

An Orange Socks Story: Stephanie- Autism and Epilepsy

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: Stephanie, thank you so much for taking the time to meet with me via the phone to talk about your brother, Mick. Tell me about Mick, I know he is older than you, just tell me what his diagnosis is and just a little bit about him.

Stephanie: To paint a picture, my brother Mick is a big guy at 6'3 and about 200 pounds. He is a large guy and is really tall, really big, but he is autistic, and he also has epilepsy and has seizures as well. He's pretty verbal sometimes, though with his seizure medication, he can be very lethargic, very tired and sluggish. That's just sort of his background. He goes to a day program where he does volunteering and community work. Recently though, he's been having to change his seizure medicine a lot, so he's actually not been going to that for the last couple of weeks. So right now, Mick has not been doing so hot. He just went to the doctor yesterday, and he's going in for an EEG in August. On August fifteenth he's going in to get a sleep study, which we are really, really excited about. My mom is very stressed about his EEG test because it's five days he has to be asleep in a hospital. We've been talking about doing this for years, and it's finally happening. I think she's very nervous. As to Mick, we are very blessed to have him. He rarely has any maladaptive behaviors, he never lashes out, and he is never very violent. About 90 percent of the time, he is fun to be around and very chill, especially since he's been using these meds. He's actually too chill and is really tired all the time. Mick loves to do chores around the house. He's just so funny, but honestly, that is his favorite thing to do. He loves doing the dishes and folding our laundry and pumping gas in our cars and stuff like that. Mick can't be by himself because of his seizures, he has to be monitored at all times, and that has been a job that I've done. I've just been sort of that built-in caregiver my whole life, always there for him and for my parents. Back in his teenage years and early pubescent years from 11 to 14, he had a lot of maladaptive behaviors, and that was very hard on our family, but we got through that.

Gerald: He sounds delightful. You are a younger sibling, so you're two years younger than your brother. When did you realize that your family was a little bit different than, perhaps, some of your friends' families?

Stephanie: That's a really good question. I want to say, gosh, I think I realized that we were different probably back when I was starting to go to school. I would say I realized that we were different because most siblings all go to the same school. My sister is the oldest in our family at 25, four years older, and we are all a few years apart. When you realize that your sibling doesn't go to the same school, that's kind of weird, because most siblings all go to the same school regardless. My family is very religious, so my sister and I went to a religious school, and they don't provide the best special ed services, if at all. So, my brother had to go to a public school so he could get all of his services. I honestly don't know the terminology about special ed,

but he had to go to a different school than us. I think that provides a different dynamic because my sister and I were in the halls giving high fives. When you go to school with your siblings, you sometimes see them and give them hugs throughout the day, but none of my friends really saw my brother unless they came over to my house, or saw us at church or something like that. That's when I realized it was different, that was the first difference I would say. Aside from the little differences, the biggest difference that I realized was that it's hard, because there are so many nuances that can be so different from other families. When I was 10 or 11 years old, and given those responsibilities to take care of my brother and to watch over him, that's when I realized I was different from my friends because they didn't have to worry about or watch their older siblings, that's not something that other people do. I had a second wave of, "Whoa, I am different," when I was 10 or 11 years old because no one else was watching their big brother. I was the only person like that, and I would have to cancel plans sometimes to stay home and watch my brother who wasn't able to go. Some things were fine, but other times, my parents had to work that out.

Gerald: Did you ever feel like some of your needs were ignored? Did you feel like, I guess, the glass child with your parents? Could you tell me a little bit about that? Did you get less attention or more attention because you had a sibling with disabilities?

Stephanie: Definitely I got more attention when I did good things and less attention when I was struggling because my parents can't handle any more struggles. It's just too much. I'd say, yeah, I definitely had some issues. These problems that I had were not really focused on early in my life, but now they are. I've had to kick and scream and do lots of things to get the help that I now need. There's a lot of guilt that comes with having my own problems, because I have the mind and capacity to know I have problems. At the same time, my parents needed to focus on me, but you can imagine, every time we're at home, their attention is refocused, and I'm always going to come second to my brother's needs.

Gerald: You made an interesting comment, because of your brother's needs and their stress level in caring for him, you felt the need to not to add to their emotional burden by talking about your own. I think that is a very interesting comment. In some ways, you were left to work through your own pain or misery because you didn't want to add to your parents', that is a very interesting thing.

Stephanie: It's really hard, and I kind of kick myself in hindsight because of it. Like I said, we're a very religious family, and because of that, sacrifice and powering through and fighting is very honorable, and is our belief system. I believe that I've taken that so much to heart that, "Oh, well, my suffering is the best thing I can do because talking about my suffering doesn't make any sense. I can at least talk and do things, and I just need to power through." But as I've gotten older and have friends who have their problems, I can see much clearer the typical threshold of pain and stress. I've had to get help because I've shown so many signs of being broken and

being very tired and much older for my age than I actually am with the stress. I had to face the facts and get some good help.

Gerald: Well, good for you. What have been some of the joys? What has been the good part?

Stephanie: I'd say some of the big joys are when we see our extended family interacting with my brother. My family and I always have these inside jokes about Mick, but when our extended family can interact with him, we will make funny comments about his behaviors. It does bring a lot of joy, because it shows we are not alone, and that people care and do love him, and it's not just us who are giving so much of our love and our time and care, other people and our family do too, and they just want to support us, so that does bring a lot of joy.

Gerald: That's great. It seems like you had to share the stage with your brother. Your needs were often not met, and you felt like you needed to protect your parents, but at the same time, there were challenges. On the other hand, you just described some of the joys and gave a good example of something that you have. How do you think having a sibling with a disability has shaped you to become the person that you are now?

Stephanie: It's very hard to get into that because it's someone I've lived with and gotten to know as much as I can know someone. So much of who I am is just getting to know him and be with him my whole childhood. There are just so many deep-seated ways through the whole situation, because it's not necessarily him, not really, it's the situation. When you have a disabled sibling, your whole world changes because the whole world has to support him. It takes not just one village, but many, many villages. That showed me that sacrifice is the best way to show your love, and giving of yourself means not just your time, not just your money and not just your extra time, it is the giving of multiple parts of yourself at once, and giving them 100 percent. I'm giving them 100 percent of my time and using 100 percent of my knowledge and 100 percent of my talents, all three of those at the same time, and that is the truest form of love.

Gerald: What would you want to tell parents about being a sibling of somebody with a disability?

Stephanie: My biggest advice is to be as real as possible with that child and with all your kids, because they are going to see some real moments of trying to discipline. You're kind of trying to get them to eat and sometimes other not normal things, and that's going to get to be their normal. Say you have a child with a feeding tube and you have to use a syringe to give them food or something like that that's not typical of other people in our world and doesn't really happen in many families. With that, you have to get real with your kids and talk to them about statistics at a young age, and talk to them about what the word means, because that will only help them in the end. My advice is to keep it very real and be real with your kids, especially when

they are given the responsibilities of caring for their sibling, and especially if they are girls. Girls are given more caregiver responsibilities than boys at a younger age. For me, I was caring for my brother at 10 or 11 years old when I was still treated like a child at the same time. I wasn't told a lot of the intricacies with his disabilities, not given a lot of paper knowledge. I just had my experience, all I had was my 10-year-old brain to assess the disability of my brother. If my parents had been more real with me about the problems when I was given more responsibility, that would have helped me so much more.

Gerald: Appreciate your insight, Stephanie, thank you so very much for taking the time to meet with me.

Stephanie: You're welcome. I hope everything works out, and I thank you for asking me. Nobody asks me, it's just too hard and sometimes hard to talk about it. I'm going to be honest, if you would have asked me a year ago to talk about this stuff, I probably wouldn't have, but I've taken steps to really embrace who I am and embrace the fullness of myself just this past year. Now that I'm old enough to do so, it's a little bit complicated, but just thank you so much, because I know you care so much, and that just means the world to me.