

Spinal cord stimulation

This leaflet aims to answer your questions about having spinal cord stimulation. It explains the benefits, risks and alternatives, as well as what you can expect when you come to hospital. If you have any further questions, please speak to a doctor or nurse caring for you.

What is chronic pain?

We think of pain as an unpleasant sensation that warns us when a part of our body is at risk of being damaged. This is acute pain. This is short-lived and fades once the threat is removed and healing has taken place. However, sometimes our pain systems become oversensitive and pain persists in the absence of real threats to our body. If pain has persisted in this way for over three months, we call it chronic pain. Medicines effective in acute pain are often less effective in chronic pain.

People who are in pain tend to do less physically and socially – this often makes chronic pain worse as people become less fit and have less enjoyment in their lives. Problems of poor sleep, fatigue, boredom, depression and anxiety often accompany chronic pain. It is important to recognise and address all of these problems in chronic pain and not focus only on the pain. Spinal cord stimulation can relieve pain in some people with certain types of chronic pain but is only one part of a treatment strategy and not a complete treatment on its own.

What is a spinal cord stimulator?

A spinal cord stimulator system is made up of an implanted battery which is attached to a small lead. The leads are programmed to create a small electrical field. The leads are precisely sited next to a nerve, and the electrical field can result in a reduction of a specific type of pain. Once the spinal cord stimulation system has been surgically implanted, it is controlled by the patient using a handheld controller. Spinal cord stimulation is also sometimes called neuromodulation.

For some patients, low frequency stimulation, where you feel some tingling (paraesthesia) will be used. For other patients higher frequency stimulation, where you cannot feel anything, will be the best treatment for the pain. The type of stimulation is selected by the pain consultant, and is determined by the pain condition you have.

Is a spinal cord stimulator right for me?

A spinal cord stimulator can only treat certain types of pain. The National Institute for Health and Care Excellence (NICE) is the organisation responsible for recommending which treatments are used by the NHS. NICE recommends spinal cord stimulation for the following diagnosed conditions;

- Pain which is neuropathic, meaning that it is pain which is caused by an insult or injury to the nerves, rather than pain caused by damage to the other tissues, such as the joints and muscles.

- Failed back surgery syndrome, when patients are suffering with neuropathic pain, rather than mechanical pain.
- Complex regional pain syndrome.

Spinal cord stimulation is recommended for patients who have severe chronic pain that is limiting their daily life and who have already tried all reasonable, more traditional therapies such as painkillers and physiotherapy.

A spinal cord stimulator cannot be used as a standalone treatment for chronic pain. The British Pain Society recommends that all patients who are being considered for a spinal cord stimulator are assessed by a multidisciplinary team, this includes doctors, clinical nurse specialists, physiotherapists, occupational therapists and psychologists. Our treatment pathway (treatment plan) follows this guidance, and in order to ensure best possible care, patients must engage with all elements of the treatment pathway.

Reasons why spinal cord stimulation may not be suitable

Significant pain that will not benefit from spinal cord stimulation, for example, pain due to arthritis or spinal instability.

- You must be willing to stop or reduce excessive medication. Scientific evidence has shown patients on high doses of opioid medication (doses equivalent to 100mg of oral morphine) would have a less effective response to neuromodulation. Therefore, you may be asked to reduce to a specific target dose or stop opioid medication completely for least six weeks prior to the trial. The team will support you and your GP with this.
- Significant pain beyond the area that a spinal cord stimulation system can cover such as widespread pain syndromes.
- Anatomical problems that mean it is not possible to implant a spinal cord stimulation system safely. For example, major spinal deformity, extensive spinal metalwork, or extensive spinal scar tissue in the epidural space.
- A BMI of below 18, or above 35, as this results in an increased risk of complications.
- An active infective illness.
- Postural orthostatic tachycardia syndrome (POTS) (Abnormal increase in heart rate that occurs after sitting up or standing).
- Some chronic medical illnesses, for example; multiple sclerosis, severe respiratory disease.
- A psychiatric illness or psychological difficulties which may impact on ability to effectively manage the device and/or manage the treatment care pathway at the time of assessment.
- Excessive use of alcohol, prescription drugs, and or recreational drugs.
- Please inform your consultant if you have a metal allergy, such as a nickel allergy, as several devices contain nickel so this would form part of the decision as to which type of device could be used.
- Some memory or cognitive difficulties may impede your ability to manage the device and/or provide informed consent to treatment. Patients must be able to manage the technical demands of the equipment.
- The patient must be eighteen years of age or older.
- Traditional therapies to manage the pain must have been tried before a spinal cord stimulator is considered.

Spinal cord stimulation treatment pathway

A spinal cord stimulator can reduce the intensity of the pain, but it cannot resolve the pain completely and is not a cure. It is most effective when combined with other treatments that address the impact pain is having on a persons' quality of life, emotional well-being and level of physical functioning. Our spinal cord stimulation treatment pathway is designed to maximise the benefits of spinal cord stimulation. The information given below outlines the treatment pathway.



Neuromodulation clinic assessment

A pain management consultant will assess whether your pain is medically suitable to be treated with spinal cord stimulation. After you have been assessed, an appointment with the physiotherapist and psychologist will be organised if you are to continue on the pathway.

Psychology and physiotherapy appointment

This is a joint assessment where you will be seen by both a psychologist and physiotherapist. We take time to look at how the pain is affecting your quality of life, including; your physical function, your level of activity, your emotional wellbeing, relationships, family life, sleep, work, hobbies etc. We also discuss your expectations of spinal cord stimulation and how you hope our package of treatment will be of benefit to you. Additionally, we discuss how you might feel if the trial is unsuccessful.

Following the assessment most patients go on to complete our two-week pre-implant pain management programme. Less typically, some patients may be suitable to attend our technology day. Both of these options are detailed below. It is important to consider your individual circumstances, if appropriate we may also consider whether it is the right time go forward on the pathway.

The two week pre-implant pain management programme

This programme is run by the INPUT pain management team. Our centre at INPUT has been at the forefront of research and clinical practice in the area of pain management. Our two week programme is delivered by a dedicated specialist team of psychologists, physiotherapists, occupational therapists and clinical nurse specialists. We work together with you to develop

skills that will be important for you to make the most of your spinal cord stimulator, and to move forward with what is most important to you in life.

The aim of the programme is to support patients to:

- Clarify what is personally important, to set realistic goals related to this and to act upon them.
- Increase awareness of familiar responses to pain and habitual activity patterns, and where helpful, to consider other ways of approaching activity that may bring them closer to reaching their goals.
- Practise an open and flexible approach to doing meaningful activities even when faced with difficult thoughts, sensations, and emotions related to pain.
- Commit to goals in the presence of difficulties and barriers.

Staff also provide education and information related to:

- The nature of chronic pain.
- The long term use of pain medication (including an individualised medication review with a specialist pain nurse).
- The technical information on spinal cord stimulation required to be able to make an informed decision about having a neuromodulation device.

The programme is eight days in total (9am to 5pm) spread over two weeks and is delivered in a group format (usually 11 per group). It is a residential programme and all patients are expected to stay in our on-site accommodation for the duration of programme returning home for the weekend in between. Whether or not you proceed with spinal cord stimulation, the skills attained through the programme can enhance your ability to effectively manage the impact of pain on your life.

The technology day

For a small number of patients, our technology day may be the next step. Patients who attend this day usually have a higher level of daily functioning and experience less psychosocial impact of pain on their life. Some patients who have recently completed and benefited from a pain management programme elsewhere may also be eligible for this day.

It takes place over one day, and sessions are delivered by a clinical nurse specialist, physiotherapist, and psychologist. On the day you will be provided with the technical and practical information required to make an informed decision about having a device. Sessions will also raise awareness of other considerations that can impact on the success of spinal cord stimulation, such as other barriers to getting back to meaningful activities in your life. It is also a good opportunity to ask questions about the device and the pathway. Relatives are welcome to attend

Consenting to spinal cord stimulation

Following completion of the pre-implant programme or technology day, you will have another appointment with a pain management consultant to discuss whether to proceed with a trial of spinal cord stimulation. If a decision for a trial is made, you will sign the consent form and undergo an anaesthetic pre-assessment. These appointments may take up to three hours in total, including waiting time.

Spinal cord stimulator trial

A trial of spinal cord stimulation is carried out before considering a permanent implant. This is because not all patients will find that their pain responds to spinal cord stimulation. It is therefore important to trial the spinal cord stimulation, before surgically implanting the whole system. During a spinal cord stimulator trial, the leads are implanted, but the battery is not. The trial usually lasts for 14 days.

The trial is normally performed as a day case procedure at Guy's Hospital. Local anaesthetic and sedation are given. The spinal cord stimulation leads are then carefully sited and then attached to an external hand held controller which allows you to control the stimulation. A pain management nurse will review all patients before they go home to ensure that they are confident in using the equipment. You will return to the Pain Management Centre in the middle of the trial for a review with the clinical nurse specialists and the pain consultant. It is important that you contact us if you have any concerns or problems during the trial (contact details are at the end of this leaflet).

What happens if the spinal cord stimulator is not successful?

Spinal cord stimulation trials are only successful in seven out of ten cases. For the trial to be considered a success the device must have a significant impact on your quality of life and on the intensity of your pain. If the trial results in a moderate impact, it is not considered successful. This is because the amount of pain relief provided by the spinal cord stimulator will reduce over time.

If your pain does not respond to spinal cord stimulation your care will be transferred back to your referring consultant. We hope that the two week pre-implant pain management programme continues to provide our patients with useful skills which help them to manage the impact that pain has on their quality of life, whether or not the trial is successful.

What happens if I receive the permanent implant?

If the trial is successful, another day surgery procedure is required to fully implant the device. The first stage of this procedure is placement of the stimulating lead in the spine, similar to the trial. The second stage of the permanent implant involves inserting the battery, this is performed under deep sedation or general anaesthetic. You will need to discuss the position of the battery with your consultant prior to the procedure. The position of the battery will vary dependent on the individual patient, it will usually be in your back, but can also be in your buttock or abdomen. A small incision in your skin is required to place the battery. You will usually be able to return home within a few hours of the procedure, depending on how long your doctor or nurse wants you to stay for recovery.

If you receive a full implant of a spinal cord stimulator, it is important that you continue to use the pain management strategies, learnt during the two week pre-implant pain management program, or the technology day, alongside the device. This will enable you to get the best possible benefit from the device.

What are the risks or complications of a spinal cord stimulator?

- Painful battery/connection site. If severe, further surgery or removal may be advised.
- Infection occurs in less than five in 100 people. If this happens, the whole system may need to be removed.
- Implantation of a spinal cord stimulator could cause bleeding which may lead to bruising and in rare cases may require further surgery.
- There is risk of the dura (protective layer around the spinal cord) being punctured during the procedure. This can result in a severe headache which may require treatment with a spinal injection if it does not improve within days.
- The leads may move or stop working and may need another operation to correct.
- Unpleasant sensation from the stimulation may occur. This may not respond to stimulation adjustment and could mean that the spinal cord stimulator is removed.
- Stimulation felt outside of painful area is common, but only a problem if unpleasant.
- Failure to capture the area of pain, or no pain relief, which may lead to consideration of revision surgery to re-site the leads or remove the system.
- Allergic reaction leading to removal of the spinal cord stimulator.
- Decrease in pain relief with time.
- Nerve damage leading to nerve pain, numbness and weakness. This may be temporary or permanent.
- Paralysis. This is extremely rare and affects two patients in one million.
- There is a risk that a granuloma, which is scar tissue, could form on the leads, at the wound site or at the battery site.

Do I need to take any precautions with spinal cord stimulation?

- Some physical activities may need to be avoided during the first 12 weeks to help prevent the leads moving. Your physiotherapist will discuss this with you.
- If you require surgery in the future, you must inform your surgeon and anaesthetist that you have spinal cord stimulation as they will need to use a different type of instrument which is called a bipolar diathermy.
- Depending on the type of device chosen, it may be not be possible for you to have an MRI (magnetic resonance imaging) scan, but CT (computerised tomography) scans and X-rays are allowed.
- Stimulators may activate airport detectors and anti-theft devices in shops. These, along with strong magnets, may turn your stimulator off and affect your battery.
- You should not drive with the device on if you have low frequency stimulation as sudden increases in sensed stimulation may interfere with driving.

Who will be responsible for my care?

Following your permanent implant, the Pain Management Centre at Guy's and St Thomas' Hospital will be responsible for your spinal cord stimulation system. The clinical nurse specialists will continue to provide ongoing support and advice. An annual appointment is organised either over the phone or in the clinic. Appointments can be arranged for review or programming in between this if needed.

Patient responsibilities during the spinal cord stimulator pathway

We need to be informed if any of the following changes occur whilst you are on the spinal cord stimulator pathway;

- Significant changes to your physical health, such as a new diagnosis or a change in your physical function
- A change in your mental health
- If you are undergoing any treatment, such as surgery, that may have an effect on your pain condition.

Contact us

If you have any questions or concerns about spinal cord stimulation, please contact the pain management centre on **020 7188 8877** (Monday to Friday, 9am to 5pm). Out of hours, please contact your local Medical Services. If your local Medical Service requires our support, they should contact the switchboard on **020 7188 7188** and ask to speak to the on-call Pain Consultant

If you require clinical advice during working hours, call the hospital switchboard on **020 7188 7188** and ask for the bleep desk. Ask for bleep 0360 and wait for a response. This will connect you to the nurse specialist directly.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline. **t:** 020 7188 8748, Monday to Friday, 9am to 5pm

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch. **t:** 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day. **t:** 111

NHS website

Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing. **w:** www.nhs.uk

Was this leaflet useful?

We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk

Leaflet number: 3693/VER2

Date published: November 2018

Review date: November 2021

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A list of sources is available on request