An Orange Socks Story – Kellie: Spastic Quadriplegic Cerebral Palsy

Interviewed by: Dr. Gerald Nebeker, President of Orange Socks

Welcome to the Orange Socks podcast, where we are inspiring life despite a diagnosis. I'm your host, Dr. Gerald Nebeker. In this episode, I have a sibling interview with Kellie. Kellie is three and a half years older than her twin sisters who have spastic quadriplegic cerebral palsy. I know you will find her experience interesting as the older sister to two siblings who have required total care for 41 years.

Gerald: Kellie, thank you so much for taking the time to do a sibling interview for Orange Socks. I really appreciate your talking about your experiences with your sisters. Your twin sisters, Kay and Kara, have spastic quadriplegic cerebral palsy. How old were you when your sisters were born?

Kellie: I was three years old. I don't really remember the early part of their life. I don't remember too much, I don't really recall my mom even being pregnant with them. It's just little bits and pieces of my early youth that I remember.

Gerald: When did it occur to you that some of your friends didn't have sisters like yours?

Kellie: Early on, I had lots of little playmates who would come to the house, and they were fascinated by my sisters. It was always an interesting conversation. They always had questions, but it didn't really affect who came here. It was so normal for me that I never really thought anything about bringing someone here. They just came and played, and we just answered questions when they had them. They would help me babysit and different things, so it never really was a huge difference to me, other than their reactions in first, second, and third grade.

Gerald: Did you ever have any teasing because you had siblings with disabilities?

Kellie: I don't recall any.

Gerald: Or were you the cool kid because you had siblings with disabilities?

Kellie: I don't remember it being too different. I remember thinking to myself that I wish I had sisters who could share my clothes later on in life. I wished I didn't have the responsibility that came with it, because my friends were going places and doing things. And they would vacation with their families and be able to do things that I couldn't do. Or their parents would be able to do different kinds of things that mine were not. However, I never realized until later in life, in fact, very recently, how much of an impact the girls had on my friends. With Kay's passing, I had a lot of comments on a Facebook post that I made, where my close friends could remember them. They really had an impact on my friends, several of them commented that they really had been blessed by knowing them.

Gerald: What was the hardest part for you, having siblings with disabilities?

Kellie: Probably not understanding the time aspect of it. My mom not being able to be where I wanted her to be, or be able to run me here or run me there. She couldn't because she had two twins, and she didn't have anyone else to care for them. It's not like she could just pick up and leave or run somewhere. There was that, and then the vacationing stuff.

Gerald: One of your sisters passed away just a little over a month ago.

Kellie: Yeah, just barely.

Gerald: She was 41, what impact did that have on you, to lose a sister? What was that like?

Kellie: Initially, it's a sad thing, but I've been ready to lose them for a long time. My mom said that we were always told that they wouldn't live to be this, or they wouldn't live to be that. So, I feel like I've always been ready to lose them. Because they were perfect and going to be so much better off, I don't think it was as sad for me. Of course, I miss her presence here, but I feel like I was eager for her to go and find out what was waiting for her. I was also grateful that my mom could have some relief. I've watched her give her whole life to them, and watched the impact it has had on her life, and so I guess I was a little bit excited for my mom to have a little freedom. There was some guilt that came with that feeling, but then I thought that Kay would want that too. I guess I taught myself through that part of it, but the loss hasn't been as heavy for me.

Gerald: What were some of the joys, or the fun parts of having siblings with disabilities?

Kellie: Early on, it was just the fact that people liked to come and be here. I did a lot of babysitting, so people would come and help me. It was like being in charge of something, or feeling kind of cool about that responsibility. I don't really feel like there was any one thing.

Gerald: I've heard this term, and it's new to me, relative to siblings called the glass child, which means that the parents often look right through the siblings of people with disabilities because of the needs of the children with disabilities. Did you ever feel that way?

Kellie: No, not like that. I felt like they tried the best they could with the resources they had. They still did what they could to meet my functions when they could, and I don't feel like they ever overlooked me. My mom said that we had so much family support, that I didn't mind if there was a lapse in that I had others to fill it. With my grandparents and aunts, I don't feel like I had a huge lapse in anything like that, but emotionally, sometimes I felt like it affected me. That maybe my parents weren't as emotionally available for me because they didn't have a lot of emotional stuff to give, since they gave a lot.

Gerald: Tell me about the impact of that in your life, having siblings with disabilities. You became a nurse, and you told me a little bit about that before we started. You're now, obviously, an adult with children of your own. What kind of impact did that have on you personally and professionally?

Kellie: As a mother, I think it was a great thing. I never felt there was a real huge transition into becoming a mother, that I've been able to face that maybe would have freaked other mothers out, or would have been new to someone else. I had a lot of confidence in becoming a mom, and I was excited about it. I felt like I had done a fairly good job despite all the things that I had to base in my job choices when I was young. I used to babysit other children like the girls. Other parents would have me come be with their kids, and it was fun to meet other kids who were like Kay and Kara. I would go with them to therapies, and I would see that, to me, they weren't super authentic. There was a whole school full of them at Elk Ridge, and we spent a lot of time there. I guess I was a good resource for those other parents, as a teenage babysitter. Later in life, I chose some opportunities to be in classrooms with individuals with disabilities through the school district, and then later on becoming a nurse. So, I guess it all just led me there.

Gerald: If you could have waved a magic wand, would you have changed anything about your life?

Kellie: I would always say that, yes, I wish I would have been able to have them as normal sisters, because I missed out on a lot of that part. I was an only child, so I didn't have that interaction of the fighting, and I guess it was a good thing too, because I didn't have to share my toys, and I didn't have to share anything. I always wished I could, and always wished I had that part of someone to argue with, someone to blame something on, to chat with and tell secrets with, I didn't get that. That's the only part I really always wished I had, but what I did get far exceeds what I didn't. What they taught me in being with them and being able to care for them is incomparable from what another sibling would get from another sibling.

Gerald: What advice would you want to give to other siblings based on your experience as a sibling? What would you tell another sibling if they were to need some experience?

Kellie: Love them, love them, love them. And be proud of them, and excited to introduce them to people. Get people talking, because people act strangely because of what they don't know. So, the more people know what's going on, or what they have, or why they are acting this way, then they don't tend to be as afraid. Just say that, "This is my sister, she has so and so." I think that's when we were anywhere, that's how my mom handled things, and that's how she taught me. That was a really good example and something I would encourage them to do in order to touch other people's lives.