Epilepsy Action Australia

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SURGERY FOR EPILEPSY

FACT SHEET

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SURGERY FOR EPILEPSY

Epilepsy surgery represents a valuable treatment option for some people with drug-resistant epilepsy.

Epilepsy surgery is a form of treatment to remove the part of the brain tissue causing the seizures. It offers a chance to be seizure-free or at least to have fewer seizures.

NOTE: This is general information about epilepsy surgery. Institutions will vary in their practices and approach, so it is best to speak to your neurologist or epilepsy nurse at the hospital you are attending.

Why epilepsy surgery?

People who may be eligible for epilepsy surgery are generally those who are still having seizures despite trialing two or more medications. This is mainly;

- People with focal onset seizures (which may or may not develop into tonic clonic seizures)
- People who have debilitating tonic or atonic seizures, otherwise known as “drop attacks”
- People who have a lesion in their brain causing their seizures.

Your neurologist will be able to tell you if your type of epilepsy is suitable for surgical assessment.

Surgery may be considered when:

- Seizures are resistant to medication and still having seizures (drug resistant epilepsy)
- Seizures start from one small area of the brain
- Seizures are particularly debilitating or dangerous such as tonic, atonic seizures (drop attacks) and status epilepticus (very long seizures)
- Seizures are happening frequently, making normal life impossible
- The cause of seizures requires surgery, e.g. a lesion such as a tumour or abnormal brain tissue

Before surgery

Before surgery, all patients undergo an extensive assessment to find out where the seizures are coming from and to make sure that the part of the brain can be removed without causing major problems. This usually involves a period of prolonged monitoring in hospital to observe and record seizures, brain scans, tests of brain functions like memory and mental health assessment.

These tests help to pinpoint the area in the brain where the seizures are starting, and to determine whether surgery is possible without causing harm or any impairment.

Some tests may be done before hospital admission.

Speak to your doctor about epilepsy surgery if you are still having seizures despite trying different medications.

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TESTS BEFORE SURGERY

Video EEG (VEEG)

This is a continuous recording of your brain waves (EEG) with video to record your seizures, which can sometimes take several days.

This can be a difficult and frustrating time. You will need someone (family or friend) to be with you 24/7 during this time for safety reasons.

There may be a waiting list of several months for this VEEG process, depending on the centre.

Tips for when you are in hospital

- Bring clothes that button or zip up at the front or back. You won't be able to pull them over your head
- Bring items that do not need to be attached to a power source such as books, journals, games and puzzles. You may use electronic devices, but they will need to be charged away from the monitoring equipment.
- Watching television or videos and having lots of visitors can also help.
- If you smoke, consider giving it up before admission or purchase nicotine patches. You will not be able to smoke at any stage during the admission.
- Chewing gum will not be allowed as it interferes with the EEG.

Brain imaging (scans)

MRI – Magnetic Resonance Imaging

MRI uses a magnetic field and radio waves to record pictures of the brain, which is effective in identifying some brain abnormalities seen with epilepsy. The scanner is like a tunnel and makes loud thumping noises. Most MRI scanners are equipped with mirrors, microphones and music so you will be able to relax or communicate with the technician. The MRI may last from 30-60 minutes and uses no radiation.

fMRI – Functional Magnetic Resonance Imaging

This measures brain activity during MRI by detecting the changes in blood oxygenation and flow that occur in response to brain activity – when a region of the brain is more active it uses more oxygen and to meet this increased demand blood flow increases to that area.

Tip:

- It is important to tell the doctor and technician before the MRI if you are stressed by confined spaces as a short acting medication can be given.

PET – Positron Emission Tomography

A PET scan uses a radioactive tracer to identify the specific area of the brain where seizures originate. It measures the brains use of glucose (energy). The seizure area often shows reduced activity (unless a seizure happens during the test). You'll need to fast beforehand.

An EEG is done at the same time to help match brain activity with the scan results. The whole procedure usually takes about two hours, including about 30–45 minutes for the scan itself. You will be asked to stay quiet but awake.

Women of reproductive age will have a pregnancy test beforehand, as the scan isn't performed during pregnancy due to the use of a small amount of radioactivity.

! You may not need to have all the tests listed here

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TESTS BEFORE SURGERY

SPECT – Single Photon Emission Computerised Tomography

You may or may not have this scan. A SPECT scan looks at the blood flow within the brain. A radioactive substance is injected into your bloodstream and carried to the brain. Usually, two of these scans are done if surgery is being considered:

1. When you are not having a seizure. The blood flow in the brain tissue should be reduced in the the seizure zone.
2. Immediately after a seizure (the injection is given during the seizure) The blood flow should increase in this area during a seizure.

Once all brain scans are all completed, they will be viewed and compared by your Neurologist and Team.

Neuropsychological Testing

This evaluation helps to determine which regions of your brain may be affected by the seizures. It gives an indication of which parts of the brain, if any, are not functioning well.

The neuropsychologist will test your mental functions such as memory, problem-solving, attention, learning, language, behaviour and personality. There are no invasive procedures, no pain, no needles, or electrodes. The neuropsychologist may also ask you about your family and medical history.

Testing may take 6-8 hours to complete, often in blocks of 2-3 hours when you are functioning well and there is no pass or fail.

Tip:

- Let the neuropsychologist know if you are feeling overtired or have had a recent seizure. It is important they know this as it can affect your results.

Invasive monitoring

Sometimes, the video EEG results may be inconclusive, and further monitoring is needed. This can mean electrodes need to be implanted directly into, or on the surface of your brain.

This is a major surgical procedure. After the electrodes are implanted, there will be another period of video-EEG monitoring to record your seizures. The type of electrodes and surgery varies and will be fully explained to you prior, and you will be asked to complete a consent form.

What next?

The decision to operate is only made after all the tests are done and is based on the results of tests, a joint decision by the team, and you wanting to proceed with surgery. Your health team will meet, and all the test results are discussed and compared. Surgery will not be performed unless your doctors are confident that you will obtain significant benefit.

Your chances of successful surgery and risks for complications will be explained to you by your doctor and the surgeon.

At any stage during the pre-surgical work-up you can decide that you do not want to have surgery. Also be prepared that surgery may not be an option for you.

! The goal of epilepsy surgery is to improve your quality of life by stopping or reducing the seizures, without causing neurological impairment.

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THE SURGERY

Preparing for surgery

When you are about to have surgery, it is important to:

- Stay healthy
- Take your medications as prescribed
- Ask questions about the surgery and post-surgery time so you are well informed and know what to expect
- Talk to your family and friends about the surgery
- Speak to someone who has had the surgery if possible.
- Plan ahead if you are working or have other commitments

The operation

The surgery can take a few hours. Afterwards, you may spend the first night in intensive care and then about five days in a ward. The area around the incision site and sometimes the eyes can be puffy and numb.

As with most surgery there are risks like infection and bleeding. Common symptoms straight after surgery are numbness around the incision site, dizziness, unsteadiness, nausea, vomiting, headache, jaw ache, swelling, bruising, blurred vision and short-term depression.

After surgery

- Discharge from the hospital following surgery is usually about a week.
- The surgery scar should be kept clean and dry. It is important to let the surgeon know if it is red, swollen or painful. Hair washing is okay, but do not use hair dyes for a few weeks after surgery.
- It is important to rest following surgery, gradually increasing activity but avoid exhaustion and overdoing it.
- All contact sports should be avoided for 12 months while the skull bone is healing.
- Time off work to recover will be necessary. How long will depend on how you are feeling and the type of job you have. It is best to discuss this with your surgeon or neurologist.
- The neurologist may change your medications on discharge from hospital or at follow-up appointments.
- Regular follow-up appointments with the Neurologist and the Neurosurgeon will be arranged. You may also be asked to see the Neuropsychologist to retest and assess any possible changes.
- Some people experience mild depression following surgery, but this is temporary and should resolve within 3-6 months. If you feel you are experiencing depression, you should speak to your Neurologist.
- Speak to your neurologist before drinking alcohol
- You will not be able to drive for 12 months following surgery. This Will be extended if you have any seizures

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LIFE AFTER SURGERY

Up to 60-70% of people become seizure free after surgery.

No longer having seizures can cause big changes to life, such as relationship dynamics, employment options and choices. Often this is a time people make life-changing decisions.

Although a lot of these adjustments are positive, some people encounter difficulties adapting.

Do not be afraid to seek help if you feel you are not coping, as this can be a normal response.

Not all people who have epilepsy surgery are seizure-free following surgery, but there is usually a significant decrease in seizures. Some people may have some seizures immediately after surgery, but this does not mean that the surgery has not been successful.

Listen Here to Erica Jacobsen, Neurosurgeon, answer many questions about epilepsy surgery.

This video was developed with the support of LivaNova Australia

For more comprehensive details about the above procedures, speak to your doctor. Often the hospital providing the service will have their own information handouts.

Epilepsy Clinics

It is recommended that Australians with drug resistant epilepsy be referred to a comprehensive epilepsy centre to gain a clearer diagnosis, review of their epilepsy and targeted management as soon as possible to improve their seizure control.

These centres are best equipped to evaluate people who have DRE and offer a better chance at finding the most appropriate treatment.

All states have a comprehensive epilepsy centre apart from Tasmania.

To find the closest comprehensive epilepsy centre in your state contact us on:

Phone: 1300 37 45 37

Email: epilepsy@epilepsy.org.au

Book a telehealth appointment with an epilepsy nurse

Visit our website

Disclaimer: This information is given to provide accurate, general information about epilepsy. Medical information and knowledge changes rapidly and you should consult your doctor for more detailed information. This is not medical advice, and you should not make any medication or treatment changes without consulting your doctor.

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