

Seizures (epilepsy) and brain tumours

- living with

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:

- Living with seizures
 - Emotional aspects
 - Identifying triggers
 - Driving
 - Safety and first aid
 - Resources

This is the 3rd 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 - treatment.

Living with seizures

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 don't understand epilepsy. This can lead to a sense of insecurity.

People sometimes mention feeling socially isolated and that it's difficult to make and maintain social relationships, work etc.

You may also be 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 or GP – they can provide or signpost you to emotional, psychological and 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.

The Brain Tumour Charity has active Facebook support groups 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're not ready to speak to others directly, you can simply read about the experiences of others.

bit.ly/FBSupportGroups

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

thebraintumourcharity.org/get-support/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's also our Information and Support Line that you can call for free: 0808 800 0004 or email ***support@thebraintumourcharity.org*** or just chat to us online at ***thebraintumourcharity.org/live-chat***

Other suggestions which people told us have helped them deal with the emotional impact are more practical:

- Work with your healthcare team or GP to find the best treatment for you to reduce the frequency of seizures and reduce the emotional load.
- Minimise the effect of your seizures by looking at tips for safety in the home, when you're out, etc. With these in place it can help you feel more secure and/or more in control.

Identifying triggers

Triggers are situations that can bring on seizures in some people with epilepsy. It's important to know that they don't cause epilepsy and many people don't have any triggers.

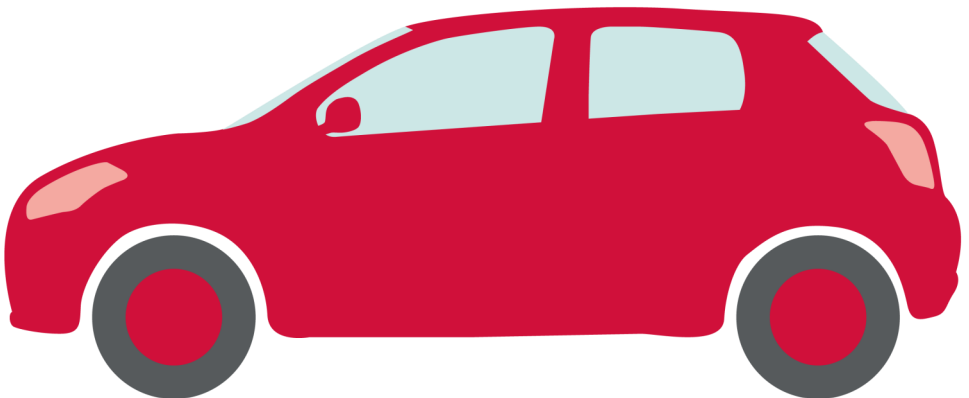
However, if you can identify any triggers, you may be able to avoid these and so reduce the chances of having a seizure.

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).

Driving

If you've been diagnosed with a brain tumour before you have a seizure, you'll probably have had to give up your driving licence. This is due to your increased risk of having a seizure.



However, it may be you've not yet given up your licence, e.g. a seizure was the symptom leading to a diagnosis of a brain tumour, or you've 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.

There are regulations relating to brain tumours and to epilepsy, which govern when and if you may be able to reapply to the DVLA (Driver and Vehicle Licensing Agency) for your licence.

For brain tumours, 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's likely to be more.

The length of time before you can reapply for your licence after a brain tumour diagnosis depends on:

- your type of tumour
- where it is in the brain
- your symptoms
- the treatment you've had
- whether you have any residual impairment likely to affect safe driving
- risk of further symptoms.

When you can apply to have your licence 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.

You must satisfy both sets of regulations to be able to get your licence back.

For more information, see our *Driving and brain tumours* webpage and fact sheet, and the DVLA's *Assessing fitness to drive* listed in the Resources section at the end of this fact sheet.

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 measures you may want to put in place. The Epilepsy Society has resources to help you think about this. bit.ly/epilepsy-risk-assessment

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, and 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, friends or work colleagues. 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



Caring for someone with a brain tumour can be emotionally stressful. It's important to look after yourself too.

See our *Being a carer – looking after yourself* webpage and fact sheet.

If you're 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's important that you know what to do to keep them safe when they have a seizure.



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 immediately.

Focal seizures

Depending on whether it's a focal aware or focal impaired awareness seizure, the person may not be aware of their surroundings or what they're doing.

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.

DON'T:

- restrain them
- act in a way that could frighten them, e.g. shout at them or make sudden movements
- assume they're aware of what is happening, or has happened
- give them anything to eat or drink unless they're fully recovered
- try to bring them round.

Call the ambulance if:

- you know it's their first seizure
- the seizure lasts more than five minutes
- they're injured during the seizure
- you believe they need urgent medical attention.

Generalised (tonic-clonic) seizures

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

DO:

- protect them 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

bit.ly/recovery-position

- stay with them until recovery is complete.

DON'T:

- restrain their movements or try to move them, unless they're in danger
- put anything in their mouths or give them anything to eat or drink unless they're fully recovered
- try to bring them round.

Call the ambulance if:

- you know it's their first seizure
- the seizure lasts more than five minutes
- one tonic-clonic seizure follows another without them regaining consciousness inbetween
- they're injured during the seizure
- you believe they need 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.

bit.ly/epilepsy-app

Other ways you could help:

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

Resources

DVLA Assessing fitness to drive – a guide for medical professionals

bit.ly/fitness-to-drive

gov.uk/guidance/general-information-assessing-fitness-to-drive

gov.uk/epilepsy-and-driving

gov.uk/brain-tumour-and-driving

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

Epilepsy Action ***epilepsy.org.uk***

Epilepsy Society ***epilepsysociety.org.uk***

Epilepsy Scotland ***epilepsyscotland.org.uk***

Epilepsy Wales ***public.epilepsy-wales.org.uk***

Young Epilepsy ***youngepilepsy.org.uk***
(for children and young people under 25)

Matthews Friend's ***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**

Disclaimer: This resource contains information and general advice. It should not be used as a substitute for personalised advice from a qualified specialist professional. We strive to make sure that the content is accurate and up-to-date, but information can change over time. Patients must seek advice from their medical teams before beginning or refraining from taking any medication or treatment. The Brain Tumour Charity does not accept any liability to any person arising from the use of this resource.

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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Registered Office:

Hartshead House
61-65 Victoria Road
Farnborough
Hampshire
GU14 7PA

01252 749990

enquiries@thebraintumourcharity.org

