

NICE technology appraisal

Spinal cord stimulation for chronic pain of neuropathic or ischaemic origin

Pelvic Pain Support Network written submission

What is it like to have the condition ?

The symptoms of chronic refractory pelvic pain of neuropathic origin such as nerve entrapment or damage are generally constant severe pain aggravated by movement.

This affects all aspects of day-to-day life with many patients unable to sit. Standing and walking can also be affected. This has a major impact on ability to work as much employment involves sitting. Employers lack understanding of the issues and generally do not want to employ anyone with such difficulties. Likewise this has a huge impact on family and friends because the patient is unable to participate in normal social activities which generally involve sitting such as meeting a friend for a chat, eating out, going to see a film, concert or to the theatre. Families members may find this extremely difficult to cope with and they may be embarrassed by having a partner or parent in this position. Partners may become frustrated, angry and unwilling to help exacerbating the difficulties for the patient. Friends similarly may drift away leaving the sufferer isolated. This can easily lead to depression.

What are the outcomes that matter most to patients ?

The aspect that patients most want the technology to help with is reducing the level of PAIN. Patients will not necessarily expect to be completely relieved of pain and may accept that even a 30 % or 40% reduction in pain is of huge benefit which would enable them to function/increase activity.

What difference does the technology make ?

Refractory pelvic pain of neuropathic origin is unresponsive to other medical and surgical treatments. Spinal cord stimulation is an invasive procedure. It can reduce the level of pain to enable the sufferer to cope better. It can also give the sufferer some control over the strength of stimulation although this may need to be adjusted by the pain specialist. The presence of the device may be felt as dull pain in some cases. The difference to a patients long term health can be considerable in that it can be the difference between having a very poor quality of life and being able to function/cope sufficiently in order to be a participating member of society at work or through volunteering and in a social capacity. Family and friends are more likely to stay around. This also has a knock on effect in relieving/preventing depression.

The technology needs to be recharged intermittently. The frequency of this depends on the type of device and the setting used by the patient. The more frequently this has to be done, the less convenience there is for the patient. The positioning and movement/migration of the leads can be a problem. Patients considering this procedure should be aware of this. The placement of the leads involves surgery. The battery in the device also needs to be replaced after a number of years. There are variations in the length of interval between replacement depending on the device used. All of these factors should be discussed openly with the patient.

Using the technology

It is necessary for patients to go into hospital to receive this technology. It should be implanted and monitored by specialists who perform the procedure on a regular basis in centres of expertise. A handful of procedures annually is not sufficient to be able to deal with

patients who have wide ranging symptoms and possible complications. The patient needs to be willing to travel significant distances to access such expertise. A trial of the procedure for sufficient length time should be carried out in order for the patient and clinician to assess the potential benefit of the device before proceeding with implanting the device. This is a huge advantage here in that there is the opportunity to make an informed judgement/choice before committing to a permanent implant. The procedure is also reversible which is not the case with many treatments.



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