

# **A Conversation With My Daughter**



Recently, I sat down with my daughter, Rebecca, to discuss our dynamic and how caregiving plays a role in our relationship. Rebecca is 37 years old; she is a manager at the company she works at, a college graduate, loves photography and has a great sense of adventure. She's kind, caring, thoughtful and is protective of the ones she loves. Everyone is always saying to us: "you two are twins!" We can't go anywhere without people commenting on how much we look alike. Becca, with her sense of humor always tells them, "Nope, never met her! I just found her"!



Becca has been caregiving for me since 2009 when my MS really started progressing more rapidly. She takes care of household duties (cleaning laundry, cooking). I try to sneak some laundry and dishes in, but I usually get the “mom look” from her when she gets home from work. She has taken care of me after every test, procedure and surgery I’ve had. One of the biggest and most valuable things she does is accompany me to my doctor appointments. She listens, takes notes and ask questions when I’m unsure of something. Having an extra set of eyes and ears is so important because doctor appointments can sometimes be overwhelming and hard to cognitively process. She doesn’t let me get away with anything in those rooms!

I think we make a great team. We care for another, we hold another accountable, we laugh until we pee ourselves, and we take on whatever is thrown our way together.

Here are a few things we asked one other about what the caregiving process is like.

### **Becca to Mom:**

#### **How did you feel when you told me about your diagnosis?**

I always knew that you were aware that something was going on with me. When I finally found a doctor who believed in me and was officially diagnosed, a weight was lifted. We went straight into action and developed a plan of attack.

#### **What would you want me to know about MS?**

I want you to know that this is a disease that can potentially progress. It won’t stop us from having a great life, but we just might have to do things differently than planned.

#### **How can I be the best caregiver to you? What are some things you need from me?**

As a caregiver, don’t treat me like a disabled person who cannot do anything for themselves. Treat me like your mom, your friend and your partner in crime.



### **What is the best piece of advice you can give me for the future?**

My best piece of advice is to never settle for second best, don't always worry about me and live your life to the fullest.

### **How do you think we're alike/different?**

We're alike in the sense that we're both caring, we both put others before ourselves, we both have a great sense of adventure, and we always try to look for the positive in every situation. We're different in the sense that I'm more of an immediate action taker. Whereas you are a planner and like to analyze before taking action.

### **What is the hardest part about being a parent with MS?**

The hardest part is that physically, I find it harder to do certain things with my kids. I sit on the sidelines more often. Even though my head/heart say yes, my body often says no.

### **What advice would give someone who is newly diagnosed with MS?**

For newly diagnosed people with MS, find your tribe. Seek out others like you. Form a healthcare team that listens to you, believes in you and values you as a human being. Advocate, advocate, advocate for yourself!

### **Are you scared of me ever developing MS?**

I'm not scared of you developing MS. I believe everything happens for a reason. And if you do develop MS, we have a better understanding of the disease than we did when I was first diagnosed.



### **Mom to Becca:**

#### **What were your thoughts when I told you about my diagnosis of MS?**

Initially, I was scared and nervous after hearing the diagnosis, but I knew like everything else we had been through, we'd get through it together.

#### **How can I communicate to you what I'm going through?**

Communication is key! Don't sugarcoat how you're feeling. No telling me that you're "fine" if you're really not. Be honest.

#### **Is there anything I can do to make caregiving go more smoothly?**

To help caregiving go more smoothly, we need to stay in constant communication with one another. You need to be honest and open with your wants and needs. I need to be honest if I need help or if I need a break. The more we talk and work things out, the smoother the process will be.

#### **What is the hardest part about being a caregiver?**

The hardest part is that your stubbornness can sometimes drive me crazy! You're strong-willed and independent, which sometimes can make it challenging to help you. Sometimes I just want to say "Mom, I got it!" or "Mom, go sit down!"



**What do you think the biggest misconceptions are about being a caregiver?**

One misconception is that caregiving is not rewarding. Sometimes people think that caregiving is something that a loved one is obligated to do. For me, caregiving is 100% rewarding. I've always said that it's my purpose in life and why I was put on this earth. Like you mom, I believe everything happens for a reason. You care for and love me so unconditionally, why wouldn't I do the same for you?

**What advice would you give to other caregivers?**

Be patient. Have a sense of humor. Take time for yourself and don't feel guilty about it. Your mental and physical health is just as important as the health of the individual you are caring for.

**Are you ever scared of developing MS?**

I'm not scared of developing MS. Like you, I have enough information now to lead me in the right direction. The MS community is so strong and supportive, and I know I'd have the best support system around me.