

# LIFE AFTER AN ADULT DIAGNOSIS

*Life is full of challenges, yet most of the time they flower into more strength, insight and wisdom...*

It felt quite strange when I was diagnosed with a very rare degenerative muscular disease about four years ago. It was having an effect on me with weakening my limbs and breathing. I couldn't help but wonder how can such a tiny invisible missing enzyme disable such a complicated vehicle, "my body"? A lot of memories started to come back about the very early symptoms that were misinterpreted as signs of "stress" due to the ongoing difficulties I was having in my life. However, that did not change anything. All of a sudden I began to acknowledge the reality of my situation and understood the daunting truth that I needed to learn to live and cope with. I went from shock to anxiety, panic attacks, and depression. I'm a single parent with no family in Australia and the government will not subsidise my very expensive monthly treatment because they don't believe it will "prolong" my life, but for me, who will look after my son when I go away?

After few months of suffering, a light bulb went on in my mind and heart I said to myself,

"I have few years to live with my son. I can either spend them feeling depressed and sad, or live them to the full and leave my son with beautiful memories and a living example on strength."

I chose the positive option and decided to live each day as it comes. I made a conscious effort to stop worrying about the future or remembering the past, which has changed my life tremendously. I opened up about my disease and did not feel embarrassed to talk about it to friends and a few strangers when they asked.

I stopped feeling embarrassed about using a walking stick to avoid falls. In



fact, I've had lots of laughs with elderly people who use the stick and it always guarantees me a seat in the train when I go to work, even in peak hours! Instead of stressing about how many times I will have to wake up at night to adjust the C-Pap machine mask, I made jokes about it as it looks like an elephant trunk, and sent a photo to my friends to share the laugh. I am learning that being open and having some humour about adversity makes a big difference. As my body weakens more and more, I learn about the importance of accepting help from friends and loved ones. Doing so can be a challenge for me at times, as I have always been so independent in all areas of my life. It is a lesson in humility at its best, unlike what I originally thought.

Sometimes through adversity, life shows us how many beautiful people are out there. How cooperative and caring our community is. A bright example is all the help and support that I have been receiving from

Muscular Dystrophy NSW. Marie, one of the social workers there, is not just doing her job professionally; she is genuinely interested in providing all the help possible. She connected me with other services where I met very loving and kind people who helped me and my son. She also helped me to go on two days' respite, which was of extreme importance at the time. I relaxed in bed not having to worry about a thing in the world, just looking outside the big window at the beautiful trees and flowers reflecting on life and having very nice meals. I came back home feeling very light and refreshed.

We really don't need to be and cannot be super humans but we can discover the incredible strength within ourselves through our journey, if we pay enough attention, open up, and smile.

## **Lama Al-Akhras, 47yrs**

Lama is a member of MDNSW and has an extremely rare neuromuscular condition called Pompe Disease