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Introducing MarlaJan Wexler

MarlaJan Wexler, a registered nurse, supports young people with stories similar to hers: congenital heart defects and open-heart surgeries. In this twelfth episode in the series about Young Adults with Complex Conditions Transitioning from Pediatric to Adult Medical Care, MarlaJan relates her evolution from child to a person advocating for herself to an advocate for others. She describes the challenge of leveraging her ‘been there, done that’ experience while gauging the readiness of young adults and parents to hear the lessons she’s learned. Finally, MarlaJan opens her heart (so to speak) to her struggles with PTSD and finding compassion for herself.

I so appreciate this conversation with MarlaJan. She’s one of my heroes. We found common ground in the value we’ve found in a career in nursing, our general restlessness in career and life, our empathy for the people we serve, and the humor that bubbles up from our spiritual core and life circumstances.

Health Hats: Good morning. I'm with MarlaJan Wexler. Thank you so much for taking the time to chat with me.

MarlaJan: Thank you for inviting me.

Health Hats: MarlaJan, how do you introduce yourself in a social situation?

MarlaJan: That's a loaded question. It depends on the type of situation. Is it a more professional social situation?

Health Hats: Sure, start with that?

MarlaJan: At the event right now, at the palliative care conference, I would approach someone and say, “Hi, my name is MarlaJan Wexler. I'm a patient advocate; I'm a nurse.” Get into what I do and why I'm here.

Health is fragile 02:20

Health Hats: When did you first realize that health was fragile?

MarlaJan: For me, it's been my entire life. I was born with a complex congenital heart defect. My parents were told I wouldn't make it past two — spoiler alert. I'm here; I'm 37. But I've always known at a young age that health is really fragile. I think as a child, I didn't necessarily not take it for granted. I didn't completely understand the enormity with just how sick that I was, but I think I knew from a young age that things could go bad quite quickly.

Health Hats: Let's look at the other side of that. You've had health issues all your life, and since you were conscious, you knew it. So, what does healthy look like?

MarlaJan: For me, healthy is being able to get out of bed every day. Be able to do the tasks that I want to complete. Be able to socialize and do those types of things that I would like to. But healthy also comes with taking handfuls of pills every day and injecting myself with medication and some degree of pain no matter what. So, I think my idea of health is slightly skewed

Speaking up for yourself 03:08

Health Hats: It is interesting how perspective will adjust your view. When did you start wanting to speak for yourself? In terms of your health

MarlaJan: In terms of my health, it's funny. I did some advocacy work for the hospital that I work for as a nurse. They have a heart and mind education day, and I would speak to teenagers on having congenital heart disease and transitioning from pediatric care to the adult world, going on to college - things like sex, birth control, drugs, and drinking. All the things that kind of go through the mind of someone going away to college. So, I did do that, and I guess I don't necessarily consider that advocacy work, but it wasn't until I started my blog in 2012 and started getting a little bit of a following and realizing that my voice really could have an impact.

Health Hats: I was first introduced to you through your blog and then through this conference.

MarlaJan: This conference two years ago. When I first started my blog, it was just a means to vent. I didn't think anyone, but my mom would read it. I'm not a writer; I'm a nurse. So writing is not my forte, for sure. But I won the WEGO Health Hilarious Activist award in 2014. That's what snowballed me into realizing that I can do more than just writing my blog. I could go out there and speak and share my story and try to make changes in healthcare for patients like us.

Health Hats: So, go back to say ten years old or 12. Speaking up for yourself either at school or at the doctor's office. Where did you begin to transition in your mind from "my mom or my parents are looking out for me" to "I'm looking out for myself"?

MarlaJan: I would say probably around the age of 16, my cardiologist at the time, my parents always came with me to the appointments and the cardiologist came out, "I'm just going to see MarlaJan for a little bit." I remember he sat down and drew me a picture of my defect. Drew the surgeries that I had and how they repaired it and said, "You need to know this stuff. You're 16 years old. You're going to be going away to college." I think it was it was between my Junior and Senior year of high school when he did that. Yeah. I remember being like blown away and like oh, yeah, I guess I really am going to make it and now I know I have to start taking the reins and taking control of my health and my parents were quite good about it. Once I turned 19, I started going to my appointments by myself and speaking up, and I'm just taking control and scheduling the appointments and go into the tests. I think there was one year I skipped, and I still hear about that from my mother.

Health Hats: Skipped going to the doctor?

MarlaJan: I go twice a year and have my big annual visit where I get MRI Echo stress test. I skip that. I did blow it off.

Nursing wasn't my first degree 08:44

Health Hats: How did you end up deciding to go to nursing school?

MarlaJan: It's funny. My Nursing degree isn't my first degree. I went to school for biology, and I minored in Law Justice thinking I was going to be the next like Olivia Benson from the Special Victims Unit. I wanted to be a forensic pathologist. I saw my first autopsy and passed out. After I graduated with my degree, I started working in a lab. I realize you don't get to work for the FBI right away. You don't go to crime scenes right away. You have to put your time in. I hated like the cold sterility of the lab and quit after like a week. I started bartending much to my parents' dismay. I guess at age 20, I took about a year off between and before I realized like oh nursing. I felt like I would love it, and I always remembered how amazing the nurses were. When I was the sick one in the hospital as a kid and even something as simple as like drawing little hearts and flowers on the hat that goes in the toilet that you pee in. It just to make it like a little personal and fun. Who wants to pee in a hat? Just remembering things like that. And I had a nurse that I loved. Her name was Maria. She always let me sit at the nurse's station with her and would give me like blank nurses notes and let me fill on my stuff like the patient and let me listen to her and I just really resonated with me. I realized like oh, that's what I should be doing. I shouldn't be stuck in a lab or stuck at crime scenes.

Health Hats: You go to nursing school and not only are you an older student who's already been to school, but you're

MarlaJan: not that much older.

Health Hats: Not out of high school. But also, you're a person who's received a lot of nursing care and it. By experience, so I'm a nurse, too, and my experience was that people in school seemed so focused on the skills of nursing that they didn't really. It took a while to appreciate the recipient of nursing care and what they were going through. But here you were somebody who has been part of the medical system all your life and has seen both good and bad nursing care. And so how was that being in school, having that perspective which might have been unique of the students.

MarlaJan: It certainly was an interesting perspective. I still was like single focused on the task at hand and not necessarily like the empathy and compassion that go into nursing, but once we got into clinical rotations and I was human to human and not putting a Foley in a dummy

Health Hats: A Foley catheter

MarlaJan: Foley catheter. I realized that I don't know if it's necessary. I felt like I was able to take my experiences and turn them into compassionate nursing care.

Unique vantage point – patient and nurse 12:10

Health Hats: Okay? So now you're older. You have been managing your medical issues, and you've been a nurse for a while. From that vantage point, what would you recommend to young adults and their parents as they begin to transition to adult care? In hindsight, what would you advise?

MarlaJan: It's start sooner rather than later.

Health Hats: Start sooner

MarlaJan: yeah like so and we were talking about this yesterday. I told you how I became very passionate, and my work with transitioning care from pediatric to adult medicine. With some of the research I've done, it's around age 14 is when it should start. Okay, just that process in general because it's not it shouldn't be, "okay next time you're across the street at the big boy hospital." It needs to be a process not only for the patient and the provider but also for the caretakers, it's a huge learning curve. I was very lucky that my parents were understanding, very good about it and let go of the reins. Sometimes it's the caretakers that do more of the hindering and aren't comfortable feel like the patient can't take care of themselves can't do this for themselves.

Health Hats: So, it's a self-fulfilling prophecy, or it could be.

MarlaJan: Yeah, but it is something that I think is a years-long process which I know sounds like a long time, but it's not. It's probably not enough time. Maybe it should start easier, but as I was saying yesterday, I feel like it should start with simple tasks. Especially now that we're in such a tech-driven

society, download the CVS app and teach a child how to refill their own prescription. You don't even have to talk to anyone anymore. You just hit a button to make your own appointments. Maybe the age 15 to start to learn your disease defect. Have you learned your medications why you take them and their names? Not just a blue pill that makes me pee - blood pressure medicine. Know why you're taking them and be that person be that expert for yourself?

Health Hats: Again, with your vantage point, how would you advise nurses or nursing schools or the clinical folk to be more welcoming as people cross a threshold from pediatric to adult care?

MarlaJan: It needs work. The process is not great right now. Some transition programs are better than others. And it also depends on what type of nursing. If you're at the bedside, in an ICU or even - I say cardiac because that's what I do and know. Even in the cardiac step-down unit, it might not always be the right time, the right place to bring up transition. You make those relationships with patients and families where you feel you can talk more and be more open and even about your own life in general. Those types of patients, I always I feel like I was able to have those conversations openly. Then sometimes I would say something to Mom about their 17-year old. Oh, well, you know a really starting that process. And they're like, "oh my God, we don't talk about it." And it's almost this urban legend of transition. We know it's going to happen, but we don't want it to happen. I think specifically for nursing, it needs to start more in the clinic, then at the bedside - inpatient. Because when you're inpatient you're already so stressed. Anyway, there's you know, you're clearly there for a reason whatever it is and right and maybe bringing up that whole process like, "oh look at the hearts and flowers now", but in a couple of years you're going to be next door. I think there are a time and place to bring up that process and it does need to happen. But you also need to have that compassion and empathy and that little bit of knowing that there is a correct place for it to have them.

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Been there, done that 16:57

Health Hats: So, you're pretty comfortable talking about yourself and the challenges. You're the funniest website, you know, your sense of humor in your work is striking. but I have a sense that you grew into that

MarlaJan: For sure.

Health Hats: Sharing your experience with young people, that your nursing is something that's evolved. So not only have you evolved. So first, how have you evolved in your comfort and how you share?

MarlaJan: Um, you know, but before lupus and cancer and everything,

Health Hats: So, you're not just dealing with that you had a heart defect? Okay. We'll get into that in a minute.

MarlaJan: Though as a kid, as an adolescent even into college like I didn't talk about it. You know people saw my scars, what's that from? I wear a Medic Alert bracelet. But at that age, you don't want to be seen as different ever. I went through that phase where I hid my scars and gave my parents hell because I couldn't do the things my peers could do. So, I think at that point like I certainly hadn't grown into being comfortable sharing my story. Once I started my nursing career and started working with congenital heart disease patients. It's not like I walked into a room, "Hey, my name is MJ. I'm your nurse and been there, done that. You have to build relationships and rapport with your patients and their families. I wasn't comfortable talking about it with everyone I took care of. But you form those relationships and those bonds where you feel comfortable talking about yourself. I did feel that once I did create that more trusting relationship that I could talk to a patient. Especially a teenage patient who the last thing they want to do after open heart surgery is their incentive spirometer or getting out of bed eat and drink. I could really sit down, "listen, I've been there. Probably in the same bed and on this unit. I know what it's like. I know how awful it is, but I'm telling you, it helps, and it gets better. I promise it gets easier. Those are the patients that truly listened, and sometimes it was a hindrance. I had a parent who I hadn't shared what I had been through. Maybe I was a little tougher on some of my patients because I knew that's what they had to do. If I had to do it before Fentanyl and Dilaudid, then you're sure as hell getting up and doing it now. I had a couple of parents say that I was a little hard and they thought that I was pushing their kids too much. I remember with one parent; she was quite angry with me and yelling at me. I was able to bring down the tension a little bit and say, "Listen, I've been there. I've done this I know what it's like. It changed the entire trajectory for the rest of their admission in the hospital because the mom realized there was a method to my madness.

Health Hats: Pretty sobering to hear.

MarlaJan: She was like, "oh my gosh, I had no idea." And I never wanted to be about me. That's another reason why I don't. I'm not always comfortable within the context of my work as a nurse in the hospital. I wasn't always comfortable sharing my story, because I never wanted it to not be about that patient. I remember that vividly just the tension just dissipated and whatever his name is you're getting out of bed. And he looks at his mom, "Wait, I thought..." She was like, "no, this is what you got to do; she knows what she's talking about. You're going to do it." You won't know as a nurse that getting out of bed and your incentive spirometer, all that crap you don't want to do, will either get you home faster. You won't risk pneumonia and pleural effusions and be back. You will be back, and all those things that we don't necessarily as a patient think of because we're like the last thing we want to do is take a deep breath and let the little ball thing and go up. But for the most part, I've been able to make it a positive in my work.

Ready or not – the right time 22:04

Health Hats: What do you look for as a nurse when you're gauging readiness for either the young adult or the parent? What helps you know where they are on the continuum of readiness to help them push ahead a few degrees and to know what are those? What do you look for? What do you see? What do you see as you're gauging that? I'm sure you're not always doing a consciously, but you've done it so much, and you've lived it.

MarlaJan: So, before I worked in the cardiac ICU, I worked on an apheresis unit.

Health Hats: Okay, and what's that?

MarlaJan: Apheresis? It's so it looks like a big dialysis machine and whereas dialysis filters and cleans your blood, apheresis is an exchange. Our main population was with Sickle Cell Disease. So in Sickle Cell your red blood cells are diseased. The patients got hooked up with a port or through peripheral IVs. They got hooked up to the machine one tube pulled their blood out of their body. It goes through a centrifuge. It separates off the diseased red blood cells and it goes into a waste bag. The patient gets back their white blood cells and all the other components of their own blood and got healthy donor blood, donor red blood cells. I did that for a few years. Like you. I like to bounce around. So, I did that for a few years. Those patients came every three or four weeks. Over the years, you get to know them. You get to know their families. I really gauged the readiness on the questions. If they ask questions about their disease? If they were paying a little more attention to the machine. A little more engaged and interested in what was going on and not just there for their treatment. Then I would start the process. What else did I do? I did a bulletin board. So, I did a big transition to care board. And it's funny because our medical director of apheresis wrote the book on pediatric apheresis. So, she still the medical director. I think she's probably in her eighties. And she wanted nothing to do with that. She didn't want to give up her patients. Like that was her life that she poured out her, her life's work that she poured everything into. But I gauged it on patients asking questions, parents asking questions if I noticed kids coming to treatments by themselves. I was like, well if you can come to your treatment by yourself, and then it's time to learn your disease. That's where I gauged it there from a cardiac standpoint. When I worked at the bedside in the ICU, it was a little different. I was taking care of critically ill patients when they were ready to go to the step-down unit. As I mentioned earlier, if I had that type of bond and relationship, I would bring it up. Especially with the teenage population. If the parents weren't in the room, I would sneak in those conversations about drinking, drugs, sex, that you don't want as a sixteen-year-old talk about with your parents around. That's a huge thing because I was very realistic. I think because I went through it. My poor mother, it's not necessary that she drilled into my head if you do those things at college, you're going to die. But she drilled into my head, like don't do those things. At 18 years old with my first taste of freedom, what's the first thing I did? I went to a frat party and had beer. We need to have realistic expectations for our patients, especially with their transition process and especially with something that's lifelong and if they've spent an exorbitant amount of time in the

hospital as a child. Going away to college you want to feel that Independence and you want to feel like your peers

Health Hats: Is your approach a harm reduction approach?

MarlaJan: Harm reduction

Health Hats: You're gonna drink. Here's what's going to happen and here's how you handle it?

MarlaJan: Some parents were horrified. How could you? Really?! Do you really think? Do you really think? And not just drinking and drugs but like safe sex and especially for the patients who had genetic components of their condition. Like these are the things you have to think about, you know, if you have unprotected sex it and your Susie gets knocked up, and these are the things you have to think about and also what sickle-cell. For my Sickle Cell patients, it's a huge component. The genetic piece that goes into it and I think. If maybe not so much in this generation, but in my generation, they were so hell-bent on keeping us alive that no one had those conversations with us. So, we were coming back from college sick sometimes because no one had those conversations. No one told us.

Community? Not as a child 27:27

Health Hats: When you say, "no one told us." Have you always felt like you were part of a community of people when you say us?

MarlaJan: No, never. I didn't feel like part of a community until the other the adult health issues came to fruition. I always felt like I was alone. No one understood what I went through. I didn't know anyone else who had open heart surgery, let alone four. Listen, I know I did feel very alone. So when I say us, I mean that more in my adult life with chronic illness. Now it's much more, especially with social media and patient advocacy groups, and support groups. Things didn't exist then. But now our patients and us, - I say with air quotes - feel more supported and feel like they have people behind them.

Health Hats: Yeah. So, do you let young people know that you've vetted some groups like, "here's a URL of or a Facebook page or here's a good community that you can plug into?"

MarlaJan: Yes, for sure.

Health Hats: I assume people are open to that.

MarlaJan: Yeah much more now. Of course, to talk and to communicate and learn. We can all learn something from each other, especially if we've all been through the same thing. I always find it very fascinating to see how people have evolved differently.

Compassion for myself. Not Super Woman 29:19

Health Hats: So, what should I be asking you that I haven't?

MarlaJan: I could tell you about my adult life.

Health Hats: Please tell.

MarlaJan: In 2008, my husband and I got married at the end of February. We went on our honeymoon. Ten days in St. Lucia, where we just baked in the sun. Three weeks after we got home I woke up and looked like Shrek. My face was swollen; I was covered in rashes. That was the beginning of my journey to getting a diagnosis of lupus and from that point from lupus turned into a diagnosis of several other overlapping autoimmune diseases to cervical cancer diagnosis. It's such on the back burner for me. Of all the things I've been through like cervical cancer was just this little blip, and then in 2014, I underwent a double mastectomy when a lump was found in my breast.

Health Hats: Oh, my goodness.

MarlaJan: Yes, and it completely changed all of that changed my life exponentially changed the direction of my career

Health Hats: Because you didn't necessarily have the energy?

MarlaJan: So, I saw my first several years with my lupus diagnosis. I was still working in the Cardiac Intensive Care Unit. I was back in school for my master's degree and just myself ragged. I was in denial. Lupus is an invisible disease. If I can't see it, it's not really there. If I act like it's not there, then it can't hurt me. In 2012 I found out that lupus started attacking my heart. I already had cardiac issues. And that was my wake-up call. I remember my rheumatologist after I was in the midst of a horrible flare, I lost 15 pounds in two weeks. I was a mess. I couldn't get myself out of bed. And I remember her looking at me, "Marla Jan, you have to respect Lupus." I guess I do. That was my wake-up call once I've realized that lupus was more than just some joint pain and rashes that it affected my organs and affected my life exponentially. I took what was supposed to be a six-week leave of absence from the cardiac ICU, and that turned into five years on disability. I got very, very sick before I even started to get better. Like we were talking about yesterday. I was on extremely high dose of steroids. I gained 65 pounds in six weeks. I walked with a walker. Not with a walker, with a cane for about nine months. Lupus also affected my lungs and my brain. I took a little bit of a cognitive hit. I never finished my master's degree. I was a semester and a half away from being a pediatric nurse practitioner. And it changed everything. Unfortunately, my brand-new marriage couldn't handle all of that. We got divorced. The divorce was finalized at the end of 2017. So, we had a good run. Wow, almost ten years.

Health Hats: Well, that's a lot. My experience with you, which is two conferences, and following your blog is you seem to have a strong spiritual core. I know nothing about religion in you, but that's not really what I mean. But I mean a sense of your self-worth and that there's a strength there that's helped you get through all this.

MarlaJan: It's so funny on that on the outside I have this Super Woman persona. I think It was almost, not from my parents, almost expected for me as a young child. This is a lot of what I'm speaking about today at this conference: the severe complex PTSD that I've been living with my entire life and never, never did anything about until about a year ago. Started seeing a therapist who specialized in complex trauma and started working on myself. I have my religion. I'm not a very religious person. It's important to me but it doesn't encompass my everything. I'm much more spiritual if you will. It's just really working on myself and finding this strength myself that I knew wasn't there. Almost like that talk that we just listened to about self-compassion. I have none. Even now, I don't have as much. I don't have much if at all. I'm learning that I need to be compassionate for myself and take care of myself and do what I need to do mentally and physically. I've come a long way.

Health Hats: Wow. Thank you. This is great. Thanks for spending the time with me.

MarlaJan: Yeah, of course, loved it.

Reflections 35:14

Many times during the interview I wanted to stop and hug MarlaJan - some for me and some for her. She touched me. Unfortunately, lapel mics and hugging don't mix well. Finding the silver lining in our dilemmas balances the bitter with the sweet. Marla Jan sees the silver linings. Silver linings hold us up when the shell wants to crumble. While MarlaJan told us that you can't just walk in and say, "been there, done that." Actually, she did. Life changing for her charges. I wanted to cry as I edited this interview when I heard again that cervical cancer was on the back burner when Lupus and breast cancer knocked her over. I was going to end this series after two more interviews that are ready to produce, but I think I'll add another one about PTSD. I know just who to invite. So, MarlaJan, love ya, thanks for inspiring me.