



Information for patients considering Sacral Nerve Stimulation

**(This is also known as sacral neuromodulation,
SNS or InterStim Therapy)**

Building healthier lives

Introduction

This leaflet is designed to give you information about sacral nerve stimulation. It is essential that you read this booklet carefully before the surgery so that you fully understand the operation and the care that is required before and after.

If you have any questions or concerns about the procedure, you can contact the specialist urology nurses on 0121 371 6932.

Why do I need sacral nerve stimulation?

When the communication system between the nerves, brain, bladder and muscles related to passing urine is not working correctly, the following bladder control problems may arise:

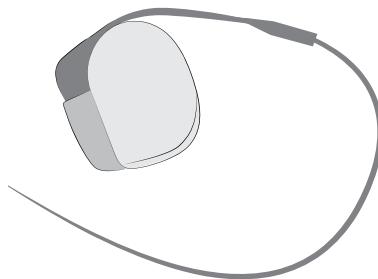
- **Urinary retention** – symptoms may include the need to spend a long time at the toilet but only a weak stream is produced. You may not feel the sensation when your bladder is full or you may leak urine because you do not empty your bladder fully and have to use a catheter to assist emptying.
- **Bladder over activity** – symptoms may include needing to pass urine frequently with or without an uncontrollable urge. Leakage of urine associated with the strong desire to go to the toilet may also be a problem.

What is sacral nerve stimulation (SNS)?

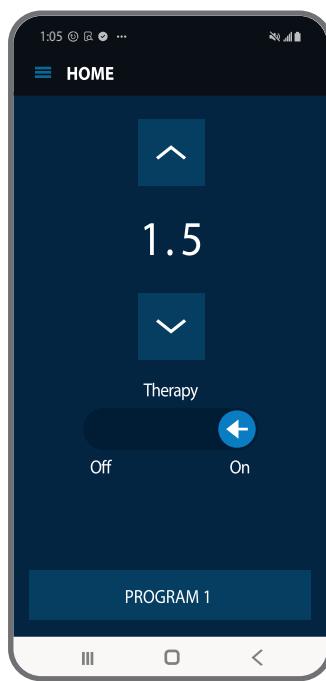
Sacral nerve stimulation (SNS) involves applying an electric current to one of the sacral nerves via an electrode (thin wire). The electrode is attached to an implantable pulse generator which stimulates the nerves associated with bladder function. The aim of the stimulation is to make the bladder work in a more controllable way; a bit like a pacemaker used for the heart.

The implanted device consists of:

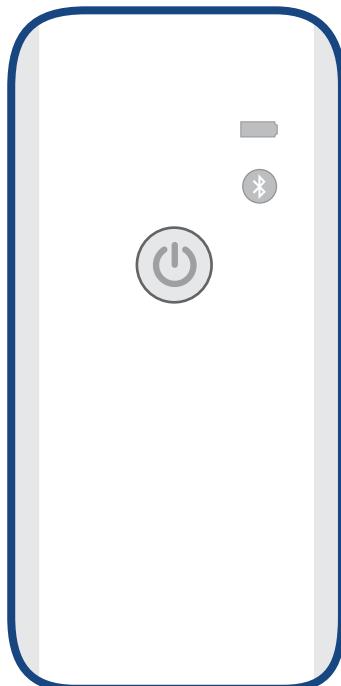
- An electrode and a stimulator device which is inserted under the skin approximately the size of a £2 coin (pictured below)



- A hand-held programmer that enables the level of stimulation to be adjusted and the implant to be turned on or off (pictured below)



Programmer



Controller

The success rate of SNS is around 70% with patients reporting a significant improvement (not cure) in their symptoms. Unfortunately not all patients are suitable for SNS.

Are there any alternative treatment options?

You may have already considered or tried:

- Bladder retraining
- Physiotherapy and pelvic floor muscle exercises
- Tablets
- Botox injections into the bladder
- Bladder enlargement or replacement using a piece of bowel
- Urinary diversion into a stoma
- Posterior tibial nerve stimulation (PTNS) – electrical stimulation of a nerve near the ankle. This can be used but is not widely available as an NHS treatment
- Intermittent self-catheterisation
- Permanent insertion of a catheter
- Mitrofanoff procedure – creation of a continent catheterisable channel using a segment of bowel connected to your bladder

Contraindications

SNS should not be used for:

- Patients who are unable to properly operate the system
- Patients for whom test stimulation is unsuccessful

The procedure

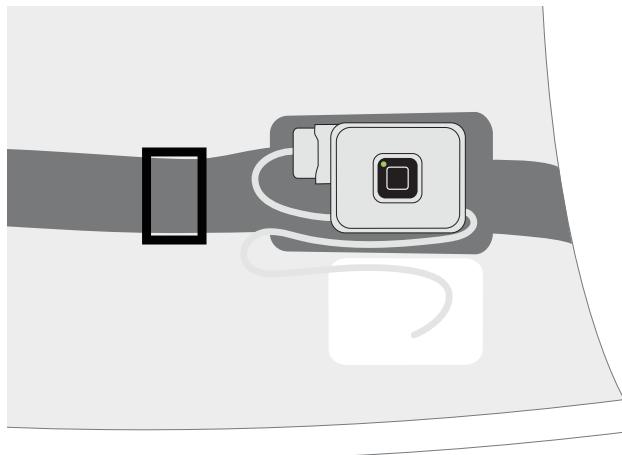
The treatment occurs in two stages several weeks apart.

Stage 1: The test phase

This is known as a primary percutaneous nerve evaluation (PNE) test.

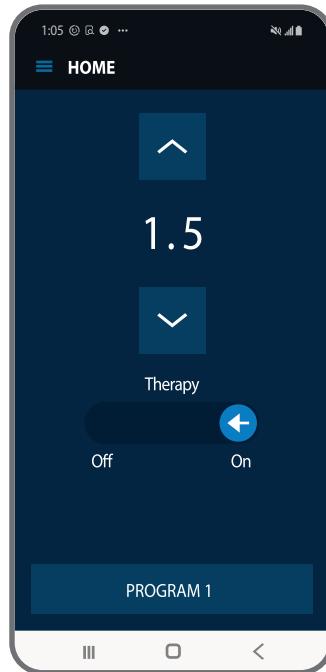
You will need to stop taking any anticholinergic medication such as Oxybutynin, Vesicare, Detrusitol or Betmiga on the day of the test phase. Medication can be resumed once the test wire has been removed at your review appointment in 2-3 weeks.

- You will be admitted to Solihull Hospital or Ambulatory care at Queen Elizabeth Hospital Birmingham (QEHB) for implantation of the test wire which will stay in place for a period of 2-3 weeks
- This will take place in theatre
- You will need to lie on your stomach for approximately 30-45 minutes
- An anaesthetist will administer light sedation before the surgeon makes a tiny cut in your lower back to insert a temporary test electrode near your sacral nerves. X-rays are used to make sure it is in the correct place
- The wire is connected to a stimulator box outside your body



- The stimulator box produces electrical signals to the nerves and needs to be worn at all times. It will be secured with dressings and a belt worn around the waist

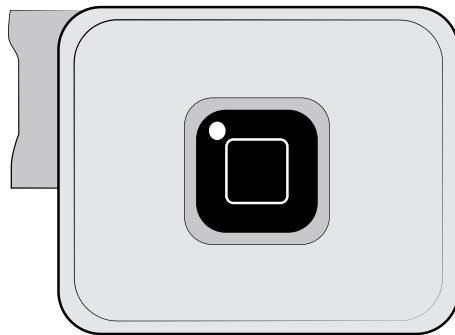
- You will normally go home on the same day but sometimes an overnight stay is needed
- The stimulator will be switched on and programmed to obtain maximum benefit for your symptoms before you go home
- Once switched on you will feel a mild tapping, pulling or tingling sensation in the genital area (vagina/scrotum) or rectal area (anus/back passage)
- You will be shown how to adjust the stimulator strength yourself using a programmer



- Over time the sensations may become less noticeable as the body adjusts to the stimulation
- The sensations should never be painful
- When at home you must keep the dressings clean and dry. If they start to lift, you should apply more dressings on top – please do not remove them. This is to ensure the wire does not become dislodged or removed

- Please do not bathe or shower during this test phase. Keep yourself clean by strip washing
- Once home it is important not to perform any strenuous activity including sex. This again is to prevent movement of the wire
- You will be required to keep a bladder diary to help us monitor the effect of the stimulator on your bladder on a day-to-day basis. This will help us decide whether or not you would be suitable for implantation of a permanent device

If your controller is unavailable or not responding, press and hold the ENS button on the external stimulator box until you feel the button click, then hold the button for a count of 10.



Review appointment

- At the end of the 2-3 week test phase period you will be seen by the nurse specialist to review your bladder diary and your symptoms. If your symptoms have improved sufficiently, permanent stimulator implantation will be deemed appropriate and you will be counselled for this
- The test electrode will be removed at this appointment
- Once the test stimulation has stopped, your bladder symptoms will usually return within a few hours

Risks and side effects

The majority of patients do not suffer problems after this procedure, however the most common side effects that are reported include:

- Wound infection bruising
- Pain from wound
- Urinary tract infection (UTI)
- Difficulty in passing urine
- Change to bowel function
- Movement of electrode – dislodged or broken
- Device malfunction
- Battery failure
- Hospital acquired infection e.g. MRSA – in rare cases the device may need to be removed

If any of these occur before your review appointment please contact your Nurse Specialist on 0121 371 6932, consultant's secretary on 0121 371 5730 or your GP.

Frequently asked questions

Am I able to work during the test phase?

Yes, unless your work requires intense physical activities. It is suggested that you take 1-2 weeks off from work to obtain the optimum result from this test.

Am I able to bathe or shower?

No, the external stimulator box and controller must be kept dry. To avoid the electrode becoming dislodged, we advise limiting physical activity to moderate levels avoiding bending, stretching, sexual activity and lifting heavy objects.

Can I use my mobile phone?

Yes.

Do I need to have my dressing changed?

Keep dressings dry and intact. The electrode is temporary and held in place by the dressing, not stitches – **it is therefore important that**

you do not take the dressing off or allow anyone else to. If the dressings are starting to lift add more tape on top.

If you notice any redness or swelling at the site, please contact your Nurse Specialist on 0121 371 6932, consultant's secretary on 0121 371 5730 or your GP.

Am I still able to go to the gym?

No, during the test phase physical activities must be restricted to prevent the electrode becoming displaced from its initial position, as this may affect the test results/outcome. Changes in body position may affect the intensity or location of the stimulation requiring you to make adjustments with your controller.

Am I allowed to drive?

Yes, but it is advisable to turn the stimulator off while you are driving and turn it back on at the end of your journey. This is precautionary for safety in case you experience an unexpected jolt or shock.

Is the test reversible?

Yes, the test stimulation can be stopped at any time and is reversible.

Do I have to complete bladder diaries?

Yes, without the information gathered it will not be possible to establish whether you are suitable for a permanent implant.

Will you tell my GP?

Yes, your GP will be kept up to date with a letter following each appointment detailing them of your progress.

If the test stimulation is successful

If the test stimulation is successful, permanent implantation of a stimulator will be discussed with you. If you agree, you will be placed on the waiting list. It is difficult to state how long this waiting list will be as it may change on a day-to-day basis, as cancer surgery takes precedence.

Once your implantation date is confirmed you will receive an appointment for your pre-operative assessment which usually takes place 1-2 weeks before your operation.

Stage 2: Implantation of the permanent sacral neuromodulator

- You will be admitted to Solihull Hospital or ambulatory care at QEHB for implantation This will take place in theatre
- You will need to lie on your stomach for approximately 30-45 minutes
- An anaesthetist will administer a general anaesthetic before the surgeon makes a tiny cut in your lower back to insert a permanent electrode near your sacral nerves. X-rays are used to be sure it is in the correct place
- Through a small incision (3-4cm) in your upper buttock the permanent neuromodulator (battery) is implanted in a sub-cutaneous (below the skin) pouch, so others will not see it
- The buttock chosen is dependent upon the best stimulation response
- The wounds are closed with dissolvable stitches which can take up to a month to dissolve and glue
- You should be able to go home on the same day but sometimes an overnight stay is needed
- The stimulator may be switched on, when you are back on the ward or we will send you an appointment to return to outpatients

Post-operative Recovery

- Once home it is important not to perform any strenuous activity or any stretching of the lower back for eight weeks to prevent movement of the wire
- You may bath or shower after 48 hours
- You will get mild discomfort at the operation sites which may last for several days. This can normally be relieved with mild painkillers such as paracetamol
- If you require antibiotics these will be dispensed on discharge
- If you experience any flu-like symptoms, redness or throbbing in the

wound, pain or burning when passing urine, please contact your nurse specialist on 0121 371 6932 as soon as possible or your GP

- You will be given your hand held patient programmer to bring to your appointment and your personal InterStim implant identification card. It is important to keep this information safe (if you lose this card please contact the nurse specialist for a replacement)
- You will be given a copy of your discharge summary and a copy will be sent to your GP

Follow up

An outpatient appointment will be sent to you to review your symptoms but if there are any concerns you may contact the Urology CNS nurses for advice.

Handheld patient programmer

The patient programmer is used:

- To show whether the stimulation is on or off
- To turn it on or off
- To show the level of stimulation and adjust it

Neurostimulator battery

The battery lasts between 10 and 15 years depending on the level of stimulation it is set at and you will notice your symptoms starting to return. In this instance, you should contact your nurse specialist on 0121 371 6932 so that the battery can be checked.

If the battery has run down, it will need to be replaced. The electrode does not usually need to be changed. A battery change requires a minor surgical procedure under general anaesthetic.

Precautions

- To avoid an unexpected jolt or shock, you should **turn off** your neurostimulator before undertaking activities that could become unsafe for you or others e.g. driving or operating power tools
- Medical procedures and equipment – **always** tell your doctor or

dentist that you have an implanted InterStim system. Most medical procedures and routine tests such as X-ray should not affect your stimulator. However, the following may affect you and your stimulator adversely:

- Heart defibrillators
- Lithotripsy (e.g. for Kidney stones)
- MRI (Magnetic resonance imaging) – put device into safe MRI mode before an MRI
- Radiation therapy over the neurostimulator
- Radiofrequency ablation
- Ultrasound scanning

It is also important to inform your doctor that you have this device before you have tests such as electrocardiogram (ECG) or electroencephalogram (EEG) as the pulses from your stimulator may interfere with the test. The stimulator may be turned off during the test then turned back on when completed.

- **Commercial electrical equipment** – for example ARC welders, induction furnaces, CB or Ham radio, as well as high voltage power lines may interfere with your nerve stimulator if you get too close to them
- **Electronic devices** – theft prevention and security systems (for example in shops or airports) may interfere with the device.

Screening systems can cause the neurostimulator to turn on or off. The manufacturer, Medtronic, advises users to ask security personnel if they can bypass the screening device. If this is not possible then they recommend the user turns the stimulator off, approach the centre of the screening gate then walk through normally.

- **Microwave oven** – most home appliances including microwave ovens do not affect the way your nerve stimulator operates
- **Surgical diathermy** – cutting and coagulating (stopping bleeding) tissue during surgery is usually done by using diathermy (electrical current). The current from some types of diathermy equipment can damage your stimulator. Please tell your surgeon about your stimulator so that only safe diathermy equipment is used
- **Pregnancy** – the effect of neurostimulation on pregnancy is

unknown. It is advised that you turn the implant off if you are planning to start a family and inform your doctor/specialist nurse

- **Sports and exercise** – After your recovery 6-8 weeks after permanent implantation of the nerve stimulator, you can do most forms of exercise such as swimming, running, aerobics and sex. **However horse riding, skiing and contact sport seem to be associated with more lead/electrode breakages**
- **Diving** – this is safe **but do not dive below 10 metres of water or enter hyperbaric chambers above 202.65kiliopascals (kPa), (2.0ATA)**
- **Theme park rides** – some rides that cause the rider to be shaken or jolted may cause the stimulator lead to dislodge
- **Cremation** – if you wish to be cremated the device will need to be removed first

General advice/troubleshooting

- **Pain** – if you feel any pain that you consider to be associated with your stimulator, turn it off and contact your nurse specialist on 0121 371 6932 for advice.
Pain and discomfort are normally caused by the stimulator being turned up too high. If you experience pain, turn the voltage down or switch the stimulator off for a few hours and turn it back on to a setting you can faintly feel. Once the stimulator is turned off, the discomfort will begin to subside. Note this can take a few hours, or even overnight.
- Stimulation programmes can take several weeks to become effective. Please do not change programmes more frequently than every four weeks
- **Symptom return or if you cannot feel stimulation** – check the stimulator is switched on using the programmer
 - If the icon is showing the stimulator is switched off, switch it on
 - If the icon is showing the stimulator is switched on consider the following:
 - Do you have a urinary infection?
 - Have you been constipated?

- Have there been changes in other medical conditions you may have?
- Have there been changes to your diet or drinking habits?
- Have there been changes to your medication?
- Have you recently fallen or suffered trauma to your body?
- Have you recently had any procedures or surgery?

Contact your nurse specialist on **0121 371 6932** to arrange a review appointment.

You may also contact the Medtronic (manufacturer) Technical Support Helpline: **01923 205 101**, open 09.00-16.00 (Monday to Friday)

- **Intermittent stimulation** – consider whether or not the stimulation is positional
 - **If yes** change to a different programme recording symptoms or contact your nurse specialist on 0121 371 6932 to arrange a review appointment
 - **If no** contact your nurse specialist on 0121 371 6932 to arrange a review appointment
- **Shocking/jolting sensation** – turn the stimulator off
 - Are the sensations resolved?
 - **If yes** leave stimulator switched off and contact your nurse specialist on 0121 371 6932 to arrange a review appointment
 - **If no** the sensation is unlikely to be related to the stimulation contact your nurse specialist on 0121 371 6932 to arrange a review appointment

Insurance

We advise that you add your programmer to your home and contents insurance as you will be liable for the cost of replacement should the device become broken, damaged or lost.

If travelling abroad please ensure you have medical insurance and that your provider knows about your sacral nerve stimulator device.

Important

Please note the precautions listed are not exhaustive so please ask your nurse specialist for further advice should you have any concerns.

Who do I contact?

If you have a query regarding a clinic appointment:

- **Nurse Specialist's secretary**

0121 371 5733

- **Consultant's secretary**

0121 371 5730

For advice and support please contact:

- **Urology Nurse Specialist**

0121 371 6932

For additional technical support:

Medtronic Technical Support Helpline

01923 205 101 open 09.00-16.00 (Monday to Friday)

If urgent advice is required please call your GP who will contact the urologist if necessary.

Where can I find further information?

- www.professional.medtronic.com/pt/uro/snm/prod/interstim-ii/manuals-technical-resources/index.htm
- www.bladderandbowelfoundation.org
- www.nice.org.uk/guidance/ipg99/informationforpublic

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