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 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 spinal cord stimulation?
Spinal cord stimulation systems, (sometimes known as neuromodulation), deliver small electrical fields to the spinal cord. These electrical fields mask areas of pain by changing the pain messages your body sends to your brain. This can significantly reduce pain in conditions such as failed back surgery syndrome, neuropathic (nerve) pain, and complex regional pain syndrome. It is effective in five to seven out of ten cases. Spinal cord stimulation is reserved for patients who have severe chronic pain that is limiting their daily life and who have already tried all reasonable, more conservative therapies, such as painkillers and physiotherapy.

Spinal cord stimulation requires a minor surgical procedure under x-ray control in which a lead is precisely sited within the spine in the epidural space. The lead is then connected under the skin to a battery device which is surgically sited in the buttock or abdominal wall. The battery powers the electrical stimulation of the lead in the spine. Once the system is set-up, it can be controlled by the patient using a handheld controller.

What are the different types of stimulators?
Many factors, including site and type of pain, are considered in determining which type of system to use. There are two types of stimulators:

- **Lower frequency spinal cord stimulation.** This uses frequencies which may provide a tingling sensation in the painful area.
- **High frequency spinal cord stimulation.** This is usually not felt.
How do I know if spinal cord stimulation might be right for me?
Spinal cord stimulation may be appropriate for you if you meet the criteria listed below.

Medical, physical and psychological (mental and emotional) factors are all important and all potential patients undergo assessment by a doctor, a physiotherapist and a psychologist. The criteria below list reasons why spinal cord stimulation may not be appropriate for you. All patients who go forward for stimulation attend either a technology day or a two week pre-implant programme, for education about spinal cord stimulation and physical and psychological health strategies.

What are the guidelines for spinal cord stimulation?
The National Institute for Health and Care Excellence (NICE) is the organisation responsible for recommending which medicines and treatments are used by the NHS. NICE recommends spinal cord stimulation for severe prolonged pain that has responded to a trial of stimulation in failed back surgery syndrome, complex regional pain syndrome and neuropathic pain.

As per the British Pain Society recommendations, all patients are treated within a multidisciplinary team that includes doctors, nurses, psychologists and physiotherapists. This helps patients to make an informed decision about whether they want to go ahead with spinal cord stimulation, as well as understanding what is happening to them throughout the treatment.

Who can have spinal cord stimulation?
In order to be considered for spinal cord stimulation you must:

- be eighteen years of age or older
- have been diagnosed with one of the following conditions, as per NICE guidelines:
  - failed back surgery syndrome
  - complex regional pain syndrome
  - neuropathic pain
  - have moderate to severe chronic pain measuring greater than five out of ten on a pain rating scale
- have tried and not responded to conservative treatments
- be willing to stop or reduce excessive medication, and use pain management strategies
- be able to manage the technical demands of the equipment.

Who cannot have spinal cord stimulation?
You should not have spinal cord stimulation if you:

- have significant pain that will not benefit from spinal cord stimulation (for example, pain due to arthritis or spinal instability)
- have significant pain beyond the area that a spinal cord stimulation system can cover (widespread pain syndromes)
- have 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
- have an active infective illness
- have some chronic medical illnesses, for example multiple sclerosis or severe respiratory disease
- have some psychiatric illnesses
- have a very high or very low body mass index (you are either very over or underweight)
- use alcohol, prescription drugs, and/or recreational drugs excessively
- have an allergy to nickel or any other components of the implantable device.
What will happen at my first appointment?
This is a medical assessment by a doctor to determine whether your type of pain is suitable for spinal cord stimulation and you meet the criteria to proceed on the spinal cord stimulator pathway shown in the diagram below. After you have been assessed by the doctor, an appointment with the physiotherapist and psychologist will be organised if you are to continue on the pathway. The final decision on proceeding with a trial of stimulation will be decided once you have completed the pre-implant programme or technology day.

What will happen at the psychologist and physiotherapist appointments?
This is a detailed assessment to determine your suitability for a pre-implant programme or technology day. The physiotherapy assessment looks at your pain problem and your physical function. The psychology assessment looks at the impact of chronic pain on your activities, mood, relationships and sleep. We take time to explore how you are managing your pain right now. We ask you about your expectations of spinal cord stimulation and how you would feel if spinal cord stimulation does not work for you.

What is the pre-implant programme?
The pre-implant programme is a residential group programme lasting for eight days spread over two weeks. Overnight accommodation is situated in St Thomas’ Hospital grounds. This is the preferred route in the pathway to ensure patients have long term success in managing their pain with or without the stimulator. However, you need to be fully able to care for yourself, as the accommodation is not staffed at night. We will give you more information about where to come and what to bring with you before you attend the pre-implant programme.

The aims of the pre-implant programme are to:

- increase the effectiveness of spinal cord stimulation treatment
- provide information on the procedure and potential risks and benefits
- increase the understanding of chronic pain
- provide individual medication advice
- work on maximising your physical fitness and function
• help you to work towards realistic goals
• maximise psychological well-being, flexibility and vitality
• help you to meet other patients who have similar experiences
• provide support in decision making and help you to give informed consent for any future procedure.

What is the technology day?
This provides technical and practical information on the usage of the spinal cord stimulator. This day is for patients who do not meet the physical or psychological requirements for the residential programme. The sessions last four hours and relatives may also attend. The sessions are delivered by a nurse, physiotherapist and psychologist.

Will I have a follow up appointment?
Following completion of the pre-implant programme or technology day, you will have an appointment with a consultant pain specialist 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, which includes MRSA (meticillin-resistant staphylococcus aureus) swabs. These appointments may take up to three hours in total, including waiting time.

Why do I need a spinal cord stimulation trial?
A trial of spinal cord stimulation is carried out before considering a permanent implant because the effectiveness of spinal cord stimulation varies from patient to patient.

The trial is normally performed as a day case procedure at Guy’s Hospital. You will receive local anaesthetic and sedation, and stimulation leads are carefully sited in the epidural space within the spine. The leads are then attached to an external hand held controller which allows you to control the stimulation. Occasionally, if you have other medical conditions, you will need to stay in hospital overnight.

We like you to have a trial for seven to 10 days at home. This is the best way to assess how effective the stimulator is for you. We look at your pain score, your activity, your medication use and your sleep pattern. You will return to the Pain Management Centre at the end of the trial for assessment. 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). If the trial is unsuccessful, we will organise a further follow up, or discharge you back to the care of your local pain clinic.

What happens if I receive the permanent implant?
If the trial is successful, you will require another procedure for a full implant. 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. The battery placement is discussed with you before the procedure. A small incision in your skin is required to place the battery either in your buttock or abdomen. You will need to stay in hospital, normally for one night.

How long does the battery last?
This depends on the type of battery inserted and how much you use it. On average, a non-rechargeable battery can last five to seven years. Replacing the battery requires a simple day surgery procedure where the previous incision is opened under sedation and local anaesthetic and the battery replaced. A rechargeable battery may last longer but needs changing if it doesn’t recharge properly. The pain medicine specialist will decide on the most appropriate battery for you.
What are the risks or complications of a spinal cord stimulator?

- Painful battery/connection site. If this is severe, further surgery or removal of the system may be advised.
- Infection (less than 5 in 100 people). If this happens, the whole system may need to be removed.
- Bleeding, which may lead to bruising and in rare cases may require further surgery.
- Severe headache, which may require treatment with a spinal injection if it does not improve within days.
- The leads may move or not work. This may need another operation to correct.
- Unpleasant stimulation, which may not respond to stimulation adjustment and may require stimulation to be abandoned.
- Stimulation felt outside of the painful area is common, but only a problem if unpleasant (see above).
- 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 system.
- 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 (two patients in one million).

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

- Some physical activities may need to be avoided in 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 you will need bipolar diathermy.
- Depending on the type of device chosen, it may 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 (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 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.

Please discuss with your pain medicine specialist or nurse if you have further questions. More detailed information is provided on the pre-implant programme or technology day.

Further information

British Pain Society
Information about spinal cord stimulation for the management of pain, and recommendations for best clinical practice.

w: www.britishpainsociety.org
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 the operator on 020 7188 7188 and ask for 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.

Patient Advice and Liaison Service (PALS)
To make comments or raise concerns about the Trust’s services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

- e: 020 7188 8801 at St Thomas’
- t: 020 7188 8803 at Guy’s
- e: pals@gstt.nhs.uk

Pharmacy medicines helpline
For information about any medicines that you have been prescribed at Guy’s and St Thomas’ hospitals, you can speak to the staff caring for you or call our helpline.

- t: 020 7188 8748 9am to 5pm, Monday to Friday

Knowledge & Information Centre (KIC) – For more information about health conditions, support groups and local services, or to search the internet and send emails, please visit the KIC on the Ground Floor, North Wing, St Thomas’ Hospital.

- t: 020 7188 3416

Language support services – If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

- t: 020 7188 8815
- fax: 020 7188 5953