

## (9) Parents: Other treatment options

Where drug treatment is ineffective, surgery and other treatments have been used with different success rates. Your doctor or epilepsy specialist nurse can discuss all the options with you.

### **Ketogenic diet**

This prescription only diet can sometimes be an option for the kind of epilepsy which does not respond to anti-epileptic drugs. Many studies have shown that the ketogenic diet can reduce seizures in up to 60% of children whose epilepsy is drug resistant. For these children, a third could have a 50% reduction in seizures, and a third could have a 90% reduction in seizures or become completely seizure free. However, for the remainder the diet will have no positive effect.

Parents and medical professionals often turn to this diet as a last resort because it can appear a daunting prospect at first. Dietary treatments have, however, greatly improved over the years, and are becoming easier for families to follow. There is also a choice of diets. If the diet proves successful, drugs can be reduced, or some children can be completely weaned off them.

### **What is the ketogenic diet?**

The diet is very restricted, involving high fat foods with just enough protein and very low in carbohydrates. It can only be managed and supervised by a qualified dietician trained in the ketogenic diet. Throughout this process a child will also need to be carefully monitored by medical staff for any adverse health effects.

The diet is not for life. Usually children are only on the diet for a maximum of two years and can then be weaned off. Many children will remain seizure free even when they have come off the diet. The diet can be given for longer if necessary, but this needs to be constantly monitored by medical staff and a dietician for adverse health effects.

## How does it work?

Our bodies need carbohydrates for energy; because the diet is very low in carbohydrates the body has to burn fat for energy. During this process, ketones are produced. For some reason, this state of 'ketosis' can have a positive effect on seizure control. We still do not fully understand why this is, but it can be very effective for some children. Simple urine tests are usually done to monitor the amount of ketones in the body.

## Dietary treatment of epilepsy for adults

The ketogenic diet is not recommended for adults. There are however similar diets, such as the Modified Atkins Diet and Low Glycemic Index Treatment, which can be used for older children and adults with drug resistant epilepsy. More research into these adult versions is currently going on.

## Further information and support

If you want to find a qualified ketogenic dietician in Scotland, contact the charity [Matthews Friends](#) for details of your nearest ketogenic diet clinic. Your child will usually need a referral from their neurologist / paediatrician to one of these clinics.

Matthews Friends are a comprehensive source of information for dietary treatments of epilepsy and have up to date information on all the different diets for both children and adults. For more information, visit their website [www.matthewsfriends.org](http://www.matthewsfriends.org) or contact them on 01324 836571.

## Surgery

This can be an option for a small number of children with epilepsy whose epilepsy is drug resistant. It is usually only considered as an option if the first two to three anti-epileptic drugs have been ineffective. Epilepsy surgery tends to be considered for focal (partial) seizures only but can still be an option for certain types of generalised seizures. Several detailed tests will be necessary to find out the exact location of the seizures in the brain and whether all the seizures start in the same part of the brain.

The tests will also determine whether this part of the brain can be removed without affecting other functions such as speech or movement.

Your child's doctor will discuss all the potential benefits and risks with you in detail. Your child, if old enough, as well as the whole family should be involved in making this decision. Only a small number of children (and adults) are considered suitable candidates for surgery. The success rate of surgery, however, can be high. For example, for seizures coming from the temporal lobe the success rate can be as high as 70% or more.

## **Vagal Nerve Stimulator (VNS)**

VNS is like a pacemaker for the brain. It uses a small medical device, which sends electrical impulses to the left vagus nerve in the neck. This nerve is a major communications link between the body and the brain. Electrical impulses are sent to the brain and can help prevent the electrical irregularities which cause seizures.

During surgery, a pulse generator is inserted just below the collarbone. A further small incision is made in the neck for a wire which connects the pulse generator to the vagus nerve. The generator sends signals to the brain via the vagus nerve. The surgery lasts about 45 minutes to two hours, usually under full anaesthetic.

The generator is programmed to send regular signals to the brain. Latest models also have a mode that detects a change in heart rate which can be a sign of a seizure to come. In response to that change in heart rate, the device can deliver an extra dose of electrical impulses to the brain.

In addition, a magnet can be used to stop a seizure before it happens, provided the child has a warning sign or aura sensation. This magnet is usually worn like a watch. It stimulates the generator and sends an additional signal to the brain. If a child is having a seizure, someone else can use the magnet to try and stop the seizure or at least reduce its severity. VNS may have other positive side effects such as

improving a child's alertness, memory, or moods. The device is also sometimes used to help control depression.

VNS is usually only available to children who have not responded to a number of different anti-epileptic drugs and / or are not suitable for brain surgery. Your child's doctor or specialist nurse will discuss with you if this is an option.

Most children on VNS continue to take anti-epileptic drugs. VNS is very unlikely to stop seizures completely, but it can be effective in reducing a child's severity and number of seizures. VNS can take a while, sometimes up to two years, to have an effect. If or when it does, medication can sometimes be reduced. It does not cure epilepsy.

There can be side effects such as discomfort in the throat, a cough, difficulty swallowing or a hoarse voice. These side effects usually go away over time, but this is not always the case. It is also possible to adjust the settings of the device to try and reduce any side effects. If VNS does not work for a child, the device can be switched off and most parts removed safely.

If you want to know more about VNS, visit the manufacturer's website [www.livanova.com](http://www.livanova.com). Your child's doctor or specialist nurse will also be able to give you more information.

If VNS is suitable for a child, health boards in Scotland may fund this surgery.

## Complementary therapies

There is a lot more to managing epilepsy than just seizure control. A good quality of life is important, and this is where complementary therapies can be most effective. They should not be seen as an alternative to taking drugs.

Complementary therapies such as herbal medicine, aromatherapy, osteopathy or hypnotherapy can sometimes help in managing or reducing certain triggers for

seizures such as stress and anxiety. This can have a positive impact on the overall wellbeing of a child and could potentially help reduce the number of seizures.

Before you see a complementary therapist, do your research, and do not lose your sense of caution as the internet is full of claims of miracle cures for epilepsy. It can help to find out more about the therapist's qualifications and training, whether they are members of a professional body and whether they are fully insured.

Always talk to your child's doctor or epilepsy specialist nurse first.

Doctors usually have limited knowledge about complementary therapies and may err on the side of caution when consulted about these therapies. There are often good reasons for this caution as, for example, some herbal remedies or aromatherapy oils are known to trigger seizures or can make anti-epileptic drugs less effective.

A qualified and reputable therapist who has undergone detailed training should know about epilepsy and what kind of treatments or remedies are safe. They should never claim to be able to cure epilepsy. If anyone suggests you stop your child's medication, walk away.

Looking after a child with epilepsy, especially at first, can be physically and emotionally tiring. You too may find it helpful to seek out some therapies which are relaxing and give you some time out.

## Biofeedback

This therapy is not widely used in Scotland and the UK. You may come across this also being described as neurofeedback. It is a form of behaviour therapy where some children can learn to have some control over their seizures. The therapist will train a child's brain over a series of sessions in a similar way to how people learn to ride a bike. This therapy requires detailed input and training.

As with all other therapies, never stop your child's medication. Your child's specialist will always need to be involved in any such decision. If this therapy has a proven positive effect on your child's seizures, it is likely that the specialist will be interested to work with the therapist.