Young Adult Series
Growing Up With MS – Part 2
Episode 14

Host: Hi and welcome back to the CanDoMS podcast. This is part two of the young adult series if you have not listened to part one yet, please make sure to go back and check out the last episode. In this episode, we have both Channing Barker and Roz Kalb joining us once again. They will be discussing how Channing's diagnosis at age sixteen impacted her romantic life, what dating looks like today, and how MS has shaped what she is looking for in a partner.

Dr Rosalind Kalb, PhD (aka Roz): Hello Channing, I am very excited to be here with you again I have had the opportunity to talk with you before in a podcast and I am looking forward to our conversations about dating. Could you tell us a little bit about yourself so that our audience can get to know you a little bit?

Channing Barker: Certainly Roz, of course, it is an honor to be with you again. I was diagnosed in two thousand six when I was sixteen years old. I was a junior in high school and was completely caught off guard by this unknown disease. That was a very young time to be diagnosed so I did not really know what the future held but I went on to live the life that I wanted to and I went to college, I went to college at the University of Arkansas. I am originally from Tulsa, Oklahoma and I graduated with a degree in political science and a degree in broadcast journalism, and I went on to take a job as a TV news anchor and a TV news reporter for about five years and was able to complete the job and do the dreams that I wanted to do with this disease. Just a little bit of life editing, I guess along the way, it was what I had to do because when you are diagnosed with that, we have to shift a little bit. I live in Fayetteville, Arkansas still and I have a dog who is precious to me and he is about five years old and I just bought a house and we enjoy hiking and being out on our trails and watching hockey and I am thirty years old, I just turned thirty in the spring so I am just loving life.

Roz: That is wonderful. I am so glad you are here to share a little bit about your life with us. And what we are talking about today is dating and the dating world is pretty complicated these days for everybody with or without MS and I am sure that living with MS adds some of its own challenges to that. Could you start by telling me how having a diagnosis of MS has impacted you starting back when you were a teenager? How did it impact your social life back then? And then we will work our way up to the present.

Channing: Yeah. I think the best way to start off is to lay a foundation of the fact that I went to school with about the same twenty-seven people in high school that I had gone to school with growing up so I was very close to these people that I had, that I was experiencing this diagnosis with and they were very understanding and this high school I went to was very very tight-knit and so when I was diagnosed, it was like the community really hugged us. Being in a larger area like Tulsa, it might feel like it is a large city, I guess to some people but it is actually very very very close very very tight-knit. When I went off to college it was this whole new world that I did not really know anybody and that was my purpose because I wanted to get out of my comfort zone and so I got to know people that were not from my area of the world. I will never forget my first date that I went on in and college because I was very cognizant of having MS but I also did not want to be labeled as the girl with MS.

Roz: Right.

Channing: Because when you have this rare disease, you do not want to have a label you throughout your entire life and my date was dropping me off in front of my dorm and I was using my handicap sticker at the time because in Arkansas, in August, it is so very hot. It is dreadfully hot, especially to those of us living with this disease. And I remember this guy, we went to dinner and he was dropping me off and my car was parked in the handicap spot and he went through this process of asking me questions to eliminate why there was an Oklahoma car with my sorority letters parked in the handicap spot. "Is there anybody from your sorority that lives in your dorm?", "Yes." and, "Oh is she from Oklahoma?", "No." And then he said, "So why is your car parked in the handicap spot?" And I just had no idea. I was so thrown off so I just told him I had asthma and I got out of the car and I just ran off and that is the moment I decided, "Okay, I gotta figure out what I am doing here." And I do not know if it has gotten easier but I have definitely put together a game plan in my head and decided how I approach it a little bit more openly and I do think that vulnerability is one of the bravest features of our generation right now and it opens up conversations.

Roz: You were clearly caught off guard as a newcomer to the college dating scene. Now that you are an adult, you must have some thoughts about what you are looking for in a potential partner. Has that been affected by the fact that you live with MS or is it just been affected by growing into an adult.

Channing: It is kind of twofold, right? One of the biggest symptoms with MS that I struggle with is fatigue and I push that to the side a lot in college because again, I did not want to be labeled. So back in college, I did not want that to affect me in my dating life so I would stay out too late, because I was trying to get to know everybody and now as an adult, that is very clearly one of my characteristics like I have to be, I want to be home by ten. Even if it is a Saturday night because that let us be real, on Friday after work, you do not want to be out very late anyway, because you are tired from the workday. I think in a partner right now, empathy has grown to be the very top factor because I think if you can find someone who you can live with, who you can be partners with, in this world and they have empathy whether it be they have a disease that working through or whether it be that they are struggling with something or that they know someone, maybe empathy is not the correct term. Sympathy. That they are able to understand what you are going through and they can accommodate that. I used to think it was religion or their political beliefs or their family dynamic, that is quickly all dissolved and sympathy, and being able to understand where I am coming from has been my top characteristic.

Roz: And if they understand where you are coming from and that you are dealing with symptoms like fatigue and other things that challenge you, you need to be flexible with those symptoms and I guess that means that they need to be able to [inaudible] symptoms as well and adapt to what is going on.

Channing: I think adaptability is actually a really good point that you are making, Roz and we both have to be very clear in what we are adapting to and why and so putting together a very clear conversation of 'Here is what I am dealing with.', 'Here is why.' Because most people that you go on dates with do not know about MS or do not know a lot about it. And so, it is my job to then educate them which I take a lot of pride in but I also have to be very clear in communicating with them. "I am not feeling well today so I am going to go home at nine-thirty and I am perfectly fine with you going to get that round of drinks with your friends and I do not take offense to it." And so there is just a lot of clear communication that has to happen in those points.

Roz: Any events that happened along the way that you look back and really chuckle about?

Channing: Yeah, I think the handicap sticker story was probably my go-to dating story. I went on a date one time that was like probably second or third day and I would say we were meeting up for yoga after work and I had not told him about having MS yet. It just had not come up in conversation. And he said, "Yeah, let us meet up for yoga, here is where the studio is...", "Okay, great." So I get off work, I put on, get there, get to the studio and he is already inside the studio and I am like signing in and they said, "Okay, so you are setting up for the hot yoga class." And those of us with MS know that hot yoga is very discouraged for a number of reasons. And so I love yoga, but I cannot function very well post-hot yoga. Anyways, I was not about to stand down. I am going to do this darn yoga class in the heat so I went through it and I am not somebody who is pretty when they sweat either. I do not think most people are pretty when they sweat. I do not glisten for sure but I was really, I was like, "Okay, I am going to do this." And so I did the hot yoga and I just chuckled to myself and said, because the irony of the whole thing, because it is one of those things we have to include communication about, heat is very bad for me. I am going to be fatigued after this so work on Wednesdays will be very hard for me because I did hot yoga for an hour. It is all about clear communication from the get-go. Granted, I do not know that I would have changed anything because I was so early on my dating experience. Then after our hot yoga class, we went to have dinner at a pizza joint around the corner and I said, I just mentioned it laughingly like, "Oh, so also, I have this disease and heat is really bad." And I should have known at that point because he still wanted to go to hot yoga. I should have known at that point that that was still, that he did not really get it? So I think getting it is also very key. Yes.

Roz: He did not have quite that understanding that he might have to be flexible...

Channing: Yeah, flexibility.

Roz: Because you cannot tolerate heat.

Channing: Yeah.

Roz: So now, when you are out with somebody, at age thirty, how do you decide what to share about yourself and when to share it?

Channing: It is a very personal thing that you decide, I do not think you ever get it right. I do not think there is a book on how to date with an autoimmune disease or how to date with any struggle you are going through but I would say I am guarded to a degree but also I tell when it feels right so I do not usually tell on the first date unless it comes up naturally. I live in an area where I used to be a news anchor so there is a good chance that they know my story before we meet because meeting through friends, they usually know a certain amount about me and I was very open about living with MS in TV and I am very open about it on social media so sometimes it just so happens that that vulnerability kind of works in my favor [inaudible] have to ever talk about it and when you are doing any online dating too, you have the person's name and so then you can stalk their social media or whatever it is that you can do. There is a couple of different things but I would say I am guarded about it to a degree and also I would really strongly tell folks if somebody asked me for advice on dating with MS, that is a very personal decision and that once you tell that piece of you, you cannot really get it back so think about it and put it in very clear terms because I have learned that when I break down the barriers of what a complicated disease MS is, then someone else can relate to it so much better instead of using complicated terminology like what you do in our doctor's office. That works much better and again, going back to being very clear about, this is what does not work for me. I think probably the best way I can explain it is, kind of the thing that you have said Roz, if you would want to know from them on a third date, then that- if you are sharing very important information about yourself on the third day, if they are sharing very important information about themselves on the third or fourth day, that might seem like a good timing.

Roz: Those of you who are hearing us tonight cannot see Channing but I will share that she is a beautiful, healthy, outgoing person, very engaging. People cannot see the symptoms that challenge you the most when they look at you. Is it hard for people you go out with to understand all those challenges when you look so fantastic?

Channing: Well, thank you. That is such a compliment Roz and that is funny because that is the one thing that I think we, as people living with MS, we always hear, "Oh, but you look so good." And I have had to kind of ring people in sometimes and sometimes like a backhanded compliment, we can fake it really well. So yes, it is extremely difficult for a partner to understand those symptoms. Sometimes it works really much better in our favor if we do not wear makeup or if we have not showered in a few days, but no...

Roz: See the real you.

Channing: Yes, see the real you. Yeah, I am not encouraging that but I do think that is something I struggle with because when you do want to go on date night, when you do want to go to a nice place for dinner on a Saturday night, and feel special but you are so fatigued and your [inaudible] your stomach is numb and you are exhausted beyond belief. How do you communicate that to somebody that you do not know very well yet? I can understand that.

Roz: Do you think you found some pretty good ways to communicate what people cannot see or is that still something you are really struggling with?

Channing: I think with the people I am close with I have been able to and that did not really happen until my late twenties because I try to be like a 'yes ma'am' to everything and I finally had to set some boundaries like, "I am not going to go to dinner tonight.", "I am not going to make supper club tonight.", "Too tired." I also think it is a really good way to weed out the bad ones.

Roz: Can you say a little bit more about that?

Channing: I think if someone does not understand, and not necessarily in a negative way to that person, but if they do not understand that you cannot physically be the best person that you want to be at that moment, they probably do not deserve you. I would say that if they do not- I know there is a saying that, "If they cannot handle me at my worst, they certainly do not deserve me at my best." But I think too, it goes the other way as well. If they cannot handle me at my best, when I am trying to be my best, they do not deserve the honor of caring for me at my worst because I think that my support partners, and friends at home, my mom, they take it as almost like it is something that I take very seriously when they have to take care of me. Not an honor because that makes me sound like I am a queen but I think it just means really cementing of the relationship you have with that person so I do not- and I do not frankly want to be taken care of by someone who does not invest that and does not understand that. [inaudible] struggle with because I do not know that on a day four, five I can say I have to go home really early and I have done that before and it is the last I have heard from them, but also, I am thirty and I do not want to stay out until one a.m. I have always been that old soul anyways, I want to be home.

Roz: You are an old soul.

Channing: Yeah.

Roz: Do you have any advice for other young adults who are living with MS? Things you have learned along the way that you just want to pass on?

Channing: I would say that this is a hard one for a lot of people because I know that holding this disease close to the vest is very important to a lot of folks and I push back a little bit up against that because I have found such vulnerability and openness to when I do share that I live with this disease. I am not speaking about when you are disclosing to an employer just to be completely clear in this and transparent but speaking with new friends or possible mates, I have found such blessings and finding the appropriate time and talking to that person about it, and yes, I am still single so it has not all- and I do not think that I am single because I have MS. I think that you share these very sacred parts of yourself with someone and when they are able to accept and understand and work with you on that it goes both ways because there is going to be a time in their life when they are going to need you to accept their differences, and their changes, and their stumbling blocks as well. I cannot tell you how many times I have said something about living with MS and that has brought in so many conversations about, "Oh, I am really struggling with depression or I have been really struggling with this new diagnosis of this really rare disease, can we talk about this?" One of my very best, best, best friends that I made in the last two years, this is really funny, we actually met on a dating app and we realized very quickly that he said, "Oh wait, I think I know who you are. You are the girl with MS." And then he went through this whole thing and he said, "I know this is really weird that I know this about you but I was diagnosed with MS the last two years" And I looked up Northwest Arkansas Multiple Sclerosis and your name popped up because I did not know what to do because I was somebody in my twenties that had MS, I have never heard of this and turns out he actually did not have MS, he had another autoimmune disease, but that has been one of the dearest friendships of my life and we have seen each other through struggles and we have seen each other through really intense times in the last couple of years living with these diseases. It is just funny and ironic how that worked out because I know so many other times where it has been non-dating and where it has been being open about what is actually happening to me that day and either within my friends, or my book club, or even in dating and sometimes it does not work out dating-wise, but sometimes it does allow that person to know that I am open to what you are dealing with too. I know that we all have struggles. Nobody is out there, no matter what Instagram might tell you, nobody is out there living this perfectly polished filtered life.

Roz: Well, thank you very much for sharing so openly with us and giving such good advice to people. I think you have a gift for sharing yourself and bringing out the best in other people.

Host: Make sure to catch our next episode in the young adult series. You will hear more from Channing and Roz again as they continue their discussion. This time focusing on resilience. And a huge thank you to all of our sponsors who make podcasts like this possible. We would like to thank Biogen, Celgene Genentech, Sanofi Genzyme, and Novartis for sponsoring the young adult series. For other great resources, check out our website CanDo-MS.org. We would specifically like to recommend the Young Adult Webinars.

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