

Muscles with a mind of their own!

I went for EMG testing of both my internal pelvic muscles and my gluteals (buttocks) and finally got numbers to corroborate the fact that (a) I can't feel anything (b) I can't move anything voluntarily and (c) the muscles stay permanently tensed up. I only have a tiny amount of 'useful' muscle contraction. As the tester said, "Your muscles are in a world of their own, aren't they!" I thought "No kidding, I've only been trying to tell docs that for years!"

So fortunately she has realised that biofeedback is a pointless exercise, in fact she went so far as to declare it would be 'cruel' to make me do it. I am going to try a little external stimulator gadget, although I am still unsure how that makes the muscle relax. We shall see. If it doesn't work, she reckons I am a good candidate for a sacral nerve stimulator which could make a real difference to managing the problems I have (just got to get funding....!)

A stimulating topic?

I mentioned a sacral nerve stimulator in my last blog and want to clarify what it is...and isn't.

SNS is a gadget that is implanted to send electrical impulses to the sacral nerves. It is not a spinal cord stimulator (SCS) although the technology is similar. In SCS the electrodes are located adjacent to the spinal cord and are tuned to send an impulse to block pain signals (like an internal TENS machine): so a sensory effect. SNS is for stimulating the sacral nerves to assist with the function of pelvic muscles so has an effect on the motor function.

Although both are implanted foreign bodies and carry certain risks (e.g. infection, nerve damage), the risks are higher with SCS. I must stress however that both SCS and SNS should be regarded as highly specialised treatments used as a last resort. SNS in particular is only indicated for very specific problems.

In the UK, getting funding for trial and then implantation can be difficult and is only granted by PCTs (Primary Care Trusts) in what they term "exceptional circumstances".