



- ◆ Trabajo realizado por el equipo de la Biblioteca Digital de la Fundación Universitaria San Pablo-CEU
- ◆ Me comprometo a utilizar esta copia privada sin finalidad lucrativa, para fines de investigación y docencia, de acuerdo con el art. 37 del T.R.L.P.I. (Texto Refundido de la Ley de Propiedad Intelectual del 12 abril 1996)

## What I might have been

Sue Ruben

The past 37 years have been shaped and overshadowed by the fact that I have a minor disability. I am dystonic down the left side of my body and until recently I thought that this was due to a structural lesion in my basal ganglia, caused by the measles virus. I only asked my general practitioner if I could be referred to another neurologist to help me justify my decision to finally apply for a disabled sticker for my car.

I had not seen a neurologist for 10 years and had come to terms with my diagnosis as best I could, but I needed an expert's permission for the orange badge. I have always resisted artificial aids, preferring to stagger about, although I had reluctantly started using a stick for long walks and evenings, which are my worst time.

I have seen neurologists on and off all my life. As a small child in Belfast my initial diagnosis was made by a wonderful doctor, Louis Herwitz, who has been a lifelong inspiration to me. He was the adult who encouraged rather than restricted me. He always spoke to me not my mother, he was interested in me as a person, not a diagnosis. My decision as a 10 year old to aim to study medicine was based on my admiration and love for Dr Herwitz and, of course, Dr Kildare.

Life has been a struggle, both physically and emotionally. People stared, accused me of daytime drunkenness, assumed mental deficiencies, walked off dance floors rather than be my partner. It was worse for my mother. It was her tragedy, she prayed a lot, even took me to a faith healer—doomed to failure because of my lack of faith—and I was spoiled by numerous sympathetic adults. They spoke to my mother in hushed tones and called me brave. Thankfully, I rebelled in adolescence, wishing to escape from my overprotected world. I was fortunate to be bright enough to fulfil my ambition to study medicine and

rebellious enough to insist on leaving Ulster.

At medical school in Edinburgh I was shown little sympathy. I still cannot forgive the dean, who refused to help when I requested a clinical attachment to a ward near the door where I parked my bicycle, telling me that if he had realised I had a disability I would not have been admitted to his medical school. I took great pleasure in keeping him informed of my future career, achieved despite individuals like him who, of course, consider themselves normal. During house jobs I cycled around the hospitals (including corridors) and was often the first and least breathless at a cardiac arrest.

---

*"I would not be the person I am today if I had been treated sooner."*

---

My decision to specialise in psychiatry was based on the recognition that I was best relatively desk bound, relying on mouth rather than leg muscles. I do not regret this decision, although had I been more mobile I think that I would have been a physician. I have always tried to do whatever I want within reason. I have played sports badly, climbed hills slowly, and fallen over regularly. On my journey through life I have generally found people to be helpful, kind, and generous, with a few notable and personally painful experiences.

All this has now changed. I did not get the orange sticker. Instead I got a new diagnosis and effective treatment. Suddenly, like a light switch turned on and off, I stop being dystonic if I take levodopa, since I have hereditary progressive dystonia, also known as dopamine responsive dystonia. Apparently levodopa gives a marked and sustained

response without marked side effects. Having read the literature, I can report that so far this is true. When Nick Fletcher, my latest neurologist, suggested that my original diagnosis was erroneous I left his office with a bottle of pills to try. I felt speechless and shocked. I have spent so long coming to terms with a permanent and I believed untreatable disability that I doubted a simple solution.

I was so nervous that I waited until my partner was around to take the first tablet. I can only describe the effect as miraculous. My walking has dramatically improved, the stick is now a thing of the past. I volunteer to take the bus, I want to stop complete strangers to tell them my good fortune. Now that I am so different I realise how restricted I used to be and I am glad that I just used to get on with life, relatively unaware. I could have taken levodopa some years ago had the diagnosis been made earlier. I have been asked if this fact makes me angry. I hope I am being honest in saying no. I am not glad I was dystonic and I always rejected the notion fed to me in childhood that it was a gift from God because I was special. The fact is that it was me. I would not be the person I am today if I had been treated sooner. I can only speculate who I might have been.

For me to start to regret the past is too daunting and I want to fully enjoy what I have gained. I am sad that my father died before I was treated and that my mother is too senile to appreciate my new found mobility. I have to explain to my children that they might be carriers of the gene and I hope that other people with the same disease as me can be offered effective treatment. I am concerned that the new NHS will increasingly deny people like me access to high quality help which could never be provided in a primary care setting.—SUE RUBEN is a consultant psychiatrist in Liverpool

### Secret of the knights' success

I have often wondered if the Knights of Malta had a better recovery rate from operations than others,

"The Sacred Infirmary, overlooking Fort Saint Elmo, at the tip of Valletta, Malta GC, was the most celebrated institution of its kind in the Western World. It is believed that in the 17th Century, the Sacred Infirmary introduced the practice of keeping the surgical instruments in boiling water before use with the humane object of making operations less painful."<sup>1</sup>

The hot instruments would have reduced the pain and would also have been effectively sterilised. Was the infection rate lower and did wounds heal better? Did the knights notice and did anyone take the practice back to other hospitals? For the battlefield there might not

have been time and hot water would have been a luxury. On board a ship in battle a fire to heat the water would be out of the question. Perhaps so many wounds were contaminated by earth and dirt that the effects of sterile instruments would have been marginal.—H V WYATT is an honorary research fellow in public health medicine in Leeds

1 Luke, Henry. *Malta, an account and appreciation*. London: Harrop, 1960: 65.

We welcome filler articles of up to 600 words on topics such as *A memorable patient*, *A paper that changed my practice*, *My most unfortunate mistake*, or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk.