

## **Edith Mowatt's experience of Spinal Cord Stimulators**

*Edith Mowatt has had an implanted spinal cord stimulator for over ten years. This is her story.*

I had had several operations on my back. None of them had made the pain better. Some of them had made the pain worse. I was spending a lot of time lying down. Just getting from bed to bathroom brought horrific pain. I was referred to my local pain clinic. I tried a range of therapies, injections, acupuncture, coping techniques. Finally, the pain clinic suggested I try an implanted stimulator.

It gave me my life back. Without it I can barely walk. I can barely live! The pain is so horrendous.

Before I had the implanted stimulator, I needed strong painkillers like morphine. I couldn't think straight because of the medication and pain. I hated it. With the implanted stimulator I get pain control with lighter medication. I take tramadol. I have got my head back. I'm in control!

When I got my implanted stimulator I did struggle with work at first – gradually I got the hang of how to use the stimulator to get the best pain relief and change my medication – gradually I got into a routine of what works best for my pain. Over time I managed to do more and more. These days I work full time. I couldn't do that without my stimulator.

I don't sleep with it switched on. When I lie down the stimulation is too uncomfortable to be able to sleep. But the first thing I do in the morning is look for my remote control. I switch myself on again!

There has to be a screening process before getting a stimulator. That has to include psychological screening. You have got a foreign body inside you. You and your partner have to be able to cope with that. Can your partner accept a foreign body? Will it have an impact on your sex life and your relationship?

I also think that you need ongoing professional support, especially initially, to help the whole family adapt. After all, there is a remote control that switches on and off a machine inside mum's body. Children have to adapt to that. Also it's important that your family understand that when you die the stimulator must be removed from your body before you are cremated or buried. The family need to be able to deal with that.

When I first got the stimulator I had to be careful about what I did. I find I can do anything now – swimming, sports, travel. The simulator doesn't take away the all the pain. It replaces it with a vibration, which blocks the pain pathways to the brain and therefore the perception of pain is very different. I would say pain is reduced by 50%. But that is an awful lot of pain. You can start to live again.

I am now on my second machine. In between the two machines the pain returned. I had forgotten how bad it was. My life is far nearer to normal now than when getting from bed to the bathroom was a horrific experience.

## **Points to remember**

Implanted spinal cord stimulation (SCS) is not appropriate for everyone. But for Edith and others like her it is a humane option. Constant severe pain is difficult to bear. Every moment of the day is blighted by pain. Professor McEwen, Emeritus Professor in Public Health commented that one third of people with chronic pain are so weighed down that they cannot tolerate any more.

SCS doesn't take away all the pain, but the gain in quality of life can be huge even with a 50% reduction in pain. The point is that it reduces it to a level where you can function and think. As Edith says you can live again. Because these pains are incurable, spinal cord stimulation can provide long-term benefit. People whose pain is inadequately controlled use health services up to 5 times more frequently.

Edith rightly says the whole family has to be signed up to having a foreign body inside the person in pain. But if pain is inadequately controlled relationships suffer. Pain is disabling. Job loss and loss of status within the family are big issues. Sexual dysfunction is common (43%). Depression is common (49%). Children often end up as carers for their parents. One young child who was being bullied at school felt she couldn't tell her mother because she was in so much pain. She didn't want to add to her burden.

SCS needs to be looked at as part of an overall treatment strategy. Lifestyle management and learning to manage and cope with residual pain are vital.

At present, it is common for SCS to be offered as a treatment of last resort. This has the drawback of driving people to disability before considering SCS as a treatment. It could transform situations if it could be considered, not as a first resort nor as a last resort, but as a later resort – allowing some to stay at work and taking the pressure off families and carers.

SCS is an invasive procedure. People need to make an informed decision before consenting. They need good quality information about risks, complications and restrictions (e.g. the need to have access to specialist centres). However many people are resorting to invasive back surgery without being assessed for SCS. Like Edith, they often find their pain is worse after the back surgery. Considering SCS as a treatment of later rather than last resort could prevent more invasive surgical procedure that may not improve and may even worsen the person's condition.

It is important that spinal cord stimulation is available to NHS patients. Not all patients need it or will benefit from it. But when it is appropriate it can make all the difference.

Visit [www.britishpainsociety.org](http://www.britishpainsociety.org) for the booklet *Spinal cord stimulation for pain: Information for patients* or write to the British Pain Society at 3rd Floor, Churchill House, 35 Red Lion Square, London WC1R 4SG. It costs £1.00 to order the booklet by post.

Edith says “Not everyone can get back to work in the environment or profession they were in before but there is always something that you can do that’s in keeping with your new situation and comfortable with the pain you still have. Never say never and always yes; always stay positive. Control your pain; don’t let it control you”.