
Seizures (epilepsy) and brain tumours - treatment

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:

- Treatments that are available
 - Anti-epileptic drugs
 - Surgery
 - Vagus nerve stimulation
 - Complementary therapies

This is the 2nd of 3 fact sheets on seizures and brain tumours.

Other fact sheets in the series are:

Seizures (epilepsy) and brain tumours—introduction.

Seizures (epilepsy) and brain tumours - living with

What treatments are available?

Treatment of seizures in people with a brain tumour can be difficult due to the additional impact of having a brain tumour and its treatment. The different types, locations and grades of brain tumour, the different tumour effects and treatments all interact with the variety of seizure types.

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

The following section looks at epilepsy treatments you may hear or read about and explains why they might, or might not, be suitable for treating brain tumour-related epilepsy (BTRE).

Anti-Epileptic Drugs (AEDs)

AEDs are the main form of treatment for most people with epilepsy, including people with a brain tumour.

AEDs cannot cure epilepsy, but they can help stop seizures from happening. You may have to have more than one AED.

The aim is to control seizures effectively while taking the fewest types of AEDs, at the lowest dose and with the least side-effects. This is called optimal therapy.

If you have a brain tumour and are thought to be at high risk of having a seizure, you may be given AEDs even before you've had a seizure. This may be the case if you're having surgery.



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

- 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).

You're likely to be given what are known as second generation (newer) drugs. These drugs are preferred for patients with a brain tumour because they tend to have fewer interactions with other drugs, less of a negative effect on other therapies you may be receiving, and have fewer side-effects.

They include:

- levetiracetam (Desitrend[®], Keppra[®])
- lamotrigine (Lamictal[®])
- lacosamide (Vimpat[®])
- pregabalin (Lyrica[®])
- tiagabine (Gabitril[®])
- brivaracetam (Briviact[®])
- zonisamide (Zonegran[®])
- oxcarbazepine (Trileptal[®])
- topiramate (Topamax[®])
- eslicarbazepine (Zebinix[®])
- perampanel (Fycompa[®])
- gabapentin (Neurontin[®]).

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

Pharmacoresistance

It's been found that if you don't respond to the first two drugs you're given, it's likely that you won't become seizure free with subsequent drugs.

It's not known why, but brain tumour-related epilepsy is more likely to be drug-resistant than non-brain tumour-related epilepsy. This is called pharmacoresistance.

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

If the second generation drugs don't work, you may be given first generation (traditional) drugs, such as:

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

Side-effects of AEDs

As with all medications, AEDs can have side-effects. These side-effects will depend on which drug you have and how you react to it. 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 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.

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're 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 of the first generation drugs are more likely to cause cognitive effects.

The Epilepsy Society has a list of AEDs with the common side-effects.
bit.ly/anti-epileptic-drugs

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

Drug-drug interaction

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

Surgery to reduce seizures

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 occasionally used to reduce or stop seizures.

Around 70% (or 7 in 10) people with a brain tumour, who have surgery to treat the seizures, find that it stops their seizures. However, this depends on how much of the tumour is removed and whether the area causing the epilepsy (the epileptogenic area) is also removed.

To achieve seizure freedom, or at least a good reduction, the whole tumour and epileptogenic area needs to be removed.

However, epilepsy surgery is only possible in a small number of brain tumour patients.

For people with low grade, slow growing tumours, surgery to remove the tumour may not be an option, because a major operation on the brain may cause more harm than good.

For more information, see our *Watch and wait (active monitoring)* webpage and fact sheet.

Or the location of your tumour may make surgery difficult – either because it's difficult to reach, or because it's near to important areas of the brain, such as those that control speech.

In both these cases, surgery to treat seizures would carry the same risk, and would only be considered if the seizures were debilitating or causing psychological or psychiatric issues.

If surgery for your brain tumour is an option, surgery for your seizures may still not be possible.

The exact location of the area causing the seizures (the epileptogenic area) needs to be established, i.e. how far around the tumour it spreads, or even if it's in the same location as the tumour.

If this covers a difficult to reach or important area of the brain, total removal of the epilepsy-causing area may not be possible. If total removal is not possible, the benefit from the likely reduction in seizure frequency may not outweigh the risk of surgery to the brain.

In addition, for people with high grade tumours, the tests to establish the exact location of the epileptogenic area can take time. This would delay the surgical treatment for the tumour, carrying obvious risks and often making such testing impossible.

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

Other treatments

Vagus nerve stimulation (VNS)

For people with epilepsy that is not controlled despite trying several AEDs (referred to as refractory or intractable epilepsy), or people who aren't eligible for (or don't want) brain surgery, VNS could be offered as a treatment option.

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 a particular nerve, called the vagus nerve, which then sends it onto the brain. Stimulating the vagus nerve seems to help calm down the irregular electrical brain activity that causes seizures.

However, it's important to know that VNS is rarely used for patients with brain tumours.

VNS must 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 brain tumours, particularly if they are fast growing, high grade tumours.

For some people it doesn't work at all.

Complementary therapies

There's a lot of 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's no scientific evidence to suggest that they do reduce seizures.

If you 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, or other treatments you're having for your brain tumour.

This includes any dietary or vitamin supplements and, particularly, herbal medicines, as some (such as 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 and low in carbohydrates (sugars), with a controlled protein content.

Originally used for treating epilepsy before AEDs were available, its use declined with the arrival of AEDs. However, in the last decade interest has grown again for controlling seizures that are not controlled by AEDs.

Most of the studies so far have been in children who don't have brain tumours, where it's 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, nor in people with brain tumours and epilepsy, so it's generally not been used for their treatment.

It's become of interest to brain tumour-related epilepsy patients because they sometimes find AEDs don't control their seizures (pharmacoresistance) and so look for alternative treatments.

How is the diet thought to work?

Our bodies usually use glucose (a type of carbohydrate) for energy. Reducing our intake of carbohydrates makes our bodies use the fats we eat to produce molecules called ketones and use these ketones for energy instead.

When ketones enter the brain, they appear to reduce seizure frequency. It's not known how they work, but they may alter the balance of chemicals involved in the electrical activity in the brain.

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

It's 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, while it's thought that tumour cells cannot. By reducing the tumour's energy source, it's hoped that the tumour growth may slow or stop.



If you're interested in the ketogenic diet, it's important to know that this diet in the treatment of epilepsy is a medical treatment.

You should only try this diet under the supervision and guidance of your doctor or dietitian.

This is because it can affect your standard treatment and interfere with observations of your condition by your medical team.

It can also cause side-effects, such as weight loss, constipation and fatigue. These may be short-term and your doctor/dietitian can help to alleviate or prevent these side-effects.



Anyone with a pre-existing medical condition, such as diabetes, should always consult their doctor before making significant dietary changes.

Cannabis

We regularly get asked about cannabis-based medicines and oils, for treating brain tumours and their side-effects, including seizures. If you are considering using any cannabis-based products you must be aware of the following:

- Legal issues

Cannabis and cannabis oil are classified as a class B drug in the UK, meaning that it is illegal to possess or supply it.

This is because they contain the cannabinoid known as THC, which causes the psychoactive effects of getting 'high'.

(Cannabinoids are various substances in cannabis that cause an effect on the cells in the body.)

It has sometimes been prescribed under special circumstances.

CBD oil (or cannabidiol) is different from cannabis oil in that it contains the cannabinoid CBD. This does not have psychoactive effects, but there is some evidence that it can affect positive effects on the body, e.g. pain relief, seizure reduction, in some people.

It is currently legal in the UK, as long as it has been produced from an EU approved strain of hemp AND as long as it is marketed as a food supplement without any medicinal claims.

- Interaction with medication you may be taking

Cannabis and its derivatives may interact with other medications you may be taking, such as anti-epileptic medicines, steroids or chemotherapy.

We would always recommend that any supplements or complementary treatments you are thinking of using should be discussed with your medical team.

For more information, see the following articles:

[*bit.ly/CannabisOilRightToChoose*](https://bit.ly/CannabisOilRightToChoose)

and

[*scienceblog.cancerresearchuk.org/2012/07/25/cannabis-cannabinoids-and-cancer-the-evidence-so-far*](https://scienceblog.cancerresearchuk.org/2012/07/25/cannabis-cannabinoids-and-cancer-the-evidence-so-far)

Resources

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

Epilepsy Action [*epilepsy.org.uk*](https://epilepsy.org.uk)

Epilepsy Society [*epilepsysociety.org.uk*](https://epilepsysociety.org.uk)

Epilepsy Scotland [*epilepsyscotland.org.uk*](https://epilepsyscotland.org.uk)

Epilepsy Wales [*public.epilepsy-wales.org.uk*](https://public.epilepsy-wales.org.uk)

Young Epilepsy [*youngepilepsy.org.uk*](https://youngepilepsy.org.uk)

(for children and young people under 25)

Matthews Friend's [*matthewsfriends.org*](https://matthewsfriends.org)

(provides information about dietary treatments for epilepsy)

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



Live Chat

Get in touch with us online via
thebraintumourcharity.org/live-chat



Join one (or more) of our
closed Facebook groups:
bit.ly/FBSupportGroups



thebraintumourcharity.org/getsupport

**Want to make a difference
through your diagnosis?**

BRIAN can help. Sign up at:
thebraintumourcharity.org/BRIAN

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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

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

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

call us on 01252 749043 or email

fundraising@thebraintumourcharity.org



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