

Funia's Story – On Getting Outside

In the Spirit of Adventure

This is not about an African safari or climbing mountains or eating exotic foods. This is about our Wednesday outings. It is about a very kind young woman volunteer with a big heart and a comfortable van. It is about me, with ALS, limitations, and my wonderful caregiver. It is about my highlight of the week, the “girls” day out.

Where do we go?

Sometimes, on memory lane visits to the neighbourhoods where I have lived in Toronto. I mostly view those places from the door and window of the van.

Transferring from the van to a wheelchair and back is difficult and stressful. The thoughts in my head are screaming in excitement when I recognize a familiar place, a school my children attended, a library we all used. My mouth opens to share my thoughts and memories with my companions, but even incoherent sounds refuse to come out. I am able to share my thoughts on paper only in a limited way.

Sometimes we will go to the mall, hoping it is wheelchair-accessible. Buying a few birthday cards for my children and grandchildren is a big accomplishment for me. We might browse in a bookstore with longing. I look at the books that I love, yet feel too weak to read. A visit to the hairdresser makes me feel well-groomed. The most exotic restaurant is the one I can find food that is easy to swallow.

The “girls” reassure me that they have a great time. I hope so!

I come home and fall into my bed, exhausted but full of recollections and thoughts about how I was and how I am. The difference is a sad realization about an illness that strikes with such cruelty and destroys your body and spirit in a short time, and also affects the lives of those around you.



The cause of ALS is unknown in this age of man landing on the moon, high advancements in technology that controls our lives so efficiently. How devastating for those of us that experiences the effects of this little-known malady. Maybe with awareness will come some research and a cure.

Where are we going next Wednesday? Which mountains are we going to climb, “girls?”

In tribute to Funia and to share her valuable insights, we are featuring this and a number of her other articles in the Homecare Library.

In addition we have prepared a booklet entitled ***“The Way I Am: Living with ALS”*** which has assembled all these thoughts and more. This can be viewed on our website.

You may also order free copies of the booklet by filling out the form on the website.

