



Can Do MS Podcast

Embracing Carers: Talking Self-Care With Jon Strum

Episode 40

Krista Sipf: Hello and welcome to the Can Do MS Podcast. My name is Krista Sipf and I am a Programs Manager here at Can Do MS. I want to fill you in on something, November is National Caregivers Month. At Can Do MS, we talk a lot about the journey of the caregiver or support partner. Living well with MS takes a team effort and we often say MS is a "we disease" not a "me disease". It affects not just the person with MS, but also their family, friends, and others who support and care for them.

Today's podcast is Episode 40 and is part of the Embracing Carers Series. We'll hear from psychologist, Roz Kalb, and guest, Jon Strum. Some of you may be familiar with Jon Strum as he is the host of the podcast RealTalk MS. We're pleased to have him today and we're going to flip the script and put Jon in the guest seat. You'll hear about his story and experiences as a support partner.

Roz Kalb: Hello, I'm Roz Kalb, a psychologist with Can Do Multiple Sclerosis. I'm really thrilled today to be here with a friend and colleague, Jon Strum. Jon, can you just introduce yourself?

Jon Strum: Oh, sure. Hi Roz. I'm thrilled to be here. Let's see, I spent about 23 years as a caregiver for my wife, Jeanne, who lived with a very advanced case of progressive MS. Just ramping up serving six years on the Scientific Steering Committee for the International Progressive MS Alliance. I'm an MS activist. I'm a trustee for the National MS Society. I also chair the societies' California Government Relations Advisory Committee. At this very moment, I am thrilled to be talking with you today.

Roz: Well, you have a lot to share with us. Before we jump in and talk more about the main part of your life story which is as a caregiver for your wife, Jeanne, I just want to talk about vocabulary for a minute. Because our listeners will hear caregiver, care partner, support partner, supporter, as well as partner, spouse, friend, lover, whatever. From your point of view, what's important about this vocabulary?

Jon: I think the most important thing about all the various terminology, really lies in the ear of the beholder. How do people process those kinds of terms? In my mind, a support partner sounds like it can be almost anyone because we all want to support a friend, a family member,

a spouse, a partner. We want to support them if they are living with a chronic illness like MS. To me, I think caregiver, probably in my mind, at least requires a little more effort than just providing that support from the grandstands. It's a little more hands-on maybe the responsibility is multiplied somewhat. I think that it's tricky because not only is MS unpredictable, but it's progressive in nature. So over time, the way we define those roles can actually change, right?

Roz: I'm glad that you've explained all that. I think at Can Do MS when we offer programs to people living with MS and their support partners, we're including anyone who wants to be there either as a spouse, a friend, a child, a parent who is providing support. That in no way takes away from their roles as spouses, partners, parents, children. That stays the same but how they provide support changes over time. With that, can you share with us your story with your wife, Jeanne, and how that transitioned over time?

Jon: I guess the easiest way to talk about my role and how it transitioned over time is to explain how my wife's situation sort of changed over time. I remember one day early on we were having coffee together. I noticed there was a little tremor or twitch in her pinky finger and I pointed it out. I asked her what that was and she looked at it and she said, I hadn't even noticed it but probably something I should have looked at. She went to her doctor who surprisingly at that moment referred her to a neurologist. Long story short, 90 days later, she was diagnosed with Secondary Progressive MS. That tiny tremor in her pinky finger eventually and quickly was a tremor in her hand and then went up to her arm and then affected her head. Then it affected her other arm and then it affected her other hand leaving her unable to do just so many of the things that we take for granted. Just everyday tasks of daily living and she required assistance.

That was my introduction to being an MS caregiver. Her mobility changed very rapidly up until her diagnosis. Jeanne was someone who would... She was an avid cyclist. She'd actually ride her bike 40 miles every single morning. She'd get up at 4:00 a.m. to get that out of the way every day. And on a weekend, she might extend that ride to actually a hundred miles. She was pretty committed to that. Within just a few years, just a few years of her diagnosis, she was wheelchair-bound and very quickly became bed-bound. Beyond tremor, she, of course, lost the ability to use her legs. She suffered from swallowing issues. She suffered from speech issues suffered from vision issues. She eventually continued evolving to the point where she needed to receive all her nutrition by means of a feeding tube. She had oxygen to assist in her breathing. She had become completely nonverbal for the last maybe seven, eight years of her life. Again, I guess I want to point out that her case was particularly cruel, and not at all what most people living with MS should expect but it was what we got. It was a hand we were dealt. As she became less capable of doing things anything for herself, I became more involved in her care. Actually stopped working for about 11 years to serve as her primary caregiver.

Roz: As a psychologist and I've done a lot of work with families impacted by MS. One of the things I talked about with couples and with families and you and I have had this conversation,

Jon is that we tried to help people find ways as one person's abilities change. Find ways to maintain a give and take in the relationship. I think about this in relation to just healthy aging not just in terms of living with a progressive illness. But because I know when people become disabled or become unable to do the things they used to do for their loved ones, they feel a loss as well. Working with couples to try to help them find ways for each person to give to the relationship and to get from the relationship. The rapid disease course that you described Jeanne having which I'm glad you mentioned is pretty rare. But how did that affect your relationship as a couple and maintaining that give and take over time?

Jon: It affected it in every possible way you could probably imagine, Roz. I guess, well prior to Jeanne's being diagnosed with MS, I always sort of look at a relationship as not being 50/50 but more being kind of 105/105. Knowing that they're going to be days where your partner couldn't be there when you might need them. It was up to you to provide that extra 5% so to speak. I think that became very very clear to me as Jeanne's disease course continued on its path. I'll also say that whatever it was or whatever it is that I've learned about being an MS caregiver, I probably learned the hard way by first making every possible mistake before I started figuring things out. But I didn't get a sense of a lot of receiving for a lot of that time. Unfortunately, as you well know, more than half the people diagnosed with MS are also, at some point, diagnosed with clinical depression. That's something that Jeanne faced early on as she was as you can imagine emotionally rocked by the changes that she was experiencing. She became not sad but depressed.

Her ability to be outgoing and she was the most outgoing person I had ever met, it quickly vanished. I found I was doing a lot of giving. I had to sort of offset whatever lack of receiving I was experiencing by recognizing that for me this level of support was just the way that I defined my basic humanity. I had a need to help this person get through the day every day. I set aside a lot of what otherwise would have been regular expectations in order to make sure I could do that and be there.

Roz: That raises a couple of important questions for me, but before I do that, I just want to remind our listeners that the clinical depression that Jon is talking about that Jeanne experienced, we now know may be a reaction to the challenges and losses of a chronic illness. But we also know that it's a very common symptom of the disease itself. It's hardwired into the body of a person with MS so that as Jon mentioned at least 50% of people will experience this. It's related to changes in the immune system and the brain as well as reacting. The first thing I want to ask you is it sounds as though is you identified your role and your desire to care for your wife whom you love very much. People may focus mostly on the losses and the challenges and the pain that you two experience. But where there are some positive feelings for you that you would want other support partners or caregivers to look for in their own experience?

Jon: Definitely. For me, it was a smile that I thought for a long time might have disappeared completely. I didn't always see it but I did and it was a smile along with eye contact that, for me, sent a message. I think every couple starts to be able to read a lot of each other's

nonverbal communication, right? That's why when you're standing across the room from your partner and they give you a look, you realize you better stop doing whatever it is you're doing. They don't have to say anything. You just got the look, right? Well, I think there's a number of different looks that can be shared. Without question, I got one that was so full of love and gratitude and appreciation and support for me that it was good enough to feel me going forward.

Roz: Great. As Jeanne's MS progressed and as you mentioned, you were not either getting or expecting a lot of support back except for this fabulous smile you just described. Where did you look for support for yourself? Did you do it as quickly as you might have looking back?

Jon: The answer to that second question is no. I did not do it as quickly as I would have or I would recommend anyone else in that situation. Unfortunately, being a caregiver, especially if you're dealing with someone with progressive MS who has more than a fair share of needs, it can feel very isolating. I allowed it to isolate me for the longest time and that was not in my own best interest. It didn't certainly didn't help me be a better caregiver. Didn't help me in any way I could possibly determine. I eventually found my way to a therapist who specialized in talking with people who are affected by MS. That became a game-changer for me in terms of reconnecting with the world and even reconnecting with myself.

Roz: When you and I have had conversations about this and we've heard other support partners and caregivers talking about beginning to feel invisible. That they are seen by healthcare providers, by family members, by friends as this person's support partner as opposed to a person in their own right. Often they're not asked: "How they're doing?", "How do you feel?", "What do you need?", "What's going on?" At what point and how did you begin to recognize your own needs and comes back in connection with yourself? Was it through the therapy?

Jon: I think it was. I really do. You know question like, "How are you doing?", sounds like a simple question. I don't have a good answer. I didn't have a good answer at first, right? Then when I started to answer the question, I didn't have an answer that I was satisfied with. I was reminded of the fact that I kind of broke one of the cardinal rules of caregiving, which is taking care of the caregiver. Self-care is so vital and it's the first thing that too often gets overlooked. That has its own set of consequences.

Roz: When I meet with groups of care partners, which I do frequently in my work with Can Do MS when I asked the questions: "How come you're not taking time for yourself?", "How come you haven't seen your own doctor?", "How come the focus is always on your loved one?" The word I hear is either guilt or that would be selfish. I would just really like your perspective on where guilt and selfishness fit in here.

Jon: Well, I think guilt can fit in... I didn't experience it but I've since talked with other caregivers who certainly use that same word. I think it stems from the fact that you're the healthy one. I think as that person is in front of you, you're experiencing survivor's guilt. That

certainly can play a part in how your overall outlook for sure. I think that when you allow yourself to be overwhelmed by a situation because as a caregiver for me I kind of lost a partner in managing our lives from the littlest thing like who's going to pay the bills to more major decisions, right? I realized that I needed to fly solo there. I wished that weren't the case but I saw over time that some of the cognitive issues that Jeanne was being affected by were certainly having an impact on her ability to be a full partner in the relationship. That, by the way, was frightening because that to me was some of the greatest evidence that a person that I knew so well was literally beginning to disappear right in front of me.

That's a lot to process. At the same time, you're dealing with the financial issues that go along with not just everyday life but everyday life when there's a chronic illness in the family and there's a lot of additions. We had what was considered great private insurance and I came to understand all the things it didn't cover. The financial pressure, the emotional coming to terms with what your relationship now is, versus what you hoped it would be, versus what you think it once was. Dealing with that level of loss can easily become overwhelming. I think when that happens you kind of lose sight of your compass. It's easy to forget about the things that are about you because you are so focused on all the other stuff going on around you.

Roz: If you were in advice-giving sort and you were speaking as you often do to other support partners, what would you want them to hear right from the beginning about their role, their self-care, their own personal wellness? What would you want them to know?

Jim: I want them to know what every flight attendant reminds us of before that plane takes off that they need to adjust their own mask before assisting others with theirs, right? I think self-care is so important. I kind of look at the caregiver walking into the room where that loved one happens to be as kind of like a weather front blowing in. As the caregiver is in a healthy state of mind, is in a good place, is going to be a pretty nice day for the patient. On the other hand, if that caregiver is already treading water and feeling a little overwhelmed and without options, well, I think all of that somehow comes across as well. That makes it a stormier day for that loved one, right? I think that if you want to be a great caregiver, you have to be great at taking care of yourself too. And first, so that you can be there for your other person. That's the first thing I would say. The second thing I would say is nobody makes it alone in much of anything in life including being a great caregiver. You want to build your social network before you need it.

I mention that because especially because we know that almost three times as often as men, it's women who are diagnosed with MS which means it's more frequent that men become that caregiver. I don't know that we, as a gender, have been adequately socialized and how to rely on a social network. I think that's one of the reasons that caregiving becomes a difficult fit for a lot of guys. But trust me when I say build that social network before you need it and use it once you've built it. That will make a tremendous amount of difference. I would mention those two things. I would also mention, you were in you got into that relationship with that other person with your loved one for some reason, continue investing in that relationship. Even if you don't feel like it is a 50/50 co-investment, that's okay because you're the healthy

one. Continue investing in that relationship. Keep communicating. Keep doing the things that you know are important to get along with anyone let alone a loved one partner, right?

Roz: I think the only thing that I would add to that for my experience with all of these support groups that I've done with care partners most of whom are men, is you say is that sometimes it is helpful for me to talk about it in terms of keeping your toolbox in order because somehow many guys seem to have an okay time relating to that. The toolbox has a lot of things in it. I think it has knowledge about MS and as much as you can, knowledge about the healthcare system in which you have to operate, which is a challenge but it means getting as educated as you can. It's the people who support you. They're also part of your tool chest. Resources from important places like Can Do MS, The National MS Society. I have to mention here your show, RealTalk MS, where people can come and hear from Jon himself and other experts about all aspects of life with MS. Again, that's RealTalk MS. But keep that toolbox as full as you can. Jon, one final question for you. If you had to pick one thing, one thing that was the best tool in your toolbox that has sustained you, what would it be?

Jon: You know what they say, knowledge is power. You want to be not only an effective caregiver but a great partner and a great advocate on behalf of your partner when you take on the healthcare system. There will be moments where you will feel like you're taking on the healthcare system. Knowledge is your best friend and getting credible reliable information from places where you can trust what you're hearing. That means places that you've just named like it's Can Do MS and it's The National MS Society. I'd like to think my podcast plays a tiny role in all that compared to what the rest of you all do. But educating yourself and it doesn't mean you need to become an amateur neurologist. But you want to be included in the conversations about treatments and options and things like that because, like all things that couples or families take on together, those kinds of things tend to be a group decision. You want to make sure that you can play your part in arriving at the best decision with your partner and the healthcare professional you're talking with.

Roz: Well, thank you. As always, I've enjoyed talking to you, Jon. I hope there are other opportunities for us to do that. Thank you for sharing your story and sharing your relationship with Jeanne. That's very precious for all of us. Thanks very much.

Jon: Thanks so much for having me, Roz.

Krista: This podcast is part of Embracing Carers. 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. Can Do MS thanks you for tuning in. Please check out more of the Embracing Carers Program on our website at cando-ms.org. Thank you for joining us and have a great week.

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