



Young Adults Series Career Planning Employment Issues Episode 1

Anne Gilbert: Hi everyone, and welcome to the 'Can Do MS' podcast. My name is Anne Gilbert and I am excited to be your host today. We are thrilled to bring today's podcast to you. Not only is this the first episode of our young adult series but this is our first-ever 'Can Do MS' podcast. So thank you all for joining us. To start off our young adult series, we have two guests with us today. We have psychologists Lucy Carriere and we also have KoriJo Beck who has been living with MS for the last ten years. With Lucy and with KoriJo, we are going to dive in and we are going to talk about how MS can impact career planning and employment while living as a young adult with MS. And we are also going to discuss some of the challenges as well as strategies of how to manage the unpredictability of living with MS and welcome Lucy to our podcast. So Lucy if you would like to just introduce yourself and tell us a little bit about how you came to work as a psychologist for people living with MS.

Lucy Carriere, PhD: Yes. Thank you, Anne. I am really excited to be a part of the young adult series podcast. I am a licensed psychologist and I have been working in the field of MS for approximately four years. I trained as a psychologist in a specialty MS Clinic, a large one for approximately a year, and really developed my love for working with MS and specifically the clients that I was able to work alongside. Which has been really beneficial for me as a clinician and quite I think personally rewarding and so I have continued that in my career. My various capacities presenting, researching, and working clinically with individuals with MS.

Anne: Awesome. Yes, we are really lucky to have you here to help provide us with some of your expertise about coping and living with MS. We also have KoriJo and I would like to welcome KoriJo. So if you can tell us a little bit about yourself, maybe how old you are and when you are diagnosed and what you do for work?

KoriJo Beck: Awesome, thank you guys so much for having me. I am excited to be here. I am twenty-eight years old. I was diagnosed in 2008. I had just graduated from high school when I was diagnosed. So it was a little bit of a shock. I am currently a gymnastics director and a gymnastics coach.

Lucy: Tell us, KoriJo. How long have you been in your role as a director and coach at your gymnastics studio?

KoriJo: So I have been in the director role since January of last year so a little over a year and a half and before that I had been coaching at that gymnastics studio since I was nineteen I believe, so a while.

Lucy: Yes, so it sounds like you have really enjoyed your time there so far.

KoriJo: Yes. I really have.

Lucy: And with you being diagnosed as you had mentioned a minute ago, gosh right out of high school that is such a really big time for a lot of people in deciding what direction they are going to go down in terms of

their career and the path they are going to take. Tell us about kind of the decision-making process for you and your kind of path into gymnastics?

KoriJo: So I grew up doing gymnastics, dance, and cheer and then when I graduated high school, I went to college like everybody else does but after the diagnosis of MS it kind of made it a little bit hard for my life to decide where it was going to go and I ended up going into teaching just because I have such a love for children. I taught for a year and decided that is not what I wanted to do. And so I ended up getting to... I got offered this job position as a director and I got to do both of what I got to work with kids and I got to do gymnastics. I got to coach gymnastics, which is what I love to do. So I really got the best of both worlds. I am very lucky.

Lucy: Yes, it sounds like it working like you said with children and also with gymnastics sounds like a long term kind of area of interest for you or strong area of interest.

KoriJo: Absolutely.

Lucy: Well great. You mentioned that when you had the diagnosis, you were really trying to decide "Okay, which path am I going to go down?" And you chose education and then decided that really was not a good fit for you. Do you think MS had much to do with that?

KoriJo: I think that it did because the hours were very long and very demanding. I have a lot of fatigue and that definitely made it very hard to keep focused throughout the day and when you are teaching you have to be on top of everything. Make sure your kids are always doing what they are supposed to be doing and involving them in everything. And so I had a lot of issues just keeping my energy up. So I really do think they think that MS affected that decision to be done teaching after the first year.

Lucy: Yes. So sounds like you had to make a pretty big decision rather early on in your teaching career.

KoriJo: Yes, unfortunately, I did.

Lucy: Yes, tell me was that a difficult decision in terms of switching careers with MS being such a big influence in that decision?

KoriJo: It was but at the same time it was not. I did not love teaching as much as I thought I would so it actually kind of worked out.

Lucy: Sounds like it was almost kind of a silver lining to "Okay, I need to do something that is maybe a better fit for me both physically, emotionally, and interests wise." And so it really caused you to kind of slow down and say "Okay. What do I want to do?"

KoriJo: Absolutely. I mean it was hard. It was definitely a hard decision. I had spent all that time and all that money doing something that I thought that I was going to love for the rest of my life and deciding that that was not the route that I wanted to be on and that I had to make that decision it was a very pivotal point in my life. But now with what I am doing it works. It works really well with me. It keeps me active. The hours I can actually work with my MS which is awesome. And in this role, it sounds like it is a lot more flexible for you in terms of managing those symptoms as well as just the better fit for your personality and interest.

KoriJo: Yes, it absolutely is. I am very very lucky.

Lucy: You mentioned KoriJo the fatigue and how difficult that was in your role as a teacher and I am wondering how much of that played into deciding "Okay, what is going to be the next step for me in terms of a career and what path I want to go down?"

KoriJo: I went to a lot of different routes. As funny as it sounds, I did hair for a while which I still do on the side. That was a lot harder than teaching because obviously the hours are long and standing up but it also gave me more time to express who I am. So that was actually very very nice, but I do not even know how I got back into where I am at. Everything worked out. All my ducks got in a row and it basically presented itself to me.

Lucy: Working at the gymnastic studio?

KoriJo: Yes, taking on the director role not just being a coach. I was actually asked to take on more responsibilities and be a bigger part in the gym, which I appreciated.

Lucy: So talk about a very physically strenuous job as a gymnastics instructor.

KoriJo: Absolutely. There are definitely days that I struggle spotting and doing what I love but it also is very rewarding because I am actually in the gym. So I am working out a lot, which is really great for the MS. It keeps my flexibility up. I am constantly moving which is really good. But on the days that my MS is kind of acting up or I am not feeling up to par that definitely makes it a little interesting.

Lucy: Quite a bit of an added challenge for you for sure.

KoriJo: Yes.

Lucy: So for you, how do you know it is going to be a rough day at work? What are some of the things that stand out for you or some of your kind of first signs?

KoriJo: I get a lot of the fatigue like we had mentioned before I actually get a lot of numbness and tingling in my hands and I lose feeling in my left leg and then usually my speech goes. I stutter a lot when I am having problems and then obviously the cognition point is right there as well. So all of those things definitely make my job ten times harder, but everyone at work is very supportive and very helpful with everything that I deal with. I am lucky.

Lucy: With regard to kind of your current place and you having been there a while. It sounds like there is certainly a strong level of comfort amongst your co-workers. And if you have superiors also there and owner of the studio. I wondered if you could talk a little bit about what it was like disclosing to them? Your diagnosis since it sounds like you are pretty open with them about symptoms and when it might be most days and what was that like deciding what to disclose and when to do that?

KoriJo: So I feel like I am actually a lot different than a lot of MS patients. I am very open about the MS. I have MS and it does not have me and I tell people, I do not try to hide it because I feel like people around me need to know if something happens. I need them to be aware of what is going on. And I need the support. Personally, that is just how I am as a person. So I just make sure that everyone around me is aware of what is going on and it is really hard for people for me to have people stare at me and look at me when I am not able to talk or not able to walk. And look at me like "Oh my goodness. What is going on with her? You look completely healthy, but what is wrong?" That is really hard for me. So when I am open about it, it makes me feel like I am in power like I have the control which I need.

Lucy: Yes. Yes. Absolutely. That sounds like for you one way in which you have kind of cope with the diagnosis and being as active as you are in your career. It is being really open with those around you and letting them know what is going on for you and being really genuine.

KoriJo: And I also look at it that it is a really good way for the kids around me, the kids in the gym to see someone that can completely look normal and talk and walk and just be a normal person and then the next day, have no feeling or no speech or anything like that. So I think it is actually a really good learning point for the kids and I think it is good for them because that is life and I love to be able to teach them different things about life really.

Lucy: That is great. I think that really speaks to your resiliency in dealing with it.

KoriJo: Thank you.

Lucy: Only being twenty-eight and having lived with this for ten years. You have kind of had to learn very early on.

KoriJo: And getting through college was really really hard. So it is been learning for me and I have gotten to learn about myself through the process it is taking a long time. But I have learned a lot about myself.

Lucy: What do you think stands out? If you have some of the biggest things you have learned about yourself and being so active in your career with MS.

KoriJo: I have learned how strong I am and that I can do anything if I really do want. If I want it bad enough I can do it. I just have to do it in my own time, and I have to listen to my body. I think that is been the hardest thing for me is listening to what my body is telling me. Whether I am tired or whatever it is. I have to just take a step back and I have actually had to learn how to tell people no. "No, I cannot do this. No, I cannot go out with you. I cannot do a private lesson." You know what I mean?

Lucy: Mm-hmm.

KoriJo: I have always been a people pleaser my entire life and so I have gotten to know myself and I have gotten to be more of an advocate for myself over the last five years. The first five years that I had MS, it was a mess. It truly was a hot mess.

Lucy: So it sounds like just really like you said learning your body and knowing what your limits are. I think it is only natural that it is taken time for you to learn what those limits are both physically, emotionally, cognitively, and what fits for you.

KoriJo: Absolutely.

Lucy: You mentioned college was particularly challenging for you. What did you find were some of the biggest challenges that you faced as a student?

KoriJo: So I found out that I actually have anxiety which goes along with the MS. And I had a lot of issues with concentration. I actually was able to get some extra help which really made a huge difference in my college career.

Lucy: And certainly, with the anxiety, that is going to be a challenge with or without MS. And yet in the face of kind of battling with this chronic illness and kind of the unpredictability of it as a college student, it sounds like you just really added a lot more on your plate to manage.

KoriJo: Yes, it did and being diagnosed right out of high school and then going to college, I did not have time to for it really to set in before I went off to college. Dealing with the injections and college life really. And balancing that I did not do a very good job with that. So that has actually made my life now. That has definitely contributed to me learning what my body needs which has been actually very helpful in my current career.

Lucy: Yes, so it sounds as though you have kind of taken those experiences from college where it was really challenging on your body, on you emotionally with the anxiety, which we know is rather common living with MS and you really tried to take those learning experiences with being in this career now that you love. And that you are so kind of fully invested in such that it does not feel like it is so overwhelming for you day to day.

KoriJo: I look forward to my everyday life now.

Lucy: That should be a goal for all of us, right?

KoriJo: Oh, yes.

Lucy: So in terms of your day-to-day life as the director, as a coach, it sounds like you wear a lot of different roles. And so as you were saying earlier, fatigue can certainly get in the way sometimes. The cognitive difficulties can be a challenge, I am wondering for you what has it been like in terms of developing may be some flexibility or some creativity and still completing some of the things and aspects of your job but yet acknowledging that this is going to be a little bit more than acknowledging. What has that been like for you?

KoriJo: It has been a little difficult, but I just know that any time I need help I have to ask for help and that is been the hardest thing and sometimes it can take me longer to do something so silly as moving a mat. Or walking from the front of the gym to the back of the gym, which is a huge part of my job. And whenever I am having problems and if a parent needs to speak with me, I do not talk on the phone or I do not talk in person I have them email me. It is silly things like that that make a big difference. But I also have the support of all of my co-workers and if I need help doing something or spotting someone because the safety of the children is obviously the number one priority. I know that I have a lot of weaknesses and I have to just admit that and I have to be okay with that and asking for help is okay. Everyone at work is very helpful. They are always there and if I am having problems, they see that and they acknowledge that and they tell me that whatever I need just ask. And that definitely makes me feel more comfortable with what I am doing and it makes me not so self-conscious as well.

Lucy: Oh, yes, I would imagine. You said a really important thing. You said, "I have had to learn over time how to ask for help." And recognize when having that additional help kind of outweighs the frustration of fighting through something that is probably going to be really challenging.

KoriJo: Yes.

Lucy: In terms of the day-to-day things that you do, you talked about the fatigue, tell me a little bit about how you work through some of those cognitive difficulties which we know can be quite common living with

MS? How that has affected the workplace for you?

KoriJo: I just kind of take it as it comes because you never know when it is going to be an issue. Anytime I am asked something, I cannot always remember what the issue is or what my brain is supposed to be doing. It is basically like brain fog and I just have to kind of step back and take a breath and realize that it is okay. It is fine.

Lucy: Again kind of using the same kind of things about yourself that you learned when you were in college. With okay, really challenging, step back sounds like you have tried to adapt to the system of that now here in your career.

KoriJo: Yes, absolutely. I have.

Lucy: Alright. Well, KoriJo, you have talked quite a bit with us about kind of how you have managed the fatigue, the cognitive symptoms, and the anxiety. And how from your MS and how that has kind of translated day-to-day in the workplace with MS which "My goodness, how challenging." But I think your resiliency has certainly shown through and something you have talked quite a bit. I am wondering as we wrap up if you could talk a little bit about how you kind of work towards that work-life balance that we all hear about day-to-day? What is that like for you living with MS in your career?

KoriJo: My husband is actually the one that helps me keep my work and my real-life kind of balance. He is basically my word of reason and he makes sure that he listens to my body. If I am tired I have to sleep and whether that means I take a fifteen-minute power nap. Okay, or maybe I have to sleep for six hours in the middle of the day. I listen to my body, for example, my work schedule is in the evening which is really really helpful. So when I sleep, I sleep up until my body gets up and that makes a huge difference. I do not have to force myself which like I said, the fatigue is huge. If I am tired, I am tired and I just have to deal with it and I have gotten really good at shedding my work life out of my home life. When I am at home, I am at home. I am focused on cooking dinner or spending time with my family. When I am at work, I leave home life at home. So that makes a big difference and that way I am not stressing out about silly little details about the day. Whether that be whatever happened at home, my dog did something bad or you know.

Lucy: Set those boundaries.

KoriJo: Exactly. And I mean that is just for anybody, that is just life, but that also just truly does help with the stress factor. So that way I am not dwelling on silly little things and causing my brain to constantly work which also causes the stress which also causes this. You know what I mean like one thing always leads to another thing, which does not help.

Lucy: Absolutely. So for you, you have learned this really snowballs my fatigue, affects my anxiety and my anxiety is going to worsen my fatigue and there goes your focus.

KoriJo: Exactly.

Lucy: You know that you are on a spiral. So like you said learning your body. Doing that body check and recognizing when you need the extra rest or you need to take kind of a timeout so that you can be kind of fully present at home or at work and being kind of the most authentic you.

KoriJo: Absolutely and doing yoga helps meditating and all of that. That really does make a big difference too.

Lucy: That is fantastic. That is a really great point that you mentioned. Certainly, I am sure some days working towards that balance is probably harder than others.

KoriJo: Oh, absolutely, life.

Lucy: Right. You have the plan in place and how you need to do it but some days with the unpredictability and uncertainty sometimes with these symptoms that sounds like where you have kind of pulled on that flexibility and resiliency.

KoriJo: Absolutely and thank you. I appreciate that.

Anne: I think this is kind of a good place for us to wrap up. I think work-life balance can be a challenge for all of us. I know for me too. And I like what you said KoriJo is you leave work at work and when you are at home, you are at home and you focus on being at home and relaxing and listening to your body. So I really appreciate you both joining us Lucy and KoriJo. I had a great time listening to the conversation and learning more about the ups and downs of living with MS. And how to balance your work and how to make it work for you. So KoriJo, thank you so much for sharing your experience with us.

KoriJo: Yes, and thank you guys so much for having me. I appreciate it.

Anne: Yes, absolutely. And thank you too, Lucy. I did want to share for those of you that are listening that there are resources out there for you to access about whether it is about had to disclose to your employer about your MS or just how to manage some of your symptoms. You can access resources on our website through some of our employment webinar series, or you can also go to the National MS Society's website and find some local employment resources as well as some programs available there. So there is a lot of resources out there for people living with MS that might be dealing with some of these employment issues.

Anne: Before we would conclude, I do want to recognize some of our sponsors that helped us to deliver this podcast. Thanks to Above MS that is brought to us by Biogen, EMD Saronno, Genentech, Novartis, and Sanofi Genzyme. We really could not put on these programs without our supporters. And also, please do not forget to tune in to our second podcast in this young adult series on the topic of mood and cognition and that will be available on Tuesday, August 28th. So, thanks so much for tuning in everyone, and we will see you next time. Thanks again, Lucy and KoriJo.

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