

My Encephalitis:

How it happened:

My encephalitis started from one day to the next. I was 16 at the time and it was half way through our lunch hour when it happened. All of a sudden and without any warning, I felt very dizzy and lost all sense of balance. I spent a good deal of the afternoon with friends in the school library sitting down not being able to move much. Later in the afternoon I was taken to hospital. There, the first reaction was that I had taken some drugs or something maybe because one of my pupils was fully dilated. I stayed in the hospital overnight and they only suggested the next day I might have some sort of virus of the central nervous system. By then, my left side was almost completely paralysed. No exact diagnosis was ever given and I was told nothing was known about which virus had affected the top of the spinal cord where the brain meets it. The name was encephalitis and they were sure it was viral but, despite several lumbar punctures, they could never be sure. I was also given some generic drugs against the herpes zoster virus. I stayed in hospital for around a month and recuperated basic motor and mental skills rather quickly. However, the same cannot be said about all the more subtle skills. Before my illness, I used to be able to windsurf and cycle rather well (I had gone on a 200 mile cycling trip the year before on my own). After my illness, this was not even close to what it used to be and neither were my mental abilities. In fact, the doctors often likened what happened to me to a computer when you ripped all of the connections and wiring off.

Afterwards:

After I got out of hospital, all these things had to be re-learnt almost from scratch as things like balancing on a surf board no longer came automatically. The same was true for what regards mental activities, these had changed radically to a large extent and I could no longer simply remember everyday facts. As a result, my studying slowed down dramatically and I very rapidly went from being drawn to science in general to being drawn to just mathematics instead as everything has its logical sequence and order and there is not too much to remember. If there is, it can usually easily be found in a book in the library. In this slowing down, I lost one year at school because it was decided that the wisest thing would be to spread my final year and end of school exams over two years instead of one. This was still very challenging for me and I did not do particularly well in any of my subjects apart from mathematics. My results, together with my inability to remember things very well meant that I went to university in London to study for a BSc. in mathematics. The BSc. was achieved, but again, it was not particularly good, however, it was good enough for me to carry on to an MSc. and then also a PhD in mathematics. This meant I spent approximately 10 years in London and, as time passed, things very gradually improved and I was able to explore more complicated things, hence the PhD.

Today:

At present, I am 45 and working as an accelerator physicist in a lab in Europe. I feel my illness has very much affected my character and I am very much of an introvert but I do have a wife and two children. I still find it exceedingly difficult to remember small everyday facts though, by now, this may be more due to age than anything else. I read books, for example, and I remember having read them and the opinion that I had of them but very few of the contents. I have a disproportionately high sense of empathy from my illness which I try to compensate for with an artificially callous attitude at times. However, by and large, I am happy.

Recommendations / suggestions:

Now I feel fully recovered, apart from a slight hearing loss in one of my ears which is permanent I believe, and is due to the virus attacking the nerve, which does not grow back, rather than the protective sheath or myelin which can.

If faced with the same or a similar illness to mine, my main recommendation is not to give up and never to let it and especially its consequences take over. I know it sounds trivial and obvious and it may not be the case in general but it was certainly the case for me and the doctors noticed it as well and my determination played a vital role in my recovery.

After you are out of hospital, it is still far from over so prepare yourself, and those around you, for some deep character changes in yourself and a period of roughly ten years before you can consider yourself truly well again, but it can be done.

I am happy to help anyone in a similar position and can be contacted via the website organisers.