An Orange Socks Story: David and Valerie: Down syndrome

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: 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 the privilege of speaking with 92-year-old David about his daughter, lovingly referred to as Sharmi, and Valerie, Sharmi's older sister, who eventually became Sharmi's guardian. Sharmi had Down syndrome and lived most of her life at home. Towards the latter part of her life, Sharmi was placed in a local group home. She passed away a few years ago. I know you'll find David's and Valerie's perspective interesting as they reflect on their life with Sharmi. I know I did. When David and his wife found out their daughter had Down syndrome, their doctor gave them a grave picture.

David: All they could do is lay out a black label, she's not going to be able to walk, and she's not going to be able to feed herself.

Gerald: The doctors encouraged them to put Sharmi in an institution, but David's wife wouldn't have it.

David: She said, "No, she's my daughter, I want to take care of her."

Gerald: Valerie, Sharmi's older sister, loved caring for her.

Valerie: She was our baby sister, and what little girl doesn't want to help with a baby in the family? She was a baby a lot longer than most babies. When I got older, I realized that babies grew a lot faster than Sharmi did.

Gerald: The family worked together to teach Sharmi some basic life skills.

David: One of us would get deodorant underneath her armpits, and the other one would be down on the floor taking her feet and walking around the house, and the next thing you know, she was hither and yon.

Gerald: Sharmi learned to walk, feed herself and accomplish all of the things the doctors said she would never do.

David: She would have never done any of the things that she did if it wasn't for the family working with her.

Valerie: We all helped take care of her, and we spent a lot of our playtime, especially when we were younger, playing with Sharmi. We wanted to teach her how to walk. She never really did learn to talk. She could say a few words, she could say, "I love you," but nobody else would be able to understand it. She did much better with the sign language. She was so much fun. She was a person of habit, she liked things the way they were. We would have popcorn on a Sunday night and watch "The Wonderful World of Disney." If Dad hadn't got the popcorn popper out by then to start popping popcorn, she would get the popcorn popper out, she knew the routine.

David: I'd purposely not put the popper out. She'd go get it out of the drawer, set it on the counter with the popcorn and stand back. She wouldn't speak, she'd just look at you like, "Come on, let's get going."

Valerie: Sharmi was my sister, and that was all I ever thought of her. When my friends would come over to the house, I would introduce her and say, "This is my youngest sister, Sharman, and she has Down syndrome," and if they didn't know what Down syndrome was, then I would briefly explain to them. Then it was okay. She was always just part of the family, and I never had any friends who didn't accept her or who made fun of her. We used to bottle beans. Mom and Dad had a big garden in Morgan. They would bring in a batch of beans, and you'd snap the ends off of them. Sharmi could break up a bean, break it in half, pick up that bean, break it in half, put it in the bowl, pick that half up and put it in the bowl. One time we made the mistake of giving her a big handful of beans, and then we ran out of beans. She would not let you take her beans and help her finish; she had to finish her own beans. She could do a lot of things.

Gerald: As a truck driver, David was away from his family a lot. When Sharmi reached her 20s, she lived with her parents and her grandma Lucy, who spent time delighting in Sharmi, introducing her to her friends and dancing with her.

David: My mother would call her down the hall. She spent much of her time with my mother. Mom would always say that she was the daughter she never had.

Gerald: But with all the siblings away from home, Sharmi was lonely, and the family decided to place her in a group home with other women who also had developmental disabilities. She'd go home on the weekends. After her mother died, Sharmi spent the weekends with her sister Valerie.

Valerie: I was married, and my children were very accepting of Sharmi. We had one funny experience when we had a few Korean students living with us. We had a new student, and we put him in the downstairs bedroom. Sharmi came to stay the weekend, and she'd been sleeping in the downstairs bedroom, and like I said, she was very much a creature of habit. She takes a long, long time to get ready for bed, so I would make sure she had all of her things laid out, and then she would go in the bathroom and take care of her needs, and then she would put her pajamas on. It might take a half an hour to 45 minutes for her to do that. I had gone to bed, and I had made her a bed on the couch and told her that's where she should sleep, and she headed downstairs and crawled in bed with our Korean student. He came up, knocked on the door and explained what had happened, and we were able to get him all settled down.

Gerald: Looking back, Valerie is grateful for her sister and everything she learned from Sharmi. She admires the qualities of people with Down syndrome.

Valerie: They are completely without guile. They love everyone and they're continually positive. They overlook all of your flaws, and it's like a spirit surrounds them. We always felt like she had an extremely positive impact on our family. I realized what a wonderful person she was and for the opportunity to have this wonderful person in your life, and to share her with your friends. At the workshop that they had for her, they would iron napkins. Sharman wasn't able to do the ironing, but her job was to pick up the napkin from the basket and hand it to the girl who was ironing. She was very good at that, and she enjoyed having a job. They just want to be with and participate with everybody else as much as they can, and that's how she was with our family, if we went, she went.

Gerald: When Sharmi reached 40, things changed.

Valerie: It was slow and progressive. We had to stop bringing her home on the weekends, because when she would come, sometimes I'd get her to the house and she wouldn't come in, or we'd set food on the table, and she loved having dinner at our house always before, but sometimes she wouldn't eat. I started visiting her more at the group home rather than bringing her home. She still knew who I was, she still responded when I would come, but I could no longer take her shopping and have her try on clothes. Then she started to have some seizures and to have blisters on her feet because her circulation was poor. The last five years she was in a wheelchair. Between the seizure medication and her brain dysfunction, she just couldn't respond like she used to. She would go every day to the center for people with disabilities, and they do fun stuff all day, and even though she couldn't participate, she enjoyed going and responded to many of the staff. She just always had this pleasant way about her that just made people love her and want to be around her.

Gerald: During her last days in the group home with a medical bed and staff to take care of the tasks of showering and feeding, Sharmi contracted pneumonia and was put on hospice. Valerie had mixed feelings at the time.

Valerie: You didn't want her to go, but at the same time you did, because you knew that she was suffering and could no longer participate in the world. A couple of weeks later, she passed away very quietly and peacefully, which is what we wanted for her. I don't think you ever go wrong when you serve somebody, and Sharmi would do anything for anybody that she could.

Gerald: Many people with Down syndrome age at an accelerated pace, and many have Alzheimer's symptoms much earlier than the general population. I was particularly interested in visiting with Valerie and David because they may be an example of how my life will turn out with my daughter with Down syndrome in 30 or so years.

Gerald: Thanks for listening to this episode. Orange Socks is an initiative of Rise Incorporated, a non-profit organization dedicated to supporting and advocating for people with disabilities. Follow Orange Socks on Facebook and Instagram, and visit our website orangesocks.org for more stories, and to find national and local resources to help parents of children with disabilities.