

## Epilepsy (seizures) and brain tumours

*Epileptic seizures are the most common first (or 'onset') symptom that leads to a brain tumour diagnosis in adults. Many other people with brain tumours develop epilepsy later during the course of their illness. Around 60% of brain tumour patients will experience a seizure at least once.*

*A seizure can be a disturbing, frightening event, particularly the first time you have one, both for you and those around you. The diagnosis of epilepsy (more than one seizure) can take time to get used to and lead to a whole range of emotions as well as having a strong impact on the quality of your life.*

*This fact sheet gives information about epilepsy resulting from a brain tumour, to help you understand and manage it.*

### In this fact sheet:

- What is epilepsy and what is a seizure?
- Why do some brain tumours cause epilepsy?
- Emotional aspects of epilepsy
- Treatments and side-effects
- Other aspects about living with epilepsy

### What is epilepsy?

Epilepsy is defined as the tendency to have recurrent seizures. It is usually only diagnosed after you have had more than one seizure.

It is a common, serious 'neurological' condition. (This means it is a condition of the brain). More than half a million people in the UK have epilepsy - that is around 1 in 100 people. There are more than 40 types of epilepsy and most of these people will not have a brain tumour.

However, epilepsy is one of the most common symptoms in patients with brain tumours. Seizures are the onset (first) symptom in 20-40% of patients, while a further 20-45% of patients will develop epilepsy during the course of their illness.

You are more likely to develop epilepsy if you have a slow growing, low grade tumour. You can develop epilepsy if you have a high grade tumour. In this case though, your tumour is likely to be smaller than high grade tumours not associated with epilepsy.

*(Brain tumours are graded 1-4 according to their behaviour, such as the speed at which they are growing. Grades 1 and 2 are low grade, slow growing and sometimes referred to as benign, though this term is used less often nowadays as such tumours are still serious. Grades 3 and 4 are high grade, fast growing and often referred to as malignant. For more information, see 'What is a brain tumour?' fact sheet).*

You are also more likely to develop epilepsy if your tumour is located 'supratentorially'.

This means it is located in one of the lobes of the cerebrum (cerebral cortex) or the meninges (the membranes that cover and protect the brain and spinal cord), rather than deep in the brain or in the brainstem or cerebellum. (See the 'Human brain' fact sheet for more information).

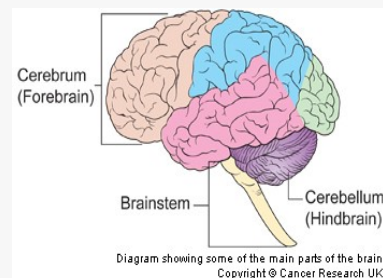


Diagram showing some of the main parts of the brain  
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### What is a seizure?

Our brains have millions of nerve cells which control the way we move, think and feel. They do this by passing electrical signals to each other. Electrical activity, therefore, is happening in our brains all of the time.

A seizure is a short episode of symptoms caused when there is a burst of abnormal electrical activity that disturbs the way the brain normally works, 'mixing up' the messages.

When people hear the term seizure, they often think of convulsive seizures, where the person loses consciousness, their body goes stiff and they fall to the floor with their limbs jerking. However, there are many different types of seizures. They can range from 'feeling a bit strange' or 'absent' to convulsive seizures (sometimes referred to as 'fits' but more correctly called 'tonic-clonic seizures').

People can have more than one type of seizure. A seizure of one type can progress directly into another type during one seizure episode.

### Types of seizures

Seizures are normally grouped into two categories, depending on how much of the brain is affected.

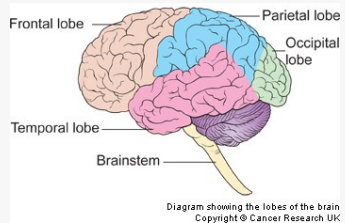
#### Focal (or partial) seizures

These are where only part of the brain is affected - the 'focus' of the seizure. Focal seizures are the usual types of seizure associated with brain tumours.

There are two types of focal seizure:

**Simple focal seizure** – only a small part of one of the lobes of the brain is affected.

- you will be conscious, normally know what is happening and will remember afterwards.
- symptoms will depend on which lobe the seizure happens in, but during the seizure, you may feel 'strange' and not be able to describe the feeling afterwards. This can be frustrating or upsetting.



These 'strange' feelings can include:

#### Temporal lobe

- an intense feeling of emotion
- an unusual smell or taste
- feeling of 'déjà vu' (I've been here or done this before) or 'jamais vu' (familiar things seem new)
- rising feeling in the stomach, as you may get on a fairground ride

#### Frontal lobe

- stiffness or twitching in muscles that can spread from the hand or foot and can affect half of the body
- feeling of not being able to speak despite being fully conscious

#### Parietal lobe

- numbness or tingling
- burning sensation
- feeling that an arm or leg is bigger or smaller than it is

#### Occipital lobe

- visual disturbances, such as coloured or flashing lights
- hallucinations (seeing something that isn't there)

If your tumour is located over two different areas of the brain, then you may experience a combination of these symptoms.

For some people, simple focal seizures can spread to both sides of the brain i.e. become generalised. When this happens it is called a secondary generalised seizure and is often a tonic-clonic type of seizure. (See 'Tonic-clonic seizures' section further on in this fact sheet). If this happens quickly, you may not be aware that it started as a focal seizure.

As such, these simple focal seizures can act as a warning for some people that a more severe seizure is imminent. They are often referred to as 'auras'.

**Complex focal seizure** – a larger part of one hemisphere (side) of the brain is affected.

- your consciousness will be affected, so you may be confused, not aware of what you are doing, and are unlikely to remember what happened afterwards
- you may not fully understand people or be able to respond to them, even though you can hear them
- if spoken loudly to, you may think the other person is being aggressive - some people react aggressively back
- you may wander around or make strange or repetitive movements or sounds (called 'automatisms')

Again the location of the seizure affects the symptoms:

#### Temporal lobe

- picking up or fiddling with objects or clothing
- chewing or lip-smacking movements
- muttering or saying repeated words that don't make sense
- language problems, such as comprehension
- wandering around in a confused manner

These may start as a simple focal seizure and usually last 2 - 3 minutes.

#### Frontal lobe

- making strange movements or postures, such as cycling or kicking, usually at night
- making a loud scream or cry or laughing uncontrollably

These usually last 15 - 30 seconds.

#### Parietal or occipital lobes

- like the simple focal seizures in these lobes, these can affect your senses or vision

These are less common than temporal or frontal lobe complex focal seizures and usually last 15 - 30 seconds.

After a complex focal seizure, you may still feel confused, making it difficult to tell when the seizure has ended. This is called 'post-ictal' (after seizure) confusion. You may also feel tired and need to rest. Complex focal seizures can spread to become generalised seizures - usually tonic-clonic seizures. (Please see next section of this fact sheet).

#### Generalised seizures

These are seizures that begin in both sides of the brain almost simultaneously (at the same time). There are six main types of

generalised seizure and in most types result in the person becoming unconscious, even if only for a few seconds, and unlikely to remember what has happened. ('Unconscious' means not aware of yourself, your acts and surroundings).

**However, generalised seizures are usually genetic and are only rarely associated with brain tumours**, though, as previously mentioned, some focal seizures can become generalised, usually as a type known as a tonic-clonic seizure.

#### Tonic-clonic seizures - sometimes called 'grand mal'

These are the seizures most people think of as epilepsy.

- initially you will become unconscious (not aware)
- your body will become stiff, so you may fall, usually backwards
- you may cry out or bite your tongue or cheek
- your muscles will jerk (convulse)
- your breathing might become more difficult or noisy
- your skin may change colour - either very pale or may blush
- you may lose control of your bladder (wet yourself)

They normally last 1 - 3 minutes.

Seizures can also happen in your sleep. These are known as 'nocturnal seizures' or 'asleep seizures'. They will still be one of the types previously described.

Your seizures may not be exactly as one of the types described, but they will usually last the same time and follow the same pattern each time they happen. For some people, however, their seizures do not follow a pattern nor last the same time.

#### Status epilepticus

Occasionally, seizures may not stop, or one seizure follows another without any recovery in between. If this goes on for 30 minutes or more it is called 'status epilepticus' or 'status'. This is uncommon, but potentially serious, and requires hospital treatment.

**If a seizure continues for more than 5 minutes or repeated seizures occur without recovery in between, emergency (rescue) medication should be given and/or an ambulance should be called. (Do NOT wait for 30 minutes.)**

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## Why do brain tumours cause epilepsy?

Although epilepsy is more likely in low grade tumours and in tumours in the cortex, the exact reasons why these brain tumours can cause epilepsy are not fully understood.

For example, it is thought that epileptic seizures in patients with brain tumours do not start in the tumours themselves, but from the area of the brain next to the tumour.

### Cortical dysplasia

Some studies have shown that the area around some types of brain tumour is characterised by brain cells that have developed abnormally. This is known as 'cortical dysplasia'. ('Cortical' means relating to the cortex or cerebrum; 'dys' means 'ill' or 'abnormal' and 'plasia' means 'formation').

The abnormal nerve cells in the area of cortical dysplasia 'fire' (send messages) more frequently, causing uncontrolled, disorganised electrical activity in the brain. This process is often referred to as 'hyperexcitability' and is what leads to seizures.

Cortical dysplasia also occurs in the brain without the presence of a brain tumour and is known to be a common cause in people with non-brain tumour-related epilepsy.

Despite this, it is not clear whether cortical dysplasia plays a part in causing brain tumour-related epilepsy. Firstly because complete resection (removal) of the tumour alone often results in seizure freedom. (Though this could be because the neighbouring epilepsy area is also removed). Secondly, because cortical dysplasia is not present in all tumour types that are associated with seizures e.g. most gliomas.

### Neurotransmitters and signalling pathways

Other research has suggested that certain 'neurotransmitters' and the pathways down which they send their signals may be involved.

The brain consists of over 100 billion nerve cells that communicate with one another by releasing chemicals that either excite or inhibit connected nerve cells. These chemicals are known as neurotransmitters. The main chemical (neurotransmitter) that excites cells in the brain is 'glutamate' and the main chemical (neurotransmitter) that inhibits nerve

cells in the brain is 'GABA'. An imbalance between these can lead to too many nerve cells firing, resulting in the 'electrical storm' that is a seizure.

The presence of a tumour can cause changes to the structure or the chemicals of the cells, both within the tumour and the tissue surrounding it, thereby affecting the electrical activity of the brain.

In particular, evidence indicates that too much of the neurotransmitter 'glutamate' may be present around tumours, and this may abnormally excite surrounding nerve cells, leading to seizures.

**It is important to know that an increase in the frequency of your seizures does not necessarily mean that your tumour has returned or is re-growing.**

## Emotional impact of epilepsy

Having seizures and being diagnosed with epilepsy on top of the diagnosis of a brain tumour can be overwhelming. You may feel frightened, worried, anxious, depressed, angry - or all of these at various times. You may be worried by the unpredictability of seizures and about having a seizure in public, plus the reaction this can bring - as many people still do not understand epilepsy. This can lead to a sense of insecurity.

People sometimes mention feeling socially isolated and that it is difficult to make and maintain social relationships, work etc. It may be that you are also unable to drive, or have other visible effects that are due to the brain tumour and/or its treatment e.g. speech or movement difficulties, hair loss, sight problems or weight gain from steroids.

All people react differently, but the psychological impact (often never knowing when a seizure might happen) and the frustration caused by seizures and the feeling of losing control of your body, should not be underestimated. In addition, seizures themselves may affect the way the brain works and make people more prone to depression and anxiety.

It can be helpful to know that this is a common way to feel. Talk to your Clinical Nurse Specialist - they can provide psychological and emotional, as well as practical, support. Find other people you can talk to. This could be a close friend or relative, or a counsellor. Or it could be someone else who is going through the

same thing i.e. via a support group, an online community or a support line, such as those provided by The Brain Tumour Charity.

The Brain Tumour Charity has an active Facebook support group that you can access anywhere in the world and at any time, where you can 'meet' others (brain tumour patients and carers) and discuss your worries, fears and share ideas. Or, if you are not ready to speak to others directly, you can simply read about the experiences of others.

<https://www.facebook.com/groups/114009085471466/>

If you want to meet face-to-face, a list of local support groups around the UK can be found on The Charity website.

<http://www.thebraintumourcharity.org/support-information/Support/Support-in-your-area/Support-groups>

We also have telephone support groups, where you can talk with others and ask some of the questions that your healthcare professionals may not be able, or have time, to answer.

There is also our Support & Info Line that you can call for free: 0808 800 0004 or email [support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)

Other factors which have helped people to deal with the emotional impact are more practical. One is by controlling seizures as well as possible, in order to reduce the emotional load. This involves establishing the best treatment for you to reduce the frequency of seizures. (*For more information, please see the 'What treatments are available?' section later in this fact sheet.*)

Others are the practical elements that can help to minimise the impact of your seizures e.g. safety in the home, when you are out etc. With these in place it can help you feel more secure and/or more in control. (*For more information, please see the 'Living with epilepsy' section later in this fact sheet.*)

## What treatments are available?

Treatment of seizures in people with a brain tumour is particularly complex and difficult due to the additional impact that having a brain tumour causes. The variety of tumours (type, location and grade), tumour effects and treatments all interacting with the variety of seizure types.

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As a result, some treatments for epilepsy may not be suitable for you, or you may have to try several treatments before you find the one that is best for you.

## Anti-Epileptic Drugs (AEDs)

AEDs are the main form of treatment for most people in the general 'epilepsy population'. They cannot cure epilepsy, but they are a type of medicine that can help to stop seizures from happening.

The aim is to control seizures effectively whilst taking the fewest types of AEDs, at the lowest dose and with the least side-effects. This is called "optimal therapy". Currently, the management of epilepsy in patients with a brain tumour also relies mainly on anti-epileptic drug therapy.

Anti-epileptic drugs can be divided into two groups - first generation (or older) drugs and second generation (more recently developed) drugs. First generation drugs used in patients with brain tumours include:

- phenytoin (Epanutin®)
- carbamazepine (Tegretol®, Carbagen SR®)
- sodium valproate (Convulex®), Eplilim®, Episenta®, Epival®)
- benzodiazepines, such as clonazepam (Rivotril®) and clobazam (Frisium®)
- barbiturates, such as phenobarbital

Second (newer) generation drugs used in patients with brain tumours include:

- levetiracetam (Desitrend®, Keppra®)
- lamotrigine (Lamictal®)
- lacosamide (Vimpat®)
- pregabalin (Lyrica®)
- tiagabine (Gabitril®)
- zonisamide (Zonegran®)
- oxcarbazepine (Trileptal®)
- topiramate (Topamax®)
- eslicarbazepine (Zebinix®)
- permpanel (Fycompa®)
- gabapentin (Neurontin®)

Your specialist will prescribe the drug that is most suitable for you depending on:

- type(s) of seizure you have
- interactions with other medications or therapies (that you may be receiving as part of your treatment for your brain tumour)
- impact of a drug's side-effects on any other effects your brain tumour may be causing, e.g. problems with cognitive function (thinking, memory, attention)

Most drugs that are used in epilepsy work by either increasing the neurotransmitter GABA signalling, decreasing the neurotransmitter glutamate signalling, or by decreasing the excitability of nerve cells.

### Effectiveness in brain tumour-related epilepsy

Research studies on the older AEDs in brain tumour-related epilepsy are few and give conflicting results. More research has been done on the second generation AEDs,

However, even here the studies have been on small numbers of patients, usually as an add-on to another drug, and rarely comparing one drug against another. This, plus flaws in the designs of the studies, make them difficult to compare and give an accurate overall view. For example, the percentage of patients who become seizure free using levetiracetam ranges, in various studies, from 20% to 88%.

As a result, to find the drug which works best for you, you may have to try different AEDs, or use some in combination.

In general, the newer generation of drugs are preferred for patients with a brain tumour. This is because these drugs tend to have fewer drug interactions, less of a negative effect on other therapies you may be receiving, and have fewer side-effects.

### Pharmacoresistance

An additional factor in the choice of AEDs for people with a brain tumour is that brain tumour-related epilepsy is more likely to be drug-resistant than non-brain tumour-related epilepsy. You may hear this referred to as 'pharmacoresistance'. The reason for this resistance is not clear, because the causes of brain tumour-related epilepsy are not fully understood.

There are three theories, however. The first (the target hypothesis) is that the targets on the cells, which the AEDs

normally bind to, are altered in brain tumours and the cells around them, so the AED cannot bind to them and be effective.

The second is the transporter hypothesis. Molecules, known as 'multi-drug transporters', are important in defending cells by removing dangerous substances out of the cell. They are also important in the blood brain barrier. However, they have been found to be over-expressed (there are too many copies) in brain tumours and in the cells forming their blood supply. It is thought that they may be rejecting the AEDs from the tumour cells making the AEDs less effective.

The third theory (the intrinsic severity hypothesis) is that a person's inborn difference in the severity of the epilepsy may influence an individual's response to treatment. People who have more frequent seizures in the early phase of their epilepsy tend to experience more resistance to AEDs.

### Other factors

It has also been found that if you do not respond to the first two drugs that you try, there is a high chance of not becoming seizure free with subsequent drugs.

However, even in this instance, using anti-epileptic drugs in combination can be effective and often reduces the severity and frequency of seizures.

More research is needed on the efficacy (effectiveness) of anti-epileptic drugs in patients with a brain tumour. Currently, whilst the effectiveness of anti-epileptic drugs has been widely investigated in the general epilepsy population (and there are comprehensive guidelines on treatment in this population), there has not been much research on AEDs in brain tumour patients.

### Side-effects

As with all medications, AEDs can have side-effects. These side-effects will depend on which drug you have and how you react to the drug. Different people can respond differently to the same drug.

Unfortunately some studies have shown that side-effects seem to be more frequent in patients with brain tumour-related epilepsy than those in the rest of the 'epilepsy population'. Patients with a brain tumour also seem to be more sensitive to the side-effects i.e. they may have them more severely.

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Common possible side-effects include:

- skin rashes
- nausea/vomiting
- bowel problems e.g. diarrhoea, constipation, wind
- dizziness/unsteadiness
- drowsiness/fatigue
- headache

**You should report severe reactions to your doctor. Also report any skin rashes, as this could be a sign of allergy and can sometimes be serious.**

Other side-effects, which are common depending on which AED you are taking, include:

- impaired co-ordination or tremors
- psychological effects e.g. anxiety, agitation, depression,
- cognitive effects e.g. impaired memory

Those AEDs with cognitive effects can worsen problems that brain tumour patients already have due to their tumour and/or tumour treatment. This makes them unsuitable for some patients. Some first generation drugs are more likely to cause cognitive effects.

The Epilepsy Society has a list of AEDs with their common side-effects. <http://www.epilepsysociety.org.uk/list-anti-epileptic-drugs#.VED1yP5OXMB>

Your health team will give you information about the possible side-effects and discuss the issues with you.

### Drug-drug interaction

In general, the second generation drugs are less likely to interact negatively with other drugs you may be taking to treat your brain tumour. Some studies have shown levetiracetam to be one of the optimal (best) AEDs in this respect.

Always let your specialist know of any over-the-counter (non-prescription) drugs you are taking, including vitamins and supplements, in case they may react with the AEDs you are prescribed.

## Surgery

Surgery to remove the area of the brain that is causing the seizures, or to separate this area from the rest of the brain, is

sometimes used to reduce or stop seizures in the treatment of epilepsy. In the general 'epilepsy population', around 70% of people (7 in 10 people) who have surgery, find that it stops their seizures. For people with brain tumours, the number is similar or higher, depending on the amount of tumour that is resected (removed) and whether the area causing the epilepsy is also removed. If all the tumour and the epilepsy-causing area is removed, the person will normally be seizure free.

So why doesn't everyone with brain tumour-related epilepsy have surgery to remove the epileptogenic (epilepsy-causing) area? The reason is that there are other factors that need to be considered before deciding to have epilepsy surgery, particularly when you have a brain tumour (see below). These factors mean that epilepsy surgery is only helpful in a small proportion of brain tumour patients.

### Low grade tumours - watch and wait

In some cases, for people with low grade brain tumours, who have no 'neurological deficits', whose tumour is unlikely to progress and epilepsy is the only symptom, then surgery could be considered. ('Neurological deficits' are problems caused by decreased function of the brain or nerves e.g. vision changes, walking problems, mental function problems). Even in this case, various factors need to be weighed up.

It may be that you are on a 'watch and wait' approach to treatment for your low grade brain tumour. (*For more information, see 'Watch & wait' fact sheet*). The reason for this approach being used is that any surgery (and undergoing general anaesthetic) carries risks. Also performing neurosurgery in particular, can have a greater risk of causing harm to the brain than not doing anything. (*For more information about neurosurgery, please see the 'Neurosurgery' fact sheet*).

Similarly with surgery for epilepsy, more harm than good could be done. To achieve seizure freedom, or at least a good reduction, the whole tumour and epileptogenic area will need to be removed. The location of your tumour may make this difficult - either because it is in an area of the brain that is difficult to reach, or because it is near to important areas of the brain, such as those that control speech. The exact location of the epileptogenic area will also need to be established i.e. how far around the tumour it spreads, or even if it is in the same location as the tumour. Again if this is in a difficult to reach area or near

an important area of the brain, total removal may not be possible. If total removal is not possible, the amount of likely reduction in seizure frequency may not outweigh the risk of surgery to the brain.

In some cases, neurosurgery has been known to even increase seizure frequency.

### Low grade tumours - surgery

If you are due to have surgery for the resection (removal) of your tumour, it may be possible to undergo tests to find the exact location of the epileptogenic area beforehand. Tests that are used routinely in non-brain tumour-related epilepsy may be used. These include:

- 'functional MRI' - measures which areas of the brain are active when particular mental processes are taking place e.g. speech
- 'video-EEG telemetry' - involves admission to hospital to record a seizure with video and EEG to make sure the tumour is the cause of the seizures. (EEG stands for 'electroencephalography' and is the recording of electrical activity of the brain via sensors placed on your scalp)
- neuropsychological assessment - to determine the risk of surgery to memory and cognition (thinking/reasoning etc)
- neuropsychiatric assessment - to determine the risk of depression after surgery.

There may also be additional specialised scans.

Occasionally other tests can be done under anaesthesia or during surgery:

- 'interictal electrocorticography' - electrodes placed directly on the brain to record electrical activity and define the epileptogenic area more accurately
- 'electrostimulation' during awake craniotomy - this is where you are woken during the operation on your brain (craniotomy) and areas of the brain are stimulated using probes to find the areas responsible for particular functions, such as speech. This is to make sure they are separate from the tumour and /or epileptogenic areas that are to be removed.

(*See the 'Neurosurgery' fact sheet for more information about awake craniotomy*).

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Using these tests to locate and remove the epileptogenic area along with the tumour, has been shown to result in more patients achieving seizure freedom (82 - 92%) than people who have had only the tumour removed (65 - 70%).

Having these tests, however, would not necessarily mean surgery for the epilepsy is a possible option, as they may reveal that the epileptogenic area is in an area that is not operable.

Despite this, studies have found that removal of the tumour alone often results in seizure freedom, particularly if the tumour is totally removed.

If you are having surgery for a biopsy, it is unlikely that the epileptogenic area will be removed, as a biopsy is the removal of a small sample of the tumour through a small hole in the skull. (See the 'Neurosurgery' fact sheet, for more information.)

### High grade tumours

Whilst high grade brain tumours are less likely to cause epilepsy, some people do experience seizures. As with low grade tumours, surgery may not be an option due to the location of the tumour, therefore surgery to remove the epileptogenic area may also not be possible.

If you are to undergo surgery for your brain tumour, combining it with epilepsy surgery may still not be possible. For epilepsy surgery to be successful, identifying the location of the epileptogenic area is crucial. However, the tests to establish this can take considerable time. This would delay the surgical treatment for the tumour. In the case of aggressive, fast growing, high grade tumours, this delay carries obvious risks and often makes such investigation impossible.

Surgery to remove the tumour may still help to reduce seizure frequency for reasons discussed in the previous section on low grade tumours.

## Other treatments

### Vagus nerve stimulation (VNS)

If epilepsy is poorly controlled despite trialling various AED's (often referred to as 'refractory' or 'intractable epilepsy') and you are not eligible for (or do not want) brain surgery, then VNS may be offered as a treatment option. VNS is rarely used for patients with brain tumours, however.

VNS involves implanting a small device under the skin by the collarbone, which acts in a similar way to a pacemaker. It passes a regular dose of electricity to one of the 'vagus nerves' which then sends these stimulations into the brain. It is believed that stimulating the vagus nerve changes the chemical transmissions to the brain and helps to calm down the irregular electrical brain activity that causes seizures.

It needs to be used alongside AEDs, not instead of them. It can take up to two years before it starts to have an effect. This makes it less suitable for people with fast growing, high grade brain tumours. For some people it does not work at all.

Few studies have looked at the effect of VNS in patients with brain-tumour related epilepsy. However, one study found that the effectiveness of VNS in these patients was comparable in seizure reduction and response rates to the general population of VNS therapy patients. It also found that outcomes were better in patients with stable, low-grade tumours (around 66% experienced reduction in seizure frequency) as opposed to those with progressing, high grade tumours (around 11% had decreased seizure frequency).

## Complementary therapies

There is much information online and elsewhere about various complementary therapies for the treatment of epilepsy. Some people say that various complementary therapies work for them. However, as yet there is no scientific evidence to suggest that they reduce seizures.

If you do decide to use a complementary treatment, speak to your doctor first, who will be able to advise if the treatment may cause problems with your epilepsy or AEDs. This includes any dietary or vitamin supplements and, particularly, herbal medicines, as some e.g. St John's Wort can interfere with AEDs and lead to loss of seizure control.

**Do NOT stop taking, NOR reduce, your AEDs without the agreement of your doctor.**

### Ketogenic diet

The ketogenic diet is a diet that is high in fats, low in carbohydrates (sugars), with a controlled protein content. This diet has been receiving increased interest recently, particularly from patients.

It was one of the treatments used for epilepsy before AEDs were available. The arrival of AEDs led to its usage declining, but in the last decade there has been much interest in it once more - for controlling seizures that are not controlled by AEDs.

Most of the studies so far have been in children, where it has become an established treatment option for children with hard to control epilepsy - reducing seizure frequency and having a positive effect on behaviour.

Until now, little research has been done on the benefits in adults and it has generally not been used for their treatment. However, interest in this area is growing, both in adults in the general epilepsy population, and also in brain-tumour-related epilepsy patients, where pharmacoresistance (described earlier in this fact sheet) may lead to them looking for alternative treatments.

How is the diet thought to work? Our bodies usually use glucose (a type of sugar/carbohydrate) for energy. Reducing our intake of carbohydrates makes our bodies use the fats we eat to produce molecules called 'ketones' for energy instead.

When these enter the brain, they appear to have an effect by reducing seizure frequency. Their exact mechanism of action is not known, but they may alter the balance of chemical compounds and neurotransmitters involved in exciting and inhibiting electrical activity in the brain.

Other recent evidence has indicated that certain fats can have a strong anti-seizure effect, meaning that it may be the fats themselves, rather than the ketones, that affect seizure frequency.

It has been suggested that ketones may be particularly important in brain tumour-related epilepsy and brain tumour growth, because healthy cells are able to use these ketones for energy, but it is thought that tumour cells may not. By reducing the energy source of the tumour, it is hoped that the tumour growth may slow or stop.

**If you are interested in the ketogenic diet, it is important to know that the ketogenic diet in the treatment of epilepsy is a medical treatment and:**

- **should only be used under the supervision of an epilepsy specialist with the help of a dietitian**

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- is usually only considered (even for children) when suitable medications have been tried and not worked
- in high levels, ketones can be dangerous. This serious condition is known as ketoacidosis and, if left untreated, can lead to diabetic coma or even death.

The symptoms of ketoacidosis can be confused with other conditions (e.g. flu or a stomach virus), so if you are using this treatment, talk to your doctor about plans to test for ketones.

It is also important to ensure protein levels in your diet are suitable for you as an individual and that fat levels are determined to ensure your weight is controlled.

More research and scientific evidence is needed about the impact and results for adults before it can be established whether this diet can be useful in the treatment of brain tumour-related epilepsy.

## Identifying triggers

Triggers are situations that can bring on seizures in some people with epilepsy. It is important to know that they do not cause epilepsy. Many people do not have any triggers. However, if you can identify any triggers, you may be able to avoid these and so reduce the chances of having a seizure.

Common triggers include:

- stress or anxiety
- lack of sleep/tiredness
- alcohol
- some recreational drugs
- some medications e.g. some anti-depressants and antibiotics
- illnesses causing a fever, such as flu or other infections
- menstruation (periods)

As stress is a common trigger of seizures, stress-relieving and relaxation therapies, such as exercise, yoga/meditation, or just doing something you enjoy, can help.

## Living with epilepsy

### Driving

If you have been diagnosed with a brain tumour previous to

your diagnosis with epilepsy, you will already have had to give up your driving licence. This is due to your increased risk of having a seizure. (Sixty percent of people diagnosed with a brain tumour will have a seizure at least once).

Under the regulations relating to brain tumours, you may be able to reapply to the DVLA (Driver Vehicle Licensing Agency) for your license after a particular time. This would usually be at least one year - though for some low grade, 'benign' tumours it may be less, and for other higher grade tumours, it is likely to be more.

The length of time depends on your type of tumour, where it is in the brain, your symptoms, the treatment you had, whether you have any residual impairment likely to affect safe driving, and the risk of further symptoms.

If you have not yet given up your licence (due the diagnosis of epilepsy and brain tumour occurring at the same time) or you have had your licence returned after brain tumour treatment, **you must stop driving and tell the DVLA if you have a seizure - of any type.** This is a legal requirement. You will have to surrender your driving licence.

When you can apply to have it returned will depend on various factors, such as the occurrence and type of seizures you have, as well as the restrictions applied because of your brain tumour.

*(For more information, please see the 'Driving and brain tumours' fact sheet and the DVLA 'At a glance guide to the current medical standards of fitness to drive' - see the 'Resources' section at the end of this fact sheet).*

The following information is relevant to people holding a group 1 licence (for cars and motorcycles). Rules relating to group 2 licences (large lorries and buses) are different. *(You can find out more about group 2 licences from the DVLA. Their contact details are given in the 'Resources' section at the end of this fact sheet).*

#### Seizures - consciousness affected

If you have been diagnosed with epilepsy i.e. had more than one seizure, you may qualify to have your licence back, once you have been seizure-free for one year.

#### Seizures - consciousness NOT affected

If you only have seizures that do NOT affect your consciousness e.g. simple focal (simple partial) seizures, you do not necessarily have to be seizure-free to drive. You may be allowed to drive

once you have at least a one year pattern of only these seizures. You must remain fully aware and able to act, react and control a vehicle normally during your seizures.

You must also have never had any other type of seizure that affects your consciousness or ability to control a vehicle e.g. where you become confused, feel numb or weak, or are unable to remember what has happened. The DVLA will look at your symptoms before making a decision.

#### Asleep seizures (nocturnal seizures)

If you have seizures only when you are asleep, you are allowed to drive when you have been seizure-free for one year, or you have a one year pattern of seizures only when asleep and never when you are awake.

If you have previously had awake seizures, but now only have asleep seizures, you must have a three year pattern of only these seizures.

#### Isolated seizure

If you have an isolated seizure i.e. only one seizure, you will be allowed to drive after six months, as long as you have not had another seizure in that period. There must also be no other medical factors or investigations which might suggest you are at an unacceptably high risk of another seizure. The DVLA will contact your consultant to establish if you have any impairment that may prevent you from driving safely. Any restrictions on driving due to your brain tumour will still apply.

You may also be considered to have had an isolated seizure if you have been seizure free for five years, then had only one seizure, followed by a seizure-free period of six months.

#### Breakthrough seizure

If you have been seizure free, but your doctor changes or withdraws your medications (AEDs), you are at risk of a 'breakthrough seizure'. This is a sudden, unexpected seizure after a period of reliable seizure control/being seizure free. If a breakthrough seizure happens, you still need to tell the DVLA, but if you go back on the same medication and remain seizure-free for six months, you can then apply for your licence back.

If the breakthrough seizure does not affect your consciousness or ability to drive, or is an asleep seizure, you may still be

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allowed to drive i.e. not lose your licence. The DVLA will decide, based on the whether the seizure is of the same type as the seizures you have had previously.

### Reapplying for your licence

When you surrender your licence (or it is taken away), the DVLA will send you a letter stating the period of time you will have to wait before getting a new licence. You can reapply for the licence eight weeks before the end of this period.

Check with your doctor that you meet the medical standards for driving before reapplying.

Any restrictions due to your brain tumour will still apply, even if you qualify to drive under the epilepsy restrictions.

### Learning to drive

If you are having seizures and want to learn to drive, the same conditions apply to both the epilepsy and also to your type of brain tumour.

## Epilepsy safety

As brain tumour-related epilepsy is often difficult to control, safety may be an issue depending on the type of seizure you have. It may be worth carrying out your own 'risk assessment' to see what safety measure you may want to put in place. The Epilepsy Society has resources to help you think about this.

<http://www.epilepsysociety.org.uk/risk-assessment#.VE93Xf5F1Hg>

### In the home

There are lots of things you can do to make your home safer in case you fall when having a seizure e.g. choosing cushioned flooring, using protective covers on sharp edges, covering glass with a protective film, having appliances (such as irons) that turn themselves off after a set time.

### Alarms

You may also find it useful to have an alarm that can alert family or friends. These include seizure alarms, fall call alarms and even a safety pillow, if you have asleep seizures.

There are also seizure alert dogs. These are specially trained dogs who can give 10–55 minutes warning of an oncoming seizure, allowing the person to find a place of safety.

### Medical ID cards/jewellery

Some people choose to carry a medical ID card on which you can give information about your seizures, medication and how you like to be helped. A variation on this is medical jewellery, such as necklaces, bracelets or watch-style jewellery, with information inside.

Epilepsy organisations have lots of other information on all aspects of seizures and safety. For their contact details, please see the Resources section of this fact sheet.

## Information for carers - first aid

If you are a partner, family member or friend of someone recently diagnosed with epilepsy due to a brain tumour, you may find yourself in the role of carer, particularly if their seizures are unpredictable or more severe. It is important that you know what to do to keep them safe when they have a seizure.

### Tonic-clonic seizures

These are what most people think of as epilepsy, when the person falls to the ground and jerks or convulses.

- do NOT restrain the person's movements or try to move them, unless they are in danger
- do NOT put anything in their mouths or give them anything to eat or drink unless they are fully recovered
- do NOT try to bring them round

Instead DO:

- protect the person from injury by removing any nearby harmful objects
- cushion their head
- be calmly reassuring
- time their seizure
- put them in the recovery position to aid breathing, once the seizure has finished (<http://www.epilepsysociety.org.uk/step-step-recovery-position#.VF1-zf5F1Hg>)
- stay with them until recovery is complete

Call the ambulance if:

- you know it is their first seizure
- the seizure lasts more than five minutes
- one tonic-clonic seizure follows another without the person regaining consciousness in between

- the person is injured during the seizure
- you believe the person needs urgent medical attention

### Focal (partial) seizures

The person may not be aware of their surroundings or what they are doing.

- do NOT restrain them
- do NOT act in a way that could frighten them e.g. shout at them or make sudden movements
- do NOT give them anything to eat or drink unless they are fully recovered
- do NOT try to bring them round

Instead DO:

- guide the person from danger
- be calmly reassuring
- time their seizure
- stay with them until recovery is complete
- explain anything to them they may have missed/forgotten

Call the ambulance if:

- you know it is their first seizure
- the seizure lasts more than five minutes
- the person is injured during the seizure
- you believe the person needs urgent medical attention

The Epilepsy Society has a free smartphone app which contains first aid information, including when to dial 999 and a visual aid to putting someone in the recovery position. It also has seizure management tools, such as a seizure diary.

<http://www.epilepsysociety.org.uk/free-epilepsy-smartphone-app#.VE-Dgv5F1Hg>

### Other ways you may be involved in caring

- noting any patterns or triggers to their seizures, especially if they don't remember what happened
- helping with the routine of taking their AEDs (anti-epileptic drugs)
- going to appointments
- acting as an advocate or representative with their doctors or others involved in their care
- joining in with their leisure activities
- providing transport

Continued overleaf >



- helping them to adapt their homes or lifestyle
- dealing with the psychological impact of epilepsy e.g. stress, depression, mood changes, frustration

This is on top of, or in common with, all the responsibilities and emotional aspects of caring for someone with a brain tumour. As such, it is important to look after yourself too. (*Please see the 'Carers - looking after yourself' fact sheet*).

## Resources

The following organisations provide help and support to those who have been affected by epilepsy:

Epilepsy Action <https://www.epilepsy.org.uk/>

Epilepsy Society <http://www.epilepsysociety.org.uk/>

Epilepsy Scotland <http://www.epilepsyscotland.org.uk/>

Epilepsy Wales <http://public.epilepsy-wales.org.uk/>

Young Epilepsy <http://www.youngepilepsy.org.uk/>  
for children and young people under 25

Matthews Friend's <http://www.matthewsfriends.org/>  
provides information about dietary treatments for epilepsy

DVLA <https://www.gov.uk/epilepsy-and-driving>  
*At a glance guide to the current medical standards of fitness to drive*  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/383428/aagv1.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/383428/aagv1.pdf)

## What if I have further questions?

If you require further information, any clarification of information, or wish to discuss any concerns, please contact our Support and Information Team:

**Call: 0808 800 0004**

(free from landlines and most mobiles:  
3, O2, Orange, T-mobile, EE, Virgin and Vodafone)

Email: [support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)

Join our closed Facebook group:  
[bit.ly/supportonfacebook](http://bit.ly/supportonfacebook)

## About us

The Brain Tumour Charity makes every effort to ensure that we provide accurate, up-to-date and unbiased facts about brain tumours. We hope that these will add to the medical advice you have already been given. Please do continue to talk to your health team if you are worried about any medical issues.

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours and is the only national charity making a difference every day to the lives of people with a brain tumour and their families. We fund pioneering research to increase survival, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

We rely 100% on charitable donations to fund our vital work. If you would like to make a donation, or want to find out about other ways to support us including fundraising, leaving a gift in your will or giving in memory, please visit us at [thebraintumourcharity.org](http://thebraintumourcharity.org), call us on 01252 749043 or email [fundraising@thebraintumourcharity.org](mailto:fundraising@thebraintumourcharity.org)

## About this fact sheet

This fact sheet has been written and edited by The Brain Tumour Charity's Support and Information Team. The accuracy of medical information has been verified by leading health professionals specialising in neuro-oncology. Our fact sheets have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence. If you would like a list of references for any of the fact sheets, or would like more information about how we produce them, please contact us.



# Epilepsy (seizures) and brain tumours

Your notes



Registered office:  
Hartshead House  
61-65 Victoria Road  
Farnborough  
Hampshire  
GU14 7PA  
01252 749990  
[enquiries@thebraintumourcharity.org](mailto:enquiries@thebraintumourcharity.org)  
[thebraintumourcharity.org](http://thebraintumourcharity.org)  
Registered Charity 1150054 (England and Wales) SC045081 (Scotland).