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# Seizures (epilepsy) and brain tumours

## - introduction

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*Seizures are the most common first (onset) symptom that leads to a brain tumour diagnosis in adults.*

*Many people with brain tumours develop seizures later in the course of their illness. Up to 60% of brain tumour patients will experience at least one seizure.*

*A seizure can be disturbing and frightening for you and those around you, particularly the first time you have one.*

*If you have more than one seizure, you'll be diagnosed with epilepsy. This diagnosis can take time to get used to. It may lead to a whole range of emotions and have a strong impact on your quality of life.*

*Brain tumour-related epilepsy (or BTRE) has some differences to other types of epilepsy.*

### *In this fact sheet:*

- ☐ What is a seizure?
- ☐ What is epilepsy?
- ☐ Am I likely to have seizures?
- ☐ What happens during a seizure?

This is the 1st of 3 fact sheets on seizures and brain tumours.

Other fact sheets in the series are:

Seizures (epilepsy) and brain tumours - treatment.

Seizures (epilepsy) and brain tumours - living with.

## What is a seizure?

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

A seizure happens when there's a burst of abnormal electrical activity that disturbs the way the brain normally works, mixing up the messages. This causes a variety of symptoms .

When people hear the term seizure, they often think of convulsive seizures. This is 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 (spaced out), to the 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.

## What is epilepsy?

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

It's a common, serious neurological condition (condition of the brain). More than half a million people in the UK have epilepsy—that's around 1 in 100 people.

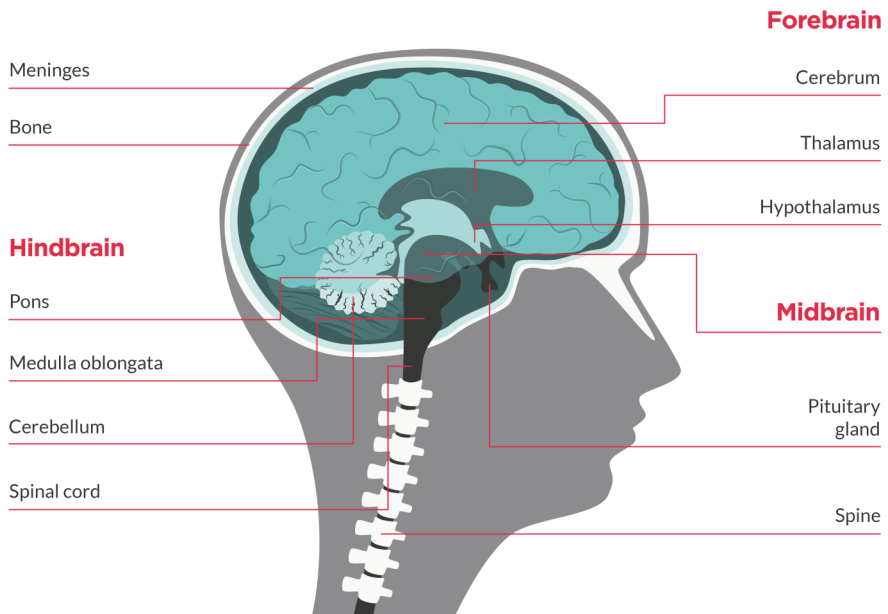
There are more than 40 types of epilepsy and most of these people won't have a brain tumour. Brain tumour-related epilepsy (BTRE) has some differences to other, more common types of epilepsy.

## Am I likely to have seizures/BTRE?

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. But this means 40% of people with a brain tumour **WON'T** have seizures.

You're more likely to have a seizure or develop brain tumour-related epilepsy if you have a slow growing, low grade tumour. But it's important to know that this doesn't mean you will have seizures.

You're also more likely to develop epilepsy if your tumour is 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.



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**For more information, see the *Human brain* webpage and fact sheet.**

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## ***How are brain tumours graded?***

Brain tumours are graded 1–4 according to their behaviour, such as the speed they're growing at.

Grade 1 and 2 tumours are low grade, slow growing, relatively contained and unlikely to spread to other parts of the brain.

There's also less chance of them returning if they can be completely removed. They're sometimes still called benign.

These low grade brain tumours can still be serious. They can cause harm by pressing on and damaging nearby areas of the brain, due to the limited space capacity of the skull. Or they can block the flow of the cerebrospinal fluid (CSF), causing a build-up of pressure on the brain.

Grade 3 and 4 tumours are high grade, fast growing and may be called malignant or cancerous growths.

They're more likely to spread to other parts of the brain (and rarely the spinal cord) and may come back, even if intensively treated.

They cannot usually be treated by surgery alone, but often require other treatments, such as radiotherapy and/or chemotherapy.

Some tumours contain a mixture of cells with different grades. The tumour is graded according to the highest grade of cell it contains, even if the majority of it is low grade.

You can develop epilepsy if you have a high grade tumour. It's more common in people with smaller high grade tumours than those with large high grade tumours.

## What is likely to happen if I have a seizure?

This will depend on:

- the type of seizure you have
- where the tumour is in your brain.

### Different types of seizure

There are many different forms a seizure can take, but only some of them tend to happen in people with brain tumours.

Seizures are grouped according to:

- where they start in the brain (the onset)
- whether the person's consciousness has been affected (their level of awareness)
- whether the seizure involves other symptoms, such as movement.

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**There is a pictorial summary of the following text on page 8.**

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### Where the seizure starts in the brain (the onset)

Depending on where they start, seizures can be called:

- **Focal onset** (previously called *partial seizures*)

These start in and affect only one part of the brain – the focus of the seizure.

**Focal seizures are the most common types of seizure associated with brain tumours.**

- **Focal to bilateral**

These start as a focal seizure, then spread to both sides of the brain.

- **Generalised onset**

These start in and affect both sides of the brain at the same time. They start without warning.

- **Unknown onset**

This is when it's not known where in the brain it started. This can happen if the person was asleep or alone and the seizure wasn't witnessed. These are known as nocturnal or asleep seizures.

## Level of awareness

Focal onset seizures can be divided into the following, according to whether your awareness is impaired or not:

- **Focal aware**

(previously called *simple partial seizures*).

Only a small part of one lobe of the brain is affected.

You're fully aware, even if you can't speak, and you'll remember the seizure afterwards, even if you can't describe it.

- **Focal impaired awareness**

(previously called *complex partial seizures*).

A larger part of one side of the brain is affected.

Your consciousness is affected – you may be confused, unaware of what you're doing, and 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').

After this type of seizure, you may still feel confused, making it difficult to tell when the seizure has ended. This is called post-ictal confusion. You may also feel tired and need to rest.

- **Generalised seizures**

Both sides of the brain are affected.

Generalised seizures always affect your awareness in some way.

Generalised seizures are usually genetic and are only rarely associated with brain tumours.

## **Whether the seizure involves movement or not**

People's movement is controlled by nerves called the motor nerves, so the term *motor* is used to describe this aspect of seizures.

- **Motor seizures**

The seizure involves a change in your movement, e.g. plucking at your clothes, or your muscles going stiff before making jerking movements.

- **Non-motor seizures**

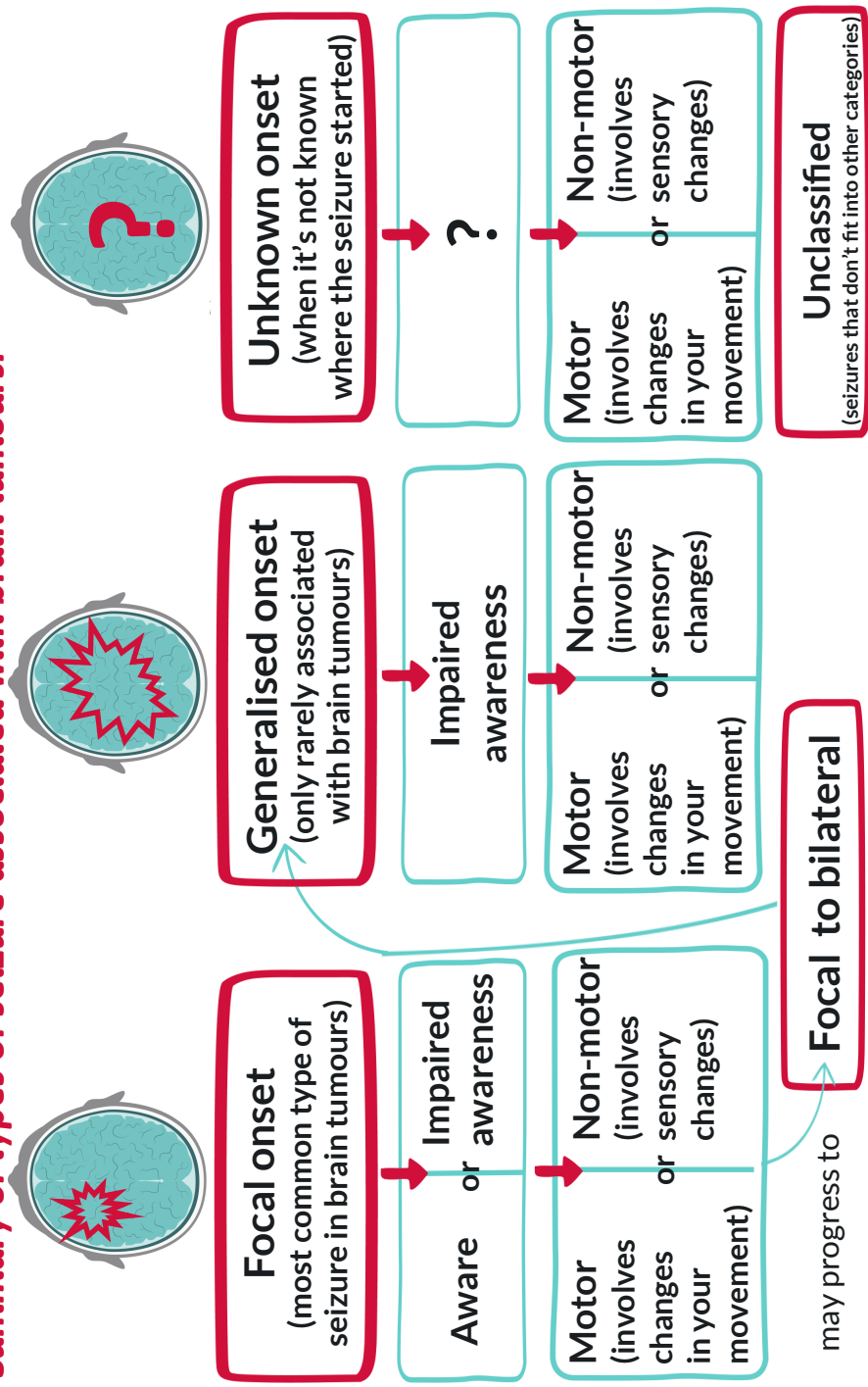
The seizure doesn't involve any change in movement, but may involve changes in vision, smell or hearing.



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Diagram showing the two sides of the brain.

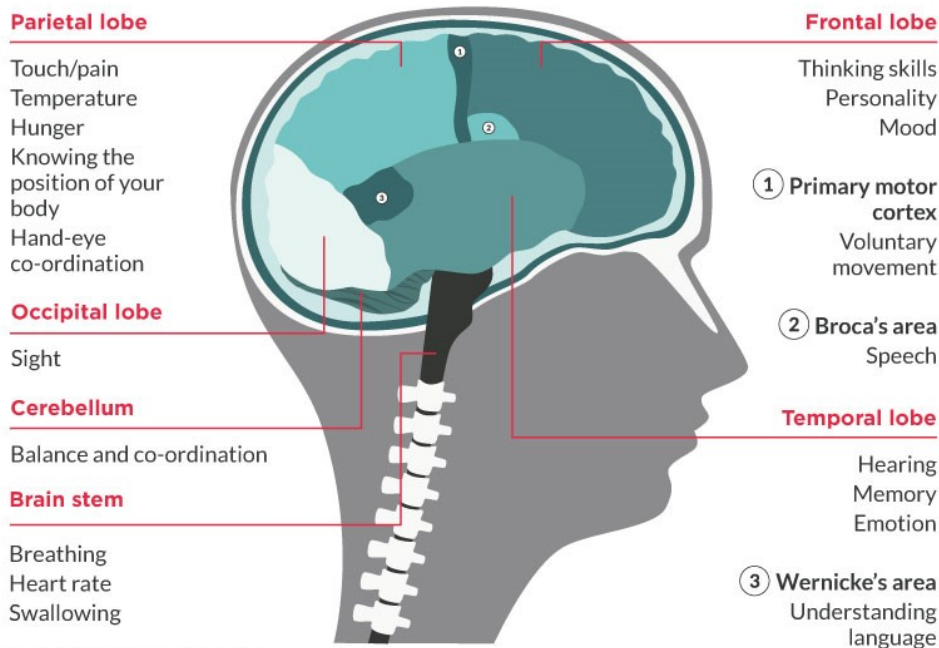
# Summary of types of seizure associated with brain tumours.





## Location of tumour in the brain

Look at the diagram below and identify the area(s) of the brain where your tumour is located. The following information can then be mapped to your personal situation.



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The following are examples of what can happen – you may experience something different.

## Temporal lobe

### Focal aware

- 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, like you may get on a fairground ride.

## **Focal impaired awareness**

- 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 focal aware seizure and usually last 2–3 minutes.

## **Frontal lobe**

### **Focal aware**

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

### **Focal impaired awareness**

- making strange movements or postures, such as cycling or kicking, usually at night
- screaming or crying out loudly or laughing uncontrollably.

These usually last 15–30 seconds.

## **Parietal lobe**

### **Focal aware**

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

## Focal impaired awareness

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

These are less common than temporal or frontal lobe focal impaired awareness seizures and usually last 15–30 seconds.

## Occipital lobe

### Focal aware

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

### Focal impaired awareness

- like the focal aware seizures in this lobe, these can affect your senses or vision.

These are less common than temporal or frontal lobe focal impaired awareness seizures and usually last 15–30 seconds.

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

For some people, focal onset aware seizures can spread to both sides of the brain. When this happens it's known as a **focal to bilateral** seizure.

If this happens quickly, you may not be aware that it started as a focal seizure.

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

Focal impaired awareness seizures can spread to become generalised seizures – usually tonic-clonic seizures.

## Generalised seizures

Though generalised seizures are rare in people with brain tumours, occasionally focal seizures can become generalised – usually as a type known as a tonic-clonic seizure (see below).

In generalised seizures, consciousness or awareness is always impaired. The person becomes unconscious, even if only for a few seconds, and is unlikely to remember what's happened.

Generalised seizures can also be non-motor or motor.

In generalised non-motor seizures, the person may appear absent or unresponsive, or may repeat words, sentences or actions that don't seem to make sense.

A generalised motor seizure is still referred to as a tonic-clonic seizure. This is where the muscles stiffen and relax, causing the body to jerk.

### **Tonic-clonic seizures**

(previously sometimes called *grand mal*).

These are the seizures most people think of as epilepsy.

- initially you'll 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.

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Your seizures may not be exactly like one of these, but for most people, they'll last the same time and follow the same pattern each time they happen.



## **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's 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. **DON'T** wait for 30 minutes.

## **Why do brain tumours cause epilepsy?**

Although epilepsy is more likely in certain low grade tumours, the exact reasons why they can cause epilepsy are not fully understood.

Suggestions include abnormally developed cells around the tumour that fire (send signals) more often, causing disorganised electrical activity in the brain, which leads to seizures. This is sometimes the cause in people with non-brain tumour-related epilepsy.

Or it could be due to the tumour causing a disturbance in the balance of chemicals in the brain, causing the nerve cells to fire more often.



It's important to know that an increase in the frequency of your seizures doesn't necessarily mean that your tumour has returned or is re-growing.

## What if I have further questions or need other support?

You can contact our Information and Support Team in the following ways:



**0808 800 0004**

(Free from landlines and most mobiles:  
3, O2, EE, Virgin and Vodafone)



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



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## About this information resource

The Brain Tumour Charity is proud to have been certified as a provider of high quality health and social care information by The Information Standard - an NHS standard that allows the public to identify reliable and trustworthy sources of information.

Written and edited by our Information and Support Team, the accuracy of medical information in this resource has been verified by leading health professionals specialising in neuro-oncology.

Our information resources have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

We hope that this information will complement the medical advice you've already been given. Please do continue to talk to your medical team if you're worried about any medical issues.

If you'd like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on **0808 800 0004** or  
**[support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)**



## About The Brain Tumour Charity

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 worldwide, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

We wouldn't be able to make the progress we have without the incredible input we receive from you, our community.

Whether it's reviewing our information resources, campaigning for change, reviewing research proposals or attending cheque presentations, everything you do helps to make a difference.

To find out more about the different ways you can get involved, please visit [thebraintumourcharity.org/volunteering](http://thebraintumourcharity.org/volunteering)

**We rely 100% on charitable donations to fund our work.**

If you would like to make a donation, or find out more about other ways to support us, including leaving a gift in your Will or fundraising through an event, please get in touch:

Visit

**[thebraintumourcharity.org/get-involved](http://thebraintumourcharity.org/get-involved)**

call us on 01252 749043 or email

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