



Can Do MS Podcast

Managing Bowel and Bladder Symptoms

Episode 37

Can Do MS Host: Welcome back to the Can Do MS podcast, this episode features psychologist Roz Kalb and guest couple, Randy and Sue. We'll discuss how Randy's MS diagnosis and particularly the challenges he's faced in relation to bowel and bladder symptoms have shaped their relationship. We'll also hear which management strategies have empowered Randy to live his best life. Thanks for tuning in, please welcome Roz, Randy, and Sue.

Roz Kalb: Hello. I'm Roz Kalb, I'm a clinical psychologist with Can Do MS and I'm here today talking with Randy and Sue. We're going to be talking about bladder and bowel changes and how they can be managed so that people continue to live very full and active lives. So thank you for being here with me. So I'm going to start with you, Randy. Can you just fill us in a little bit about your history? What your life was like before your MS diagnosis?

Randy: Well, very active, I would hunt and fish a lot with my dad, well, my parents and my grandparents. I also did a lot of coaching with the boys from their little league football, baseball, and track, and continued that up until my diagnosis in 2011, and I was actually on a hunting trip when I first have my first symptoms. I had some numbness in my left foot and I was constipated during that trip which for me, for the Marlatt [?] family, constipation was not something or is not regular. That was always something that I had. So anyway, I went through that hunting trip and come back and I called my family doctor. He thought it might have been a pinched nerve but he didn't at that time tell us that he was suspecting possibly MS but it was a few weeks later, we were at a museum here close to our home and the boys are with us and we went through the museum and as we were exiting to come home and it's only about six miles away from our home, so as we're coming out the doors, I said this ooh, I should have probably gone to the restroom.

Well when I pulled in the driveway, I realized that I had wet myself and that's really what scared me because I didn't know until I went to get out of the car that that happened. So I called the doctor right away, the one that I had talked to before, and that's when he said I'm gonna contact the emergency room and I want you to go to the ER but don't be alarmed by that. He said I want to get things started right now and so he said take your time and that he would inform the ER doctor what he was looking for. So that's when the ER doctor comes back and said well, there's good news and bad news. The good news is it's not a pinched nerve. The bad news is he didn't know what it was. That's when he set us up with a

neurologist and that was in 2011.

Roz: How old were you when you were diagnosed, Randy?

Randy: Well, now I have to do the math, Roz. So 2011, it's ten years ago, so I was forty-two.

Roz: Okay. Thanks. Sue, when did you and Randy get together?

Sue: We were ninety-four.

Roz: Okay. So, you've been together a while and certainly before any of these symptoms happened.

Sue: Yes.

Roz: So, can you tell me a little bit about your sons and what was it like for you and the boys who were much younger when these symptoms happened in became more challenging?

Sue: Once Randy got the diagnosis of MS, we decided to be open with them. I know everyone has a whole different level of comfort of how much they want to share with their kids and we just knew because of the outward symptoms that Randy had, it was better to be open with them so that it wasn't embarrassing or confusing and so that we could talk about some of those limitations. We did discuss when we go on trips if there were issues and the boys understood that we had to make some adjustments and so we were pretty open with them.

Roz: Randy, we're talking about bladder and bowel issues here which are not the easiest of MS symptoms for people to talk about and they have all obviously brought a lot of challenges into your lives. So before we get into those specifically, what do you think are your strengths that helped you manage these very intrusive symptoms? what is it about you that made it possible?

Randy: Before MS, I was really independent in everything, and obviously, with some of those limitations that I have now, obviously, Sue has to assist in a lot of that stuff. I think that my independence helps with that where I want to do things myself but knowing that I can't do everything now but knowing that by the end of the day with her help, we can get through it.

Sue: Roz, if I could add.

Roz: Of course.

Sue: Randy is extremely open with his doctors which I will be honest, for me initially, I am a little more reserved and I was like oh, I can't believe he's sharing all of these details. Well, that was really important that he shared all of those details with his doctors because then they would tell him, well, that's a natural part. You'll see that in MS. That could be something that

we have a solution for. So I think Randy's ability to not only communicate with his doctors but his group of friends and workout partners at MS forward, having that support system that he's always been willing to share and he knows he can work out solutions just like other people can too.

Roz: You sound like a problem solver, Randy.

Randy: Yeah.

Roz: What about you Sue, what are the strengths that you bring that have made all of this possible and workable?

Sue: I think it's teamwork. I think that again, we both have frustrations, Randy with some of the body limitations, and like Randy said sometimes it's extra stress on having to come home from work to help out with something that might have happened but yet it's keeping the open communication, talking to each other and again, trying to figure out what the new normal. How we're going to keep moving forward and try to stay as active as possible.

Roz: So for the benefit of our viewers before we talked a little bit in more detail about the bladder and bowel management solutions. Can you describe Randy, what the rest of your MS is like now? What you're able to do? What you're not able to do?

Randy: Well, it started out where it was mild symptoms where I was able to use a cane to walk at the beginning and I didn't have to use anything then it progressed to where I was using a walker. Now, I'm in the powerchair all the time that I'm out of meds. So the limitations that I have, I have numbness from about the belly button, a little bit above the belly button down where I can't use my legs. So my upper body is strong but other than that, the limitations were what we're going to talk about, the bowel and the bladder issues. The big challenge was figuring that out and when to make those decisions and what to do about that.

Roz: Let's start with the bladder first. You mentioned that you had an accident on the way home and that was one of your very early MS symptoms. In fact, it was so early you didn't even know that you had MS yet.

Randy: Right.

Roz: So at what point did using a straight cath which for our readers is a catheter that a person uses him or herself to empty the bladder and then you put it away until the next time you need to do it. So what point did you need to start using a straight cath?

Randy: It was when I would start leaking and I would have to wear a pad and if you are active like I am, you don't think about that during the day. I didn't have that sensation or that pressure that hey, I've got to go to the bathroom. I had to remember, I got to go drain my bladder at a certain point in time, and depending on what I was drinking or what I was doing,

maybe I didn't get that done and I would leak and so I was happy to change several times a day. I started wearing Dermot pads to absorb that and it continually got worse to wear then the urologist said let's do this straight cath and so that's when I was introduced to that. So I continued to wear that then I had to proceed even further with the Foley cath which is all the time and drains into a bag and then I just have to drain the bag. It really eliminated the leaking or the soiling of the clothes I wear. That was a huge step in I guess the quality of life because I didn't have to worry about hey, I just wet myself and if I was out or whatever. You didn't have to worry about ever being in that situation where you had to cover something up or embarrassed or whatever.

Roz: Sue, is there anything you want to add to that description of the bladder management that went from a straight cath to an indwelling Foley catheter?

Sue: I think again, it was during the doctor's visits with his MS doctor, and his urologist where Randy would share what was actually happening and share that frustration if there were bladder accidents that occurred and how he could handle that or deal with that, and then when you went from a walker to the powerchair, and then it became much more difficult to constantly do the straight cath. So then his urologist talked to him about the Foley cath and there were all sorts of things that ran through my mind and I know Randy's mind as far as well, now you're constantly wearing a bag and how does that affect what you're wearing shorts or pants or just management of that. I think that was a great change when he actually did start using the Foley cath because when we go to the boys' activities, he didn't have to worry about rushing to find a bathroom or if there was even an accessible bathroom.

Randy: That the key part is the accessibility, knowing that you have someplace you can go because what started with the Foley cath was, we were planning a trip to Alaska with the boys and so I had a discussion with my urologist, we had to do a flight first and with the straight cath, how am I going to go to the bathroom on the airplane? It's not going to happen and so that's when he suggested the Foley Cath and we were kind of just playing it for this trip because we did a cruise and so on a cruise ship, at your room, you can possibly get into the bathroom but not everywhere else is going to be accessible. So that's when he suggested the Foley cath and I was able to change that myself. I didn't have to go into the clinic or whatever to have that change. So I'm still able to do that now. That has been extremely helpful to be able to manage that even if it was just going out to dinner or whatever, the first thing I would do going in the restaurant would be where's the bathroom? I got to see if it's successful and I would send one of the boys. Tyler was the best one that had to go check the bathroom out for me to make sure I would get in there.

Roz: If I'm understanding this correctly, the straight cath was the first strategy and that helped you actually time your voiding. So you would straight cath in order to avoid accidents because you kept your bladder empty. When that stopped working for you because you were in a powerchair which made it harder to self cath, the Foley became your link to freedom because you could do that yourself, you could do it at your leisure and we've already heard you're going to games, you're going to Alaska and cruises. So clearly it is giving you that

independence and freedom that's so important to you. What about the bowel?

Randy: That is the real reason, that's within a month and a half where I had issues with being constipated all the time and battling with using laxatives and I couldn't find the happy medium where I was either constipated, or it was just an explosion and that is an understatement sometimes. There were several times where laxative would be to the point where I couldn't control it because I don't have that sensation to hold it in or hold it. It would just come out. So I would be at home and typically, I'm home by myself a lot, I do go work out every other day and it was the point where I would rather be constipated than having it loose because I could control it. I would know that hey, in the morning that's when I go.

Sue helps me on the commode chair and I go and then if I was to go to the gym, there would be days that depend on what I ate maybe for breakfast or whatever. I would go to the gym and I would be concerned if I strain too much, it's going to happen and it did happen a couple of times there. I would call Sue up hey, I'm headed home. I need you to come home. We need to change. It was just a process because everything was dirty. So we had to clean the chair, clean myself, get in the shower again, and by that time I was so exhausted and coming out of the shower for the second time now within a few hours and that's when I had the discussion with the doctor regarding those issues and he left it up to me. He says I can help you but it's totally up to you that if we go with the ostomy, you have to be ready for that but he said I can tell you it will be life-changing for you.

Roz: Sue, can you describe from your perspective as a wife, as a mom, as clearly a teammate managing all of this, what this transition time was like for you? Because obviously, if you're being called home from work to help with an accident that has a significant impact on your life. What was that like for you?

Sue: Number one, it was challenging seeing Randy go through all of those body changes that he didn't have control over and I know that he was frustrated because he was a very strong independent person and he didn't have the ability to have control over that. When he first started having the bowel issues, as he mentioned, not only was it something where you might be out and about, and then you had a bowel incident and had to leave a function or had to leave a store or even an appointment but then he also started having wounds.

He started having sores on his bottom. So we would deal with the wound doctor and it would take months to heal those wounds. So in that transition, there was a lot of time and I know Randy was always worried about calling me home and it might take me a while to drive home and it was fairly quick to get resituated and get back to work but I know that frustrated him every time he had to rely on me to help him fix the situation. So when he started to talk to the doctor about the ostomy, I was pretty nervous and I don't know that I really shared this with you because it was another surgery and it was going under anesthesia and with his MS, I knew when he had a surgery years ago, it had an impact on some of the walking or it might have just been coincidental that there was a decrease in the amount of walking at the same time as the surgery.

So it's his body and his choice and I always support his decisions but I had a little bit of concern about having another surgery and what did this mean that now there's a second bag. So we had an appointment with the doctors to talk about what this ostomy bag actually looks like? Where does it actually go on your body? Could we see a sample? Can you show us what that might look like under the shirt? How does he sleep with it? Having all of those questions addressed to know before you go into surgery, that it's something that you can manage in your daily life and that it's not going to have a bigger impact. So I really appreciated the doctors having those meetings with us while Randy was making his choice and I think it was probably COVID-19 played in a little bit as far as delaying it but I think you had a six-month period wherein you first started talking to the doctor about it and when you came back again and said this is the choice I want to make.

Randy: Yeah. I'm glad that I had the opportunity to do it. It is a change but as the doctor said, it is life-changing and it has been life-changing. So if I was to say anything to somebody else that has the same type of issues that I was having, I can only say please talk to your doctor and discuss that and make sure that it's the right choice and I know it's the right choice that I made. I am so glad that it happened and the last month and a half has been life-changing because I don't have to worry about it. The only thing you have to worry about and it's a learning curve on how it all works and you'll figure it out but I figured it out and it's only been a month and a half since my surgery and it has really changed everything that I do. I go to the gym, I don't worry that I'm going to have an accident. It's all controlled. You don't have to worry about anything.

Roz: Could you just describe for our listeners what the ostomy is? How does it work? We understand that the indwelling catheter, urine collects in the bag that you then change whenever it needs to be changed. People may be less familiar with an ostomy. Can you just describe what that is?

Randy: Okay. The surgery is basically your intestine is then routed to somewhere on your belly. Mine's just to the left side and typically it's on the left side because that's where your intestines are located, above and to the left of my belly button and they will go through and figure out where it is best for the positioning of that for your body structure and that. So your intestine is sticking out of your stomach and don't be grossed out by it because I'm telling you, it is nasty to look at but it is actually your intestine and it stays moist. You don't have to worry about infection or anything like that because that was my concern, how are you going to keep this clean enough to keep it from being infected?

The doctor's explanation was simple to me because he's talking to me and not another doctor. Your intestine always has poo in it or stools in it. So don't be concerned that their stools setting on there because there will be all day long. It's setting there and it's draining into a bag and that is stuck to your skin and the bags, I've had been amazed by how they stick to your skin and my skin has not been irritated by it. There's an awesome doctor that we've seen and she goes over that with how to change that bag and all that but the problem that I

was having with the discharge through the rectum is all gone now. I don't have to worry about moisture down there, and I can't tell if it's moist until Sue comes home and we get into bed, and then she'd say oh, you're wet.

Well, I don't have that issue anymore. I don't have to worry about the sores that were created because of all the moisture or the stools that I didn't know were there because sitting in this powerchair all day unless you move within the powerchair, there are times when you don't smell it. So that's what created the pressure sores, the breakdown on the tissue. It was months, I had a pressure sore for four months and that was frustrating because I couldn't control it. I couldn't change it, Sue then would have to at night time or whenever during the day if I need to change a bandage or something like that. I haven't had any of that issue and now that they've rerouted that, I don't have to worry about that and it's been really nice to be able to put me more in control because all I have to do is pay attention when that bag fills up and then go drain it. It's fairly simple and I just hope that other people that are maybe going through this that they realize that it only comes down to just talking to your doctor.

Roz: It sounds as though it's not just independence and control which you've obviously regained and you're using to the fullest but you've also taken steps to protect your health because the skin breakdown that you're talking about can be life-threatening. So you really solved some big problems by making these adaptations. Sue, is there anything you want to add to that?

Sue: Again, communication is key. When Randy would go to the wound doctor when he first had the ostomy bags, there were some challenges and she asked if there was leaking and we thought it was maybe just more user error and it's like do you want to admit that you don't know how to do it right because it shouldn't be that difficult but when we did talk with her about that concern. She said well, we need to look at your stoma because there's a different type of bag that's convex and you shouldn't have any leakage and so just that message again of sharing with your doctor what's going on because again, we thought it was user error and she said there's a simple solution and that should never be happening. Let me help you find the solution and so I think that's always an important key.

Roz: So I have one final question for the two of you. What's the most fun thing that you've been able to do in the last month that you weren't able to do before? Most fun thing.

Sue: Well, definitely we traveled to Colorado quite a bit to see our boys since they're both in college there and with these changes, we've been able to drive. We can be on the road for seven hours, we can drive to the parking lot and attend the spring game and not have to worry that we're going to leave the spring game and we can hang out with the other parents that are there too and the social setting, we're at an RV park. Again, we don't have to worry about leaving because of the situation.

Randy: Yeah. That's probably it. Being able to travel, to travel to Colorado and see the boys and attend their football games. Now, I don't have to worry about a bathroom because I can

do that in the van and that doctor has told us you can drain it into a water bottle, the bladder. You can drain the stools into a ziplock bag and I don't have to worry about finding a bathroom and that's the challenging part. I mean, there's a lot of great places that are accessible but there's a lot that are not and they say they're accessible. Now, even a motel room, they say they're accessible. Well yeah, they're accessible but whether I have to get onto a toilet, no, sometimes they're not. Well, I don't have to worry about that anymore. I can go poop quicker now than I could before.

Roz: I was going to say there are some advantages that the rest of us [inaudible] because the rest of us are still looking for the bathrooms. So thank you very much, Randy and Sue. This is a very helpful conversation for lots of people, and your willingness not just to talk to your doctors but to share with others is a gift. So thank you so much.

Can Do MS Host: Wow. Thank you so much, Randy and Sue, for sharing pieces of your journey with us. Bowel and bladder symptoms can be very difficult to talk about so we really appreciate your openness. Big thanks to Roz for facilitating such a thoughtful discussion. Finally our biggest thank you goes out to you, our listeners for tuning in to another episode of the Can Do MSpodcast. If you haven't already had a chance to listen, please be sure to check out our other podcast episodes. For additional bowel and bladder-related resources, please visit www.cando-MS.org/bowel-bladder. A link to that page can also be found in the show notes for this episode. Thank you so much and we'll see you again soon.

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