying

therapy, you know, sure, I would bounce, be there to bounce off, but that was her body, she needed to make the decision on what was best for her. So, and I, you know, I kind of feel like MS has gone from being a roommate in our lives to a visitor where we're not in daily contact about it, it's more like, oh, yeah, and then there's this MS in our life that we deal with. So, and she still will say we got diagnosed which I think is funny. We were just talking about that recently. I don't correct her but we've talked about this is her disease but she knows and is sensitive to the fact that it changed my life as well.

Roz: You know...

Patti: When...

Roz: ...it's wonderful to hear you say that, Patti, because we, we, uh, it can do a mess We make a big deal about that actually with couples and families that this is not a me disease, it's a we disease, and it's sort of means you're to think about that and talk about it when it relates to spouses or partners. But I think it's a very sensitive young adult who realizes that this has a tremendous impact not just on him or herself, but on all the people who care, right?

Sarah: Mm-hmm.

Patti: Yeah, yeah, very life changing.

Roz: And it's life-changing for all the people who care, so.

Patti: Yeah.

Roz: So, it sounds as though I've been talking to 2 amazing parents, who really have worked hard to have strong, close, healthy relationships with their kids, and they're lucky to have such smart, engaged, proactive kids who are taking care of themselves in a variety of ways. Those things aren't always true in families and you 2 have navigated this beautiful. So, I'm wondering if you each have any words of wisdom for other parents, Sarah, you wanna go first?

Sarah: Sure. You know, I mean, I think it sounds like it's easy, it was easy now, but it took us a little while to kind of find our rhythm and I think Patti kind of alluded to that as well, right? But for me, it's listen to your child and ask lots of questions. I think that's an important thing, you know, a lot of times they will skirt around the real issue. And so early on, you have to ask those questions and get them to be comfortable with that. You know, I still go to, other than his primary care, has his visits down with his neurologist, I go to every visit or his father goes to every visit and we share information around that. And I'm not afraid to challenge or ask difficult questions of his physicians, either, even with Mitchell in the room. And it's up to Mitchell at any point in our, in those doctor's appointments, at what point does he want to bring me into the room, if it all, and he always pretends to bring me in at some point. But, you know, challenge, the doctors to treat the whole child, not just the MS, treat the nutrition, the exercise, the psychological needs, that's so important...

Roz: Yeah.

Sarah: ...for sure kids because they won't necessarily tell us everything that's going on with them and they need someone to talk to. And I keep an open dialogue with him, ask him what, what's new in the MS world, and what should they be looking out for? Be flexible, change is constant and don't be afraid to try something new. So, whether it's a cane, you know, uhm, Mitchell had one for a while, he doesn't use it anymore. But he had one for a while because balance, his balance was so bad and he didn't like to take it to

school because he felt, you know, 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. So, you have to address those psychological issues around that as well. Uhm, and and get involved with your local community.

I had some of the best resources we've had with respect to MS and how to move forward have been through, you know, can-do MS, the national Multiple Sclerosis Society, you know I've reached out for psychologists, for neurologists, for recommendations for things and also just, you know, be informed about what's going on in encourage, encourage them to be informed but be a critical thinker too of the information because there's a lot of bogus information out there too.

Roz: Uh, Patti, advice for parents?

Patti: Well, I, when 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, your emotions are valid, and work through those. Let your child know that you're there for them unconditionally, um, and do the kinds of things as a support person. Be the note-taker at the doctor visits because that is always, always needed. You can go in and not say a word and just because I go in and just start on my phone and I take notes and I don't say a word unless I'm asked. And I don't go to all of her appointments now before she's 31 years old but still go in with a list of questions herself and take notes. But it's harder if you're there by yourself, you sometimes forget. 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 30 minutes, sometimes for an hour, maybe you have a day, that's bad, but don't allow yourself or your child to stay there. Help them to see the silver lining. I think that's our, our role as parents too.

Roz: I think this wonderful advice for parents. I have 1 follow-up question for you Patti. So, 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?

Patti: Oh, yes. Definitely. Those calls were she'll set the expectation for the call, those calls start with, I don't want you to worry dot dot dot, that. Now, we've talked through the depression, the times of depression and sadness that she's 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 your car and very sad. And she took her aside and she said, I just, talk to me, tell me what's going on. She said, I just want everyone to be okay. And Mrs. Pickett said, but you're not okay. And she said, but I'll, I'll be okay. And she said, well, let me tell you this, my daughter has diabetes and sometimes she gets down, and so we set aside a certain amount of time that she can have to just grieve and get mad and do all this 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. And that was the conversation that was a game-changer for her. And she still refers to that today, 15 years later. So, you never know the power of your words and I have thanked Mrs. Pickett countless, countless times.

Roz: I'm sure you do. It was that advice. Well, thank you both so much for taking the time to share your experiences and talk to me. Yeah, I've always loved working with the 2 of you and I look forward to having more conversations in the future. Thank you very much.

Patti: Well, we appreciate so much all the good work you do at can-do Ms. It's been so valuable to our lives.

Roz: Thank you.

Sarah: Thank you for all this.

Roz: [Background music] Thank you to our listeners for tuning in to another episode of the can-do MS Podcast. This podcast was made possible by the support of Biogen and other program sponsors. Thank you. If you enjoyed this episode, please be sure to leave us a rating and review. Thank you. And have a wonderful day.

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