

Brain Tumours and Epilepsy

Information Booklet
2



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BRAIN TUMOUR ACTION

People with a brain tumour and epilepsy will have seizures because the tumour cause disturbances in one area of the brain. Drug treatments can reduce the frequency and severity of the seizures and sometimes stop them completely.

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What is epilepsy?

Epilepsy occurs where there is a disruption to the normal electrical and chemical messaging throughout the brain. It is when there is too much electrical activity in the brain. This can lead to seizures. Usually the diagnosis of epilepsy is only given when somebody has had more than one seizure and where no other cause is found. However, in exceptional circumstances the diagnosis may be given after one seizure, such as when a tumour is the cause.

How common is it?

Epilepsy is relatively common. It is most common in childhood and in those aged 65 years and older. Sometimes the only visible symptom is the seizure or seizures.

Types of Seizures.

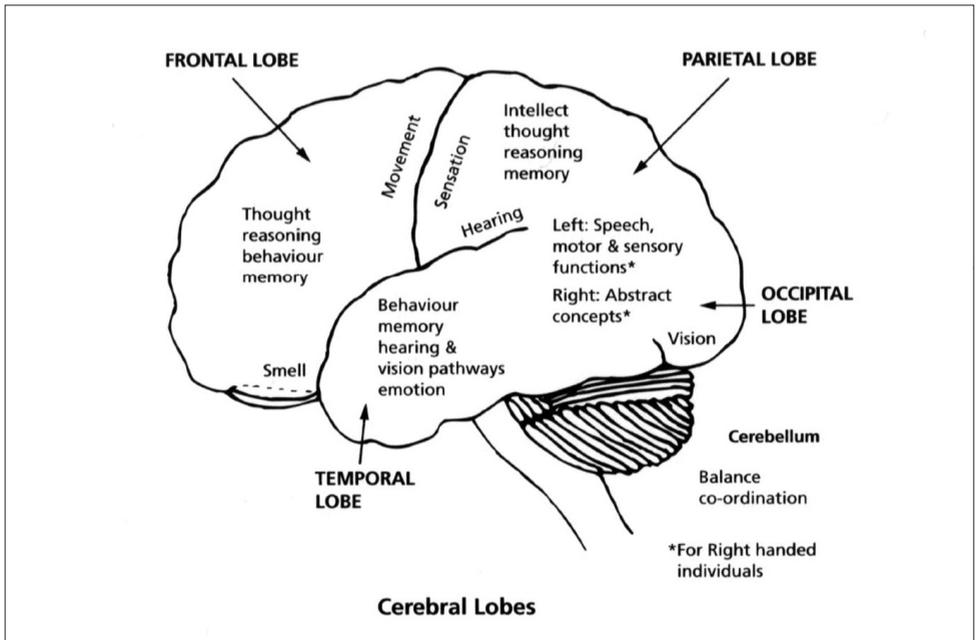
There are two broad categories of seizures: **generalised** and **focal**.

Generalised seizures involve large areas on both sides of the brain where consciousness and awareness is often lost. **Focal seizures** affect a smaller portion of the brain. Some may briefly affect awareness and some may have absolutely no effect on the level of awareness.

How somebody behaves or what sensations or feelings they experience during a seizure can give clues to where in the brain the seizure is starting and where it is spreading to.

Occasionally the focus of electrical activity can spread from a localised area to involve the whole brain. When this occurs it causes a convulsion with loss of consciousness and movements of arms and legs (generalised seizures). These convulsions may be preceded by a warning of some sort (an aura) before consciousness is lost.

Functions of the cerebral hemispheres: Frontal, Temporal, Parietal and Occipital Lobes



Seizures disrupt the normal functioning of parts of the brain. For example, a seizure which takes place in the area of the brain responsible for movement may result in jerking of the arms or legs (see diagram). Seizures which involve odd sensations such as pins and needles or a prickly sensation may be coming from the part of the brain responsible for interpreting sensations. Complaints of funny smells or feelings of déjà vu or strange recurring thoughts come from the part of the brain responsible for memory or smell. As stated previously awareness can sometimes be affected, but not always.

Seizures involving both sides of the brain can lead to convulsions. This is when somebody will lose consciousness. They may become

stiff and have jerking movements of their arms and legs. There may be a warning but not always.

Occasionally people may have a focal seizure which then evolves into a convulsion (see above).

Most people with a brain tumour and epilepsy will have focal seizures because the tumour causes a focal disturbance in one part of the brain.

Is epilepsy a common problem?

Epilepsy is fairly common. As many as 1 in 103 people will have epilepsy which equates to 602,000 people with epilepsy in the UK. Most people with epilepsy will have a normal brain scan and only a small number, less than 10%, will have a brain tumour.

What are some common types of brain tumour?

Primary Brain Tumours are those that arise directly from the brain cells.

Secondary Brain Tumours are those that arise in another site in the body and spread (metastasis) to the brain.

Primary brain tumours include:

Meningiomas which arise from the coverings of the brain (meninges).

Astrocytomas, a type of glioma.

Neuromas, such as acoustic neuroma, arising from the nerves in the brain.

Pituitary Adenomas which arise from the glandular tissue of the pituitary gland.

Oligodendrogliomas which develop in cells called oligodendrocytes.

There are other, less common types.

If I have seizures does it mean my tumour is more severe?

No. About 80% of people with low grade brain tumours will have seizures and only about 20-30% of people with higher grade tumours. If seizures are present from the start, the overall outlook is better than in people who present with other symptoms such as weakness or headache. Seizures can also occur with tumours that have spread to the brain from another site (metastases).

How is epilepsy diagnosed?

The diagnosis is made from the description of the precise features of the seizures and the circumstances in which they occur.

An EEG test (electroencephalogram) may be helpful in determining the type of seizure and site of any problem. (See photo 1 overleaf.) The EEG is a painless, safe procedure where thin wires are placed onto the surface of the scalp. These wires (electrodes) can demonstrate any irregularities in the normal electrical activity of the brain. Frequently, however, the EEG is completely normal between attacks.



Figure 1

A CT scan or MRI scan produces pictures of the structure of the brain and will demonstrate where the abnormality is located.



Figure 2

Can epilepsy be treated?

Yes. Treatment with tablets or medicines will control seizures in about 50% of people who have brain tumours and seizures. About 50% will continue to have seizures despite treatment, but the seizure severity and frequency is much less with medication.

The treatment is aimed at trying to improve seizure frequency and severity without causing too many side effects from medication.

The role of surgery in the treatment of epilepsy is still not completely certain. Sometimes surgery can cure the seizures but occasionally seizures can occur or become temporarily worse after surgery. There are reports of radiotherapy reducing seizure frequency but not enough evidence to say with any certainty that it does.

The choice of medication usually depends on the seizure type, the possible side effects, and interactions with other medications that you may have to take.

What side effects could I have from the medication?

All medicines can cause side effects. Medication which prevents seizures (anticonvulsants) can cause side effects too, even though most people take them for long periods of time with no unpleasant side effects.

Some people can have an allergic reaction to the medication, (e.g. rash, effects on the blood count or liver upset) and others may feel tired or nauseated when a course of tablets is first started.

The tiredness and nausea may settle when you become used to the tablets, but the drug should be stopped if there is an allergic reaction (contact your doctor).

Another possibility is that if you take too much of the medication you can get 'toxic' side effects. These may cause double vision, unsteadiness, dizziness, drowsiness, nausea, headache or changes in behaviour. If you develop any of these symptoms speak to your doctor. He/she may want you to take a smaller dose of the medication or take a blood sample to measure how much is in the blood stream.

Each medication has its own list of possible side effects. If you are concerned ask your doctor for advice.

How will my doctor try and help me?

Doctors will usually introduce medication gradually in small doses and advise you to take the medication regularly. Most of the medications for epilepsy are taken twice daily. The aim is to use the lowest dose of a single medication that will control seizures without toxic effects.

Most people who have seizures because of their brain tumour may only need one drug to control them but another drug may be added in, if required. If you are suffering seizures then it is always best to let your GP or your hospital doctor or your epilepsy specialist nurse know so that they may be able to get them under control.

Stress and poor sleep can make seizures worse and doctors may suggest methods of overcoming this. Alcohol can interfere with some drugs and should be avoided in general. For some people seizure control with available medication is not possible. In such cases it is worthwhile reducing the medication in order to minimize side effects; surgery may sometimes be considered.

How can I help myself?

- Do not run out of tablets and do not miss any doses. Stopping your anti-epileptic drugs quickly can lead to an abrupt increase in the number of seizures. This must be avoided to prevent you from coming to any harm during seizure activity. If there is an occasion when you miss a dose contact your epilepsy nurse specialist or GP for advice.
- A diary of seizure frequency and severity should be kept as it will help when assessing any change in seizures related to changes in medication. Write down when seizures take place and get any witnesses to write down what they see too. Take this diary to your hospital appointments.
- If you have any other illness anticonvulsants should be continued. If you vomit soon after taking your medication make contact with your GP or Treating Team and they can advise you about whether you should take another dose or not.
- Not taking the medication regularly is the most common cause of treatment failure. Irregular therapy may be worse than no therapy at all. It may cause withdrawal effects or it may make seizures or toxic side effects worse.
- Establish a routine to ensure you minimize the chances of missing doses and forgetting tablets. Consider using a pill box divided into days of the week.
- Make sure you get sufficient sleep because sleep deprivation can make seizures worse.
- Minimize alcohol intake as alcohol mixed with your epilepsy tablets may make you very sleepy.

What should my friends do if I have a seizure?

While the convulsion/seizure is in progress:

- They should not put anything in your mouth or force your teeth open.
- They should not try to restrain your movements but let the seizure run its course.
- They should only move you if you are in danger from injury, e.g. close to a fire or on the road, and then put you on your side.
- Your friends should note the time and duration of the seizure.
- If it is a convulsive seizure your friends should put something soft under your head and remove anything hard that you may be knocking against.
- If the seizure is still ongoing at five minutes they should call an ambulance.

After the seizure has finished:

- They should roll you onto your side.
- Your airways should be checked and kept under observation. If breathing is laboured or you are making strange noises then they should check inside your mouth and observe for any objects that could be causing an obstruction.

After a major seizure:

- You may be confused and need reassurance and supervision until you are fully orientated.
- Friends should not give you anything to drink until you have fully recovered.
- Transfer to hospital is necessary only if the seizure is prolonged, repeated, or if any injury has occurred.
- Do not take additional anticonvulsants after a seizure but continue to take them at your regular time and dose. Ask your doctor for further advice if you are concerned.

How will the seizures affect my daily life?

Driving

You must tell the Driver and Vehicle Licensing Agency (DVLA) if you have a brain tumour. You must also speak to your doctor who might tell you to surrender your licence.

You must tell the DVLA if you've had any epileptic attacks, seizures, fits or blackouts and you must stop driving straight away.

You can either report your condition online or fill in form FEP1 and send it to the DVLA.

If you have had epileptic attacks while awake and lost consciousness:

Your licence will be taken away. You can reapply if you haven't had an attack for at least a year.

If you have had attacks or seizures that don't affect your consciousness or driving:

You may still qualify for a licence if these are the only type of attack you've ever had and the first one was 12 months ago. The DVLA will let you know whether or not you need to give up your licence after you've filled in the form. Until you hear from them you must stop driving.

Their medical advisers will base their decision on information you and your doctors send them. If they need to carry out an investigation they'll also let you know.

Otherwise you can reapply after a year. You can find the contact details on page 16.

Work

You don't automatically have to tell your employer about your epilepsy as long as you don't believe it will affect your ability to do your job safely and effectively.

However, if your epilepsy could cause a health or safety risk to you or anybody else, you **must** tell your employer about it.

If you don't tell your employer and it does affect your ability to do your job safely, your employer may be able to dismiss you.

If you don't tell your employer about your epilepsy you will not be fully covered by their insurance.

Health and Safety Risk Assessment: this is an assessment which your employer must do to make sure you can carry out your duties safely, for example in a situation where, if you had a seizure, you could put yourself or others at risk.

Some alterations in the structure of your job may be possible and these are called **reasonable adjustments**.

For other types of work no alterations will be necessary. For example, working with computers, display screens (VDU's) and TV monitors is unlikely to precipitate seizures.

For most jobs including the police and fire service you will be able to continue with your work although there might be some changes in your job description. If you work in the armed services then you will not be able to remain in post.

If you encounter problems at work the following link may be helpful:
<https://www.epilepsy.org.uk/info/employment/problems>

Remember that your employers may be unaware that there are many different seizure types and that not all result in convulsions where a person falls down and loses consciousness. Some seizures are very minor and brief. It is worth explaining to them in detail to help them understand your seizures.

In general, most employers and work mates are very supportive and understanding.

Home

Troublesome seizures can lead to all sorts of stresses and anxieties in the family. It is best that everyone in the family home is aware that you have occasional seizures but that they should not over-react to them.

Discuss things openly with your partner and children to ensure that they do not “overprotect” you. The well-meaning partner who does this can unwittingly find that they are contributing to a loss of confidence and self-esteem and reducing your role within the family. This can lead to frustration and depression which may in turn aggravate your seizure frequency, especially if you are losing sleep. There is good evidence that relaxation techniques can reduce seizure frequency.

It is advisable to shower rather than bathe and to use a smother-proof variety of pillows in bed. When cooking and setting fires you should be aware of the possible dangers.

Sport

Don't swim alone and do inform the pool attendant that you have epilepsy. Wearing a distinctive swim hat is a good idea. It is sensible to cycle with other people. Don't canoe on your own or go rock climbing.

Many other sports can be enjoyed except for contact sports like

boxing and rugby which should be avoided by anyone who has been treated for a brain tumour. Consult your doctor if you have any concerns.

Should I tell people that I have seizures?

It is usually advisable to tell your family, employer and work mates. If you have a 'major' seizure, they should also be told what to do (see page 10) and be reassured that the seizure is usually over in 1 - 5 minutes although you may be confused for a little while afterwards. If a generalised seizure lasts longer than 5 minutes then an ambulance should be called.

Do seizures injure the brain?

Research in this area is ongoing but it is believed that most patients experiencing very brief and infrequent seizures are unlikely to notice any long-lasting effects. However, in rare cases such as when seizures last an unusually long time or when there is a series of non-stop seizures, changes in the brain may occur that can affect the brain's abilities. It must be stressed that this is an uncommon occurrence.

Sometimes after a focal or generalised seizure there can be a weakness on one side of the body for minutes or occasionally days (Todd's paresis), but this usually resolves completely.

Could I injure anyone during a seizure?

Although a seizure involving jerking of the limbs can look violent, the movements are undirected and it is therefore not possible to carry out an intentional attack on anyone. Injury to others only occurs if they get in the way accidentally, if they are trying to suppress your limb movements or, in the period after a seizure when you may still

be confused, if you feel threatened. For example, you might react physically if someone is holding you down. Injury to you, yourself occurs rarely and in most cases only if there is a loss of consciousness (generalised seizures). You are at particular risk when working at heights or with dangerous machinery or if swimming unaccompanied. If you have generalised seizures you should be sensible and avoid situations where you could put yourself at serious risk.

If I am unable to work what benefits might I be entitled to?

You can find out about your eligibility for Personal Independence Payment (PIP) from the government website: <https://www.gov.uk/pip/overview>. Attendance Allowance is available for people aged over 65. You can also speak to an advisor at your local Maggie's Centre, Epilepsy Action or Macmillan Cancer Support. See addresses overleaf. Turn2Us is another helpful organisation where you can get advice about benefits. No one on regular anticonvulsants need pay prescription fees. Special travel passes can also be obtained.

Useful Contacts

Brain Tumour Action,
25 Ann Street,
Edinburgh, EH4 1PL.
Phone: 0131 466 3116
www.braintumouraction.org.uk

Epilepsy Action,
Phone: 0808 800 5050
epilepsy@epilepsy.org.uk

Epilepsy Scotland,
Phone: 0808 800 2200 www.epilepsyscotland.org.uk

The Brain Tumour Charity,
Phone: 0808 800 0004
www.thebraintumourcharity.org

Macmillan Cancer Support,
Phone: 0808 808 0000
www.macmillan.org.uk/information-and-support

Maggie's Centres,
Phone: 0300 123 1801
www.maggiescentres.org

Turn2US,
www.turn2us.org.uk/About-Us/Contact-us

Personal Independence Payment, PIP,
Phone: 0800 917 2222
www.gov.uk/pip/overview

DVLA Drivers' Medical Enquiries:
DVLA Swansea SA99 1TU
Phone: 0300 790 6806
www.gov.uk/epilepsy-and-driving

