

Funia's Story – A Hero with ALS

Introduction by Andrea Nathanson

I met Funia many years ago, just a few months before there was officially a Qualicare.

She was an uncommonly talented person – active in the arts, in education and in her community. She was very creative, very intelligent and very very strong-willed. She made it clear to anyone involved in her care that she was not to be pitied and not to be ignored. While ALS may have robbed her of her speech, it had not been able to take away her mind and, more importantly, it had not been able to take away her heart.

Although there were assistive communications devices that could convert typed words into synthetic speech, she insisted on using the one part of her body that ALS had not been able to impact which was her right arm. This allowed her to write down her thoughts on pieces of paper. It was a slow process but she insisted that we wait for her. She did not want us to finish her sentences, because each snippet of her thoughts had profound value.

I encouraged her to write - about how she felt, what made her happy, what made her unhappy. This she did with great deliberateness and great insight. What follows are a series of soliloquys about her self-image, her caregiver, her husband and family, her outings.

They are compelling. They are inspirational and uplifting. There is not a day when I don't think of her or a week when I don't read what she wrote.

In fact, Funia's insights have become part of Qualicare's DNA – the deep-seated belief that every person we provide care for is a complex treasure of thoughts and feelings

Here's the introduction that she wrote:

I would like to share my personal experience with this illness that I have summed up in the following essays. My goal is to familiarize the people in the medical profession, caregivers and public in general with this devastating illness and its effects on the person and their family. I hope that with awareness and research, a cure can be found.



In addition, I would like to change vocabulary like “terminal” illness to “serious” illness. Human beings are all terminal. All of us must die one day. “Terminal” implies no hope, no life, only death predicted by professionals who play God. Yet it is possible with great effort and support to live each day to the fullest of one’s ability - to light a candle each day, instead of cursing the darkness. It is possible to laugh and cry, to love or hate. We can be open to new things that we might learn each day, and thus enrich our soul and mind. We can be alive, while we live.

Eventually we might have to make a choice about the quality of life that is appropriate to our beliefs, expectations and circumstances. Not an easy task!

She died a few short months after writing the words.

In tribute to her and to share her valuable insights, we are featuring a number of her 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, www.qualicare.com. You may also order free copies of the booklet by filling out the form on the website.

