



Judith – Complex regional pain syndrome

Judith is one very busy woman. Her day routinely begins at 3.15am when she starts getting ready for her job on the Coles service desk at 4.30am. Her shift finishes at 10am, when she returns home to care for her two mischievous granddaughters (aged three and four) – one of whom lives with Judith and her husband Brian full time.

Add Brian's recent retirement from long-haul deliveries with Australia Post, and you can understand just how important it is for Judith to keep on top of her pain.

A fun-filled trip away with friends turned to disaster for Judith when she slipped and fell down the steps of the bus they had been travelling in. The fall smashed 6 discs in her lower back and left her battered and bruised.

About six weeks later she began to suffer extreme pain in her left leg, from the knee down. She paid a visit to her GP, who diagnosed her with arthritis in the knee and gave her medication. Judith soldiered on for a few weeks with no relief.

"I thought, 'This is crazy. I'm in so much pain, there has to be something else wrong'. It was getting worse and worse and worse."

She was given a referral to a knee specialist to see what he could suggest. The result was surprising:

"He told me: 'You don't need a knee doctor – it's all coming from your back.'"

Judith was referred for surgery, which involved removing fragments of bone from her back. Unfortunately, it didn't really solve the problem, and Judith was referred to another specialist when the pain began to worsen again.

This specialist discovered that scar tissue, which had formed as a result of the first operation, was choking her sciatic nerve. The result was excruciating pain travelling through her leg.

He operated on her back a second time, but after that could offer no further help.

"He told me to just learn to live with it, to 'Get over it.' That's exactly what he said. He told me to go home and get over it."

Judith began to have trouble coping with the pain.

"I was really down and depressed . You get to the stage where you are just sick of being in chronic pain. I wasn't coping with the pain, you know. I was taking drugs, but you can't live on drugs all the time.

"If I could have, I would have necked myself. You just can't live like that.

"I was taking a pill to help me sleep, then a pill to help me wake up, and then a pill for the pain. I was on uppers and downers and trying to run a family, trying to live a normal life – it was so hard. I don't know how I ever did it."

She returned to her GP, who referred her to a pain specialist.

"The pain specialist told me about the machine. It was pretty new to him at the time as well

but I was prepared to try anything. I had tried it all, physiotherapy was no good to me, chiropractors – they were just cruel. I was beginning to think it was all in my head and I should get over it. But you don't get over it.

"I just wanted something to relieve the pain because it was a 24-hour thing. The drugs did help, but they wear off. And I didn't know what damage they might do if I kept taking them long-term. I'm not a pill-popper: I hate taking pills.

"When the machine came up as an option, I thought I'd try it. I said to the doctor: 'Well, what have I got to lose? Absolutely nothing.'"

Judith was among the first Australians to be given a spinal cord stimulator, with her implant taking place in March 1995. While the procedure to implant the stimulator was difficult for Judith because having to lie on her stomach aggravated her pain, after a few days she began to feel relief.

Her stimulator doesn't remove her pain completely, but does help enough to allow her to cope with her busy lifestyle.

"The fact is, you've got to get on with life unless you want to lie down and die. This machine has helped me to get on with life.

"I'm never going to be cured and I have to come to terms with that. I've got this problem and I'm learning to cope, learning to live with it.

"The machine has taken the medication away, which has to be a plus. Panadol Forte is about the hardest thing I take these days, and that very rarely happens."

Judith doesn't use her stimulator constantly. Instead, she only turns it on when she needs it.

"I use it to control the pain. Now I can manage the pain by myself. I've got it pretty well worked out – if I don't need it, I don't use it. But I know that if I haven't used it for a few days, a certain amount of pain will come along."

Her pain does still prevent her from doing some of the things she enjoys.

"I can't go to the movies, because I can't sit for a long period of time. Even sitting watching TV can be painful. If I stand up the pain will go, but you can't stand up for the rest of your life.

"I can't do what I used to do: Everything at once. When I do anything out of the ordinary, a bit strenuous, I do suffer the next day. But you have to build your life around what you can do – not what you can't."

In order to help with her pain management, Judith swims regularly, and has also managed to shed 20 kilos, weight that had crept on with the limited mobility inflicted by her pain.

Now, ten years after receiving her spinal cord stimulator, Judith has just had her first battery replacement.

Her battery had run down during the Christmas period, and due to a combination of circumstances, she could not have the procedure to replace the unit for five months.

“That’s when I really and truly knew how much I appreciated my machine. To not have it was quite an education for me personally. I found it very difficult, those five months. I do depend on it – it helps me cope with life day to day.”

Judith would be happy to speak about her experience with other chronic pain sufferers.

“Everyone is different, and everyone’s pain is different. When someone is in 24/7 pain – well, you can’t live like that. And for anyone who’s suffering – well, sometimes they just need to talk to somebody.”