

Funia's Story – Who is “She”

My name is Funia. I am 76-years old. I am a woman with grey hair. A mother, a grandmother, a wife and a teacher with a diploma from Seneca College in Early Childhood Education and a Bachelor of Arts Degree from York University.

I am Jewish. I lived through the Holocaust. The Nazis killed my entire family. I am also an immigrant to Canada. I struggled very hard to survive and make sense of the destruction and chaos that I came from at age 20. I would say I succeeded without a big fanfare around me.

I touched many lives and many lives touched mine. I read many books, listened to music and saw many plays. I traveled a lot. I speak five languages. I raised a beautiful family with values nobody can complain about. My life was not a bowl of cherries, but a bowl of life. I worked hard. I played hard. I learned fast, catching up on the wasted years of my youth.

Right now I can't walk. My speech is impaired. I am being driven in a wheelchair. By all these implications, I am deaf, blind and my mind is not working.

My mind is working. My memory is good. I can hear and see. I listen to music; I like flowers, perfume and hot showers.

So what is wrong with me that they don't talk to me but to the person next to me? Can “SHE” sign this? What happened to her? I'll tell you what happened to her - “SHE” has ALS, diagnosed a few months ago. A terminal illness, cause unknown, that destroys muscles. No cure available. The brain stays intact and what was there before is still there. I did not ask for it. I never thought it would happen to me. But it could happen to you, and you, and you. I did not know that I had so many muscles that control the body.

What is it like to live with ALS for a vibrant, independent, creative woman? It is like being on death row waiting for your death sentence. At any time one of the muscles that controls your breathing might stop functioning. Not to be able to communicate is my biggest despair. Who knows what comes next. I cherish life.



I find beauty in sunsets and sunrise.

I love flowers.

I like children and their innocence and charm.

I like a good joke and I laugh despite my difficulty to breath, but how I would love to repeat that joke. I have so many things to say, so many stories to tell about people that crossed my life. I have to give that up because it literally takes my breath away.

So I live from day to day, dependent on help to exist. Soon I will have to make a decision about the quality of life I want for me and consequently for my family. I hope I have strength enough not to give in to the difficulties of the moment, and die in dignity. I pray that I will be fortunate to die in my sleep. Some days I am grateful that I have the good luck to be in my own home.

Some days I am so angry and desperate that fate handed me such a lemon. Why me?

Maybe my courage and strength haven't been tested enough. Maybe for the privilege of meeting gentle and caring people. Maybe to experience the seeds of love, compassion and caring I have planted in my children's hearts. I have not found an answer yet. I probably never will. Life is full of unanswered questions.

Ironically for the first time in my long life someone is taking care of me instead of me taking care of myself and everyone else. I was alone since I was 15. I have not experienced that care and love of parents, siblings and other relatives. I had to be an adult at 15. I was never a teenager or a young adult. I had to grow up fast in order to survive.

I do care and feel about others and I treat others with the respect every human being deserves.

Treat me with respect too.

In tribute to Funia and to share her valuable insights, we have prepared a booklet entitled ***"The Way I Am: Living with ALS"*** which has assembled all the articles from the Homecare Library and more. This can be viewed on our website, www.qualicare.com. You may also order free copies of the booklet by filling out the form on the website.

