

Directorate of Children's Services
Vagus Nerve Stimulator (VNS)
Information booklet for parents/carers

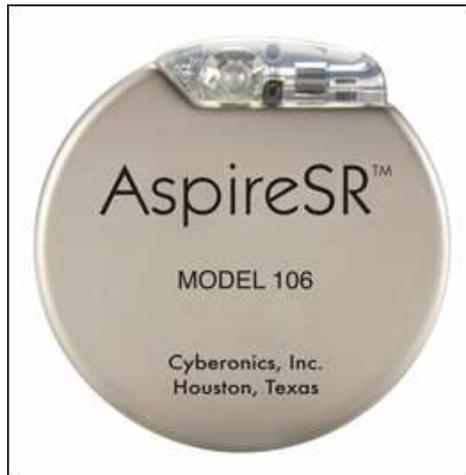
This is an information booklet for families and carers of young people who have, or are considering a Vagus Nerve Stimulator (VNS) device. If you have any further questions, please ask a member of the team caring for your child.

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?

The VNS can help reduce the rate and length of seizures for young people with epilepsy by preventing the electrical irregularities that cause seizures. The VNS Therapy system is made up of a small medical device (the pulse generator) that is implanted under the skin in the left side of the chest and a lead which connects the pulse generator to the left vagus nerve. The pulse generator sends electrical pulses through the electrodes of the lead to the brain by way of the left vagus nerve in the neck. The electrical impulses are delivered to the brain where seizures are believed to start.



How is the VNS inserted?

- The VNS system is implanted using a general anaesthetic so the patient is asleep.
- Most young people can have a VNS implanted as day surgery however in some circumstances they may need to stay overnight.
- The procedure (including anaesthetic time) takes up to two hours.
- During the procedure one cut will be made in the left side of the chest for the pulse generator and another will be made in the left side of the neck in order that the lead can be attached to the vagus nerve.
- Both sites will have dissolvable stitches and will be covered with a dressing. The dressing should stay in place and be kept dry for five days. If the dressing comes off before this time or you are concerned about the areas once the dressings are removed, please phone the epilepsy nurse specialist for advice (contact details are at the end of this booklet). The sites will be checked when you attend for the first follow up appointment.

When will the VNS start working?

- The VNS device will be switched on at the first appointment after discharge from hospital.
- You should also be given a box containing two magnets and a Patients' Manual before discharge.
- You will be contacted by letter or telephone by the paediatric epilepsy nurse specialist regarding follow up. Your first appointment will be between two and four

weeks after discharge from hospital and then every two to four weeks after this for the first four appointments.

- Further appointments will be at two to three monthly intervals.

What will happen at the follow-up appointments?

At the follow-up appointments, adjustments will be made to the VNS using a hand-held computer and a programming wand which is placed over the device through clothing. The hand held computer can also be used to perform a lead test: to check that the VNS is working properly. This will be done every six months, or more regularly if you think there is a problem.

The following information may be useful to know if your child is admitted to hospital.

Parameters which can be adjusted are:

OUTPUT CURRENT: Amount of electrical current delivered in a single pulse of a stimulation. Measured in Milliamps (mA)

PULSE WIDTH: The duration of a single pulse within a period of stimulation. Expressed in microseconds

SIGNAL OFF TIME: The time between periods of stimulation. Measured in seconds or minutes

SIGNAL ON TIME: The length of time that output current is delivered. Measured in seconds

STIMULATION FREQUENCY: The number of single pulses of stimulation delivered per second. Expressed in hertz

When the VNS is first turned on the output current will be 0.25mA, the off time will be 5 minutes and the on time will be 30 seconds. At each follow up appointment the output current will be increased by 0.25mA until the output current reaches 1.5mA. Subsequent increases of 0.25mA will be made at 2 to 3-monthly intervals. The output current may be increased as far as 2mA if your child is able to tolerate this, however some children may respond well to a lower output current. After this adjustments will be made to the signal on and off times in the hope of further improving seizure control.

What is the magnet mode?

The VNS Therapy System also has a magnet mode. The most common use for the magnet is to try and stop a seizure (focal / partial or generalised).

The magnet can be used:

- Before a seizure starts if the child / young person has warning signs that they are going to have a seizure
- At the start of a seizure
- During a seizure

To start stimulation the magnet must be passed over the VNS generator for approximately one second. **This should be in an X shape across the device to make sure it is activated.**

Swiping the magnet causes one minute of continuous stimulation.

At the end of the minute, if the seizure has not stopped, you could repeat the process to activate another minute of stimulation.

If this is ineffective at stopping the seizure, progress to emergency medication plan (if applicable).

It is important to take care of the magnets. However, if you misplace your magnet, a replacement can be obtained from the manufacturer or purchased from a charity called FABLE (telephone number 0114 2755335).

What are the side effects of VNS?

The most common side effects of VNS are:

- Hoarseness of voice
- Sore throat
- Shortness of breath
- Coughing

These side effects typically occur only during stimulation and can cause mild discomfort especially in the first 24 hours after changes are made to the output current.

Paracetamol can be given for discomfort if required. If the discomfort persists beyond

the first 24 hours or does not settle with paracetamol, please contact the epilepsy nurse specialist.

Other side effects which are possible but less common are:

- Inability to sleep (Insomnia)
- Indigestion
- Infection
- Nausea
- Pain
- Prickling of the skin (Parathesia)
- Vomiting
- Seizure frequency can increase following adjustments to increase the VNS output current. This usually lasts less than two weeks and does not happen in all cases.

Please note this list of side effects is a guide only. If there is anything which worries you, contact the paediatric epilepsy nurse specialist.

General advice

The following is general advice about living with a child with a VNS. This information has been developed from questions that parents and carers have asked about VNS.

- The VNS magnet should not be dropped onto a hard surface. If it is dropped, it can be checked by passing it over the child's VNS and seeing if stimulation occurs. If you are unsure about whether the magnet is working, please contact the epilepsy nurse specialist.
- If the casing of the magnet is cracked, the magnet should be replaced. Please contact the epilepsy nurse specialist who will arrange this.
- Keep the magnet at least 25cm away from televisions, microwaves, and other magnets.

- Magnets should be kept at least 25cm away from credit cards, computers and computer disks as the magnet may affect the stored data.
- Some electrical or electro-mechanical devices which have a strong static or pulsing magnetic field can cause accidental activation of the VNS. This includes iPad devices. It is recommended that when using an iPad, the device is kept 15cm away from the chest and never laid upon the chest, as this could interrupt VNS stimulation until the device is removed from the chest area
- The VNS can be used in water (bath, swimming pool, hydrotherapy pool).
- If needed, the VNS can be turned off by holding the magnet over the device (you can tape it in to position on the chest to keep the device turned off).
- Mobile phones and airport security measures do not affect the VNS device.
- If you are travelling through an airport, please ask the epilepsy nurse specialist for a letter explaining that your child has a VNS. This can be shown to security staff.
- Young people with a VNS device should not take part in contact sports like rugby and martial arts because of the risk of damaging the device.
- If your child sustains a hard blow to the chest over the VNS device or you think there may have been damage to the VNS, please contact the paediatric epilepsy nurse specialist for advice.
- The battery-life of the VNS is 10 years at implantation, but this will be reduced depending on the VNS settings.
- The magnet can be used as often as needed but should not be used continuously for four hours. This means that in four hours the magnet should not be used 240 times in a row.

- Head MRI can be performed but the MRI room must be told that the child has a VNS. The VNS must be turned off using the handheld computer (not the magnet) before the scan.
- Full body MRI is not possible.
- CT scans do not affect VNS.
- The VNS may need to be turned off before your child has any operation. This includes procedures such as video fluoroscopy, endoscopy, colonoscopy and cystoscopy. You should contact the paediatric epilepsy nurse specialist two weeks before the planned procedure in order that arrangements can be made for the VNS to be switched off if necessary.
- Medical advice should be sought before taking a child with a VNS into environments with warning notices preventing entry to patients implanted with a cardiac pacemaker or defibrillator.
- Diagnostic ultrasound does not affect VNS but treatment ultrasound / diathermy is not permitted. Please seek advice if this is being recommended.

If you need any further information about VNS, the Paediatric Neurology Nurse Specialists can be contacted on 0191 2821713 (9am to 4pm Monday to Friday) or you should speak to your child's consultant. Out of hours you should contact the hospital switchboard on 0191 2336161 and ask to speak to the on-call paediatric registrar.

Information produced by S Gilmour-Ivens; July 2009

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