

## Epilepsy surgery

Surgery may sometimes be an option for a small number of people whose epilepsy is 'drug resistant'. Drug resistant epilepsy is defined by the SIGN guidelines<sup>1</sup> as *'failure to achieve sustained seizure freedom after trials of two tolerated and appropriate AED schedules (whether as monotherapies or in combination).'* This means that if you have tried at least two anti-epileptic drugs over a reasonable period of time without achieving seizure control, you may want to speak to your specialist about the possibility of having surgery.

Although only a small number of adults and children are deemed suitable for surgery, the success rate can be high. For example, for temporal lobe epilepsy, around 70% of people can become seizure free, or at least experience a significant reduction in seizures.

### Who can have surgery?

Suitability will depend on a number of factors including seizure type and what is causing the seizures. Epilepsy surgery tends to be considered for focal (also called partial) seizures ie where the seizure starts and stays in one part of the brain. It may also be an option for focal to bilateral tonic-clonic seizures, ie the type of seizure which starts in one part of the brain but then spreads across the whole of the brain.

If you are being told that surgery is not an option for you, this does not necessarily have to be the end of your search for seizure freedom. Although your chances of becoming seizure free are significantly reduced after unsuccessfully trying out two to three drugs or combinations of drugs over a period of time, new drugs sometimes make it possible to become seizure free or achieve at least a significant reduction in seizures. Ongoing research into device based treatments (see our factsheet on 'Device based treatments') and dietary based treatments (see our factsheets on

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<sup>1</sup> Scottish Intercollegiate Guidelines Network, 143 Diagnosis and Management of Epilepsy in Adults, May 2015

'Ketogenic diet' for children, or 'Dietary treatments for adults') may soon offer more options for controlling seizures. Some of these alternatives are already available to epilepsy patients in the UK.

## Assessing suitability for surgery

If you are considered a possible candidate for surgery, you will be offered a number of detailed tests to explore this further. These tests will try and find out where in the brain your seizures start and whether your seizures have more than one point where they start. If this exact area has been identified, further tests will determine whether this part of the brain could be removed without affecting important functions such as vision, speech, memory or movement.

The tests you may be asked to undergo include:

**EEG (Electroencephalogram), or video telemetry** - This test will monitor and record your brain's electrical activity. This can be done as a one off, or over a longer period of time, so you may be asked to stay in hospital for a few days. The EEG can help point to where your seizures start but this test is not accurate enough on its own.

**MRI (Magnetic Resonance Imaging) scan** - This scan uses radio waves and a magnetic field instead of x-rays. It can detect structural abnormalities in the brain. Unlike a CT (Computed Tomography) scan, which uses x-rays, an MRI scan can usually pick up many more details. During an MRI scan, you may be asked to perform certain tasks such as answering questions. Doing this will increase oxygen-rich blood flow to the part of your brain which deals with these functions. This will then help show exactly which part of the brain manages important functions.

**SPECT (Single Photon Emission Computed Tomography) scan** - This scan will inject a slightly radioactive (but safe) dye into your vein which goes straight to your brain. The dye will show up the amount of blood flow to your brain. During or

after a seizure, blood flow increases, and the dye can indicate where there may be possible seizure activity.

**PET (Positron Emission Tomography) scan** – During this scan, you will be injected with a slightly radioactive (but safe) substance. The substance will measure the amount of oxygen and glucose (sugar) used by the different parts of your brain. Those areas of your brain affected by epilepsy will use less energy between seizures. This can show up on the scan, which in turn can tell the surgeon which part of the brain could be safely removed.

**MEG (Magnetoencephalography) scan** - This is a fairly new scan and may not be available in your hospital. The scanner will measure your brain's activity and will help identify which parts of your brain are active during different tasks. Knowing this will help the surgeon determine whether it is safe to remove the parts of your brain affected by epilepsy without affecting any of your vital functions.

**Depth or grid electrodes** - If other tests have not been able to determine the exact location of your seizures, you may need to have depth or grid electrodes implanted on or within your brain. As this is a major surgical procedure, you will get an opportunity to discuss this in great detail first with your medical team to allow you to make an informed decision. After this surgery, EEG/video telemetry tests will be used to monitor and record any seizures. The implants will give a much more accurate reading of where your seizures start.

**Neuropsychology assessment** - this will help to pinpoint which areas of your brain may be affected by your seizures. This assessment can last a number of hours during which a neuropsychologist will test your mental functions such as memory, problem-solving, planning, organisation, learning, language, attention, motor skills, emotions and behaviour. These tests may need to be repeated or may need to be carried out over several appointments.

**Neuropsychiatric assessment** - You may also be referred to a neuropsychiatrist as committing to brain surgery can be a stressful process. This assessment will look at how well you would be able to cope with surgery and the time after surgery.

These pre-surgery tests and assessments can take many weeks, months, even up to a year. Depending on where you live, you may have to travel to different hospitals or health board areas if your own hospital does not have these facilities. This often involves overnight stays.

## What are the risks?

Once all results have been evaluated, your neurologist and neurosurgeon will advise you of the percentage chance of a successful outcome. You will also be advised of the percentage chance of the surgery resulting in some brain damage that could potentially affect some of your functions. All of this vital information will then allow you to make an informed decision. You can decide at any point not to go ahead with surgery.

All surgery, including having a general anesthetic, carries a risk, which may increase if you have any other health problems. Specific risks of brain surgery include infection on the brain, bleeding or a stroke after surgery. If there are complications, you may need to stay in hospital for a longer period.

## Making the decision

Being told you are a suitable candidate for surgery can bring up all kind of emotions. You may feel excited and scared at the prospect of having surgery. This is an important life changing decision and you may want to involve the support of those close to you in making this decision. If you have not already been offered pre-surgery counselling, consider asking for it as there are many emotional and practical issues you need to consider.

If you have been used to living with seizures all your life, what would life feel like without seizures? If you become seizure free you may lose any benefits which you have relied upon for a long time, such as a free Scotland wide bus pass and other welfare benefits. You may need to look for work, which can be daunting if you have been out of work for many years. Having epilepsy may have become part and parcel of your very being, and becoming seizure free may mean you finding a new identity or new purpose in life.

## What happens during surgery?

What surgery you need will entirely depend on the type of epilepsy/seizures you have and the cause of your seizures. Most surgeries will be performed under general anesthetic but there may be rare instances where you may need to be awake during surgery. Your neurosurgeon will explain to you in detail what is going to happen so that you can prepare yourself for the different procedures and the recovery phase after surgery.

Epilepsy surgery can include:

- the removal of parts of the temporal lobe or just a small part of it, called the hippocampus (Selective amygdalo hippocampectomy );
- the removal of larger parts of the temporal lobe (Temporal lobectomy), usually the right side as the left side of the temporal lobe controls speech and removal of a part of the left temporal lobe carries an increased risk of damaging the speech center;
- superficial cuts in the motor areas of the brain. These cuts will not affect motor function but will hopefully prevent the spread of seizures (Sub-pial resection). This is usually carried out when it is not possible to remove the part of the brain which causes the seizures;
- complete removal of one side of the brain (Hemispherectomy), for very severe epilepsy in children;

- cutting the fibres that connect the two halves of the brain (Corpus callosotomy), used to treat children with very severe epilepsy;
- removal of a lesion, such as a tumor or cyst which is the cause of the seizures.

## After brain surgery

Immediately after your surgery you may feel sleepy and tired for a few days as it can take time for the general anesthetic to wear off.

You will be closely monitored to make sure the wound is healing well. There is the possibility of seizures occurring within a week of having surgery. This does not mean surgery has been unsuccessful. It often just means that your brain has been bruised from the surgery, and this is your brain reacting to this stress.

Recovery time depends on the type of surgery you had, and whether there have been any complications. You will need a number of follow up appointments which may involve further tests such as an EEG or neuropsychology to test your functions again.

A follow-up appointment with a neuropsychiatrist is usually arranged to discuss with you how you are coping with life after surgery. Some people experience depression after brain surgery, but this is usually temporary. It is important though to let your neurologist know if you feel depressed so that you can get the right help.

Over time, it will become apparent whether surgery has worked and if any of your functions have been affected by the surgery.

## Will I be able to stop my anti-epileptic drugs?

You will be advised if and when to reduce your medication but most people will not be able to come off their anti-epileptic drugs, even after surgery. The reason for this is that any type of surgery will leave scarring on your brain's surface, and this scarring leaves your brain still very slightly susceptible to seizure activity. So if you

are exploring the option of surgery because you do not like taking anti-epileptic drugs and their possible side effects, surgery may not be a suitable option.

## **Life after surgery**

Living a life free of seizures can bring about significant changes in your life. You will be able to make choices that are new to you. Even though these are all positive things, it can sometimes feel quite overwhelming. Do not be afraid to ask for help if you are struggling. It may take some time for you to gain the confidence of living a seizure free life, this will not happen overnight.