Shiloh's Story

Shiloh wrote her story.

Strange symptoms

I first showed strange symptoms of severe, constant migratory pain, weakness and loss of energy, and other symptoms of multisystem dysfunction at age 10. It took four years to be diagnosed with Myalgic Encephalomyelitis (ME) (previously called Chronic Fatigue Syndrome) and Fibromyalgia Syndrome. By then I'd had to pull out of beloved activities including flute, hockey and debating, then school too. I had to cut off my beautiful long hair as it gave me intense headaches and back pain. It felt like I was losing my self completely to the illness.

By the time I was 16 I was completely bedridden, rarely able to talk, feed or bathe myself. I craved company but most of the time I could not bear touch or sound as even these drained my energy. At times it hurt to think at a normal pace so I learned to slow down my thoughts to ease the exhaustion. It was this severe for a year. Then as I improved I needed to be pushed in a wheelchair, for a further two years, to be able to leave the house.

Reclaiming parts of life

By the time I was 19 I took up one subject of senior school as an adult student, and learned to drive. By age 21 I graduated high school, started one subject at university, started volunteering one hour a week at Oxfam, and moved out of home. I am fiercely independent and after being so dependent for so long I was determined to live life as independently as possible. Throughout this stage, even at my peak health-wise, I could only sit up for a maximum of five hours throughout the day, and needed 12-14 hours of sleep daily.

Writing a book: *Stranger in the Moving Chair*

From ages 16-23 I wrote poetry and drew to express my experience of life. In 2004 a book of these works was self-published, called *Stranger in the Moving Chair*. The writing process was cathartic and helped me deal with the pain, loss, and grief, while also giving me a chance to appreciate the beauty in this world and joy at being alive. Being able to share this book with people was quite profound. After eight years I am still receiving feedback from others with ME who find it empowering to read of a similar experience put into words, and they use it to describe their situation to healthy loved ones. Healthy people also respond by identifying with emotions expressed, because many of the themes in the book are universal. I continue to find the response humbling.

In 2005, soon after publication, my health plummeted and I again lost the ability to drive, study, and volunteer and I haven't regained it since. All my energy goes into looking after my health, and developing relationships with those who can help me – emotionally, friend-wise, and practical support-wise. Lifts to appointments are now necessary as I am not well enough to take public transport (yet I am still ineligible for the taxi subsidy scheme!)

My diagnosis of ME currently automatically disqualifies me from support from some agencies, because it is not considered a “Total and Permanent Disability” according to the Disability Services Act 2006. One could ask after 22 years of “disability” with no cure in sight, when it would be deemed “Total and Permanent?” There are also cases of people who have died from ME. Is that not permanent? Thankfully another agency offers me some help and able-bodied friends help out, and I accept this support gratefully.

Now, 22 years into my journey with ME, I am still severely ill, needing to lie down mostly unstimulated for 21-23+ hours daily, in constant pain, with extreme weakness, cognitive problems, faintness on standing and countless other symptoms. I always call it sitting ‘up’ never sitting ‘down’ as sitting is never relaxing. I spend my time deep in thought and the hour or two I am upright I put to good use and create art, talk to friends online, spend time with a friend visiting, or do gentle stretches at hydrotherapy which I go to twice weekly.

Throughout my life I have expressed myself through painting and drawing. There have been bouts of creativity, then times of emotional shut down when I could not create. A few years ago I was involved in a project for people diagnosed with CFS called “Creative for a Second or two” where people living with the illness contributed pages in a journal during the short moments of the day they were well enough to be creative. The journals were sent all over the world. It encouraged me to do art little by little and embrace any moment no matter how short, and use it to be creative.

In the last two years I have focused as much time as possible on creating like this. I draw while lying down and then paint when I can sit up. I also like arranging papers to create cards. Every week I send cards around the world to friends and people I have never met who are too ill to create social circles, in the hope that a little card in the mail can be enough to be a light and let them know they are being thought of.

I have created a website for my art and advocacy writing (www.shilohmoore.wix.com/byshi) and a blog (http://byshi.hogfish.net/).

There are many things I have learned along the journey with this illness and I’d like to share a few:

1. You can’t hurry the stages of grief. You need to give yourself time and acknowledge the pain of your reality. True acceptance only comes once you have given time to the other stages. It is not “being negative” to cry about your reality. My Mum says sometimes that only being positive is pretending. True positive acceptance comes only after you have acknowledged the

negativity and worked through it. With a long term chronic illness you continue to experience loss and grief, so even once you have accepted life with your illness, the pain of living with it does not end there. For me, after 20+ years, dealing with the grief has become “easier” but it is never “easy”.

2. My approach to dealing with things is different to that of many people I’ve come across. I tend to be a realistic thinker – I prepare my mind for negative outcomes if they appear likely. Then if the worst happens I’m more prepared to cope with it and if anything better happens, then I treat this as a wonderful bonus and celebrate it. Instead of being constantly disappointed that life’s not ideal, I celebrate that things could be far worse.

3. I try to deal with life as it comes. I sometimes fear the future and question “what if …?” I give these thoughts time, but try not to dwell on them. I say I will deal with what comes when it comes and the fact I have already dealt with so much gives me confidence that I will be able to cope. I realise most things I fear about the future will not actually eventuate, so I try to deal only with the load I already have – as that load is heavy enough!

4. One phrase that has helped me is: “I am a human being not a human doing.” For all those hours I spend on my own every day, lying in bed needing to be unstimulated, I realise I still have value. No matter how I am forced to live, I have value. I don’t have to “do” to achieve success at life. I also love friends who will just “be” with me.

5. I have limited energy and am always in pain no matter what I do, so I try to spend what energy I have on things that warm my soul and make life worthwhile, and say no to things that are life-draining. I describe it as learning to “choose your pain” and “do what gives you life.”

6. My Dad uses the phrase “Keep hope alive”. You always need to have something to look forward to, to keep you going. Hope is very important.

7. I always try to be grateful for the things in life that I do have going for me. Sometimes it’s hard to see through the pain, but there are always situations worse than your own. To be grateful for the things that are good in your life helps you see your life as a whole and realise it’s not all bad.

8. Finally, Eckhart Tolle speaks about “Life situation vs Life.” In applying this to my life, I realise my life situation is living with ME, and to be quite frank, that

sucks. But my life is far beyond this, and I embrace my life itself with a passion.