

Congenital Insensitivity to Pain

I am a 32-year-old woman, and both my sister and I were born with a rare condition, congenital insensitivity to pain (CIP). Although we have normal nervous systems, our nerve endings are unable to respond to pain due to a mutant gene, SCN9A. As a result I've lived a life without normal physical pain. The condition also means I lack a sense of smell and have a lack of overflow tears. It's difficult writing a short article about the condition and my experiences, as so much has happened to my sister and I. CIP has affected most parts of our lives, both physically and psychologically, and I could write a good doorstop of a book! However, the condition hasn't held us back in life. We are both university graduates with good full-time jobs. We have loving partners, lots of friends and enjoy active social lives.

I rarely divulge the fact that I don't feel pain when meeting new people, but when I do I usually get a response such as, 'That's amazing, I wish I had that condition!' Well, no they shouldn't. As I sit and write this, my seven-month-old baby daughter is sleeping upstairs and I am sat on a large cushion recovering from a severely fractured pelvis with nerve damage. Yet another thing to add to my long list of physical damage I've suffered over the years. I also receive other comments such as, 'You are like a superhero!' and probably the one I can place money on, 'So you wouldn't feel it if I punched you?' Well, I would actually. I can feel pressure, aches, sensation and temperature (although I have a higher tolerance). I have my own sort of 'pain'; I just don't feel pain the same way that other people do. It's always hard to explain, as it's how I've been born and I have nothing to compare it to.

My parents realised that my sister and I had this condition when we were little. We would fall over and not cry and were very accident prone and clumsy. My mother had a terrible time in the 70s and 80s convincing doctors of our condition, as it was so rare and very little was known about it. One of many examples is the time I broke my hand when I was around eight years old. My mother noticed my hand was red, hot and swollen, but A&E dismissed this as a bee sting and she had to fight for an X-ray that confirmed the break. I feel so sad when I think of the tough times my parents went through. Pain is there for a reason, to protect yourself. As a parent you want to protect your child and keep them safe, but this became impossible. Some people even assumed my mother was lying and accused her of child abuse. We were never wrapped in cotton wool though: we had to learn to look after ourselves. We simply learned that hurting ourselves equalled blood, scars, cuts, breaks and burns rather than pain. My mother became extra vigilant and began daily checks of our bodies. She never had the radiators too hot and kept us away from the icebox. She ordered Medic Alert necklaces that we could carry around in case of an emergency.

We were naturally more clumsy, heavy-handed and heavy-footed than other children, and still are! When you learn to walk, run and jump as a child you do so to soften the blow to your limbs and joints, but without pain this is impossible.

Our family photo album is full of pictures of us covered in bandages and plasters. To name just a few terrible incidents: chewing the mouth and tongue until they are deformed, ironing hands, falling asleep on a hot water bottle, running on a broken leg until it crumpled beneath and not feeling an eye ulcer, resulting in being almost blind in one eye.

We kept the condition to ourselves and only told close family and friends. We never tried to exploit it in the media like other families would, or gain any financial benefit. The danger of telling other school children would be that they would punch you and then say, 'Did that hurt?' There was also a danger of feeling invincible and showing off. We are aware of a child with the same condition who jumped from a building over and over again to impress friends.

By our teens we became responsible for our physical health and were aware of the dangers we faced in life. We rarely thought about it through our teens and twenties. There were odd trips to hospital for X-rays and checks and safety measures became part of my daily routine. Examples include: putting on the cold tap before the hot, checking my nails aren't sharp before I go to sleep, placing magazines on my lap before placing down a hot dinner tray and using blunt knives in the kitchen.

My sister and I didn't know the reason why we didn't feel pain. I started to think about this more carefully in my late twenties and now that the internet was at hand, decided to carry out my own investigation. I sent off emails around the country to different doctors. That led to finding out more information from the lovely Dr Bowsher at the Liverpool Pain Institute and finally being properly diagnosed by the wonderful Dr Woods at Addenbrookes. The internet was also brilliant for getting in touch with people all over the world who have the same condition or a variance of it. I found that I shared such similar experiences both physically and psychologically with others.

I was hoping I wouldn't experience any further problems as an adult but I've been through hell over the last seven months. Our friend in Norway who has the same condition and has two children said that having children was payback for all the trouble you had when you were young: you can have a wonderful experience giving birth pain free! I was quite anxious about having a baby as I thought if anything happened to the baby inside me then I wouldn't be able to feel it. However the nine months flew past and I had a lovely pregnancy and felt really healthy throughout. My waters broke and I had to be induced after no sign of baby appearing. The labour went on for hours and I felt no pain at all, and the only reason I knew I was having a contraction was that

I could see my tummy going up and down. The midwives realised that the baby's heartbeat was slowing every time I had a contraction so I had to have an emergency C-section. Luckily my daughter was delivered a beautiful and healthy baby.

When I left hospital I felt stiff down one side and couldn't walk properly. This got worse and worse over the next seven weeks until I was in so much 'pain' that I couldn't walk properly and felt wrong inside. During these weeks I questioned doctors, midwives, health visitors and physiotherapists about my problem and explained my pain condition. Initially they said it was because of the C-section, and later they said it was SPD. I was even sent home from A&E with post-natal depression! I knew something was seriously wrong with me. I soon started to lose sensation in my lower half but luckily an amazing physiotherapist saved me and got me back into A&E and scanned.

The results were a severely fractured pelvis, nerve damage and a haematoma. I was devastated but in a way also relieved as finally I knew what was wrong and could be treated. I had to spend six weeks in Addenbrookes on strict bed rest. Being apart from my baby girl was heartbreaking: I had to stop breastfeeding and missed her first Christmas. I'm so grateful to my family, friends and wonderful hospital staff for providing physical and mental help and support at such a traumatic time. Unfortunately my lack of pain is just physical and not emotional.

Since then I've been recovering at home, and the whole experience has really damaged me emotionally as well as physically. I was quite a puzzle to the doctors, and it still isn't clear what exactly happened to me. My consultant believes that the pregnancy caused stress fractures to my pelvis and then it finally broke during labour; I then walked around with the fractures for weeks, making it worse. A doctor also believes I had osteoporosis in pregnancy. I was basically extremely unlucky. I now have lost feeling in lower parts of my body and have leg length discrepancy.

It is a worry, thinking about what will happen to me later in life. I guess I just have to enjoy life as much as I can now and not worry about what is round the corner. I'm aware that there are people in this world that are physically a lot worse off than me and I am so lucky in so many other parts of my life.

It would be amazing if some good could come of all these problems that I and my family have endured over the years. Perhaps by using me for further physical studies and tests, one day a pain-free drug could be created that mimics what I feel; pain relief without any side effects. Or perhaps a drug could be created which enables children to feel pain so they don't have to go through what I did when I was growing up. This sounds awful but I felt great joy and relief when I took my baby daughter to have her first injections and she screamed her head off! ♦