



41 King William Street, Suite 206  
Hamilton, Ontario L8R 1A2

Hi, my name is Paige. When I was 14 years old my mother was diagnosed with Scleroderma. I'm not really sure if my story would count, because I, myself do not have Scleroderma but I felt it would be nice to hear from a different point of view. Not only does this affect the person suffering with it but also the people around them.

Two years ago my mom was diagnosed with Limited Scleroderma. In a very short period of time she had also been diagnosed with Raynauds, Sever Restless leg syndrome, sleep apnea, Gastrosophical reflux, digital ulcers, a leg ulcer, sever fatigue, fibromyalga, Gastropharisis and Chronic Kidney Failure. This alone has caused troubles for my family. My mother hasn't been able to care for my four year old sister, leaving the job up for my fourteen year sister, myself and my step-dad. Unfortunately, with my step-dad being the only one able to work the job is left to my sister and me.

My mother doesn't mean to be sick and I know that. Again, I'm not sure if my story would count but people need to know that Scleroderma doesn't just affect the person who has it. It affects the whole family, in different ways. When my mom was diagnosed, I was angry. Angry with her for having it, angry with myself because maybe I could have prevented this, and lastly I was angry with the doctors for not knowing how to fix this.

Within the first year in a half of knowing my mother's disease she went into Kidney failure and was hospitalized for two weeks. It was hard not knowing when she was going to come home or if she was okay. My parents had split up when I was three years old. I had always been with my mother, so to even be away from her for a short period of time was hard, let alone two weeks. She has been hospitalized for treatments and illness a total of 5 times plus 6 trips to the Emergency Room due to Scleroderma.

It was and still is hard seeing my mom go into a doctor's office or hospital because I don't know if she will be coming home that day. I feel as if I had to grow up much faster than other children my age, because of Scleroderma. Unfortunately, this is true. I know how to care for a

young child (even if she was my sister); I'm more mature for my age compared to my friends. I don't find some of their 'fun' to truly be fun because I see things through adults' eyes.

Everyday my mother has to take naps, some after school, and some before/after dinner and later at night. This does not help me because I have an IEP in school, meaning I need extra help with my homework. But because of Scleroderma, the person to help me cannot be my mother. I have family and friends to help, but it's just not the same. When my mother is having one of her 'good days' meaning she has the energy to get up and move, I help her with what she needs while going out.

It's not too bad of a job when you think about it. But when you have to grab the frozen foods, or stop in the middle of an aisle so she can take a moment to get her energy back, it becomes a real pain. It's hard when I don't have anyone my own age to talk to this about. People either don't know what it is or just don't care. My mother is one of those people who doesn't let it affect her.

She is willing to tell anyone and everyone who will listen, just so a small handful of people know of this. I am not one of those people. It wasn't until a little while ago that I decided to help out with the Scleroderma society of Ontario. Again, I'm not sure if this story counts, but it would mean a lot if even a small amount of people understood.

I'm Paige and this is my story.