

## An Orange Socks Story – Lisa and Steven: Epilepsy and Developmental Delay

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I am happy to have an orange Socks interview with Lisa and Steven regarding life with their son Matt who has an intellectual disability and epilepsy.

Lisa, when did you notice that Matt had some issues?

Lisa: Well, we knew that he didn't progress as fast as my other children had. The diagnosis came when he was six, when we saw the first Grand Mal seizure. We had been watching TV, the whole family together, and I was thinking, "This is a deja vu moment, where have I... what is this reminding me of?" He used to have nightmares when he was very young. He shared a room with brothers and sisters, and I'd go in there and he'd be panting, shaking and crying. I'd try and say comforting things, and then he'd finally lie down and go to sleep, and my husband would say something like, "You're so good at that." I don't think Matt knew I was there. When we finally got the diagnosis, we went to his second-grade teachers as he was in a Special Ed class by then. We said that he had a diagnosis of epilepsy, and the two teachers asked, "You didn't know he had epilepsy?" The petit mal thing was unfamiliar to me. Doctors had asked, "Has he had tuberculosis? Does he have epilepsy?" And I'd picture the big stuff and say, "Well." He was always checking in and out, which you didn't notice because he was very good and creative about covering it up. He was out to fool you. Really, it was the epilepsy that caused all of the uproar. In a way, I was almost relieved. It meant we could get some medical care for him. There was something we could do! It was such a mystery, and I didn't know if I was just being a bad mother. Mothers will do that because it's better to think it's something you've done than to feel totally out of control. If it's something I did, I can change, and then everything will change, and LDS women are particularly hard on themselves that way. It took actually having my fourth child, which I didn't expect to have. I mean I went out and looked for a star in the east. I just couldn't believe it, and wondered if she was trying to be our little Lord's insistence because the moment I held her, I knew he'd always been off and I'd just refused to see it.

Gerald: What were some of the most difficult things?

Lisa: Back then, I had no health insurance when he was little. That was hard. Nobody understood why he behaved the way he did. But he would fool people. I'm working on an article now called, "Would You Like it in Red?" Do you have it in red? Would you like it in red? The first time he was interviewed, he fooled the lady in a way. She did a verbal test, then realized he couldn't do that, so she'd turn the pages of a book and point at pictures, and if he knew what it was, like a giraffe, he would immediately say it. If he didn't get it right, he would give her the last answer he had given that had gotten a "huzzah." If she would not accept that, he would often just sing and dance for her, and if she wasn't buying that, he'd go off in the corner and literally curl up in the fetal position. That's my bag of tricks. And he had things like that that kept you trying to figure out whether you were the crazy one or he was. That was hard. They say it's like your brain is trying to learn things off of a radio when there's static going on every channel.

Steven: We've known each other for years. We're coming up on close to 20 years of marriage.

Lisa: Now, well 19, but we've known each other longer than that.

Steven: We've known each other since 1972.

Lisa: He knew Matt when he was a baby.

Steven: As a stepfather, the hardest thing for me was the expectation of normality. When greeted with deviant behavior, you would expect to mete out discipline and have logical consequences, which I very quickly found doesn't work with someone intellectually eight years old.

Lisa: And, he'd had me to himself pretty much for 10 years.

Steven: Yeah and Lisa had to adapt to being a single mother for many years with Matt; she had to take the path of least resistance a lot of times where I would sort of want to be the iron fist and say, now we're going to exercise discipline. It wouldn't work. It took me a long time to adjust to living with Matt.

Lisa: Matt does not respond. First, he has a much deeper voice than any male figure he had known and you just have to work it. The words from Matt's favorite primary song are, "I'm trying to be like Jesus," and I have to say, I must. Matt can only be led in a Christ-like manner. It can't be fake. The slightest kind of anger, borderline harsh tone or facial expression, and he just freezes up, and I lose all cooperation. I must, in the words of his favorite primary song, "be gentle and loving in deed and in thought."

Steven: As a stepfather, sometimes that's very difficult. I raised three children by myself as a single dad, and I kind of ruled the roost. So anytime I would exercise any harshness with Matt, the whole scene would go down the drain.

Lisa: He's come a long way since that, and so has Matt, of course, but there's an article on here right now called "Five Good Things." That's our philosophy, and I heard a trained person say this is a well-known philosophy, even though I thought we had made it up. Everybody needs to hear five good things about themselves each day, minimum. I'm that way. That's what works with Matt. He responds to that in a very pure way. I find there's always a way to do that. There's a distraction or a change in the subject and just don't go there because it's a losing tactic.

Gerald: Now the good part; tell me about the joys.

Lisa: The joys are that he can be so loving. He wants to be loving. He likes to help. He says, "I'm a peaceful fellow." He's got some gifts. He's got a real gift of memory. He will tell you it is not a problem. We can be listening to some '70s station on the radio, and he can tell me who is singing and the name of the song even if I haven't heard the song in 30 years. It's a gift.

Steven: Can't read a lick, but he can sing every song in the hymnbook at church.

Lisa: Or anywhere! He was singing along with Dan Fogelberg, from way back. He loves music. He's affectionate. He's great with the grandkids; he's an awesome uncle. Here's the thing, there are some little books that we have, that he's not reading, but his desire to please is so strong and his memory is so good that it looks like he's reading them when really, he's memorized it.

Gerald: Steven, tell me about your experiences as Matt's stepfather.

Steven: Well, it was hard for me at first, and I had several adjustments to make as a stepparent. One of the solid things that I had to come to grips with was that as I observed Lisa and her four children, I witnessed that the love that she has for Matt is no different than the love that she has for her other three children. To me, it's quite profound, because there's just not the feedback there. It's been amazing to watch how she interacts and the feeling level and the completeness in their home as it was.

Lisa: And the brothers and sisters adore him.

Steven: And my children have accepted him into just being one of the family.

Lisa: It's so sweet. We don't like the step word by the way. He's the bonus pop, B pop, bonus pop. I have three beautiful bonus daughters. Nobody ever wrote a bad fairy tale about a bonus mom. So we work that. When we were all quite young and I was trying to have Family Home Evening, just all of us, I remember one of my daughters saying, "Well we have to make it to heaven because we know that's where Matt's going to be." Yeah, they have a clear beat on that.

Gerald: Lisa, tell me about what you have learned.

Lisa: I look back now, and I cannot imagine who I would be if I hadn't had these additional years, to learn most of the good things I'm saying about my parenting now. Since the refinement, I remember telling my Bishop in Texas, "A way will open for Matt to have a fuller life on the day when I will miss him when he's gone." I would miss him. It'd be nice to have some more freedom and have some time alone, but I will miss him. He brings great joy and influence.

Steven: It's hard to not be empty nesters when you're 70 years old.

Lisa: You're not quite 70, but I am. In fact, I'm telling all my Matt jokes, but seriously, we heard him in the foyer at church telling everybody that we're old and that all we ever think about is going to bed. We thought it made us sound kind of sassy the first time we heard him say it to people, but he is quite beloved in our congregation. We have a great ward that way. We didn't have a happy household when I was growing up, so I didn't have a lot of modeling there, and I've become a completely different person by leaning on the Lord for help with this. By learning to lead with love, like I said, it's like Matt can't hear anything if it's not phrased in a Christ-like manner. Now, the world's not going to treat him that way, and maybe we need to toughen him up, but that doesn't work. It does not work. It sounds kind of selfish in a way, but I don't know who I would be if this challenge hadn't been in my life. I wouldn't be writing. I wouldn't be doing the things that I'm doing there because finally after he came home, when they kicked him out and sent him back to Texas, I was on my knees every night saying, "Lord, this is what needs to happen for Matt," as he bounces off the ceiling. Finally, I stopped telling the Lord how to solve this for me and just listened.

Gerald: And listen Lisa did. One of her answers was the creation of the Liahona Project, a website dedicated to helping people of her faith who have children with disabilities. How about you Steven? How has Matt impacted you?

Steven: It's very difficult for me to answer. It was so hard for me, for a long time. The thing I would have to say is that the prize for me in this stage of my life, that is totally different than what I would have envisioned, is that probably I have never had, nor could have had, the depth of relationship that I have with Lisa. I think that I am changed in a way that makes me a far better husband and father, not necessarily that I would have chosen that path, but the net result of it has been pretty interesting.

Gerald: Any final thoughts?

Lisa: Someone asked me, is it just like having an angel live in the house with you? And of course I said, "You've nailed it." It wasn't really like that when you got right into it. Mostly because if Matt mouthed off at me, Steven as my protector would mouth back off at him. We live very peacefully now. Matt's got a pretty good life going; he's up for a couple of jobs. Eventually we really do want him to have an apartment with friends and a basketball hoop in the backyard, but I'll miss him. I'll love having time with Steve; we have a great marriage, and we're loving the missionary work, and Matt thinks he's on the team. He holds down the fort here so we can go and do that. We'll all get to heaven, and Matt will be high-functioning, and he'll apologize to you for every door he ever slammed when he thought you spoke sharply to him.

Steven. We don't have to look very far to realize how good we have it, how compared to many, many other parents with disabled children, ours is a pretty light way especially if it's not your own child. I mentioned that in an article. It's one thing to accept it and stay with it when it's your own child.

Gerald: Thank you, Lisa and Steven. I appreciate your unvarnished depiction of your life with Matt, complete with its challenges and triumphs.