

.....learning to be strong!

Encephalitis has made my life so very different in so many ways. Most significantly I found my brain stem had been damaged, and as a consequence I had to learn ways to cope with all the major changes happening to my body. These were essential functions that the brain stem once controlled. One change that really tested me was 'losing' my voice as it had been my major 'tool' in my career as a teacher. No longer could I use it as I once had for discipline or to convey a point to my students. In fact now I could barely string a sentence together and my vocabulary was severely limited, it was a real challenge to be understood and join in a conversation. So I was sent off to speech therapy appointments nearly every day and it was such hard work. The muscles I used for speaking previously no longer worked and it was necessary for me to train other muscles in my voice box. Boy, do we take things for granted but these exercises made me thankful that all was not lost, but I certainly had to work very hard. I realised the road ahead was very steep and rocky.

I would do my exercises at home and with time I was able breathe AND talk at the same time! My lungs were getting stronger and I found I wasn't so breathless when I spoke. Of course before becoming ill I hadn't realised how hard it was to say some vowels so my teacher had encouraged me to concentrate on making certain sounds that went high or low to put some timbre into my voice. It had become so monotone, but at least I could be understood by others who were willing to be very patient with me.

Lessons were so draining as I was required to concentrate for so long now and I was still so weak in many ways. Initially when I spoke I would have to formulate a 'response' in my mind and as my short-term memory was poor, finding the right words would prove to be very difficult in many situations. I learnt to be quiet – very unlike the 'old' me! Joining in conversations was a thing of the past and I still have this dreadful habit of not really contributing as I still find it hard to find the right words. People are very patient with me and 'offer' the right words, and now that I don't get so breathless my conversational skills are much better. You can even understand me!

I can recall when talking seemed so easy, yet I'm much stronger now in the 'lung department' so each couple of words doesn't have its own breath. I do still get very breathless and have to concentrate when I talk, but nowhere as bad as the early stages of my illness. However I have to live with a voice that is so quiet and monotone – I think it is near impossible to whisper 'sweet nothings' in somebody's ear when you sound like me! I feel like every conversation is a bit like an exercise in giving my words clarity and volume and it is very difficult for me to participate in a conversation when surrounded by noise and it's a consolation that people now realise I'm not being rude when I don't join in. On the other hand I've become a very good listener and go with the flow as the frustration I used to feel is just wasted energy and I've learnt to let go as people are very understanding, especially when they know your history.

So finally when I could string a sentence together and people could understand me and I had become more mobile I thought why not go on a well deserved holiday! But this

notion had to be put on hold, as I was to face my next challenge! It was cancer! What a bother, however I learnt that the cancer I was diagnosed with, Hodgkin's Disease, was treatable and had a good success rate. My oncologist was extremely supportive, he was determined to get me well so I had lots of positive vibes around me as well as my own strong determination. All my previous hard work was put on hold as I focused on getting over my 'new' illness. In fact my whole life was put on hold for six months as the days and then the weeks seemed to consist entirely of doctors and treatment. And it was a bleak period in my life but it didn't seem to be as bad as being told I had Encephalitis. Strangely, I felt that for sure I would get better and I saw this illness as a bit of a 'hiccup' in my hard work fighting and dealing with the terrible debilitating disease I had initially contracted.

The cancer treatment really knocked the stuffing out of me and my energy levels were further sapped to the point all I could do was to read and to listen to music. Life was a bit of a drag at this stage but it did eventually pick up. After a year of being diagnosed with cancer my energy improved and then I got better to the point that after five years I was in the clear and have been clear for seventeen years now. In fact I was feeling so positive one day when I was shopping with Mum, instead of my original plan to be buy food, I ended up buying a Unit!

The unit became my main focus, but the mind as well as the body needs to develop and grow so I enrolled in several correspondence courses dealing with Human Development and Adolescent Psychology, and I joined a gym. My mind and body were developing well but I was beginning to feel increasingly restless and I felt I needed a change of scenery. It was suggested to me that I go to Western Australia which had always been a place I have wanted to visit. I couldn't just get up and go by myself, I needed someone to help and be my carer. So it was my dear sister who was to come to the rescue, to push me in my wheelchair and to drive me to lots of wonderful places. It was such a liberating experience for me as I had always been a very independent person and while I don't need much help now I cant go long distances on my own steam. Having to ask for help is one of the most difficult changes that I have had to cope with.

Another confronting concept is coping with people's attitude towards me. Some only see the walking frame or wheelchair and others have thought I'm deaf, 'simple' and one woman (I knew she was trying to be kind in her own way) patted me on the hand and almost burst into tears. I could feel her pity as well as that from many others and thought this is something I have to get used to as much as I deeply resented it. Since those early days I've slowly learnt to better cope and deal with my disability. This is my life now. I think people pick up your 'vibes' and they no longer show pity, just acceptance and understanding. When I am at ease with my situation and come across in a positive manner peoples' initial fear and uncertainty about how to react is lessened, and we are free to get on with having fun!

I enjoyed my time away with my sister and I've since found a travel agency that deals specifically with people who have disabilities of some sort. My sister was a wonderful 'carer' (as all my three sisters have been) but she is no longer able to help as she has a

few injuries which refuse to heal. How I enjoy to travel now, last year I went to New Zealand with a special carer but it is so very different when you are restricted physically. We still have many challenges to face every day, lack of public education and awareness are still problems, but improvements are slowly being made for people with a disability. We have to be strong as it is our strength of character that helps in our survival and our ability to find a rightful place for ourselves in this world.