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PATIENT INFORMATION FOR EPILEPSY SURGERY



Introduction

You have been given this booklet as you have been identified as a possible candidate for epilepsy surgery by your Consultant Neurologist. We hope the following information will be helpful and informative as going through epilepsy surgery is a big decision to make.

You have been considered for surgery because of the following reasons:

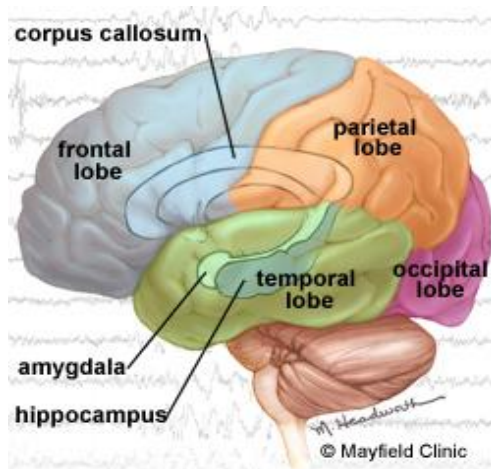
- You have tried several anti epileptic drugs that have been unsuccessful in controlling your seizures.
- Your seizures appear to arise from one area of the brain.
- The Neurosurgeon can get to this part of the brain without damaging or adversely affecting other areas.
- You have a good chance of becoming seizure free after the surgery.

PRE OP ASSESSMENT FOR EPILEPSY SURGERY

Before going through epilepsy surgery a detailed assessment of your epilepsy and brain function is needed. The assessment can take 6 months or longer in some cases.

The purpose of pre-operative assessment is

- 1) To identify the area of brain tissue that generates seizures.
- 2) To determine whether this area can be safely removed.
- 3) To assess the risk and benefits of the operation.



Essentially the basics of the assessment involve:

- detailed account of your epilepsy
- detailed brain scans
- video-EEG of your seizures
- psychology evaluation
- psychiatry evaluation

The following outlines the investigations you will go through prior to surgery for assessment

Consultant Neurologist

MRI

EEG

VEM

Neuropsychiatry

Neuropsychology

Epilepsy Team Meeting

The Epilepsy team consists of:

Neurologist

Neurosurgeon

Neurophysiologist

Neuropsychologist

Neuropsychiatrist

Epilepsy Surgery Nurse Specialist



The team meet regularly and all cases and investigations are discussed to determine suitability for surgery, discuss possible risks and plan the next steps.

The investigations you will need are explained below:

MRI Scan (Magnetic Resonance Imaging)

This can be done as an outpatient and usually takes about an hour.

The MRI provides a detailed image of the structure of your brain. It can identify abnormal tissue that can be causing your seizures.

The MRI uses radio waves and a magnetic field rather than X-rays.



EEG (Electroencephalogram)

This is done as an outpatient and will take approximately 45minutes.

A number of small electrodes are pasted to your scalp and pick up the electrical activity of your brainwaves. This electrical activity is printed for the Neurophysiologist and Neurologist to look at.

Video Telemetry

You will have to be admitted to hospital for 5 days. You will have electrodes fitted to your scalp, using special glue, to record brain activity and we will also video you continuously for the 5 day stay with the aim of recording your seizures on video alongside the EEG recording. See separate video telemetry information sheet.





Above are some pictures of our telemetry room on ward C4.

Neuropsychology

The neuropsychological assessment is conducted as an outpatient and can take as long as 6 hours. The assessment is usually completed in one day and the assessment findings are discussed during a second appointment.

This assessment will gauge what affect (if any) your epilepsy is having on your emotional / psychological wellbeing and your cognition (eg attention, thinking, memory, and language). This is important because it can help determine which parts of the brain may be involved in the epilepsy and the possible impact of surgically removing these areas. Therefore, it can help to establish what the likely consequences of surgery may be emotionally, cognitively, and for day-to-day functioning.

The impact of surgery will be assessed through follow up appointments after surgery and support and/or advice will be provided as required.

Neuropsychiatry

This is performed as an outpatient and can take up to 2 hours. Mood disorders and mental health

problems are common in epilepsy. These include depression, anxiety and less commonly psychosis (thought disorders). The aim of this assessment is to explore these problems and the impact surgery may have on them and ensure potential problems that may become worse after surgery are highlighted.

Some further tests may be required during your assessment such as:

fMRI (functional Magnetic Resonance Imaging)

This is done as an outpatient. This is similar to having an MRI scan, but during the scan you would be asked to do something such as thinking of words starting with a letter shown on a screen, tapping your thumb against your fingers or you may be asked to look at pictures or answer questions on a computer screen.

This type of MRI scan will help to show which part of the brain manages important tasks such as thought, speech, movement and sensation.

Positron emission tomography (PET scan)

This scan uses a radioactive substance called a tracer that is used to measure activity across the whole brain. Sometimes subtle changes are seen that give clues as to the areas causing epileptic seizures.

Single-photon emission computed tomography (SPECT scan)

This type of scan is used in *exceptional cases* and is not routinely available. The test involves having an injection of tracer (radioactive dye) just as a seizure starts. It is therefore done in combination with video telemetry. A scan is done after the seizure has stopped. The injected tracer measures blood flow. The blood flow is usually higher in the part of the brain where the seizure had started. The scan aims to capture this.

Intracranial monitoring

In some cases the above tests are insufficient to determine whether surgical treatment for

epilepsy is possible and further tests are needed to measure electrical activity more directly from the brain. The Neurosurgeon will place electrodes directly onto or into the brain.

This technique allows for precise mapping of areas causing the onset of seizures as well as assisting the Neurosurgeon with identifying & mapping critical areas of the brain. These critical areas control speech and motor function that will need to be avoided during surgery.

If you need this type of investigation, your Neurologist and Neurosurgeon will give you more information.

Throughout the ongoing investigations and after having surgery, you will continue to be reviewed as an out patient via appointments with your Neurologist and Specialist Nurse.

DECIDING ABOUT SURGERY

It is a big decision to make and you will have lots of questions or concerns that you may want to discuss with different members of the team.

You may find it helpful to write down any queries you may have and bring along to your next clinic appointment.

Your team will support you in making that decision whatever you decide. Remember that you can change your mind at any time.



BENEFITS OF SURGERY

The ultimate aim of surgery is to improve the quality of life of patients and their families.

Studies have shown that around 70% (the same as 7 out of 10) of people who have surgery for epilepsy are completely free of seizures after 2 years and 50% (5 out of 10) are still free of disabling seizures at 10 years. Of those that are not seizure free, the majority have a noticeable improvement in their epilepsy, for example having one or more years without any seizures.

20 -25% of people find their seizures have not stopped but are significantly less frequent.



A small number of people will not see any benefits after surgery, therefore the aim of the assessments is to avoid doing surgery in these cases.

We recommend anti epileptic medication is continued for at least 2 years after surgery. If seizure free at this stage, you can discuss with your Neurologist the risks and benefits of gradually reducing your medication or in some cases stopping medication altogether.

It is important for you to decide what your expectations are from surgery and discuss these with your team.

POTENTIAL RISKS OF SURGERY

On completion of your tests, your Neurosurgeon will have enough information about you and will explain the risks involved in your specific operation.

The risks can be thought of as general risks, that are present for anyone going through brain surgery and specific risks that relate to the type of operation or brain area being removed.

Your Neurologist and Neurosurgeon will go through these with you in detail during your clinic appointment and will send you a copy of the clinic letter that will have written figures of the risks and benefits of the planned procedure.

During the investigations it may become evident you are not suitable for surgery. We understand this news will be very disappointing for you and your family. However, your Neurologist will discuss the reasons for this with you at your next appointment.

If surgery is not an option, whatever the reason, you will continue to be managed on medication and regular reviews at the Epilepsy Unit.

Research in epilepsy is moving at a rapid pace with more advanced brain scans and new treatment developments and our hope that the future will hold a cure for all epilepsies.



AFTER EPILEPSY SURGERY

For the first few days after surgery you will feel very tired and will need to sleep, as it may take a while for the anaesthetic to wear off.

You may experience seizures initially after surgery but this is not to say the surgery hasn't worked. Seizures post operatively are thought to happen because of the direct stress the brain experiences during surgery rather than you having a history of epilepsy.

FOLLOW UP AFTER SURGERY

It is important that you return for regular follow up visits and assessments after you have gone home. Roughly we expect the following reviews and appointments to take place:

Neurologist: 3, 6, 12, 18 and 24 months

Neurosurgeon 6 weeks, 6months and 2 years

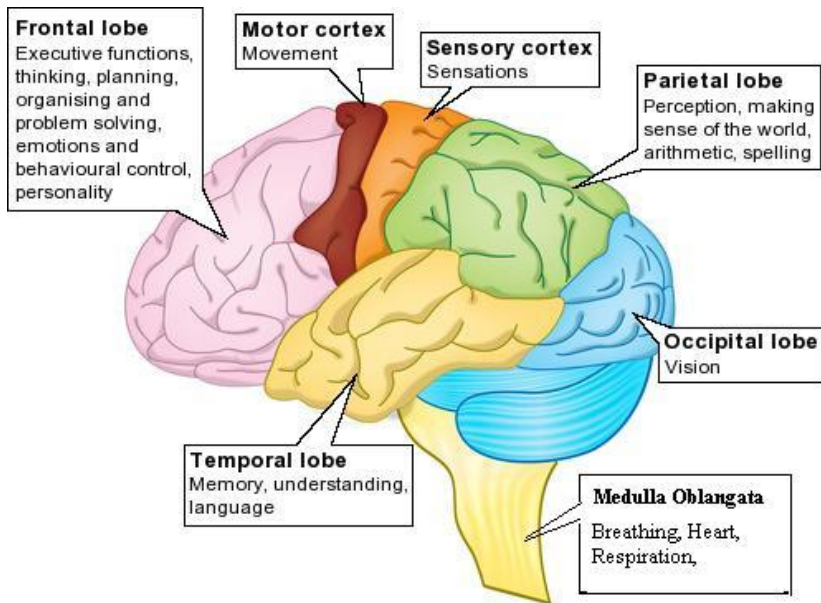
Neuropsychology: 3, 12 and 24 months.

Neuropsychiatrist: before 3 months

Repeat MRI brain scan (post operatively)

Repeat visual fields (post operatively) for temporal or occipital lobe surgery.

AREAS OF THE BRAIN



We hope the information in this booklet has been helpful and informative.

It is only intended as a guide and the epilepsy team will provide you with more information during your appointments.

Useful telephone numbers:

Epilepsy Unit – 02920745066

Samantha Jenkins - 02920 743807
(Dr Hamandi's secretary)

Catherine Gamble – 02920 744307
(Professor Gray's secretary)

Michelle Esposito - 07870 819729
(Epilepsy Surgery Nurse Specialist)

Please let us know if you have any feedback on the information provided.