



Young Adults Series Relationships Episode 3

Anne Gilbert: Hello everyone and welcome back to the Can Do MS podcast series. My name is Anne Gilbert, and I'm the director of programs for Can Do MS, and thank you so much for joining us today for our final episode of the Young Adult Series.

For this podcast, we'll focus on what relationships look like for young adults living with MS. We have with us again today Lucy Carriere a clinical psychologist who will be joined by Ashley and Matthew. They're a fun young couple that I had a chance to meet in Atlanta at a previous Can Do program. And so together with Lucy, we'll talk about how Ashley's MS diagnosis has impacted their relationship and how they have found some strategies and ways to communicate with one another to help surpass some of these struggles.

So now, I'd like to welcome Lucy Carriere and if you've joined us for our previous episodes, then Lucy should be no stranger to you. Lucy welcome and thank you for leading this conversation with us today.

Lucy Carriere, PhD: Yes, absolutely. I'm excited to be here and to talk about relationships today.

Anne: And Ashley and Matthew, thank you for joining us today. You guys are the first couple that we've had on our podcast so this is a real treat for us. Ashley, let's start with you. Can you tell us a little bit about yourself, maybe where you're from, how old you are and when you were diagnosed with MS?

Ashley Payne: Sure. Well, we're happy to be here. Thanks for having us. I am originally from Atlanta, Georgia and I am 29 years old and I was diagnosed in 2015 when I was 26.

Anne: Great. Thanks, Ashley. And Matthew, can you say hi to our audience and also introduce yourself?

Matthew Payne: My name is Matthew Payne. I'm from Bay Minette, Alabama and I am 30 years old, and I'm Ashley's support partner or husband.

Lucy: So with today's podcast, we're really going to be focusing on relationships and how MS

can play a role in the lives of young adults and their different types of relationships that they might have in their lives. And today with Ashley and Matthew I think it'll be really important to kind of hear from you guys and how MS has affected you as a couple. So I'd love for you guys to kind of tell me how you came about, how you met and tell me your story.

Ashley: So we met in 2011.

Matthew: Yes, at a friend's graduation party, or mutual friend's graduation party that Ashley was at.

Ashley: It happened to be my graduation as well, but it's funny because Matthew was really good friends with the guy graduating and his girlfriend was my really good friend. Anyways, we met at the graduation party and then got to know each other a few months later.

Lucy: So sounds like it was almost fate you guys meeting up, kind of mutual friends.

Matthew: It is perfect.

Lucy: So tell me, what kind of drew you guys to one another?

Ashley: Well, I think Matthew was the one because I barely honestly remember meeting him that day. He really made his first impression on me a little bit later when I saw him. I think was at church wasn't it?

Matthew: I met Ashley at church and saw her a few times. The mutual friend or the mutual couple friends we had kind of said "hey" or kind of pointed me in her direction. "You ought to try and get together." I really liked Ashley because she was very determined, very self-confident, and just things along those lines on top of being very beautiful, of course, but mainly just her self-confidence and who she was and what she wanted to be was really good.

Lucy: And what about you Ashley, what drew you to Matthew?

Ashley: Really, I think it was just how much he cared about everyone in his life, the way he was with his friends and family really showed me what kind of man he was.

Lucy: Great. So I take it, then you guys said, after some time you guys kind of met back and then started dating. And tell me what was life like before MS with you guys dating? What kind of things did you all like doing or what did life look like?

Ashley: Well, we spent a lot of time outdoors especially with our dogs. We'd go hiking to the nearest state park.

Lucy: So sounds like you guys really enjoyed more kind of physical activities being outdoors.

Ashley: And we both rode our bikes a lot as well.

Lucy: So it sounds like that kind of really defined that time early in your dating relationship and kind of a shared interest in your activities. And so as you guys are progressing in your relationship and starting to think about the future, I understand that's when you guys became engaged. So tell me what was it like kind of when MS started to come into the picture?

Ashley: So when I was diagnosed with MS we were long-distance and I was finishing up vet school though we were engaged. We'd been engaged for a few years by then. And so it kind of just took us by surprise.

Lucy: Yes, I imagine what that was like. So you guys were both away living different states when this happened it sounds like?

Matthew: Yes. I was back home in Alabama down in Bay Minette for about six hours apart.

Ashley: And I was at Florida. So it was tough being away from each other but then you know you add MS into the mix as well.

Lucy: Certainly. So Matthew, what was that like when you get the call from Ashley and she's telling you the news and kind of what's kind of going on and as much information as she knows? What was that like for you?

Matthew: I was a little worried but then again you got to really know who Ashley is. Before she was ever really diagnosed she already researched it ten times over and kind of had an idea on what we thought based on her father being a pharmacist and a medical type person and her obviously being a medical type person since she's a veterinarian. A lot of that information was already been talked about and everything. And you obviously find out that MS is a disease but it's not a fatal type disease. It's just one you have to learn to live with or cope with and do what's necessary to move forward. So she already kind of knew what was going on to some degree until when they finally diagnosed her we knew that it was anything that was going to stop her or caused her to slow down. It was going to require a little bit of time to get back up to speed but it wasn't a huge worry so we knew it wouldn't bring her down.

Ashley: So Matthew kind of talked about how I kind of already knew what was happening before the doctor's appointment. I had had my MRI and they couldn't get me in to see the neurologist for about a month after my MRI.

Lucy: Oh wow.

Ashley: It's a teaching hospital and it's very busy and so there was a big delay. But since I kind of know the medical field, I knew medical records would be available within 24 hours of the MRI. So I actually went and just read my MRI report myself and sort of knew where this doctor's appointment was going to lead. So I had talked about it and I had researched it and--

Lucy: You really did your homework.

Ashley: Yes, and I actually even told Matthew. I was like, "Matthew, this is what they're going to tell me in the doctor's appointment. You don't need to come take off work and come down." But he did. He was like, "We need to be together for this."

Lucy: You were kind of more on the fence of, "I can handle this. I know what's going to be said." But Matthew you were really wanting to have that presence there to kind of add that support.

Matthew: Yes and also needed more information. She's very do-it-yourself, but she worked in that cycle a little bit at least and would like some time to kind of break her into not wanting to do it all by herself. So it was--

Ashley: It's one thing MS has taught me.

Matthew: Moral support goes also for my information because I'm not a medical person. I don't really understand a whole lot about the whole medical world to begin with so.

Lucy: And I take it sounds there is some comfort in certainly Ashley's medical background, but also her father's and so you knew the information was there, but it sounds like there were some things you wanted to hear or questions answered.

Matthew: Yes, I would say so. She's not one to really let some information out or explaining the way that I need to hear it. So I had to ask some questions of my own and get better understanding of some things.

Lucy: Yes. I wonder, what were you specifically wanting to hear? What was kind of on your priority list?

Matthew: What the fatigue really was with the energy levels were, really what that was all about and how it would affect extracurricular activities, hanging out or going biking or in that level, then what's the difference between the actual relapses versus fatigue. They're two different animals within the same ones.

Lucy: So really, I mean sounds like great questions that you were really trying to get at almost to kind of give you a picture of what kind of day-to-day life would look like for her in terms of her functioning and getting around and kind of just doing the things you enjoy doing.

Ashley: Yes, we just didn't know. I mean no one knows what course the MS will take so.

Lucy: So for you guys, you had been engaged for a couple of years. You get this big news. This medical diagnosis is now a part of your relationship. So what was that like kind of moving on

after that? I mean was there continued discussions about it or would you go periods of time and not talk about MS? What was it like in those kind of first couple of months following your diagnosis?

Matthew: It wasn't anything bad. This is a statement that I've said to several different people at the Shepherd Center and to Ashley and other people that I knew. Ashley is a great person, always really focused on her job and animals and stuff and she loves doing lots of fun things. And honestly, if this is her worst attribute of her, then who am I to complain? Considering my worst attributes I can control, this is one she can't control. So it's not really something to ditch on or however, you want to say it to leave the relationship over or to be a final stopping point. I don't know. It was just a lot of good days and bad days and trying to figure out what's going on with that particular day.

Lucy: So that's a good point you bring up Matthew. When you guys think about kind of good days, bad days, how do you guys go about talking about the bad days as it relates to your MS?

Matthew: She keeps things bottled up. She doesn't really tell you. She wants to handle it on her own. So therefore it took me some time to continue to get her to open up to me in a reasonable amount of time to actually know what was going on. If she's silent and I don't know why she's silent I assume either I did something wrong or she's mad or something like that. But in reality, it's just that she has pain or she has nerves that are going crazy or something like that. So we had to open up that dialogue in over a period of time for her to be comfortable. So, "Hey, my legs are really going crazy" or "My body is doing reverse feelings than what they should be" or anything along those lines.

Ashley: Yes, and it took me a really long time and it's something I'm always working on because I don't feel like I'll ever have it down. But for me, honestly, sometimes I don't even realize I'm in pain until Matthew brings up. He'll be like, "Hey what's going on?" Because I--

Matthew: Haven't said a word--

Ashley: I haven't said a word and I just don't realize it. And I'm like, "Oh, you know what? I am in pain. I'm sorry for acting that way. Let me go see what I can do about it."

Lucy: Yes, it almost kind of takes him holding up a mirror to say, "Hey, something doesn't seem right."

Ashley: Absolutely.

Lucy: And like you said, it kind of fits with that kind of self-sufficient nature that you have but yet it might be a little more apparent to those who are very close to you such as your husband to say something doesn't seem right.

Ashley: Yes, and I think being self-sufficient has served me very well, but I think just like

anything you can have too much of a good thing. So I've definitely learned to talk to him more about what I'm experiencing, not just "Hey, I don't want to go out today." I need to explain to him, "Hey, I'm having really bad pain today" because those are two different meanings. In my mind they're the same thing but in his it's completely different.

Matthew: When she says "I don't want to go out today", I don't think about MS or fatigue or physical pain. I just think she just for some reason doesn't want to go out just wants to sit in the house or something like that. So you had to break things down for me sometimes, or all the time really. You got to go into detail for me to understand what you're saying, what you really try to say.

Ashley: Yes, a lot of it has to do with our communication. Just the more that I tell him about what's going on, the better everything will be.

Lucy: So Matthew what about you? So we've talked a little bit about when Ashley kind of has to communicate her needs to you and how that's been a process over the last couple years. What about from your perspective as a support partner and living with this disease as well how is it that you go about communicating to Ashley what you might need to be a better partner or husband?

Matthew: I want to do house chores and things and take care and really, like you said earlier, taking care of people or helping people out or caring about other people, I like that. And I like helping taking care of her just regardless of the MS or not. I mean we do talk about different things and what we can and can't do.

Ashley: Yes, and I think an important part too is, say, Matthew has wanted to hang out with me and watch Netflix or whatever for a few days in a row and just something's come up or I just needed to go bed earlier, whatever, he'll finally, tell me. He's like, "I really want to hang out with you tomorrow night". And so that way I can plan my day around having enough energy, you know for date night. And so I think that's an important aspect is kind of planning and knowing what he needs.

Lucy: Absolutely. And Matthew, I think that's a great example of you communicating to her that need of "I want to spend that quality time with you. I'm setting a time. I'm setting a date such that we can kind of maximize when your energy is going to be at its highest." You mentioned kind of early on in the dating relationship outdoor activities, hiking, going out with the dogs was really important to you. And so that has certainly been affected as MS has come into the picture with pain, with fatigue. So what do quality time activities look like for you guys now together?

Ashley: Honestly, a lot of it is inside especially this time of year. So it revolves around a lot of Netflix or comedy specials or movies. We got a couple of games we can play inside as well like a little corn hole thing that's indoor friendly I guess. But then we've actually just started back, able to walk the dog some in the evenings. And so that's been really good quality time.

Lucy: So again, really trying to find some things that are more conducive to kind of your energy level, temperature, such that you can enjoy one another and I guess not be out in the heat as much.

Ashley: Yes, and I think it is important. I definitely learned that sometimes it's worth a player. So I just have to plan for it. So it's not a deal-breaker anymore, but I just have to know and schedule, knowing how my MS affects me.

Lucy: Imagine it's still tough though some days when you guys are wanting to get out and go for a hike or do something outdoorsy and not able to do that.

Ashley: It is really frustrating for me.

Matthew: Yes, sometimes I might go anyway, or we'll just decide to watch a movie or something or on something that's not quite as hot or we just wait it out and go in the afternoon for not quite as much time as we would have liked to have spent at that activity.

Ashley: Or we find something else. Sometimes I really wanted to go to the lake but it's just not happening for several days. So we went to the arcade one evening because I was so frustrated with not being able to go. I was like, "I need to get out somewhere and have some fun." So sometimes we'll go bowling or whatever. But this time we went to the arcade and it was a lot of fun.

Matthew: It was a lot of fun. Got a parachute man [inaudible].

Lucy: So you're finding ways to enjoy one another that maybe you wouldn't have thought of prior to MS.

Ashley: Yes, probably not. I probably never would have thought about going to arcade as a date night,

Matthew: It was a lot of fun.

Ashley: It was, yes.

Lucy: So again, bringing in that flexibility and really being open to a lot of new experiences.

Matthew: Yes, just kind of playing forward accordingly.

Lucy: And it sounds like too, I mean, again I keep coming back to this. I think this is really the crux of when we talk about relationships and MS specifically in how it affects, it is the role of communication and how you guys are kind of ongoing in terms of what each needs, what each partner needs and how the other partner can really fulfill those needs and how this is

affecting you both, right? As the dyad. So I think it's really, really great, what you guys have been able to do.

Ashley: Absolutely. And it's hard for me to remember sometimes that I'm not the only one affected by MS, but I know it is so important to communicate and to get his viewpoint on how he's feeling.

Lucy: And for you Ashley, when you guys are having those discussions, is it as simple as, "Matthew. What's this like for you?" Or, "Let me sit down and tell you really what exactly I'm feeling today." What's that like for you?

Ashley: Usually, either I won't realize I'm in pain and he'll bring it to my attention or I will just say to him, "Hey, my legs are on fire right now. And even though we want to be sitting on the couch or whatever, you just really can't touch my legs right now because it's very painful even though it shouldn't be." It was just really explaining what I'm feeling.

Lucy: Yes, absolutely. And I think again that's something that you've really had to learn over the years but have really I think seen some of the benefit of that openness. So, great job you guys.

Ashley: It makes them a world of difference and I'm definitely still learning every day.

Lucy: Certainly. So tell me you guys, in terms of kind of the future. You've been married a couple of years. Thinking about family planning, is that something that you guys have been thinking about?

Ashley: Yes it is and it's something we disagree about. I want to have one kid and he wants to have two.

Matthew: Maybe, we'll just have twins and.

Lucy: There you go. Find a way around it.

Ashley: Yes, exactly.

Lucy: All right, so children are in the future. It's just a matter of kind of deciding on how many perhaps.

Ashley: Perhaps. Maybe we won't have to make a decision. I don't know.

Lucy: How are you guys thinking about family planning or children in the context of MS? Does that affect that discussion at all?

Ashley: I'm really lucky to know someone who has actually had a child after being diagnosed.

So I am friends with her and we talk all the time and she gives me tons of tips. But I think what I'm most worried about is the fatigue aspect. Raising a little one isn't easy regardless and takes a lot of energy. And so when you just compound that with MS I think we'll need more help than the average family.

Lucy: And have you guys been thinking about assistance from your extended family or outside help or hiring a nanny? Is that kind of what you're thinking about?

Ashley: We haven't gone too in-depth about it yet. But I would say help from our extended family and then hiring just some additional help would probably be best.

Lucy: Yes, and I think you know again being the planner that you are and that emphasis on self-sufficiency, you're thinking ahead. I think you have to. I think it's kind of one of those situations where we want to prepare for the worst, but hope for the best. And as you said, the fatigue can certainly play a role after you've had children and "How do I manage that with this disease?"

Ashley: I think just like life in general. You just have to adapt to what comes your way. It's not the strongest or the smartest that survives but the one that adapts. I mean, I think that's true with everyone. I just think people with chronic conditions or MS specifically, I think we know that a little bit better.

Lucy: Yes, I think you guys have certainly touched on how you've learned to be kind of flexible and work within this disease such that it doesn't overwhelm your relationship. You guys at your core are still Ashley and Matthew and MS is sometimes there and then sometimes it fades into the background. But you still are kind of maintaining that emphasis on your relationship and I think that's a nice segue as we think about kind of what the future holds for you guys. And how do you think about MS over the next 10-20 years? What's on y'all's mind when you think about that?

Ashley: No one really knows.

Matthew: I think Ashley's done a great job with managing herself, her body and getting herself back up to as good as she could possibly be, continually trying to be, better stronger, has more endurance. I mean I can see the difference for sure. She's put a lot of work into it over the last two years and she's done a great job. I mean she used to sleep a lot more and now she's sleeping pretty regular like anybody else would which showed which shows the effort that she's put into it and what and how she's managing herself appropriately.

Ashley: But the goal is just to keep getting stronger and stronger. About two years ago I couldn't walk to the bathroom and I was sleeping 14 hours a day. So to be able to be back at work and to be able to sleep eight hours a night is actually a really big improvement.

Lucy: Without a doubt. What do you credit those improvements to Ashley?

Ashley: My stubbornness. I am very determined and I started out slow in physical therapy and then did exercise therapy I knew where I was and I knew where I wanted to go.

Lucy: All right, so Ashley and Matthew, tell me. What are some of the recommendations that you would have for other couples facing challenges associated with MS?

Ashley: For the person with MS, I would say communicate every day. You have to let the other person know how you're feeling.

Lucy: Matthew, what about you, any recommendations?

Matthew: I would say for a support partner, they just need to be patient and willing to not look so deep into the way the person is acting or the way that they are responding and just kind of learn to let things brush off, roll off their back and move on.

Lucy: So learning to kind of strip away some of those defenses, not take it as personally and really be willing to sit down and have an open dialogue.

Matthew: Yes, that's a better word.

Lucy: I like the way you said it too.

Anne: Wonderful. Thank you, Lucy, Ashley and Matt for this very helpful dialogue today. It gave me some new perspectives on how couples living with MS can truly thrive and overcome hurdles by really having those clear and consistent and specific communication. I think this is something that we can probably all learn from and apply in our own relationships. And so I think that this was the perfect ending note to conclude our young adult series. So thank you so much for joining us.

And of course, before we conclude, I'd like to recognize our sponsors of this podcast series. Thanks to Above MS brought to us by Biogen, EMD Serono, Genentech, Novartis and Sanofi Genzyme. And also please tune in to our next podcast series which will be on embracing carers and this will provide resources and perspectives specifically for our support partners and caregivers of people living with MS. That first episode of this three-part series will be released on October 5th, so please be sure to check us out again on October 5th.

Thanks everyone for tuning in and we'll talk to you next time.

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