

Victoria Storey : A Personal Journey Of Hope

I was happy and content, Life was good, happily married to my husband Paul, we had bought a family home in Withyham. We enjoyed our life and loved the countryside with our rescue dogs Ben and George and our daughter Jessika. I had though suffered from strange appearing and disappearing symptoms occurring in different areas of my body mainly terrible excruciating headaches that had began to frighten me.

I had seen numerous Doctor's and nurses; it was to take 2 years of these strange symptoms before a final diagnosis of Relapsing and Remitting Multiple Scoliosis was diagnosed in December 2014.

I experienced Optic Neuritis in both eyes, I knew intuitively that the disease was aggressive, little did I know though how long it was going to take to finally get this diagnosis. I was blind for 1 year, not knowing if I would get my sight back, it was a very frightening time.

Paul didn't leave my side; he was well versed in dealing with the medical world as he grew up with doctors in West Africa as his father worked for the World Health Organisation. Which proved to be very beneficial to my situation. Paul's father tried to really help us.

It was quickly realised I had to see a serious well experienced Neurologist based upon what I was experiencing. The pain started to increase to a level I could barely cope with. The attacks were coming thick and fast, my GP told me the disease was following my pain pathway.

I gave birth to my daughter Jessika with just Gas and Air and it was a compound labour, meaning she got stuck. I was told then by the Doctor looking after me you must have a high Pain threshold to cope with a Compound Labour. The pain I was experiencing was something else I did not know when it was going to attach or when it would subside if ever?

We saw numerous professionals to try and find a way to cope with what was happening to me. In the end we chose to pay to see Sir Dr Nicholas from Imperial College London. He said he had never seen someone suffering such pain, although he did say there were other patients with MS who do suffer pain.

Paul though would work tirelessly massaging my feet at the end of our bed, to help me cope with the pain. This would sometimes be all day or if that was not possible, he would massage my feet in the evenings. It was largely down to him and his reassuring presence that in turn helped me to find the strength to face each day, which was quite hellish. We were facing a storm together not knowing where we would end up.

I felt there was a force that wanted to take my life, Stewart Korth a well-known Osteopath helped me, as did my husband and our two dogs.

I tried to commit suicide several times after diagnosis. I was so angry with God for taking my happiness away. I had had a difficult childhood and I had coped with PTSD and Bulimia. So, I knew my strength, but what I was now experiencing was on a whole new level. I tried throwing myself into the river where I lived tears pouring down my face, thankfully my neighbour stopped me. I then tried to throw myself down the stairs to the dismay of my daughter and husband.

I hated myself I saw no value to my life anymore. I thought it was all over, I reached out to a priest who said if I killed myself, I would be turning my back on God. I was furious with her for saying this, thinking she is not walking in my shoes, however her statement stayed with me. I thought she was being dogmatic and not understanding the hell I was going through.

My husband largely carried most of the daily tasks, whereas before it had been shared. Our daughter had turned 14 years old and was going through her teenage years. Wanting to rebel against everything and everyone.

I was dealing with not being able to sit in chairs and to this day I still experience pain after sitting in any chair. Laying down on various mattresses proved to be difficult to find one that supported and eased the pain I was experiencing in my spine.

Paul knew I wanted to die, I had spent two summers' indoors, not being able to go outside and enjoy the sunshine, the heat and the cold would make the pain worse as well as the rain. And still today the weather effects my body and the pain I experience as a result of what the weather is doing.

What next, we were fast running out of hope, coming up to 3 years lying down in a bedroom in our family home that I could no longer manage. We were increasingly getting further and further into debt as Paul's time was consumed in looking after me. We did however manage to go on a very traumatic walk every day for about 40 mins. Of course, I used walking aids and my husband's supporting arm. But the walks were frightening, traumatic and unpredictable as to whether I could manage them, they were many occasions when I could not.

Finally, my Uncle stepped up and talked to Paul about me having a revolutionary stem cell transplant called Haemopoietic Stem Cell transplant, otherwise known as HSCT. This is a very new treatment for MS suffers and is known for its invasive effect on one's body. There is a 1% chance of having a stroke, when the Haematologist told us this, something in me was alarmed, but I pushed the feeling to onside. My husband Paul did the research in finding the best and safest Hospital for me to have the treatment in. London treatment was taking to long, I was getting to the point where I could not sit up in bed. Karolinska University Stockholm had the safest record. It was one of the most expensive places to have HSCT.

Paul spent weeks with me in an apartment opposite the Hospital we were in isolation for this duration. It was due to risks of infection. The boardroom was palpable.

After I had had the treatment I had suffered a stroke, momentarily I crossed over the threshold, which was an incredible spiritual experience in and of itself.

I met my father who had died 4 years previously, perhaps I had to in order to bring compassion towards him later on.

I was convinced it hadn't worked when I returned home, therefore I demanded to Paul that I wanted to die as the quality of my life had not improved. I was fed up with everything and very fed up with God. My dear husband though un be known to me was battling Dignitas away from taking me to be euthanised. They were very willing to take me, Paul had to have a very serious chat with Jess our daughter and Sam Paul's son, that if he were to take me on his return he may be arrested and put into jail for 15 years.

Paul had already done the research on this, he has a very good friend who is a Judge and had checked with him. I was however, still determined, but I was beginning to see the effect of my decision on Jess and Paul.

Even though I was absolute in my thinking of ending my life, I had not appreciated how long it would take for me to recover from the treatment itself of HSCT. I had reached rock bottom and could not see any other possibility of my life improving.

I did though carry on with allowing life itself to reach me, in whatever way it wanted to. I carried on writing pros, reciting my poetry back to myself out loud day after day as well as other poems that inspired me. I performed Poetry Recitals with my husband Paul, I put a modest Poetry book together with pictures, wanting to offer this to others who found themselves in challenging situations.

I was interviewed on Women's hour a programme on radio 4 that wanted to interview people who found themselves in challenging situations and had found ways to be creative with in it. My story along with a few others were chosen to be broadcasted to their listeners.

In my interview I emphasised that life will meet you, wherever you're at, its how you see where you are at that makes the difference to what you choose to do next. Fear can be such a factor when one is told you have aggressive MS that is following your pain pathway. Or you are told you have aggressive Motor neuron disease, it is natural to fall into Flight or Fight mode. It's hard to be philosophical at this point. There are some considered factors though that make it possible to consider other options.

I had a supportive loving husband that was willing to travel along side me. He grew up in West Africa a very dangerous country. He said as he witnessed the endless attacks on me, that I was SAS he to had the capacity to be SAS, he was willing to be there with me, he did not flee at that point when I really needed him. I had the inner strength and sustenance to continue on. I draw myself towards truth, Beauty, Love. I held on in the most desperate of times. There is a saying in the Bible if you have a grain of faith you can move mountains, well I had that grain in the palm of my hands and I held it tight.

The love for my husband was not what kept me from choosing not to euthanise myself, it was nature, being a mother to my daughter Jess. The love I felt for her and the responsibility kept me holding on. Julian of Norwich, says 'All shall be well, All manner of things shall be well'. I have her book Revelations of Divine Love, dipping into this book, engaging in reading out loud gave me strength and meaning to a situation where I felt separate to the world. Accept my inner world, the spiritual world and the world of mother nature is where I engaged mostly at that time. Now in hindsight dare I say the experience is a gift. I know without arrogance that I have been tested, I also know that the Spiritual World noticed me when I was going through hell. One could even say I was truly living.

It's how we view our lives that makes the difference, how we love ourselves and how we love one another. The human spirit can overcome, it's just so hard for us to truly believe in ourselves. I held on by my fingertips to life itself and to love.

All of this stopped me from taking that next step to taking my life. As once you do there is no going back, or any opportunity to change your situation. Even if it's a terminal diagnosis one can still live life, allowing one's life to carry on. Giving opportunities for learning new experiences, bringing new awarenesses, self-knowledge. Allowing for other human beings to show their love, their humanity. We are all so connected, my life is not just my life and I believe there is a higher power that governs ones destiny. Of course we have free will always. I found the more deeply I went into exploring my options, do I or don't I the more I discovered that there was a reason why I was going through the experience and that it wasn't my experience alone to be had.

Here I am today 7 years post treatment no more lesions on my brain or my spine, I now have stable MS. I still experience chronic pain and fatigue, but I can cope with it and I am living. In the end I was alright, no one could have known this to be so. Trusting in the goodness of others and in ones goodness, believing that goodness is love and God, letting this become your driving factor can be the very aspect that safes you. I had the strength and people around me that were willing to travel along side. I am fortunate and incredibly great full for the life I have left even though its not an easy one. What I've learnt I could never have envisaged or known.