



Young Adult Series

Growing Up With MS – Part 1

Episode 13

Host: Hello and welcome back to the CanDoMS podcast the next three CanDo MS podcasts are part of the young adult series. They will feature Channing Barker, a young adult living with MS. In part 1 of the series we will hear from Channing and her mother Patty about what it was like growing up as a young adult with MS.

Host: Along with Channing and Patty we have psychologist Dr. Roz Kalb with us. She will be leading today's podcast. Thank you so much for being here.

Dr. Rosalind Kalb, PhD (aka Roz): Thanks very much. So I am Roz Cold and I have been a psychologist in MS for thirty years and a few years ago, now I had the pleasure of meeting Channing Barker and her mom when Channing was first diagnosed with MS and I am honored to be having this conversation with the two of you. Channing, could you just introduce yourself and explain a little bit about who you are and your background?

Channing Barker: Yes, thanks Roz. Yes, my name is Channing and I was diagnosed with MS when I was a teenager, I was 16 years old and I am now 30 years old. I live in Fayetteville, Arkansas, which is the Northwest part of the Natural State. And right now I am the communications director for my County Government and I have come a long way as far as from my diagnosis until now and I am really excited to be talking to you guys today about where we are and relationship as another daughter and also just how far we have come with this disease. It is very exciting time.

Roz: Thanks, Channing and Patty, could you also introduce yourself?

Patty: Yes, hi. I am Patty and I am Channing's mother and Madeline's mother as well and I am not going to tell you my age, but I currently am the hospital relations director for the major blood provider for this region. I keep myself very busy with that. I live about two hours away from Channing now in Tulsa, Oklahoma and I volunteered for the MS Society on the president of the Oklahoma Community Leadership Council and volunteer in various ways for the society and advocacy and fundraising as well.

Roz: Well, thank you both for all that you do and clearly you have very busy lives apart from dealing with the challenges of MS. So again, thank you for having this conversation with me. So I am going to start with Patty first and I just want to ask you what was your relationship with Channing like when she was a teenager prior to her MS Diagnosis?

Patty: I think our relationship was rather unique. I have been a single mother since the time Channing was in kindergarten and her sister is six years older than she is. So we had a really unusually strong bond and we talked about a lot of things. We were very transparent with each other. We call ourselves The Barker Girls our own little gang but it was not unlike a typical mother-daughter teenage relationship when she is spreading

her wings and gaining independence. But again, I think it was unique in the fact that we were very close to one another. At the time Channing was diagnosed her sister obviously was in college actually, I think she might have been in her master's program at the University of Arkansas at that point. So we had many years just the two of us and our dogs at home together. So it was a really unique relationship. I think we have always had kind of a unique bond. Our personalities are very similar which can be a blessing and a curse at times but I do really cherish the friendship and relationship that we have especially as it is evolved into adulthood.

Roz: Hearing you talk reminds me of some of the years when my daughter was a teenager and some of what you said rings true and it was a little different.

Patty: It is funny because there were every teenager has to spread their wings and discover their independent spirit but she could never buy to me. She only tried once and it was about a babysitting party well a party she had while babysitting I should say with the permission of the people she was babysitting for but not the permission of her mother and somehow I just looked at her and knew. So that was the one and only time that that.

Roz: That is remarkable and a very close bond. If you could pick that up. Channy, is there anything you want to add to the description of what life was like before you are a mess?

Channing: I think it is important as we go into this discussion to recognize that we were the best of friends and we are so very very close and very very good friends. And that was very unique not just for our situation that I think for a lot of situations for teenagers when they are in high school. We just had a very admirable respect and trust for one another and that carry still to today.

Roz: So Channing when you were diagnosed, did any of that change or how was that closeness and bond affected when you both heard this news about a mess?

Channing: Well, I think it actually strengthened our bond because we became closer as we were going through these trials and tribulations because it really was the two of us against the world. We have a team of doctors and specialists that were helping us along the way but my mom was my greatest picket. While I was unable to walk and was laying in the hospital bed. I know that she was outside the room and trying to understand and research. I can not imagine now it is thirty year old, I ca not imagine what she must have been going through. I am not a parent right now, but I can not fathom the heartache and the anxiety of watching someone you love so dearly go through what I was going through and so I know that she was taking a lot of that on herself, whether it be researching or trying to find out what doctors were talking about.

So I am in this stage of my life. I think it is strengthened our bond because we were able to go in through this very very uncertain situation together. It really strengthened us.

Roz: So Patty given what you said about how close you were and you basically knew what each other was thinking or what Jenny was trying to hide. So what was this like for you when you hear Channing's diagnosis? So as a mother, I am sure you had all kinds of feelings, worries and fears, did you keep some of those to yourself? Did you share them all? What happened for you when you heard the diagnosis?

Patty: Well, first of all I want to tell you how I was at her. I started seeing Channing in a different light. I always knew she was a bright light. I have always called her "my chanshine" instead of sunshine and seeing her smile never leave her face even when she had a spinal tap, headache whatever those are called and her pain level was remarked as being at nine. She was always smiling and she was always concerned about how

other people were doing, they came to see her. That not seeing that aspect of her character on a daily basis and seeing that face the way she faced adversity, I put my respect for her as a person on a different level.

Patty: But when she was diagnosed at Stony Brook, I remember the very moment like it was yesterday and she got in the van and she is texting all her friends "I have MS. I have MS." and she was literally excited about it. I remember my feeling looking at her and I said you heard what they said, right? and she said "Yeah, I have a mess." and I said "And you know that is not curable, right?" and she is "Yeah, but Mom, I do not have a brain tumor. I am not going to die. At least now, I know what I have and I can face it head-on" she said "Mom, everybody has something and this is just my something" and then she went back to texting and chatting and laughing and I just sat there in that van shaking my head like no adult that I know would react that way. But this is Channing and it carried on when she got home and she marched her happy self over to the MS Society office and started a walk team and got involved in. Honestly, I just followed her lead. But I was petrified in the moment but watching her, I had to follow her lead because I was not going to steal her joy or steal the confidence that she had or the faith that she had, I was not going to do that. So it was easy for me to follow her lead.

Roz: Interesting. The teenagers I think sometimes bring to life crises like this a different vantage point than adults do and so excitement at knowing finally what the answer was but also not having the full perspective of what the future can bring a loud Channing. It sounds like to just see this as the next step, next phase something to share with your friends and you meanwhile Patty were having to think as a mom and figure out what some of the next steps should be. I want to back up for a minute because in your introduction Channing, you talked about what your new full-time job is but your mom's description of your early MS makes it clear that at the very beginning you were having some very very significant disabling severe symptoms. Could you describe what your MS was like in that early time after your diagnosis?

Channing: So I am all back up and talk about how I really knew something that is wrong. On January 24th of 2006 was the day I had my very first and mess symptom that I could physically notice. Mom will say that it was even before that with fatigue...

Roz: You took that as a teen.

Channing: Yeah. Mom will back up and say that it was really when she could notice my fatigue and that late fall of 2005, but I remember it is very specifically because I was cheer leading at a basketball game and I could not jump or kick. I had to have my cheer squad take me down from a stunt that we were in because I could not feel my body. And then from that point on it was a series of spinal taps and testing and IVIG therapies and I just could not feel my body at first. I had numbness all down my right side of my body and then it started going from my stomach all the way down through my leg and then that just turned into complete weakness and inability to walk. And that feeling everybody who is with MS knows this feeling that you suddenly lose power over your leg and or your legs and it is this cringe factor when you are trying to curl your toes and you are working so hard to do that and you can not curl your toes and it is such a simple task and your brain is telling your body to do this and you are putting out so much energy to do something so simple and at is sixteen, you feel like an idiot because you do not know what is happening to your body and suddenly you can not curl your toes. Suddenly you can not dance or check or point your toes because you have been a dancer your whole life and this is just second nature to you and those symptoms were the most seen.

Channing: Those are the physical parent ones that people can notice from the outside. To me I think the fatigue was the largest symptom I have had in struggle with today. But as a sixteen year old in high school, no, you do not want to say no to anything right? You want to keep going and I was very active. I was a

dancer. I was in cheer. I was in student council. I was in faith-based group groups. I was in leadership councils. I did not want to slow down and so this disease stopped me from moving and that was the most physical parent symptom and to me that was when I knew something was wrong was that I could not keep up with that 24/7 three hundred sixty five lifestyle.

Roz: Well, we are glad to hear that a lot of those symptoms improved and we will hear more about the ups and downs you have experienced. But now we know you are working full-time and active again. And so we are very very glad to hear that. So at the time of the diagnosis you suddenly then were surrounded by this healthcare team you talked about. How did the two of you-Channing you were a minor at that time and Patty was your mom. So how did the two of you communicate with the healthcare team and direct with them? How did it work?

Channing: So I will start this one out because from just the visuals, I have been laying in the bed and having the doctor surround, it is like this team that was coming in and start analyzing, working, catching my knees say if I could feel certain things, see if I was reacting to certain tests, neurological tests. All that was spanned from Tulsa, Oklahoma all the way to Stony Brook, New York. We were finally diagnosed and I do say we because it is a team effort when you are going through this and it is not just one person that is affected when you have multiple sclerosis.

Channing: I just do not have the size to strong visual of my mom sitting in and that she is standing up, me laying in the chair and her eyes looking at me because she knew so specifically that she did not want the doctors to talk to her. She understood the language. Mom has been in healthcare and healthcare fields for a number of years working in medical sales and then in her current job, so she was understanding these jargon that was completely foreign to me. She wanted them to talk to me even though I was sixteen and in pediatric care, she wanted them to speak directly to the patient and that she was stood up for me when she knew I was understanding something because when you are in that position, when you are flat on your back literally, you are not really able to transcribe all what is happening. She knew that.

Patty: I always despised in healthcare and I had worked in intensive care before. Always despised it when doctors spoke about a patient who was laying right there. Who was perfectly capable of maybe carrying on a conversation or at least listening to a conversation and they were treated as if they were not in the room, but I also knew that whatever was happening to her prior to her diagnosis and then of course afterwards that this was her disease, this was her body and I looked at my role as being her advocate and being the note taker making sure everything was written down, that questions were written down but that she was in charge and she was a participant in her health care. That was very important to me. And it also probably selfishly helped me stay calm and helped me disengage a little bit emotionally so that I could be more rational when it came to fighting for her.

Channing: And I think it is really important for other people who have gone through this process or who are going through this process. Mom was very much an advocate that she was a partner. She did not stand behind me or in front of me. She stood beside me and that is something I look for today in a partner as well. And because she had this huge record binder folder of every test, everything that you could ever imagine and I have tried to carry that on into my adult life now, but it was very much a partnership and it was very much a lifting each other up and the holding each others hand as we went through that and that is really helped me understand my role as a patient in today's healthcare field.

Roz: So thank you both for that. It is very helpful because now- I think your 16 at the time you are diagnosed. You have a little bit of time to get your feet back on the ground, figure out what is next and then all of a sudden it is time for you Channing to go off to school. And can you tell me and we will start with Patty first

or what was it like having been so closed and walked side by side through all of this to have your youngest fairly recently diagnosed with MS head off to college?

Patty: Petrifying. I mean I wanted her to have the best college experience ever and because I certainly enjoyed a college but I also wanted her to take care of her health and place that as a priority and I am was not all that confident that was going to take place in the beginning. Because honestly, I started to feel her desire not to be identified as that the girl with MS anymore. She came from a school that was such a wonderful family kind of guarded community. She had been in school with some of these kids since kindergarten and she still best friends with those girls today, but that community had wrapped their arms around her during this whole time period. Teachers, administrators, parents of friends and now here she goes off into the wild blue yonder and I was nervous about it. I was like, "Oh, gotta let her go." but "Oh, want to make sure she is taking her shots." and we talked every day and it was a little bit difficult. It was petrifying and honestly because our home had been the place where every one of her friends had congregated and there was so much laughter and joy. When she left, just the empty nest syndrome of the silence being so deadly. That was hard. But then you are sending her off with this disease that she is still kind of getting to know. So it was it was a little nerve-wracking.

Roz: Sure. Channing, so a couple of questions related to this, I am sure you had the mirror reactions about leaving home, leaving your mom, you would go to school. So I'd like to hear about that but I would also like to hear how you talked about yourself once you got to college. Did you share your diagnosis? Did you ask for any accommodations from the school? How did you make that transition away from home into the school environment?

Channing: Well, first I will say that there is not a handbook for how to deal with the diagnosis at sixteen and in less than a year ago off to a college, two hours away from your parents and then how to live a social normal life with a disease that is hard to explain, right? There is no guidebook for that. So we kind of made up our own and we have had our own trials and tribulations with that. I think leaving-there was not really a hope. Now that I look back, I do not know the I thought a ton about living with this disease and going to school. As I was taught, you move and you press on and you live the life you wanted to live.

Patty: Well we went to-what are the things we did before school started?

Channing: We went to-they did not call it the disabilities office.

Patty: Okay. What was that called?

Channing: And we went to the Center for-oh my goodness.

Patty: Oh gosh, I can not remember

Channing: But it is like an accommodations. Okay here I will start over and one of the things that we first did when were looking at schools, we went to the center for educational access for students on campus whether it was a train campus or would we actually went to the University of Arkansas that within and talk them through what I was going through and it was a new thing for them. They had not really had anybody with this disease. And so again, this disease as many people know is not something that is consistently apparent physically. So explaining it to teachers, explaining to other professors or students what you are going through and that you may not look sick but there is a really good time that your brain is not functioning like it should be. That was really important to us and very important to me looking back.

Patty: Because you need a dorm access so that you were not having to climb stairs all the time. And you also need testing accommodations.

Channing: So one of the things that was really important and is still very important is staying out of the heat and also keeping your fatigue at a low if you can and this campus is very hilly. It does get very hot in the summer especially when going into the fall and so in order to get a dorm accommodation and not having to use the stairs constantly I had to use the center for students for accessibility. And so that was really important and I also think I did not see the need for that center. Then I look back and see how much it did for me as a someone living with a disability. So that was one of the first things that we did when going and looking at schools. And what else, I am sorry. I will need you to repeat the other question. I can not remember what it was.

Roz: How it felt for you to move away from home having been walking side by side with your mom through this, was this feeling like an adventure? Did it feel like freedom or did it feel petrifying as Patty said.

Channing: Mom is really good at hiding really how she is feeling I think that I knew that she was scared, but I think I was more scared of just being away from my best friend. There was not a scary thought of "Oh, I am worried about this disease and what is going to happen to me?" It did not really cRozed my mind a whole lot because I was living so-I was doing so well at that point with this disease. Again, it was not apparent in my everyday life so I was not having these massive relapses and as a freshman in college, I really wanted to live the full life. I wanted to go to everything. I wanted to meet new people. I did not want this disease to slow me down, but after I probably get myself a little strip myself a little too thin and I did have an episode my freshman year, I relapsed that I did have to call my mom and tell her what was going on and thank goodness that I was close to home and had a good relationship with my doctors and we were able to work that out.

Channing: It was not scary for me to leave home because I was so excited about school. It was scary for me to think about not leaving home. To think about this disease holding me back that was scarier to me and now looking back again as an adult. I think my mother did an extremely wonderful and outstanding job of being a parent and giving me this freedom. Allowing me this freedom and all those this sheltered idea of what I really was dealing with because it had not really hit me and when you are kind of living in a utopian world when you are diagnosed because you are-it does not really sink in. I do not think you do not accept this a lifelong disease for a while.

Patty: And I think when she did have that episode her freshman year is when it really sunk in to her that this is a serious thing and I need to face this head-on. I remember coming over and getting her, bringing her home for a couple of days and she went back to school a kind of a changed person. She started at the beginning of each semester giving each professor a folder explaining in us and what her limitations and needs were and what she told me later was it opened a different relationship with each one of them. And through her entire career here at the University of Arkansas, there was only one Professor who was blind and deaf and dumb to the whole situation. I think she developed deeper relationships with them. She was able to be more open and transparent with her sorority sisters and with other people that she met on campus. She like I said, I saw that she was tired of being labeled the girl with MS and so she came over here and tried to not be that girl, not talk about it and found that honestly transparency was the best policy.

Channing: So Roz I will say that if that is okay with you. I do not think I expressed that very well in my end.

Roz: Whatever you want to do.

Patty: But I answer that question.

Channing: So my freshman year I really was trying to start over, start new clean slate. So I was going in did not want to be identified as this girl with MS because that have kind of been my brand at my senior year of high school really when you think about it I was fine with that because again, these people had known most of my life and I was perfectly fine with what I was living with so moving two hours away and living with this disease. I wanted a fresh start so I did that and I did not really tell people that I had this disease. Then when I had spread myself too thin and this disease reared its ugly head. I had to take a close look at what I was dealing with and how it affected me and how I was going to communicate that moving forward and one of those Monday Morning Quarterback. Insights was hey, let us make some packets for my my professors and even for my friends give a short elevator speeches to what it is I am dealing with and those packets included pamphlets about what a mess is, how it affects me, what I need from them because really when you are talking to professor, they just need to know. Okay, so what is this mean for me and for you and our relationship? How are we going to afford? How can I make you a better student? How can you make me a better professor?

Channing: And that opened so many doors. Teachers telling me about what they were dealing with, which they never had to do. They opened up to me. Then I had very close sorority sisters who opened up to me about what they were dealing with or if they knew someone was dealing with this disease. I even met a sorority sister who lived with MS, lives with MS. And so it is really been an eye-opening opportunity to find others stories and what they are going through. That does not work for everyone and I am very understanding of that but it worked for me.

Roz: Well, it sounds as though you had a really wonderful way of both conveying your needs to other people as well as education. So they would understand what was going on and you must have done it in a very warm and caring way because you encouraged people then to open up to you so it does not get much better than that. I am sure you had some wonderful relationships. The other thing that I was thinking about something you said earlier about going to the accessibility offices before before you started school and you said you as a teenager knew MS, you did not really see how that was needed or how that would be helpful, but I do not know, somehow in your wisdom or your mother's wisdom you did that and then we are able to see in retrospect how helpful that was and how important. I just I would encourage other people to take that as a lesson as well that sometimes knowing about what accommodations are available to you. If and when you need them helps you feel more prepared if you run into difficulty down the line. So I think doing that sort of unfaith at the beginning was a very very smart wise thing to do.

Channing: Thank you. I just really encourage people to do that because if you were visiting campuses and you had get a great vibe that speaks volumes about what your future experience on that campus can be. If you do not get a good vibe, you might want to rethink that choice.

Roz: I think that is a terrific advice actually, so you both mentioned this relapse that happened and I would like you both to talk about that a little more. Channing, I am sure that that first relapse during college was a real eye-opener for you, must have been pretty upsetting in a variety of ways. How did you react to it? Do you remember?

Channing: I think that there was a real moment of darkness because I am going full throttle going to every party, going to every function, trying to make it to class. I made it to class that is prefaces. You are trying to go to class and make new friends figure out what time management is and then suddenly your life stopped because you can not move and you can not feel parts of your body. It was very dark. I got very sad because I did not know, does this mean I have to go back to Tulsa and go to college home at home, which is fine if it is what does it means. But I really had felt like I have conquered this disease and it was a very much a shock

and a face-to-face with this disease. Reality check. It was a very much reality check. I realized that I needed to find a counselor on campus. I needed to speak to a neuro-psychologist. I need to see what other options there were and it was part of learning how to be my own advocate really but I think going through this pit was part of the first step to realizing I am the one who is in control. No one else.

Roz: You think you were depressed looking back?

Channing: Oh a hundred percent and because when you are diagnosed with this disease, no one really talks to you about the mental health state you are going to be in. At least thinking for me. I do not blame anyone for that because I am a very peppy bright person, but the anxiety and the depression that come with this disease are unruly and that does not stop whether you are on medication, whether you are talking to someone. This disease makes you chronically fatigued, your in your bed five hours on a Saturday because you are just so tired and I think that that is one of the things that they do not tell you when you are going into college. Living with this disease is how tired you are going to be and you do not want to miss out on anything.

How do you handle that? And I have been on the same antidepressant for a couple of years that point.

Patty: Well we started when....

Channing: When I was diagnosed. Yeah. So there were definite mental states that I was going through absolutely.

Patty: But you learned a lot of coping mechanism. I think you relied on your faith. This is from my perspective as your mom. I mean you were talking which I think a lot of times that is very difficult for people especially man who struggle to identify those feelings. And is this valid? Am I weak? What-all the typical feelings that someone goes through trying to identify why am I feeling this way and the fact that you channeled that in ways that work for you, counseling, medication. You did try to exercise when you could and those kinds of things that help your endorphins.

Channing: It was also this relapse seems like a very much a blur to me because I do not really think I understood fully what was happening. I did not understand the stage of acceptance. I was at with this disease.

Patty: And because it is a grief process over what you originally thought you were life was going to be. She had a timeline man. She was I am going to do this, I am going to do this, I am going to do this at this age this age, this age, this age, this age. And MS Interrupts those things. It does not mean that it has to never come to fruition, but it might alter your timeline little bit. But there is just like with any loss, there is going to be grief that you must go through.

Roz: Channing, was there ever any point during that rust spot when you thought you might have to quit college or give up or change the course of things for yourself?

Channing: Yes. I very vividly remember mom coming to town when I was really struggling and we went to this little cafe that no longer exists and she would say things like "just give it one more semester, you are not going to quit, you are not going to quit." and I needed that tough laugh. I needed the someone to say "You are not going to quit. You are strong. You can do this. You can follow your instinct and what you want to do is quit right now, but wake up tomorrow and we will talk. You are going to get through this". I always failing an algebra class if I remember correctly. I was really struggling in some classes because I was just my brain was not clicking and you feel like it is completely your fault that that is happening. When in reality it was a

lot of things fatigue, anxiety, really rough depression but I wanted to stop. I wanted to come home which is funny that I am saying this now because that was the biggest fears like I do not want it like when you are going into school, like I do not want to go out. I want to go off, I want to be and do and go. And then your mom midway through your first semester like I am just going to quit. I can not throw my hands up in the air. I am too tired. I do not want to deal with this.

Patty: She had wanted to be a journalist since she was like two and a half when she could talk and stand in front of the television. She was the strangest child. She would watch the news and point at the screen and say "I want to do that, I want to do that." and that is what motivated me to say "No, you are not going to quit right now. You are going to give it one more day. Take it one day at a time. Finish the semester and then re-evaluate and evaluate". I would have welcomed her home. I would not have judged her but I just did not want her to make that decision based on those feelings at that moment.

Roz: So Patty you are now in a slightly different role than you were when Channing was sixteen and living at home. She is now closer to being that young adult. Who is moved away when these medical things happen. Did your role with the healthcare team change at all at that point?

Patty: No, not really. Unless there was something that I knew was happening to her that she was not telling them. That is when I would speak up but I really did try to remain in the background as the note taker, talk to her before the appointment and just say, "Okay. What points are you going to bring up?" She is changed medication several times. We have talked through that. They would rise this, that, the other but respected her opinion. This is I remember her telling me one time when I probably overstepped "Mom, this is my disease. I am living with this". I am like "Okay, point well taken". But you know what, as a parent you do live with this disease because there is not a moment in my day I do not think about how is the heat affecting her today?, wonder she is having a stressful day at work, all of those things. I wonder if she is getting exercise. I hope she is not exercising because it is too hot outside. All those things are in my head. Not that I am obsessive but they do pop into my head.

Roz: Well, I think we all know those of us who have been there that you do not stop being a mom just because your kid gets older. The worries get bigger not smaller because your kids are bigger and dealing with bigger things. So I think you have all navigated this in a truly feeling way. So let us fast forward to a successful graduation from college. Having stayed there and finished it out. And now you are living on your own. You are a fully independent adult. You are working full-time. You have a busy life. So if there is another relapse or any other health issue that happens, how does that get managed between the two of you?

Channing: Well, I generally keep tabs so when there is a relapse, I will go with her to the doctor. I used to go sit for every MRI, every appointment and I have kind of tough that I do not- if it is just a checkup, we will go over things so that she had notes in her phone or whatever. I do not always have to be at every appointment. When she went had her first out crevice and her second out crevice and this latest out crevice infusion I went, balancing my professional life, my personal life with that now more so than I have in the past, but when there is a bad relapse, I generally will take off work and come stay with her.

Patty: When she was on television and could not drive, I would drive her to work and come and honestly, I love it over here. So it is not a sacrifice for me. But my role now as the mother of a young woman, young professional woman is what do you need? How can I best accommodate that and I have to rely on her being honest with me?

Channing: I think that that part of our relationship has really changed in the last couple of years as I have grown and figured out my career and tried to manage my help best I could. It is become more of a typical

very much support partner relationship, I would say because I have a really good community support here with my partnerships of friends and they do a great job taking care of me and we have had to go through that time of "Hey, so until has this it is okay. You do not need to come to the appointment". I promise because you have led me on this journey because you have shown me what a doctor should look like and how I can best prepare. I am ready to take this on and I have been able to find prints were really good in those fields who can guide me and support me there. That was difficult at first for sure. We kind of both had to tug and pull and that was tough at times.

Patty: I thought I was being pushed out but it really was not that, it was just even maturity. It was just time.

Channing: And we had to work through the growing pains. What it looks like for me as an adult to live with this disease and for her to what the role of a mom, of someone living with this disease looks like and that was not easy at times and really it was hard on our relationship. I think it would come to a really good spot now where I let her know when things are-when I am not feeling well and I think the best thing that she gives me his grace. If I we talked on the weekends and she is like what you doing, I am just so tired, this last week and it was really hot and I am tired and I am just staying in bed. And she gives me this wonderful grace permission to let me sleep and be myself and that is so loving and that is so necessary and I support partner.

Roz: So Channing, you have talked about your relationship with Patty now as your mom but also as a support partner, is you look for another support partner in your life? Perhaps a partner or spouse. What would you be looking for based on the experiences you have had so far with such a wonderful loving and supportive relationship?

Channing: I think my number one quality in a person has changed quite a bit from what I was sixteen and I made this list of non-negotiables to when I was twenty two and made a mix of non-negotiables. Empathy is my number one quality I look for in a person. I think that you do not have to gone through a cancer diagnosis or have someone have a loss of a loved one that I do think having empathy is a huge huge quality that I look for. I have gone on dates with men who have had a really easy life and that is fine, but they do not understand grief and that is extremely difficult for me to relate to them. How I can fit the characteristics. I think that the grief and struggle produces empathy, it produces qualities that I am attracted to in a human because I may not be able to go to the bathroom by myself one day. I might not be able to walk. I really want them to be able to love me for who I am. What I am able to shower with myself, to lift my legs, to whatever it is that I am having to do to be able to see, drive. I want them to know what the worst could look like, but I honestly do not think that is the worst thing that could happen to us. I really just look for someone who is loving, who understands what hard times look like. Their Christianity is very important to me with their faith with higher spirit looks like but I really just I want a kind, empathetic, compassionate person.

Roz: But and I can see either one of you at this point in your lives finding other partners. You are both loving. You are both very caring people and so how would you see yourselves navigating new partners in either one of your lives?

Channing: I have found this new acceptance of myself and who I am and where I am in my life and I am basking in this beautiful acceptance of me being a very independent and welcoming human on this Earth. And if that means someone else joins me in this ride, that is great and I welcome that.

Patty: I would welcome it as well. But I look at a relationship as dessert. It is not the entree in my life. I hope to find someone who feels the same way and because then I think it is cherished and safer even more.

Roz: Nicely said from both of you. So one last question to both of you and I think I am going to start with

Patty on this one. What advice would you offer to other young adults and their parents from your very experienced vantage point now?

Patty: One of the main points as I look back on our experience is arm yourself with knowledge that does not mean get on the internet and surf every link having to do with MS but arm yourself with good knowledge so that you can speak intelligently or ask good questions during the time you have with your position. Be honest with one another. Be transparent with other people and manage your expectations of the child of the parent and the parent of the child. Give love unconditionally to one another. Be kind to all of your care partners, the nurses that text the positions, the physician, the physician assistants. Kindness goes a long way and it can be a very frustrating experience when you are dealing with insurance companies, snags when you need a prescription and you have to go through step therapy whatever but if you can take a breath and be kind to others you will find that you will get the results that you need. But mutual respect for one another in the position that you are in will lead to a much less stressful experience.

Channing: I would say respect, mutual respect is really important. I think also acceptance of one another is very important. That was a long hitter here with respect but accepting one another for who you are and where you are in the moment. There is no set of standards you have to live by with this disease. I think when you are diagnosed, it is going to look very different as a mother and child and so as to where you are when you are twenty, when you are twenty five. Every day is different but we have definitely gone through a relationship yet. There has been an evolution of our relationship with this disease and it touches every part of our lives. It really does. I think accepting that those spaces are fine, and there are spaces to be in. It is extremely important to let yourself and your support partner know, your mother, your father, whoever it is that I know that we are in a rough patch right now. We are going to get out of that. But right now here is where we are and I am okay with that. We are going to get through it. But just that solid line of communication and that a safe space place is talk freely and openly about that. This respect as line of empathy and this acceptance is still important.

Roz: Well, thank you both very much. I could not have asked for more open or honest conversation with the two of you.

Host: Thank you all for being here today and thank you so much to our listeners. I will make sure to catch our next two podcasts in the young adult series. You will hear more from Channing and Roz as they continue their discussion.

Host: 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 supporting the young adult podcast series for other great resources. Check out our website cando-ms.org. We specifically like to recommend the young adult webinars.

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