

Funia's Story – On Being Bedridden

The Bed is my Oyster

Due to ALS, my bed has become my “oyster.” That’s where I spend part of my life. I can’t walk or talk. I can’t go anywhere alone. The smallest outing is a big adventure. It takes two people and a car to get me out of my bed and apartment.

I’d like to describe my oyster.

To the right of my bed is a roof terrace where my son planted flowers. There is a bird feeder too where birds occasionally visit. In front of me in the distance I can see hills covered with grass, a synagogue with a dome reminding me of Jerusalem and the Dome of the Rock. At twilight the sunset paints the sky with magnificent colours.

Day and night, the silence is disrupted by moving trains announcing that everything is well out there and life goes on. To the left of my bed is a radio equipped with tapes and CDs. My favourite station is classical music of countries I have seen or lived in. It reminds me of people I have met, experiences I lived - some tragic, some pleasant.

The bed is my station where I can listen to other people and observe their lives. The oyster shell is closing in as I become more dependent and helpless and frustrated. I am dreaming of a brighter world that I can touch with less difficulty.

However, I am grateful to be surrounded by some beauty that I am able to experience when I am not exhausted. I am grateful for family and friends and caring people that enter my world and bring in food for body and soul. I am grateful for my caregivers that try very hard to keep me comfortable.

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.

