

Realizing Your Loved One is Sick: Chelsi's Mom

As a young child I had no idea what Huntington's Disease was or that it even affected my family. My mom, Patti, was HD positive and fought to the very end doing everything she could to help further research for HD, for my family, and for me. She was a true image of sacrificial love. Looking back, her determination to be one step closer to finding a cure was ingrained in me from a very young age. However I didn't see my mom as different until 2nd grade. After presenting a poetry project where the parents were invited to watch, one of my classmates came up to me and asked "Chelsi is that your mom?" I answered "YES I'm so glad she got to come. I've worked really hard on my lines!" The little girl looked back at my mom and then at me and said "What's wrong with her? Is she retarded or something?" I was frozen, stunned, that this girl had said this. I thought to myself "my mom was completely normal, or was she?" I quickly snapped back at the girl to shut up and leave me alone which she did. I was left in my own thoughts about this "retarded" word describing my mom and thought maybe she was right.



As a teen, I obviously learned about what Huntington's was from some of my family members. The teen years dragged on, and I could easily have a separate life by diving into as many activities as I could. Participating in the night with friends and going on trips was an escape to have some normalcy. I couldn't escape all the time, I was a caregiver and I did love my mom deeply. I was in this torn place of being "normal" and being "the kid with a sick mom."

To give you some background, my mom had me in her 2nd marriage at 42, raised me the first 6 years of my life, cooking, shopping, singing Beach Boys everyday. That quickly went away, she started to get worse and couldn't drive anymore. She soon had to be in a wheelchair from the chorea developed by the HD. I was 7 years old when my role as other caretaker began.

SO why do I share this now? What is the point in all of this? Well, this is new to me too. When I was a teenager going through this phase was extremely difficult. I didn't have a solid foundational place to process the typical changes a teen goes through, plus questions and thoughts I felt about HD daily. Fast-forward 14 years, as I finished up my masters in Youth Ministry and multiple years of trying to figure out my calling, it hit me, while presenting my dissertation. It is helping teens struggling with parents (or loved ones) who are affected by HD. Reaching teens like you and me to know that you're not alone in this giant undone puzzle of your life, that you will make it through this part of your life that is so uniquely woven into your story. I hope by connecting through these monthly articles and building this community we can grow stronger together.

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