

Counselling for epilepsy surgery

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Surgery is considered for people with epilepsy whose seizures are not well controlled by antiepileptic medication, or who continue to experience unacceptable side effects for whom the possibility of surgery has been raised.

A number of different factors need to be taken into consideration before it is possible to say whether or not a patient may benefit from surgical treatment. In the majority of cases, surgery will normally be considered if:

- Antiepileptic drug (AED) treatment has been tried using a number of different medications but these have proved unsuitable, or unsuccessful in stopping the patient's seizures
- The epilepsy can be seen to be arising from one localised area of the brain
- The part of the brain causing seizures is accessible to the surgeon and can be removed without damaging other parts of the brain or brain functions, such as speech, sight, movement or hearing
- The patient has no other medical problems which would make them unsuitable for this type of surgery
- The patient is thought to have a good chance of becoming seizure free following the surgery or having a worthwhile improvement in severity, frequency or both.

Referrals

At the National Hospital for Neurology and Neurosurgery, a dedicated epilepsy surgical counselling service exists in which all patients are seen prior to surgery. The purpose of this is to enable the patient and their family to discuss any concerns they may have and to clear up areas of misunderstanding prior to making the final decision as to whether or not to go ahead with an operation. The surgical counsellor is seen towards the end of the pre-operative investigations and referral may come from either the patient's consultant neurologist or neurosurgeon.

The counsellor has the report of the consultant neurologist or neurosurgeon to hand and will be able to advise about the patient's individual case. At this time, it is important to find out more about the patient's social support and family circumstances which vary from case to case. The planning of professional support in advance of the operation is important in patients who do not have this support at home.

Expectations of surgery

Expectations of surgery vary a great deal. This is an issue that needs to be discussed in detail with individual patients in order to find out how seizures have impacted on their lives so far and what they may reasonably expect from themselves and others if the operation is successful. Common areas for misunderstanding include:

- What the patient should do prior to going into hospital
- The length of the stay in hospital
- What happens prior to the operation
- The amount of the patient's hair to be shaved prior to surgery
- The reason for the admission to the intensive therapy unit (ITU) immediately after surgery
- How the patient will feel when they wake up
- How soon they may be visited.

Some patients may receive financial benefits prior to surgery and it is important to discuss what might happen if the operation were successful and the patient became seizure free. As with all benefits, it is incumbent on the patient to report any change in circumstances, including improvements in their health, that might affect their right to benefits, or the amount of benefit they receive. Thus, when considering surgery, it is important that the patient is made aware of this and the possible responsibility they would face if the operation were to be completely successful. The counsellor would point out that a time may come when the patient would no longer be considered disabled and therefore not qualify for the benefit that they may have been receiving.

It is very important to have a plan that goes beyond successful surgery and to take into account what the patient plans to do with their life in a number of ways. The counsellor may advise on useful organisations for the patient to contact for help with training, finding employment and general advice on grants, courses and access to education.

Practical advice

The counsellor will also discuss such issues as care of the wound following surgery, recuperation at home, how soon the patient may expect to resume a variety of activities and how long the effect of the anaesthetic may be expected to take to wear off.

Other areas of discussion commonly include:

- The importance of staying on their medication
- How soon can the patient do sport or vigorous exercise after surgery
- When the patient can have sex after surgery
- Who to contact in the case of medical problems during recuperation
- When the patient will be seen again by the surgeon, neurologist and psychiatrist
- Driving and the DVLA regulations
- How soon the patient may travel following surgery
- General advice on recuperation.

It is important for the patient to realise that losing their seizures may sometimes lead to other problems and stresses in daily life and that this is one of the reasons for continued contact with the hospital, neurologist, psychiatrist and counsellor for some time after discharge.

Common emotional problems after surgery

Patients need to understand that it is common to see mood swings and a combination of anxiety and depression in 20–30% of people who have epilepsy surgery. This may be distressing and cause tiredness, loss of sleep, and poor appetite and make the patient feel on edge. Symptoms may resolve on their own in about 4–6 weeks, although some patients may need antidepressant medication or counselling. About 10% of people may go on to develop

a more significant form of depression, with sustained mood changes and negative thoughts about the world and future. This may require more formal support including antidepressants and/or counselling. Admission to hospital is rarely required. A minority of patients may develop a psychosis post-surgically. Relatives are counselled that if they notice a difference in the patient's mood causing concern they should report it to the clinician concerned.

It is important that the patient appreciates that antiepileptic medication needs to be continued after surgery. The counsellor will ensure that the patient understands that no changes in medication will normally be made for the first 12 months and the aims of surgery will normally have been achieved within two years.