

Ken's Story

In 1963 at the age of 5 years I had an accident with a stick which left me with a left side arm and leg spasm and weakness after a brain injury, I have learned to cope with this since childhood.

Being "Different" to other children of the same age did not stop me though and in high school I competed in many sports such as basketball/rugby and cross country running. Later on I competed in sailing and helped with the North Yorkshire mountain rescue/ pot-holing team.

I was also able to pass my driving test in a manual car. (I was safely able to drive up until 1994 when I voluntarily stopped because of the amount of medication I took.) In 1984 my wife, daughter and I were involved a serious head on RTA with was very traumatic for us all, I was driving at the time and broke my left wrist in the accident. My wife was expecting at the time of the accident resulting in our son being born premature, months later our son died after an operation.

I worked as an Ironmonger/ locksmith before the accident and after recovering from the accident I returned to work. I noticed however that my left hand/ leg were going into spasm more and my G P prescribed a muscle relaxant . This helped for some time although my hand/leg would still occasionally go into mild spasm.

In 1993 after a period of ill health I contacted my G P after noticing that a normal days work was becoming very difficult, I would find myself sitting in my company car in a lay-by sleeping for hours, then come home and do the same again day and night. Eventually I had to give up work in 1994. Each day my wife had to help me out of bed to the bathroom, and help dress/ wash me, such was the extent of the tiredness and lack of energy. All my muscles ached and I was very sore in all my joints. I was diagnosed later in 1993 with Chronic Fatigue Syndrome @ Western General hospital in Edinburgh.

The diagnosis of CFS took place at a time when it was known as yuppie flu and most folk thought it "psychological and depression" . Thankfully C F S is now recognised as being a genuine illness .

In 2000 my wife and family noticed there were periods throughout the day that I was "just staring into space" and was totally unresponsive. I was diagnosed with temporal lobe epilepsy and given anti epileptic drugs. These episodes changed and increased in length from 1-2 minutes up to 45minutes and I found myself coming round with a splitting headache, and I knew nothing of previous 2-3hours. The spasms in my hand and foot increased and walking became more difficult. Things got much worse November 2008 and I became wheelchair bound. I have since come to understand that these blackouts are in fact dissociative attacks and not epilepsy.

Since this diagnosis in March 2009 I have come on leaps and bounds. Under my doctor's guidance I have gradually stopped taking the medication. The results are unbelievable. I have not had a major blackout since February and have not needed a wheelchair or stick. I am even driving again!

Functional left sided weakness and movement disorder associated with fatigue sounds like a mouthful. A note of caution though is needed in this story as I feel pacing oneself is very important. If I do too much one day and don't rest the next I suffer. It is a fine line and frustrating, but pacing does work. I have been told relapses are common, but have found reading this websites' comprehensive self helps are very useful.

In conclusion. I would say if you can spend short periods reading through the website at a time, there is always light at the end of the tunnel. Think positive .