

Vagus Nerve Stimulation (VNS) - what is it?

This leaflet provides information for patients and the carers of patients who have or who are considering a Vagus Nerve Stimulator (VNS) device.

If you have any further questions, please ask a member of the team looking after your epilepsy.

Why might VNS be an option for my epilepsy?

You are being considered for VNS because you continue to have frequent seizures and you have tried at least three or more anti-epileptic medications over a period of at least two years.

What are the vagus nerves?

The vagus nerves are a pair of nerves that go from the brain and run through other parts of the body. They send and receive messages between the brain and the rest of the body.

What is the aim of the VNS?

VNS can help reduce the frequency and duration of seizures for adults with epilepsy.

How does VNS therapy work?

VNS therapy uses the VNS system, which is made up of three parts:

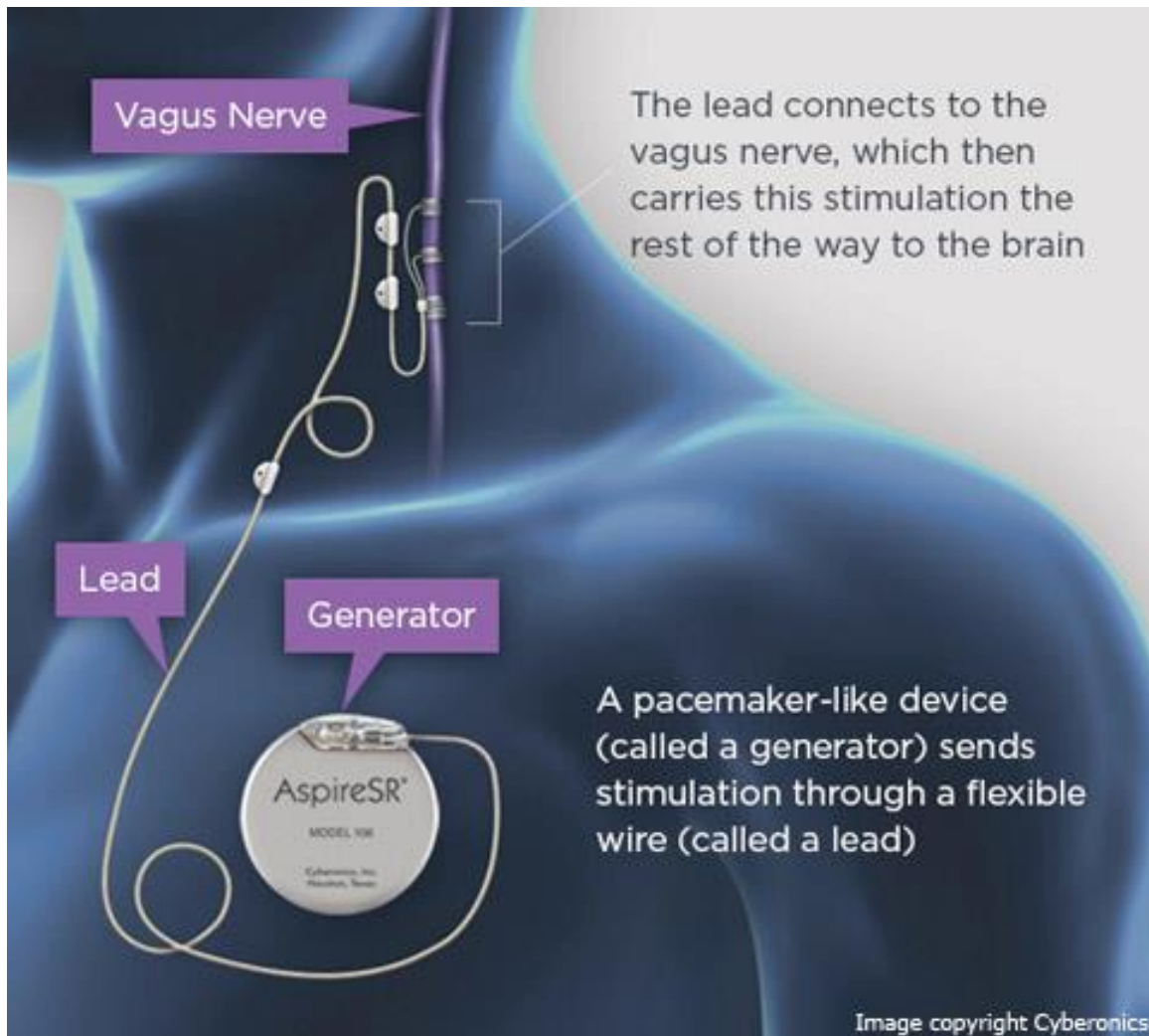
- A small pacemaker-like medical device (called the pulse generator) that is implanted under the skin in the left side of the chest.
- A thin, flexible wire, called a lead, which connects the pulse generator to the left vagus nerve.

- A hand-held magnet.

The pulse generator is programmed to regularly send electrical impulses through the electrodes of the lead to the brain by way of the left vagus nerve in the neck. It does this at regular intervals, all day, every day. The electrical impulses are delivered to the brain where seizures are believed to start and this can help reduce the number of seizures you have and make them less severe.

You can also sweep the hand-held magnet over the generator to send more impulses to the vagus nerve. This could be if you have an aura (warning) before a seizure, if you feel a seizure starting or when you are having a seizure. Some people find that using the magnet stops a seizure happening, shortens the seizure or makes the seizure less severe. A carer or family member can also use the magnet, if they see you having a seizure. The magnet can also be used to stop the stimulation for a short time.

Newer models of the VNS generator can also detect increases in heart rate. In some people with epilepsy an increase in heart rate can be a sign that they are having a seizure. When the generator detects an increase in heart rate, it automatically sends more impulses to the vagus nerve. This may help to stop a seizure happening or make it less severe.



How is the VNS inserted?

The VNS system is implanted using a general anaesthetic so you will be asleep and most patients have it implanted as a day case or with an overnight stay. In rare instances a patient may need to stay longer.

The procedure, including the time to administer an anaesthetic, takes up to two hours. During the procedure one 3cm cut will be made in the left side of the chest for the pulse generator and another 3cm cut will be made in the left side of the neck so that the lead can be attached to the vagus nerve. Both sites will have dissolvable stitches and will be covered with Steristrips and then a dressing. The dressing should stay in place and be kept dry for five days. These sites will also be checked when

you attend your first follow-up appointment after implantation.

When will the VNS start working?

You will be given a box containing two magnets and a patient's manual before discharge. The VNS device itself will be switched on at your first appointment, approximately two weeks after insertion. This will give your body time to heal from the operation. At follow-up appointments, stimulation will be increased slowly using a handheld computer and programming wand, which is placed over the device through clothing. This will give you time to get used to the stimulation. The computer can also be used to perform a device and lead test to ensure that the VNS is working normally at each follow-up appointment.

What are the benefits of VNS?

The benefits of VNS can include the following:

- Having fewer seizures
- Having less severe or shorter seizures
- Needing to take less epilepsy medication
- Having an improved quality of life.

Studies have shown that up to 3 in 10 patients can have a 50% or greater reduction in seizure frequency at three months after implantation of the device. The overall response to VNS improves with time, and at one to five years after implantation, up to 70% of patients may experience a 50% or greater reduction in seizures.

What are the complications and side effects of VNS?

Between 3 and 6 out of 100 patients who have had VNS fitted may experience immediate complications, which are typically related to infection and are managed with antibiotics or a

second operation. There are other small but important risks of surgery that your surgeon will discuss with you.

The most common side-effect reported from VNS stimulation is a hoarseness or a change in voice. Other common side-effects include

- Sore throat
- Shortness of breath
- Prickling feeling in the skin
- Coughing
- Sleep apnoea.

Other possible side effects include palpitations, difficulty swallowing and stomach discomfort. The side-effects of VNS usually happen during stimulation periods and often improve over time. If they persist, it is often possible to alter the stimulation settings to improve things. It is also possible to turn off the device for a short period by using the magnet. If it causes major problems, the device can be switched off and removed.

Is VNS better than more medications?

VNS is not a replacement for epilepsy medications and is always used in combination with medications. However, the more anti-epileptic medications a patient has tried, the smaller the chance that a new medication will stop their seizures. In this situation the benefits of VNS may outweigh its disadvantages, such as the need for surgery to have a VNS device implanted. The reader is asked to read the table at the end of this document which summarises the pros and cons of VNS, compared to the pros and cons of trialling further epilepsy medications.

General advice

The following is general advice about living with a VNS device and has been developed from questions that patients and carers often ask about VNS.

MRI scans and medical procedures

If you are ever admitted to hospital, you should always let staff know you have had a VNS device implanted. Certain precautions may be needed before medical procedures and operations. Head MRIs (a type of brain scan) can be performed but precautions need to be taken for the scan. Whole body MRI scans are not possible for patients with VNS devices. CT and ultrasound scans are not affected by VNS devices.

Airport security scanners and mobile phones

Airport security scanners and mobile phones should not affect the device or be affected by it.

Baths, showers and swimming

The VNS can be used in water and therefore baths, showers and swimming are all safe.

Other electrical or electromechanical devices

Stay at least 60 centimetres (cms) or two feet away from Electronic Article Surveillance System tag deactivators found in shops. This will avoid having your generator activated. The deactivators are found mostly in shop entrances.

Tablet computers and their covers, hair clippers, vibrators and loudspeakers can all have an electromagnetic field that you need to keep at least 20 cms or 8 inches away from your chest. If your generator does become activated just move away from the device which is causing the problem.

You will need advice from your doctor about whether it is safe for you to be where there are pacemaker warning signs. This is because the equipment that could affect a pacemaker could also affect your VNS generator.

Contact sports

Patients with VNS devices should avoid contact sports like rugby or martial arts because of the risk of damaging the device.

Battery life

The battery life of the VNS is approximately 10 years at implantation but this will be reduced depending on the VNS settings used. When the battery runs low, the device can be replaced.

Pros and Cons of Vagal Nerve Stimulator v Further Anti-Epileptic Medication Trials

Vagal Nerve Stimulator	Different Antiepileptic Drugs
Requires an operation to insert the device, small risk of infection, bleeding or anaesthetic complications. It can be painful for a few days.	No surgery, no pain, no infection/anaesthetic risks.
Very few people become seizure free with VNS alone. 3 in 10 patients can have a 50% or greater reduction in seizure frequency at three months after implantation of the device.	A fourth, fifth or sixth antiepileptic drug has between a 1 in 7 and 1 in 6 chance of leading to seizure freedom. Thereafter, the chance of becoming seizure free is very low with further trials of antiepileptic drugs.

<p>The overall response to VNS improves with time and at one to five years after implantation, up to 7 in 10 patients may experience a 50% or greater reduction in seizures.</p>	<p>4 out of 10 patients may have a 50% or greater reduction in seizures.</p>
<p>Side effects include discomfort at the site of the operation, tingling in the throat, coughing or a hoarse voice with each stimulation pulse. Side effects usually go away with time or if the settings on the device are changed.</p> <p>If necessary, the device can be switched off. VNS does not cause the brain related side effects that drugs can cause.</p> <p>VNS treatment has no effect on the development of unborn babies during pregnancy. VNS does not interact with other medications such as the oral contraceptive pill.</p> <p>Over time, VNS can sometimes help with mood and has been shown to improve the quality of life of patients, independent of its effect on seizures.</p>	<p>Side effects vary depending on the drug but often include tiredness, slowness of thinking, dizziness and sometimes effects on weight. Some drugs have a positive effect on mood, whereas others can cause mood problems. Side effects go away if the drug is stopped.</p> <p>There may be a risk associated with some antiepileptic drugs (especially when used in combination and at high doses) on the development of unborn babies during pregnancy. Some antiepileptic drugs can interact with other medications including the oral contraceptive pill.</p>
<p>Having a VNS device means that a small region of the chest (from</p>	<p>Not applicable.</p>

<p>C7 to T8) cannot be scanned using MRI.</p>	
<p>It takes about three months to see an initial effect, but the maximum effect may not be seen for one to five years.</p>	<p>It takes about three to four months (or sometimes less) to adjust the dose and know if it is helping or not.</p>
<p>If it doesn't help or causes side effects, it can be switched off. However, the scar and wires in the neck are permanent.</p>	<p>If it doesn't help or causes side effects it can be stopped with no long term/permanent consequences.</p>
<p>If it helps, you will need to have the device checked regularly (at St George's), at least every six months. When the battery gets low it needs replacing, meaning another operation (usually every few years). GPs cannot check or adjust a VNS device; this can only be done in specialist centres.</p>	<p>If it helps, you just stay on the drug. The frequency of your hospital appointments can be reduced. GPs can continue to prescribe the drug.</p>
<p>A magnet swipe over the device to trigger an extra burst of stimulation can prevent a seizure progressing (if you get a long enough warning) or shorten a seizure in some people. Newer VNS devices can also detect increases in heart rate that sometime precede seizures, which triggers an extra burst of stimulation to prevent a seizure</p>	<p>Not applicable.</p>

progressing.	
<p>If a VNS is inserted, we generally avoid trying any other new treatment (e.g., trying different drugs) until it is clear whether the VNS has helped or not. If there has been benefit, then some drugs can be lowered or withdrawn, but at least one drug is always continued and it is not a replacement for drugs.</p> <p>Having a VNS device does <u>not</u> prevent patients from trialling new antiepileptic drugs.</p>	<p>If there's been no benefit from a drug, then something different can usually be tried a few months later. Even if you have tried all the currently available drugs, new ones are being developed all the time.</p>

Useful sources of information

Epilepsy Society

UK charity helping lives of people with epilepsy through research, advocacy and care.

Web: <https://epilepsysociety.org.uk/>

<https://epilepsysociety.org.uk/about-epilepsy/treatment/vagus-nerve-stimulation>

Helpline: 01494 601 400

Epilepsy Action

Epilepsy Action is a community of people committed to a better life for everyone affected by epilepsy.

Web: <https://www.epilepsy.org.uk/>

<https://www.epilepsy.org.uk/info/treatment/vns-vagus-nerve-stimulation>

Helpline: 0808 800 5050

Contact us

If you have any questions or concerns about VNS, please contact our Epilepsy Clinical Nurse Specialist on 020 8725 4110 (Monday to Friday, 9am to 5pm, excluding bank holidays) or adult.epilepsynurse@stgeorges.nhs.uk .

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

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Tel: 111

AccessAble

You can download accessibility guides for all our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.



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