

## **Agnes' story**

Steve had encephalitis in November 1992. The first thing I noticed wrong was that although Top Gear was on television, Steve was watching the wrong channel. This was unheard of, as for the whole of his life Steve has lived and breathed cars; it was his job and his hobby. He said he felt a bit flu-ey and went to bed. The next morning he was semi-conscious, talking rubbish and vomiting, and after a visit from our GP, was admitted to our local hospital. The ward doctor was very kind and explained it might be encephalitis, which with hindsight, and with hearing other people's stories, was a pretty prompt diagnosis. I was in total shock and absorbed nothing; she could have been telling me he had an infected toe-nail – and me a trained nurse!

Steve was transferred to the neurology unit, and after a scan and a lumbar puncture, began Acyclovir treatment, intravenously at first, which we were told was new and very expensive. His diagnosis and treatment were relatively quick, and I am so grateful for that as I think this prevented so many problems. He was irrational and having hallucinations, but gradually improved. Steve's initial recovery was reasonably quick and he went back to work after 5 weeks, although it was too soon really. He continued to have recurrent, but intermittent problems as though he had encephalitis all over again, and after 2 years we went back to our local neurology unit, only to be arrogantly dismissed and told not to waste their time.

Steve had great difficulty in accepting his problems and also pushed himself too hard; it was a long time before he agreed to go to an Encephalitis Support Group meeting, but that was a real turning point for him. There, we were recommended Dr Clive Hawkins in Stoke as a neurologist who took a special interest in encephalitis. Dr Hawkins was very helpful and after a whole stack of tests he explained that Steve did not have the infection recurring, but that his damaged brain could cope under everyday circumstances and it would seem that there were few problems. However at times of stress, whether physical like a cold, or with emotional upset, the brain then fails to cope and the damaged areas fall down and cause the original symptoms again. He recommended that Steve stay as healthy as possible, and reduce the amount of stress in his life. Steve had his own garage and running this was stressful enough in it's own right, but became more so due to his disorganisation, and eventually it was sold and Steve just does a few jobs from home now. Steve saw the garage sale as a major set back at the time, but now accepts there was a real need. He now realises that when all his symptoms begin to worsen, it's a warning sign to slow down.

For recreation Steve has rebuilt a Subaru Imprezza rally car and drives this in rallies, and has just won several awards including 1<sup>st</sup> overall in the championship! Rallying has been his lifeline, and he's got the Encephalitis Society logo on the bonnet and stickers on the windscreen. We've also got a lovely rescue dog called Bruno who keeps Steve active.

Steve's life is less stressful now and he feels better for it. To meet him you would not know immediately that he has acquired brain injury, as it is not obviously noticeable. He does still have headaches, but they are now less debilitating, and I give him Reiki for these, which is very successful. His short-term memory is still poor, which is a challenge for me. His irritability is less, and when he shows signs of increasing 'tetchiness' I usually suggest it's time to take his homeopathic remedy for this, which he takes for a few days until things calm down. Steve has the concentration span of a gnat (apologies to the gnat) and can be slow at processing information. He has difficulty finding words, gets frustrated and can get emotional and depressed. He also still has intermittent balance and co-ordination problems - I've lost count of the number of cups of coffee down the walls and on the carpet! He can't think of 2 things at once and can take quite a while to process information. I cope better when I think of this as due 50% to being male and 50% to the encephalitis (apologies for lack of political correctness, but it helps me cope).

Steve remembers very little about the first few weeks of his illness, apart from the lumbar puncture which was painful, although he doesn't remember the abuse he was shouting whilst it was being done! He kept the ward awake, and he's normally so placid. However, I remember every detail of those days with clarity and after 12 years I still can't drive along the road past the neurology unit without feeling sick. Our 2 daughters, who were 6 and 10 at the time, are now adults and have coped remarkably well with dad's mood swings and forgetfulness. Steve is not the same person he was before his illness and that can be hard to accept. My main problem is my occasional (or maybe more often!) lack of patience in coping with all of Steve's problems, as I am chief organiser and trouble-shooter in helping him lead a more normal life. Although it can be very frustrating for me to cope with these problems, and at times I have been in despair, I am very aware that things could have been so much worse, and that Steve has never had any fits so can still drive which is a lifesaver for him.

Steve has now accepted he will not improve any further and is learning to live with his difficulties, as am I.