

The Kent Centre for Pain Medicine and Neuromodulation

Spinal Cord Stimulation (SCS)

Information for patients

This leaflet will give you information about **spinal cord stimulation (SCS)** to help with the management of your chronic pain. If after reading this leaflet you have any questions, please ask your pain consultant or other relevant healthcare professional.

Why have I been recommended for SCS?

Your pain consultant has recommended that you consider spinal cord stimulation (SCS) to help with the management of your chronic pain. Whilst SCS does not cure chronic pain, it can help to reduce your pain when used alongside medications and other treatments.

As SCS insertion is a surgical procedure/operation, it is important that you are fully informed of all risks and benefits before you decide that SCS is the right treatment for you.



What is SCS and how does it work?

SCS is used for the treatment of people who suffer from chronic neuropathic (nerve) pain. The nerves in your spinal cord carry messages to your brain telling it you feel pain in certain areas.

By inserting a lead (electrode) inside your spine this enables an electric current to be applied to your spinal cord, interrupting the pain messages that are received by your brain. Depending on which system is used, you may feel a pleasant sensation (called paraesthesia), which has been described as tingling, warm, or a pins and needles type sensation over the area of your pain. Alternatively, if 'high-frequency' stimulation is used you may not feel any paraesthesia at all.

You are given a remote control which allows you to turn the stimulation on and off, switch between programmes, and to increase or decrease the sensation that you receive. You cannot use the stimulation when driving a vehicle if you have paraesthesia.

The therapy should eventually mean that you can reduce the amount of painkillers that you need to help with your pain. We aim to work with you so that you can control your pain and are able to increase your movement and exercise.

What are the different types of SCS?

There are many different types of stimulation, including the following.

- Low frequency SCS, which uses frequencies which may provide a tingling sensation in the painful area known as paraesthesia.
- High frequency SCS, which is usually not felt.
- Dorsal root ganglion stimulation, which targets a very specific area of neuropathic pain, such as a foot.

Your consultant will decide which system is best for you before referring you for SCS. This decision is based on many factors including where your pain is, the type of pain, and your medical history.

Who decides whether SCS is the right treatment for me?

You will need to be assessed by the members of the multidisciplinary team (MDT), once you have been referred for SCS by your pain consultant.

- Most of our SCS patients are invited to one of our **SCS Group Education Sessions**. These sessions last four hours and we encourage you to bring a friend or relative with you. The sessions are run by a clinical nurse specialist, an occupational therapist, and a psychologist, alongside a representative of the SCS company.

Before coming to the session, you will be sent an assessment booklet to complete and bring with you on the day, along with some useful literature about the procedure. If you do not complete the assessments you will not be able to progress along the SCS pathway, as it will not be possible for us to complete the assessment process. You will be expected to complete these assessment questionnaires at intervals throughout the SCS pathway.

- Some of the aims of the session.
 - Provide information about the pathway, the procedure, and the equipment.
 - Discuss possible risks and benefits to having the procedure.
 - Help you to consider some realistic 'SMART' goals.
 - Help you to meet other patients who have similar experiences to you.
 - Provide support in decision making and help you to give informed consent for any future procedures.
 - Explore how you are managing your pain right now, and your expectations of SCS.
 - Discuss how you would feel if SCS does not work for you.
 - Explore what other options are available if SCS is not for you.
- After the education session, **your case will be discussed by the MDT** to make sure that SCS is the right treatment for you. A member of the MDT will contact you by telephone at the end of the day to let you know the outcome of your assessment. They will also let you know if we are able to offer you a date for the procedure, or if you need further appointments with a member of the pain team.
- On rare occasions, **patients may need individual appointments** rather than coming to the group session. In this happens, there will be several appointments which you must go to. You will need to see one of the clinical nurse specialists who will explain in more detail what is involved and give you an opportunity to ask questions.
- You will then be referred to a **psychologist**. They will aim to help you explore any thoughts, feelings, or expectations that you may have about having a SCS. The psychologist may also introduce you to some helpful psychological approaches, which may be of further help in helping you manage your pain.
- You will also be referred to an **occupational therapist**. They will assess your functional abilities, including the pacing of your activities before and after your procedure.

It is very important that you come to all your appointments, and that you complete all the questionnaires that you will be given at these appointments. During this time your case will be discussed at our MDT chronic pain team meeting, to make sure that SCS is the right treatment for you.

Who cannot have SCS?

You should not have SCS if you:

- have pain that will not be helped by SCS (for example pain due to arthritis)
- have pain beyond the area that SCS can cover (widespread pain syndromes)
- have physical problems that mean it is not possible to implant a SCS safely, for example major spinal deformity, extensive spinal metalwork, or extensive spinal scar tissue in your epidural space
- have an active infective illness
- have some chronic medical illnesses, for example multiple sclerosis (MS) 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
- are on high doses of opioids
- are allergic to any parts of the implantable device.

What happens once it is decided I am suitable for SCS?

Once the chronic pain team have decided that you are suitable and ready for SCS, you may be offered a temporary trial of the stimulation to see if it works for you. Or the team may feel that you are suitable to proceed direct to a full implant.

What happens at the trial stage?

The trial stage is performed as a day case in the Day Surgery Unit.

- The lead (either one or two) is inserted through a needle in the lower part of your back under deep sedation (you will sleep during most of your treatment).
- The needle is removed leaving the end of the lead exposed underneath a dressing.
- This lead is connected to a small pulse generator (a battery the size of a pocket watch) which delivers your stimulation.
- You will be given different programmes to try and a remote control which allows you to adjust the stimulation at home.

The trial stage lasts for two weeks, after which you will come back to clinic to have the lead removed which is painless. At this point depending on how your trial has gone, the team may decide to offer to extend your trial using the same trial leads, and possibly with a different system.

What does the permanent implant involve?

If your trial was successful or you have gone straight to a full implant, you will be scheduled to come back for the permanent implant. Please be aware that this will be at least six to eight weeks after a trial.

The full implant is also performed as a day case in the Day Surgery Unit.

- The lead (either one or two) is inserted through a needle in the lower part of your back under deep sedation.
- The needle is removed, and the lead is tunnelled under your skin and connected to the implantable pulse generator (IPG) so nothing is seen from the outside. The IPG is implanted under the skin above your buttock.

Depending on how you are feeling immediately following your procedure, you may be given programmes to use on the day or you may be asked to return to the Pain Clinic a few days later for 'programming'.

You will also need to make an appointment with your GP surgery practice nurse after your procedure, to have your wounds checked and any sutures (stitches) removed.

What are the risks or complications of a SCS?

As with any surgery there are risks, which your pain consultant will discuss with you.

- Your procedure may be stopped.
- A dural puncture can cause a severe headache, which may need treatment with a spinal injection if it does not improve within days.
- Bleeding, which may lead to bruising and in rare cases further surgery.
- Less than five in 100 people will develop an infection. If this happens, the whole system may need to be removed.
- A painful IPG site, but this usually resolves with time. If this is severe, further surgery or removal of the system may be advised.
- 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 need 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 you have no pain relief. This may lead to surgery to re-site the leads or remove the system.
- An allergic reaction may lead to the removal of the system.
- Pain relief may decrease over time.
- Nerve damage leading to nerve pain, numbness, and weakness. This may be temporary or permanent.
- Paralysis is extremely rare (two patients in one million).

Will I be totally pain free with SCS?

How much pain relief is achieved with SCS varies between patients, this is the reason for the trial.

Most people find this therapy helps the chronic pain they have suffered with for many years. If successful it is estimated that it could reduce your pain by half.

In time it may mean that your pain medications can be reduced. You must check with your pain consultant or other relevant healthcare professional before changing the dosage of your medications.

What if I need to cancel/change my appointment?

If you cannot come to your appointment, please phone the Pain Clinic. Please give us at least 48 hours notice, so we can offer your appointment to another patient. If you need to cancel or change your appointment more than once, we will not be able to offer you a further appointment.

If you do not come to your appointment and do not cancel it beforehand, we will have to return your referral to your GP and you will need to see them and ask to be referred again.

Further information

If you have any concerns regarding the information in this leaflet or your procedure, please phone the Pain Clinic.

Kent Centre for Pain Medicine and Neuromodulation (direct lines)

- Kent and Canterbury Hospital, Canterbury Telephone: 01227 78 30 49
- Queen Elizabeth the Queen Mother Hospital, Margate Telephone: 01843 23 50 94
- William Harvey Hospital, Ashford Telephone: 01233 61 66 91

Useful information

- British Pain Society. Stimulating the spinal cord to help with pain: Information for patients. April 2009.
Web: www.britishpainsociety.org/static/uploads/resources/files/book_scs_patient.pdf
- National Institute for Health and Care Excellence (NICE) Guidelines
Web: www.nice.org.uk
- East Kent Hospitals. Chronic pain patient information
Web: www.ekhufft.nhs.uk/chronic-pain-leaflets

This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhufft.nhs.uk/patientinformation