



PODCAST

MS Care From All Angles: Partner and Provider

Episode 160 – Podcast Transcript

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[(0:24)] Stephanie: Welcome to the Can Do MS podcast. I'm your host, Stephanie Buxhoeveden. I live with MS, and I'm also a clinician and MS researcher. This is episode number one hundred and sixty, and today we're excited to welcome our guest, Timothy West. Timothy is a neurologist who has a very unique take on MS. Welcome Timothy we're so excited to have you here today.

[(0:45)] Timothy: Uh, thanks. It's an honor to be here.

[(0:47)] Stephanie: Let's start by just hearing a little bit about your personal connection to MS.

[(0:52)] Timothy: Um, well, my mother was diagnosed with, um, multiple sclerosis shortly after I was born. Um, the only advice that she remembers from that visit was that she shouldn't have any more kids. Uh, luckily she went on and had 3 more, so I have 3 wonderful sisters. Um, you know, back then, this was in the 70s, there weren't any MRIs. Um, there weren't any FDA approved treatments for multiple sclerosis, so they really didn't do much.

They kind of just sent her on her way, and she lived with it for the majority of my, um, childhood. For the most part, she was not that effective. When I was a kid growing up, I didn't really think much about it. I just knew that mom told me she had this thing.

[(1:28)] Stephanie: Yeah. That's so different than today, and it sounds like luckily, even though there were no MRIs and no treatments back then, she did pretty well throughout your childhood, but when did you really start becoming aware that it was affecting her?

[(1:43)] Timothy: Yeah, as we've learned more about multiple sclerosis over the

years, we know that a lot of people can do quite well for a long time, and my mother was no exception to that rule. She did fantastic for most of my childhood. It wasn't really until, um, about 16, 17 years later that she really started having problems. It was kind of in my late teenage years that she started to have difficulties, and that's when she started to actually go and see a doctor again.

By then of course, MRIs had been invented and there were now FDA proof medicines. Uh, so she got an MRI was told that she'd had MS for a long time. Um, and at the time there was only one FDA approved medicine on the market, and it was in such a short supply initially that you had to enter a lottery. Um, they kind of put your name in, um, and then if they were lucky enough to draw your name out of a hat, you got the wonderful opportunity of paying cash for the medicine, because insurance companies still wouldn't cover it.

Even though it was FDA approved because it was considered to be experimental. Um, and that ended up being a really, um, important memory in my, uh, life because I have very vivid memories of my parents' sitting down at the kitchen table and trying to decide, do we pay rent? Do we pay for medical insurance, or do we pay for this medicine that might stop your MS? Um, and it was a very real thing because there's only so much money to go around, and that was a decision that had to be made.

[(3:04)] Stephanie: That must have been very impactful. Did you really understand what MS was at that point? Or did it affect your life in any unexpected ways?

[(3:14)] Timothy: Uh, not, I mean, not really. As a kid, let's be honest, kids are kind of into their own thing and doing their own thing, and I was very much a normal teenager just doing my own thing, and I just knew mom every once in a while had down days, but I didn't really think much about it, and, uh, again, it wasn't really until after, uh, after I'd already left home that she started being really affected. I just started noticing she had something as a teenager because she'd have these down days.

[(3:41)] Stephanie: What about as you got a little bit older and got married? I remember you telling me about your wedding and her having a little bit of trouble walking.

[(3:49)] Timothy: I got married when I was 23 years old, and I remember her at our wedding, she was stumbling when we were doing the dance, um, at the, uh, reception after the wedding, and, uh, it was, it was the next year after that. I have this very vivid memory of the last time I saw her walk actually. We were at my favorite park in Santa Barbara, California. We were walking along Shoreline Park, if

you've ever been there. It's beautiful. It's on a cliff with this glor-glorious view of the beach of Santa Barbara, and, uh, we as kids had gone there.

I don't know, a thousand times, and we decided to go down there and do the, you know, do the things we'd always done on this, you know, afternoon, and she had a walker and she just, one of these legs just wasn't working, and I have this vivid, this vivid image of her walking down this park, um, with this beautiful setting in the background, and, um, then I went back to college, and the next time I came home, she wasn't walking anymore, and she's been in a wheelchair ever since.

Um, so yeah, that's... I think that was the moment when I decided I really need to understand what this MS thing is because it's not what I thought it was. Um, so when I ended up getting into medical school, the... it was the summer before medical school that this all happened. Uh, that's when I-I really just... I entered medical school wanting to understand this condition more and more, and just reading as much as I could about it any chance I had.

[(5:06)] Stephanie: Now, by the time you were a young adult and your mom's MS had advanced like you said, to the point of her not being able to walk anymore and needing a wheelchair, what was it like to then go from being a child very unaware of MS, to now being a young adult who sometimes had to be a care partner?

[(5:22)] Timothy: Well, it's-it's obviously an unexpected and sort of a jarring transition. I think we all make that transition eventually in life as our parents age. It's just at 23, 24 years old, I wasn't really ready for that. It wasn't something that I had anticipated, and actually it kind of by weird happenstance, I-I was going to college in Utah and I had been accepted to a medical school in California, and in order to maintain California residency, I had to vacate the state of Utah within 1 week of graduation.

Otherwise, they were gonna consider me out of state, so I didn't have a place to stay, and I actually ended up moving back home, um, for 3, 3 and a half months right before medical school. Um, because I just, I needed to be in the state, and as such, I actually moved right in and immediately became, you know, a caregiver care partner. I was, um, acutely aware of what was going on with her because I was the one kid around, um, everyone else was off doing their things as-as we do, we go off to college and get our jobs and-and doing their careers, but I was right there in the house with all of the things going on, and it was, it was very jarring.

It was difficult to watch because it's somebody who I had always leaned on for help, and now this person needed my help, and, uh, that was, that was tough. For both of

us. Very tough for her. Um, and tough also for me, and in all honesty, I was in denial about a lot of it for a long time.

[(6:43)] Stephanie: Yeah, I imagine that's more difficult than anyone could really anticipate. Do you have any specific memories of a time as a caregiver that you were torn between being an independent young adult, and caring for your mother and being there as a caregiver?

[(6:59)] Timothy: Yeah, I mean, the answer is yes there. It's-it's tough to take on this role and it's tough for the patient obviously, the person who's asking for help for maybe the first time from somebody that they used to be the one giving the help to. Um, but there was definitely a moment that, uh, sort of changed the way I approached a lot of things, which was just a random old Monday I had gotten home from work.

Um, I was saving up money to get into med school, and I was working a full day and came home and I was just watching a football game with my dad, and he and I were kind of taking turns, uh, stretching her legs out because as I mentioned this, a lot of her difficulties initially started with difficulty walking, and, uh, it led to stiffness and tightness in the muscles, which made him feel heavy.

It was harder to move, which anyone who has multiple sclerosis just knows as spasticity. This is a very common symptom in MS. It was obviously very new to us. Um, you know, and I knew what I knew about sort of stretching out legs, had everything to do with my high school basketball career. You know, you sit, you stretch the legs, you get ready and you go and you run and you play. Yeah, it's a little different with, um, spasticity, and for some reason I was really into this football game.

I honestly don't even remember who was playing, but, um, my mother called me into her room and said, "Hey, can you help me stretch?" And, you know, it was... I had agreed to do this. It was my turn, so I-I kind of went back there and I was... her legs were so tight, they were so tight, which can definitely happen. I don't if you've... it's this almost like wooden feeling, and-and so I was pushing and pushing and pushing, and I was getting frustrated 'cause it was taking longer.

I mean, I've stretched my whole life playing sports, and it shouldn't take this long, right? And I pushed really hard on her ankle to try and stretch out that calf muscle, and the whole, the whole ankle joint sort of shifted and there was a loud pop, and I knew I had done something very wrong. Um, instantly I knew something was wrong, it felt wrong. Um, she was kind of numb in her foot, so didn't really know, but she

knew something was off as well, and then she had a little tear in her eye and she said, "That's okay, you can go back to watch your football game."

I felt horrible. I felt absolutely horrible, and I had... I-I don't know if I dislocated the joint or just sprained it, but it swelled up like a cantaloupe that night, and, uh, I felt horrible, and it was, it was really instructive for me on so many ways because, you know, A ignorance played into that. I didn't know what I was getting into. I, and-and honestly I don't know that she knew. Every-every time this happens to somebody, it's-it's new and it's scary and it's... um, you know, she didn't know what she needed or how long it helped.

This was all new to all of us, but also I was being selfish and I was being impatient, and, you know, I mean, yeah, maybe we could have waited until after the football game and yeah, maybe-maybe there could have been a better time, and I don't know, there's, there's a million different ways it could have gone differently, but the way that it did go was with my own selfish desires kind of got in the way, and I ended up hurting a person that I loved, um, while trying to help them, and weirdly, one of the first things you do when you become a doctor is you make this promise.

Um, it's part of the hippocratic oath called primum non nocere which means first do no harm, and we do this sometimes in medicine in a, in a rush to hurry and help someone. We end up doing the wrong thing and hurt them, and, um, yeah, I mean the-the-the poignancy of this particular memory in my life has played out in every day in clinic, and-and the way that I treat every patient and the way that I treat my family, and, um, the way that I interact with just people I take-take a minute, pause, try to understand the situation, and then go forward.

Um, it also underscores that being a care partner is tough sometimes. It's-it's hard, and I beat myself up for a long time about that moment, and it wasn't, it was honestly, she's 8 maybe years later that I finally talked to her about it might've been 7 years later, and, uh, she just said, don't worry about it. You know, forgave me, but I felt horrible about this for so long. Um, and I-I guess that's the thing for-for those out there who are care partners, you're going to make mistakes.

You got to, you got to move on. You got to learn and then move on, and for those who are, um, receiving the care from these care partners, you know, we have to give them the space and the grace, I guess, to sort of make a mistake and then move on and grow because we're all learning in this process.

[(11:23)] Stephanie: Absolutely, and I don't think it's selfish to want to watch a football game or get out of the house, right? Have your own life outside of those you're

giving care to, and I think that guilt is incredibly common, and I think a lot of people who are listening to this are going to be able to relate to that feeling. Now, I think you've already basically said so, but did having a personal connection to MS ultimately end up impacting your career as a physician?

[(11:51)] Timothy: I mean, it had to have, I mean, for sure, my, um, you know, I entered, I entered medical school a 100% with the goal of being a pediatrician. That was the goal. I had volunteered with, uh, children's cancer camps, and I had worked in children's crisis centers through United Way, and—and my wife actually is a child life specialist, so she, by training, um, helps kids in the hospital setting to cope with being in the hospital setting, and we had this sort of grand vision of opening up this pediatric clinic.

I was going to be the pediatrician and she was going to be the child life specialist, and it was going to be fantastic, but this—this summer before medical school, when my mother ended up going into the wheelchair, actually that same summer, my father had a stroke, and, um, within the next 6 to twelve months, I had a niece who started having seizures, and then my wife's, uh, grandfather actually ended up getting diagnosed with Lou Gehrig's disease.

I mean, from the very beginning of medical school, all I was doing was trying to understand what was happening to my family, and I was reading about neurology illnesses and all of these brain conditions, and I—I just became passionate about trying to solve, uh, solve these problems and have answers and help these people that I cared about so much.

Um, and, you know, I actually ended up taking some time off in the middle of medical school, and I—I was very fortunate to have a wonderful physician named Emmanuel Wilband, uh, who was junior faculty at UCSF at the time. Now she's sort of world famous in the MS world. Um, and she took me on as a med student and helped me to do a, uh, a research project in the multiple sclerosis clinic at UC San Francisco, and from that point forward, I was sort of hooked with, um, I loved the patients.

I loved the population, but I also was so excited that there were all these new things coming ways to help true answers, where we could actually try and prevent what had happened to my mother. Um, and that absolutely drove me into the field of neurology.

[(13:51)] Stephanie: Yeah, you went from being a kid in the time where we didn't even have an MRI that could definitively diagnose someone with MS, to a medical student

at the time when we had high efficacy therapies, infusions coming out, so must have been such an exciting development for you personally and professionally.

[(14:13)] Timothy: Yeah, I mean, I-I have to say the-the... not only, it wasn't just me, but there was this just overwhelming sense of hope throughout the MS clinic that things were changing. There was an opportunity, um, there was a way for us to actually maybe slow this-this disease down because we-we knew, we knew you-you just hang out in clinic, um, for 1 week and you just see so much destruction, so much devastation in these people's lives, and now it's different.

I mean, it's still... listen, MS still stinks. It's definitely got a lot of problems. Um, but we now can do so much more, and there is so much more hope, um, for the future of people who are newly diagnosed that it is just, it's a, it's a different field and it's, uh, it's really gratifying as a doc to be able to sit in the, in the chair of the physician and give, um, hope to the people sitting in the, in the chair as a patient.

When- when my mother was the patient, that wasn't the way that went down. It was just a very different conversation. Um, it was kind of like, listen, don't have kids and, you know, you can just plan on being in a wheelchair. Um, I would start saving because you're going to not be employed in 10 years, and it was just an... it was an awful, awful conversation. Uh, and they're different now. The conversations are very different, and that is... um, it's exciting and it's wonderful, and again, more than anything else, it offers hope.

[(15:31)] Stephanie: Definitely, and I remember my first appointment at an MS clinic being the only person in the waiting room who could walk, and that is very different. 10 years later, as a clinician and a researcher, again, we're not seeing people progressing the same way, so when is the last time you had to prescribe a wheelchair for one of your patients?

[(15:54)] Timothy: Yeah, you know, it's been a while, so that's the thing. When we... when I was at... uh, as a fellow and I was being trained, I ended up finishing up my neurology training at UCSF, and then I did, uh, an MS fellowship funded by the National MS Society at UCSF. Um, but when we were sitting there in this, uh, in this fellowship in the waiting room, we'd have a wheelchair salesman that would just sit in the waiting room, uh, once a week.

Every Monday he would just come and sit in the waiting room, and, you know, he knew that if he just hung out long enough, he'd sell a power wheelchair to someone, and those things are extremely expensive, so it was a pretty, uh, decent business model. Um, but yeah, I don't, I don't even know how to do it anymore. I've-I've

renewed a couple of wheelchairs from people who have had them for many years, but I haven't given out a new wheelchair to my knowledge in at least 5 years.

It might've been more, and I think that that's... it's funny in the, in the research when you read the research, um, there's some debate as to whether or not these medicines are really having the impact that we think that they're having, but all you have to do is hang out in an MS clinic and you know that they are, you just know that they are, because I don't, you know, we don't, we don't do this anymore.

I'm not a, I'm not a wheelchair guy. I don't even, I honestly don't even know how to do it. There was... it's a very elaborate process to get one of those things authorized by insurance, and, uh, you know, we used to have it very well mechanized, a well oiled machine. Yeah, it's all starting from scratch. I-I would, I would literally have to go back and look it up again, and that's again, it-it makes me very hopeful for the future.

Um, and now when you go to MS conferences and you're looking at the research and you're reading about it, it's just, it's a very different sort of vibe to the whole place. There's this energy and optimism and hope that is, you know, it's con... it's contagious. It's wonderful.

[(17:33)] Stephanie: Yeah, I couldn't agree more, but as you said, MS stinks, no matter if it's putting you in a wheelchair or not, and you really do know MS from both sides of the desk so to speak, so has anything about caring for your mom really opened your eyes to what patients, and their support partners go through day to day?

[(17:56)] Timothy: Yeah. Um, so many things. I've learned so many things just by sort of watching my mother navigate this process, but, um, just to get back to that point of MS stinks, it still does. One of the worst things about my job is that I can't diagnose someone before something breaks. When they get a new symptom, their new, you know, optic neuritis or a numbness in an arm or difficulty, you know, walking, that's what brings them to the doctor, and so you're not going to get diagnosed with MS unless something is wrong.

There are some out there that are fortunate enough that they heal beautifully from that first relapse, but many right out the gate have an issue, and a lot of times it's kind of silent or hidden and people are pretty good at hiding that problem, and that was one of the things that was so amazing to me with watching my mother, is that she would kind of walk a little slower initially, and man, the impatience and the rage and the anger of people who wanted to get through a door or, you know, into the

mall or whatever, when, um, she was in the way was astounding to me, because I knew what she was going through, but they didn't.

They just saw some, you know, some healthy looking woman taking a real long time getting into that door, and when she ended up getting into a wheelchair, one of the things that she said, actually when she... it first started when she used a cane or a walker, she said all of a sudden the world became polite and kind and understanding because there was an outward manifestation of her inner struggle.

Um, but so for so many, that's not the case. Um, and so, you know, weirdly, it's-it's one of those things that you see, and again, it changes the way you interact with the world. Um, also just, you know, weird practical things. We... my mother has always, always, always wanted to go to Alaska on a cruise that was like her, one of her dreams. I was... she wanted to do the thing where you go on the cruise and-and go up and look in the wilderness and see glaciers and the whole deal.

Trying to get a power wheelchair onto an airplane is a process, actually. It has to be a certain kind of airplane. Not any airplane can do that because the stowing compartment down below has to have a door big enough to be able to put it in, and you can't take a power wheelchair and put it sideways because it messes with the battery and the function of the motor, so you can't use like an Airbus, those kind of planes won't work any of those, like little sort of hopper planes, they're not going to work.

It has to be a big enough plane, um, to be able to put that underneath it, and actually Boeing's have a problem because their doors are shorter and wider. Um, and actually air buses, which is the French airplanes, those are more squareish, so if you fly an Airbus, that's much easier than if you're flying a Boeing. Like how would you even know these things? I spent hours on the phone with people, um, from multiple airlines to try and figure out what I needed to do.

I had to measure the chair, I had to measure the door. I had to like Google like the plane, like what model of plane is this flight on? And it turned out in order to get her from Salt Lake City to Vancouver, Washington, I had to fly her on a big plane all the way to Phoenix and then fly her from Phoenix to Vancouver because there was no plane from Salt Lake City to Vancouver big enough for these multiple airlines that I was thinking about using that actually could get that power wheelchair in.

I'm like, "What a nightmare. How would you even know these things?" Um, and so yeah, a lot of just stuff that we don't even think about, I'll just get online and buy a plane ticket is, it's a lot more complicated for people who have legitimate issues, and

again, that's given me a lot more, um, insight and sort of compassion, not only for the patient, but also for the people who love that patient.

I mean, geez, I was just trying to take my mom to Alaska and it ended up being such a hassle, so, um, you know, I learned a lot which was great. I also randomly learned that the... at one point the mayor of Vancouver, British Columbia was in a wheelchair, so now there's like a law that a certain amount of, uh, taxis have to have wheelchair accessibility, so that's one of those weird cities where in a wheelchair it's easier. Um, that is definitely not universal.

Uh, so yeah, I think the thing is, um, a little bit of compassionate patience, um, has been, uh, passed on with each one of these experiences, and I just... whenever I see a patient and I see they've got a brand new diagnosis, I see all of the potential problems that they could have instantly, but I also can now focus on all of the hope that they have, and my goal is to keep them from those struggles because I know what they are and what they can be in-in very, very real ways.

[(22:10)] Stephanie: Yeah, I think that's beautifully said. Now, anything else that you want our listeners to consider, or to think about before we wrap up today?

[(22:24)] Timothy: I guess the one thing that I would say is be gentle with yourself. It's hard. It's very difficult because we-we hold ourselves to these impossible standards, and I'm not just talking about patients, I'm talking about care partners. Anybody involved in MS. This is a disease of the family. Any neurologic disease really is, and it affects everyone. It affects the kids, it affects, um, it affects parents. It can affect grandparents, it can affect siblings.

Um, but just be patient and be gentle with yourself. You can't, you can't be everything to everyone, and that's hard for some people because some of us sort of take on this role in life, especially, you know, moms and dads like, they-they want to be everything to their kids, and one of the, one of the greatest pieces of advice that my mother ever gave me was, she said that she struggled intensely for years with the fact that she couldn't be the mom she always wanted to be.

There was this moment she had this epiphany where she realized that even though she couldn't be the mom she wanted to be, she could still be the mother that we needed, and that was a huge sort of freeing moment for her, and I guess that's, that, that'd be the one thing I would say is just be gentle. You, you still have inherent value. You're still an amazing person. You still have so much to give and there's so much love in you and there's so many people that love you.

Um, don't focus on what's lost. Focus on what you still can do and go from there.

[(23:45)] Stephanie: I would argue having a parent with MS talking to you, I'm sure you would've turned out very well if your mother was perfectly healthy, but having children be there through the struggles makes them a little bit more empathetic, a little bit more compassionate. Maybe they'll become an MS specialist and help prevent the next generation from going through what your mother had to go through, so with the negative comes opportunities for growth, for sure.

[(24:16)] Timothy: Always, always, always. Yep. The hope—hope for the future is, uh, is a very real thing. Don't ever let that hope die, because there's always hope for a better tomorrow.

[(24:26)] Stephanie: Thank you so much, Timothy, for joining us and for sharing your really powerful story. I can't thank you enough.

[(24:32)] Timothy: Absolutely. Thank you so much.

[(24:34)] Stephanie: Thank you for listening to this episode of the Can Do MS podcast. If you liked this episode, please leave us a rating and review on Apple Podcasts or Spotify. We appreciate your feedback. If you're interested in more resources for people with MS and support partners, please visit our website [CanDo-MS.org](https://www.CanDo-MS.org). Lastly, we'd like to thank EMD Serono, Biogen, and all our generous sponsors for their support of this episode of the Can Do MS Podcast. Until next time, be well and have a great day.

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