ME AND MY NEUROLOGICAL ILLNESS

Don't worry – it's only a

When I was born 40 years ago after a normal pregnancy and delivery, no one expected anything other than a perfect baby. Fingers and toes were duly counted and found to be all present and correct. It was only the next day when my mother was bathing me that she noticed a lump on my back just above the natal cleft. This was associated with a small hairy patch and dimple. 'Not to worry dear, baby just has a birthmark,' were the midwife's reassuring comments to my mother's anxious enquiries.

I am led to believe that I walked, talked and was potty trained at the usual times with no undue concern and have always taken the same size shoe on both feet. I only became aware that I was different from other children when I started school. No one else had a hairy lump on his or her back and swimming lessons in particular were a real trial. I have learned first-hand just how cruel other children can be to their peers and how important it is to fit in. I was also the only child who had to have a 'special examination' by the school nurse every year. This consisted of her poking my lipoma and measuring it to see if it had grown. No one ever performed even a basic neurological examination. Fortunately, I remained well throughout my early growth spurts.

By the time I started secondary school I had been experiencing back pain for several months. This was worse in the morning and exacerbated by standing for any length of time. I distinctly remember bending to pull on my socks one morning and being unable to straighten up because of severe pain. All this was always put down to growing pains! Nonetheless, I was interested in sport and was in the school hockey and athletics teams. I represented the school in long jump and high jump. I learned to ski at the age of 14 and have had my fair share of falls over the years. I have even been involved in a high-speed road traffic accident with no major injury.

I started medical school in 1980. I enjoyed anatomy and in those days we used to spend hours in the dissection room, standing at our dissecting tables pouring over Cunningham's Manual of Anatomy. After a few weeks, back pain started to become a problem. After a few

Figure 1 MRI showing low spinal conus medullaris at the level of the L4 lumbar vertebra (arrow), and associated spina bifida (arrowhead) and sacral lipoma (double arrowheads).

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birthmark

months, I was finding it difficult to sleep at night. Lying on my back was excruciating and I could only get relief by curling up into a ball while lying on my side. The pain had started to radiate down my legs. Large doses of aspirin seemed to help but I suppose this was not a very clever idea given the amount of alcohol that was imbibed at that time! Not surprisingly I started to suffer from severe indigestion and it was this that prompted me to see the doctor at the student health centre. I shall never forget the look on his face when he examined me. A few days later I was back at the medical centre for a second opinion. This time I was informed that I had a type of spina bifida and needed to be seen by a neurosurgeon. I didn't tell my parents because I didn't want to worry them but I do remember feeling immensely relieved that at last something might be done to relieve the pain.

After a few weeks, I was seen in the neurosurgical clinic. I don't remember much about this consultation but I do remember the myelogram that followed a few weeks later. It was incredibly unpleasant and I was not prepared for the after-effects. The postlumbar puncture headache and vomiting lasted for 24 h and were associated with the most awful hallucinations. The myelogram showed a low-lying conus. My pain responded a little to physiotherapy and paracetamol. I had come to the conclusion by this time that any cure was likely to be worse than the disease and decided to grin and bear it.

The diagnosis of closed spinal dysraphism with tethered spinal cord secondary to intradural lipoma was eventually made following an MR scan a few years later (see Fig. 1). Over the last 10 years I have developed dysaesthetic pain

in my left calf associated with pins and needles in my big toe. This came on suddenly one night while lying in bed and has not changed since. I monitor this closely for any signs of deterioration. Four years ago I had over 20 proven urinary tract infections in a year. It took a lot of persuasion to get my GP to send me for urodynamics, despite the fact that this often gives the first clue of neurological deterioration in patients with tethered spinal cord. There is no doubt that my bladder function is not as good as it once was.

I have learned not to flex or extend my spine quickly because this brings on severe left leg pain, which fortunately only lasts for a minute or so. I have to be careful getting into taxis because stepping inside can bring on severe pain (like an electric shock) in both legs for a second or two. Back pain is still an issue but has been part of my life for so long now that it really doesn't stop me from doing anything. The lipoma itself is a nuisance when it comes to getting clothes to fit but doesn't really bother me in any other way.

As a neurosurgeon I am understandably loathe to have an operation to untether my spinal cord at this late stage. I am fortunate not to have experienced any neurological deterioration in childhood. I am very aware that late deterioration can occur and I monitor myself closely. I am grateful to my colleagues and current general practitioner whom I trust and who take me seriously. Most importantly I have already picked my neurosurgeon should the worst happen!

SUGGESTED READING

Pang D (1995) Spinal cord lipomas. In: *Disorders of the paediatric spine* (ed Pang D). Raven Press Ltd, New York, pp.175–201.