



## **Can Do MS Podcast Transcript**

### ***Dr. Scott Newsome's Story: The Road from Caregiver to MS Provider and Researcher – Part 1***

### **Episode 92**

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Kathy Costello, CRNP: Hello and welcome to the Can Do MS Podcast episode 92. My name is Kathy Costello and I will be your host for this episode. I've been a nurse practitioner in academic medicine and specifically MS care for many years, and now lead the work at Can Do MS for programs marketing and development. In this episode, we are focusing on the role and issues facing caregivers. Caregivers also experience MS, clearly differently than the person who carries the diagnosis but experiencing the diagnosis and their own issues, nonetheless. Caregivers experience significant stress, lack of knowledge, fatigue, role change, role confusion, and even guilt.

Even though they have much to contribute, caregivers are often ignored by health care providers. While they want to be the best support they can be, they do not have a roadmap or guide that tells them what to do. They may be juggling a job outside of the home, childcare logistics and care, as well as providing support and physical care for the person whom they love, and who is experiencing the diagnosis of MS. This unexpected role creates relationship stress and often varying degrees of conflict. The role of the caregiver is often underrecognized and under-supported.

Today, we are joined by Dr. Scott Newsome, an MS physician at the Johns Hopkins Multiple Sclerosis Center in Baltimore, Maryland. Dr. Newsome is an Associate Professor of Neurology at Johns Hopkins Medicine and the director of the neurosciences consultation and infusion center at Green Springs station. He is the director of the Stiff Person Syndrome Center, [(2:00)] the co-director of the Multiple Sclerosis Experimental Therapeutics Program, the co-director of the Johns Hopkins Neuro-Immunology Clinical Fellowship program, and a member of the Miller Coulson Academy of Clinical Excellence.

In addition to his many academic appointments, Dr. Newsome has also had one other very important role and that is of caregiver for his mother, who had multiple sclerosis during Dr. Newsome's childhood and adolescence. Today Dr. Newsome is here to describe what it was like for him to have a parent with MS. His role as a caregiver and the impact the caregiver role had for him and his future. Dr. Newsome, thank you for joining us today and for sharing your story.

Dr. Scott Newsome: Thank you for the invite and please call me Scott. We are friends and colleagues, you do not have to refer to me as Dr. Newsome.

Kathy: Well, thanks for that. I appreciate that. And you're right, we have been friends for a long time. And so this is really a treat for me to be able to speak with you about really this very important time in your life. So to that end, let's wind back the clock and take us back to your childhood and tell us a little bit about your family before the diagnosis of MS. And then we'll kind of work our way through the future.

Dr. Newsome: Sure. So, you know, of course, as a child with a parent who has a chronic neurological condition, it's challenging for many different reasons, which I'm sure we'll- we'll talk about. But I would say

the first time I really noticed that there was something different about my mom, from a functional perspective and neurological functional perspective was probably around six or seven years of age. She worked in a, I'll say, a non-disclosed company. [(4:00)] I'll just say that she was uh- you know, actually highly successful and in her job and traveled the world for, for what she did and was highly sought after. And so a very high-functioning woman where at different time periods, she would be away from work, because she would have what now looking back were relapses related to her multiple sclerosis.

And at the time, you know, I didn't really have a full understanding of what the situation was but seeing my mother have difficulty walking up and down the stairs because she had a weakness, spending a lot of time in her bed because she had significant fatigue related to her weakness. And you know, she would go off and get treatment and you know, would be away for a couple of hours at a time during these episodes that she would experience, and I had absolutely no clue into why she was having to get in medical assessments and treatments and be able to work for, you know, up to two, three weeks at a time. And you know, very interestingly, you know, in between these episodes that she would experience, she was fine, completely fine. And, you know, she was a single mother raising me and amazes me, despite her challenges, how she was able to still juggle, taking care of me, getting me to school, making sure I stayed on task, making sure I was not getting into too much trouble, which, of course, you know, I tried to help with that. But, you know, it really was sort of for the age of 10, when I knew something was wrong.

And then, you know, eventually, she got diagnosed with multiple sclerosis. And, interestingly, was entered into one of the initial clinical trials of one of the treatments that we have available today that is used, you know, [(6:00)] across the globe to help prevent these attacks, these relapses and new spots in MRI and hopefully prevent disability progression over time. But I have to give my mother a lot of credit, because despite all the challenges she had early on, she did not allow the diagnosis to define who she was. And I looked up to that, I still look up to it. And I will get into this later, I try to encourage my- my patients, to not let the diagnosis define who they are. There's a lot more we could talk about. But I think that that was sort of when I came to that there was something different about my mother in her health.

Kathy: She sounds amazing, and obviously had a huge impact on you and now it makes sense to me why you're who you are. And I thank her for that. When was all this happening? You said she was in the clinical trial but then they started back in the 80s. So was her diagnosis then sometime in the 80s?

Dr. Newsome: It was. So, she actually had optic neuritis back in her 20s. And at that point in time after she saw the ophthalmologist and in fact, may have seen a neuro-ophthalmologist, they were on the fence of whether this was multiple sclerosis or just sort of a one-and-done optic neuritis like we'll see with some of our patients. And so, it wasn't until I would say and sorry about the details was a little fuzzy because you know, a little kid. But she eventually did undergo a lumbar puncture. And that's what solidified the diagnosis at that time. Because this was actually even before MRIs were becoming used in clinical practice. And in order to get into, you know, the clinical trials she was in, I believe, that was sort of around the advent of MRIs being utilized. And then that was yet another confirmatory test [(8:00)] that said, Okay, we feel pretty good about this being multiple sclerosis. And here we have this treatment option that could help people and she was enrolled in the clinical trial. And, you know, I don't recall all the details about like the study visits and, and how time, you know, the time that it took for her to be away, but I can tell you she unfortunately had side effects related to the medication that resulted in a hospitalization. And so as a child hearing, you know, she's going to be on a medication that could help her that now she's in a hospital setting because of the medication that was supposed to help her, that was, that was a big blow to me as a child. Because of the sort of, you know, a trickle-down effect where I had to have family from New York come to stay with me to take care of me when she was in the hospital. And so there's a lot of different emotions that were happening as a child, and I couldn't understand. I guess at that point in time, you know, why was my mother having a treatment-related effect that was not positive from something that was supposed to help her? So it was a very confusing time for me actually.

Kathy: How difficult for you. That must have been just awful. So, you said though, that early on, and before the trial that she was in, she had episodes or relapses. And then in between, she seemed to be okay and went back to her usual activity. Was there a time when that shifted, aside from the side effect clearly that she experienced, but was there a time when things shifted? And if so, how did that change, and where were you and growing up at that point?

Dr. Newsome: Yeah, so this- this I remember very well. As I mentioned, my mother, [(10:00)] to me was very high functioning and was like the master multitasker and was just an unbelievable person. It started taking her work home with her. So, she never ever, ever took her work home. She would finish everything she needed during the usual workday. And then I noticed, you know, not only at nights, but also weekends, she was starting to require to do extra stuff. And at the time, I didn't really understand I was like, well, is this because she's getting more added to her plate from a work perspective, because, you know, that's what happens, right? Sometimes. But no, it was in fact, because she wasn't able to keep up with her job at that moment in time.

And the- the- the sad thing about that situation is that she did not have, I think, the support she needed and required. And we've learned a tremendous amount, of course about MS and how it can affect people cognitively, how it can affect people from a fatigue perspective, both of which my mother had. And she did not want anyone to know so she resigned from her job. She actually resigned. And she ended up taking another job that was less demanding but could still keep a roof over our head. And it was- it was just a really challenging time. And then sort of the fast forward a couple of years, we ended up moving to New York, which is where she was from to be around family because it just got to a point where she was no longer able to even do her, you know, a job that was less demanding. So, we ended up having to move-- [crosstalk]

Kathy: And that was because of cognitive issues?

Dr. Newsome: Cognitive and fatigue. And at the time, she was still ambulatory. And physically speaking, you know, was still able to maintain [(12:00)] some things outside of relapses, that affected her motor skills. But yeah, it ended up fatigue, cognitive and it started impacting her mood significantly.

Kathy: That must have had an impact on you, too. How- how were you feeling at this time when it probably seemed like her personality was actually changing?

Dr. Newsome: It actually did. So, I think the disease itself did change to some degree. The personality of my mother, in a way, even beyond the mood, it was just the I think the degree of injury to the brain at that point in time when we didn't have really therapies, right, like we do now. We're very fortunate now. It was- it was tough, you know, there was a period of time. And I don't think I've ever shared this with you, Kathy, that my mother was in a psychiatric unit for a number of months, because she became almost catatonic and was not doing anything and had a lot of mood-related issues. And this was when I think I started high school. And then eventually, she got out of the psychiatric unit and was able to come back. And we were living with each other independently from family for a period of time. But it was an incredibly difficult time. Because again, here is someone who I looked up to who was like the rock of you know, everything in my world, and then you just could see it slipping away. And it was- it was difficult. It was very difficult.

Kathy: Absolutely, absolutely. When- when your mom came home after that admission, was she compromised such that you actually had to provide some care for her? Or was there a time when that actually occurred where versus watching these things happened to her, did you need [(14:00)] to participate in her care?

Dr. Newsome: I did. I did. And you know, looking back, I'm grateful for those experiences, actually, you know, for what we'll talk about I'm sure later where I am now and what I'm doing. At the time, of course, it felt terrible. And you know, I felt so bad for my mom. And, you know, as a teenager for at least I want to say two

years when we were living independently together, I was the sole caretaker for her. And I remember one story. You know, I played sports when I was in- in high school, and I was at basketball practice. And my mother was at home. And the police came to the gym to tell me that my mother was on the floor in our bathroom and was unable to get up and so she was able to actually call the police in order for- for me to be aware that she was on the floor and so I went home of course.

And, you know, there were many other situations like that, that were quite difficult. And I can't even imagine for my mother, here you have your teenage son, as a caregiver, helping you go to the bathroom into even the extent of wiping her behind as- as your son, right? As a teenage son, you know, the toll that- that took on her, which again, you know, I utilize sort of my experiences back then to try to help what I'm doing now. But yeah, it was- it was incredibly difficult. And so, it was around 16 years of age, my mother ended up having a severe relapse, that landed her in the hospital. And in parallel, she was found to have multiple clots in her legs. I don't remember if she had a pulmonary embolus, either. But from that point moving forward, [(16:00)] she actually had to be in a long-term, assistive care facility. And so from 16 moving forward, I was on my own. So, I've been on my own since I was 16 and, yeah, that was an interesting time.

Kathy: We're going to get to that. I'd like to roll back just a little bit for when your mom was home. And before that big exacerbation occurred, you've alluded to a lot of things that you've had to do. And you were in high school, and you were playing sports. Can you tell us what was a typical day like for you? It was not like other teenagers.

Dr. Newsome: No, it wasn't. It wasn't. So from my recollection, because I think sometimes to get through difficult times, you sort of block things out, and you just sort of push through. But I recall, you know, waking up quite early, helping get my mother dressed. At that time, she actually needed an assist device, which was a walker, but I'd help her get dressed, help her go to the bathroom, I would help set things out along the table that she had, you know, access to like meals and food and whatnot. Then I would go to school. Prior to practice, I would come home, just to make sure that things were okay. And then I would go to practice afterward. And in fact, you know, to still, you know, gets me at the core, I quit playing basketball, actually, because it just became too much. And, you know, I got a lot of flack from my- my friends, because they didn't understand sort of the full gravity of the situation. And at that time, I really had no idea that I'd be doing what I'm doing. And so I loved sports, it was like an outlet for me, it got, you know, a lot of stress off my shoulders from this situation at home. And so that was- that was a big change in- in life. [(18:00)] But again, I think, you know, it put me in a direction that I feel wouldn't have happened if I took those steps forward. And then I would help her get a, you know, nightly routine, in terms of bathroom, take stuff, showers, and then help her get the bed.

Kathy: That is quite the experience, to be sure. And then she went into a long-term care facility. And you two had been living just the two of you. So, you said a minute ago that at the age of 16, you were on your own. Tell me about that because you were in this home alone. How did that work?

Dr. Newsome: I was. So, we lived in an apartment, and it was very interesting, I don't think this would fly today for good reasons where there was a lot of discussion behind the scenes with various people that my mother would eventually come home. And so, for the people that were concerned like the- the place where I- you know, we had the rental property, the rental manager, the principal of my school, and the social worker. There was a little bit of oh, my mother will be home soon. Well, that- that soon did not happen. And so, you know, I lived there for the remainder of what junior-senior year of high school, and fortunately, you know, bad things didn't happen, and they could have. And I'll leave it at that because there were things that of course occurred. Your 16-year-old boy did some stuff he probably shouldn't have done but you know, meaning parties, [(20:00)] having some parties for students, and it was a- it was a good time when it was happening, but, you know, I'm just grateful that I was able to get out of that situation.

Kathy: Me too and I'm sure that your family now and your patients are also happy to hear that you came

through that?

Dr. Newsome: Well, I'll tell you-- [crosstalk] I will tell you the one most anxiety-provoking moments at that point in time, was when I decided to go to college, which I always had a feeling that it'd be going to college. But when I handed in the keys for the apartment and had nowhere to live after that, and so I moved to college. And I, you know, had families sort of in different areas. And I knew, like, if really push comes to shove, I could maybe move in with a family member. But that was really anxiety-provoking, because here I had like a suitcase, and I moved to college. And there we go. And so, I had the opportunity to live with a friend for a period of time, and I lived with a couple of different people during you know, breaks, and I had a really good support system from friends' parents when I lived alone in high school, I'd go over there and eat dinner. So, you know, it wasn't like I was totally alone in the situation. But I just remember it was really anxiety-provoking going to college because it's like, oh boy, what are the next steps? Hopefully, I don't fail out of college, because I don't know what I'm going to do afterward.

Kathy: That's just an amazing story, Scott, truly. So, while you were in those last few years of high school, your mom obviously remained in long-term care, you went off to college. What was happening then, with your mom while she was in long-term care?

[(22:00)] Dr. Newsome: Yeah. So, you know, her MS unfortunately progressed. And at that point in time, you know, different than I think, nowadays, which, you know, again, I mentioned, we're fortunate that we have many therapies nowadays. Back then there were only a couple. So, she did progress and ended up becoming wheelchair bound. And then eventually bed-bound, which, you know, wasn't overnight. It felt like overnight to some degree to me. And, you know, I had to go back and visit her as much as I could. I wasn't right around the corner. Eventually, after college, when I decided to go to medical school and beyond, we were able to reunite and be in close proximity, which I'm really grateful for because that was sort of the latter part of her years. And I got an opportunity to spend much more time even during a busy time as residency to try to, you know, spend that quality time with her. But yeah, she- she progressed, which, you know, I will say, fortunately, we see less of that nowadays.

Kathy: Absolutely, she didn't have that opportunity of being on disease-modifying therapies, other than the clinical trial, and certainly not some of the therapies that we have today that we happily don't hear these kinds of things. But there are still people who progress and have difficulties. And there are many people that I would guess, are in the same situation that you're in, that they can look back on their life and they can remember and recall similar situations, maybe not that living alone part for several years, but perhaps being a caregiver for their mom or dad, which is just incredibly difficult and challenging to be sure. [(24:00)] When you look back on that time and you reflect on it, what are the things that you... from that that you take with you now? Not just what you share with your patients, but as a person, what do you think impacted you and kind of made you who you are today?

Dr. Newsome: Yeah, we probably don't have enough time to go through all of it. So, I'll try to touch on a few things. I will say as I alluded to-- I- I looked up to my mother for a lot of different reasons. And I think early on, her desire to be the best mother she could in a situation that was out of her hands so to speak and unpredictable, that's sat with me in a way where you know when I've come up with various challenges in my own life, I just reflect back to my mother and overcoming a lot of the challenges she- you know, she did. And certainly, early on, she did not allow the diagnosis to define who she was.

And then I think, at least for the people that I see now, in my own career and taking care of patients, I try to leverage some of the experiences that I had with my mother to get a better understanding of what our patients are going through. And so, when someone talks about, you know, the hidden symptoms of MS, whether it's fatigue, cognitive issues, pain, where, you know, these are tough symptoms to quantify on the clinician side, that it's actually, these are real symptoms that people struggle with. And these are real symptoms that lead to a significant amount of disability for our patients. [(26:00)] And so having that

experience with my mother, I feel like when I hear this in clinics, I'm like, okay, I got it. This is not something made up. This is not over, you know, embellishing symptoms. This is the real deal.

And then, you know, I think one last thing is, again, I have no idea how I've gotten to where I am. I think it's amazing. It's- it's really- it's really extraordinary I guess. But looking at some of the challenges that I've had to go through and knowing that you know what, there's nothing that I feel I can't overcome with the right support system. So, this is not just a me Scott Newsome situation getting through. Now this really, and I think this may speak to some of the audience is like, you need to have people in your life. If it's possible, that can help you get through some of these challenges. And it doesn't have to be a family member. Right? It could be a close friend, it could be an advocate, a social worker, could be someone at a facility. You know, having someone by your side, if that's possible, can go a long way, in a long way, like I mentioned with some of my friends that helped out, their families that helped out.

Kathy: That's an important message to allow help. So many people are reluctant to ask for help. They feel that they're being a burden, both the person living with the disease, but also the caregiver feel that they can't give that to someone else, in a sense. So, I'm really glad that you're sharing that. Just in closing, are there some other kinds of thoughts that you have for our listeners, particularly those who are even support partners? Maybe not providing hands-on care, but you know, providing emotional support is just as important. As you've already stated, [(28:00)] a big part of what happened with your mom was her mood, and also cognitive dysfunction, and fatigue. And sometimes those are the only things that people experience and their mobility is fine. So, what kinds of messages would you like to leave with people who both have the disease and people who are helping with care?

Dr. Newsome: Sure. I think you touched on the aspect of those that have the disease, you know, being okay, to allow people to help. And I think that's critical because, you know, with my mother, there were many, many times where she did not want me to help her. And that got her into some predicaments. You know, whether it was a fall, whether it was maybe not eating something for a long period of time. And so, I think being open to allowing people to help you and, you know, when people are trying to help for the most part, they're doing it because they care about you. And even though they may not totally understand what you're going through, but they're there to try to help the sort of that extra hand to walk you through the journey.

And so, I think from the- the patient side, that that sort of, I guess my two cents. And then from the caregiver side, it's almost sort of similar and that be willing to help the individual that has the illness. You know, I think it's very easy to put walls up, especially when you don't fully understand what your loved one is going through. And it's okay. It's okay to not understand what the person's going through and you may never understand what they're fully going through. But, being there, even just as a listening ear, I think is incredibly valuable. [(30:00)] And that's- that's what I did with my mother for many, many years, I had no idea what she was going through for most of the time. But I tried to be a listening ear. And once in a while, I tried to- to speak up and- and try to provide whatever limited wisdom I may have had. And I think, you know, just being a listening ear can go a very long way. And I feel like I've tried to take that into my own sort of clinical practice is just sitting idle and not necessarily talking excessively, which I can do often. But you know, just listening to what's happening.

Kathy: Well, thank you for all of that. I know that this has been very helpful to our listeners, what an incredible story and a challenging journey that you were on. And really, as life continues now, for you, you're still on that journey. And you've carried a lot of really important things forward with you that have helped you and made you the person who you are. And for that, I'm sure you are grateful for your- the wisdom from your mother and even the experiences. And I know-- [crosstalk]

Dr. Newsome: Well, I will say-- I'm going to interject real quick. I will say, if you asked me what I would be doing in the future at the age of probably 16 through the second year of med school, there's absolutely no way I would have said I would be taking care of people with MS and related conditions. And I know we will

talk about that. And I think that that's in part because of that personal experience and I was nervous that that would be too much for me, actually, for transparency.

Kathy: That makes a lot of sense and we will hold off on that because, and I'll just let our listeners in on a little clue, [(32:00)] you're coming back. And we are going to talk about when you made that decision and what things have been like since you've actually become an MS specialist. So, with that, I wish to thank you so much for sharing your story and your experiences as a caregiver for your mom.

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Next month, Dr. Newsome will be back to talk about his career as an MS specialist, including the research he's focusing on. So, to our listeners, you've reached the end of another episode of the Can Do MS Podcast. I'm your host Kathy Costello and thank you for listening. I'd also like to take a moment to thank our sponsors for their generous support. Thank you to EMD Serono, Novartis Pharmaceuticals, Sanofi Genzyme, and Genentech. If you liked this episode, please be sure to subscribe to the Can Do MS Podcast and give us a rating and review. Thanks so much for tuning in.

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