# epilepsy action

# Epileptic seizures explained



epilepsy.org.uk Epilepsy Action Helpline: 0808 800 5050

# **Epilepsy Action – together we can change lives**

Together we can help more people gain the knowledge and confidence to live better with epilepsy. We can raise awareness, so that more people understand epilepsy.

#### Together we can:

- Provide expert information and advice, so everyone affected by epilepsy can get the support they need to live better with epilepsy
- Run local events and support groups, so that fewer people have to face epilepsy alone
- Campaign to help make sure health services and national policies take into account the needs of everyone living with epilepsy

It's only your support that can make this life-changing work possible.

#### Please donate today.

You can call the Epilepsy Action fundraising team on 0113 210 8851 or donate online at epilepsy.org.uk/donate
You can also stay up-to-date with all the latest epilepsy news and information by joining Epilepsy Action. Membership starts from just £1 a month - join today by calling 0113 210 8800 or sign up online at epilepsy.org.uk/join

Thank you.



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# Introduction

If you have epilepsy, it means you have a tendency to have epileptic seizures. But what are epileptic seizures?

Electrical activity is happening in our brain all the time, as networks of tiny brain cells send messages to each other. These messages control all our thoughts, movements, senses and body functions. A seizure happens when there is a sudden, intense burst of electrical activity in the brain. This causes the messages between cells to get mixed up. The result is an epileptic seizure.

How a seizure affects you depends on what area of the brain is involved in this intense electrical activity. You might lose consciousness, or you might stay aware of what's happening around you. You might have strange sensations, or movements you can't control. Or you might go stiff, fall to the floor and shake.

Some people only have one type of seizure, and some people have more than one type.

This booklet explains some of the most common seizure types. If you would like to know how epileptic seizures are diagnosed and treated visit epilepsy.org.uk or contact the Epilepsy Action Helpline. See page 27 for details.

Our short online first aid course shows you what different seizures can look like, and how to help when someone has one. Visit **epilepsy.org.uk/aid** 

#### The structure of the brain

To understand epileptic seizures, it's useful to know a little about the structure of the brain.

The largest part of the brain is called the cerebrum, and this is divided into two halves, called hemispheres. Epileptic seizures can start in one hemisphere, or affect both hemispheres from the start. Where a seizure starts is known as the seizure onset.

#### Focal onset

Focal seizures (also called focal onset seizures) start in one hemisphere of the brain. Sometimes, a focal seizure can start in one hemisphere and then spread to involve both hemispheres of the brain.

#### **Generalised** onset

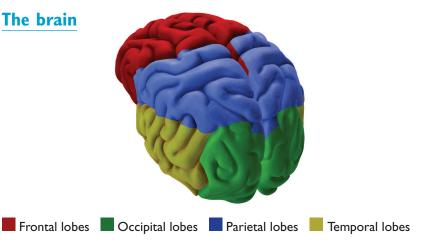
Generalised seizures (also called generalised onset seizures) affect both hemispheres of the brain from the start.

#### The lobes of the brain

Each hemisphere of the brain has four parts, called lobes, and each lobe is responsible for different functions. In our information about focal seizures on page 7 we talk more about the symptoms of seizures in different lobes.

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#### The brain



#### Frontal lobes

- · Personality, behaviour and emotions
- · Judgement, planning and problem solving
- Body movement
- Intelligence, concentration and self-awareness

#### **Occipital lobes**

• Processing visual information

#### **Parietal lobes**

- Processing language
- Interpreting the signals from our senses of touch, vision and hearing
- Understanding space and distance (spatial perception)

#### **Temporal lobes**

- Understanding language
- Memory
- Hearing

#### **Focal seizures**

When an epileptic seizure starts in one side of the brain, it's called a focal onset seizure or a focal seizure. Until recently these seizures were called partial seizures.

# What are the different types of focal seizure?

Focal seizures can be split into two main types according to what level of awareness you have during the seizure.

#### Focal aware seizure

During a focal aware seizure, you stay fully aware of what's happening around you, even if you can't move or respond. This type of seizure used to be called a simple partial seizure.

#### Focal impaired awareness seizure

If your awareness of what's happening around you is affected at any time during your seizure, it's called a focal impaired awareness seizure. This type of seizure used to be called a complex partial seizure.

#### Motor or non-motor

Doctors may also use the words motor or non-motor to describe focal seizures. Focal motor describes focal seizures where the main symptoms involve muscle activity, such as jerking, loss of muscle tone or repeated movements. Focal non-motor describes seizures where the main symptoms don't involve muscle activity. They can include things like changes in emotions, thinking and sensations.

# What happens during a focal seizure?

What happens during a focal seizure depends on which area (lobe) of the brain is affected, and whether the seizure spreads to affect other areas. Some people just experience one symptom during a focal seizure, while others experience several.

#### **Frontal lobes**

The symptoms of frontal lobe seizures can sometimes be mistaken for mental health problems or sleep disorders. Some people who have frontal lobe seizures only have them in their sleep. They are usually brief, but often happen in clusters, with several happening in a short space of time. Your awareness may or may not be affected.

Symptoms of seizures in the frontal lobes can include:

- Pelvic thrusting, kicking, pedalling, thrashing or rocking movements
- Screaming, swearing or laughing
- Unintentionally passing urine (urinary incontinence)
- · Your head or eyes turning to one side
- Having unusual body movements, such as stretching one arm while the other bends
- Twitching, jerking or stiffening of muscles in one area of your body. The movements may sometimes spread bit by bit to other areas

#### **Occipital lobes**

Seizures starting in the occipital lobe often spread to involve other lobes.

Symptoms of seizures starting in the occipital lobe include:

- Seeing flashing lights, colours or simple patterns
- Seeing more complex images, such as pictures of people, animals or scenes
- Not being able to see as well as usual, or not being able to see at all
- Having eye movements you can't control, such as your eyes closing, moving to one side or rapidly moving from side-toside
- Eyelid fluttering

#### **Parietal lobes**

Seizures starting in the parietal lobe often spread to involve other lobes.

Symptoms of seizures starting in the parietal lobes can include:

- Having feelings of numbness or tingling
- Prickling, crawling or electric-shock sensations, which may spread along the affected body part
- Sensations of burning, cold or pain
- · Feeling like part or all of your body is moving or floating
- · Feeling like a body part has shrunk, enlarged or is missing
- Sexual sensations
- Difficulty understanding language, reading, writing or doing simple maths
- Seeing things as larger or smaller than they really are, or seeing things that aren't there

#### **Temporal lobes**

If you have been diagnosed with temporal lobe epilepsy it means you have seizures starting in one or other of the temporal lobes. Seizures starting in the temporal lobes are usually focal impaired awareness seizures, but focal aware seizures can also happen. You might start the seizure being aware of what's happening, and then lose awareness as the seizure progresses.

Symptoms of seizures in the temporal lobes include:

· Feeling frightened

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- Feeling like what's happening has happened before (deja vu)
- Hearing things that aren't there
- Experiencing an unpleasant taste or smell
- Having a rising sensation in your stomach
- · Lip smacking, repeated swallowing or chewing
- Changes to your skin tone or heart rate
- Automatic behaviours such as fidgeting, undressing, running or walking

After a temporal lobe seizure you are likely to be confused, and may find it hard to speak for a short time.

# How long do focal seizures last?

Most focal aware seizures are brief, lasting between a few seconds and two minutes. Focal impaired awareness seizures usually last between one and two minutes.

# What happens after a focal seizure?

What happens after a focal seizure varies from person to person. You might feel fine after a focal seizure and be able to get back to what you were doing straight away. Or you might feel confused or tired for some time afterwards. You might need to sleep.

Some people find they have temporary weakness or can't move part of their body after they've had a seizure. This is called Todd's paresis or Todd's paralysis. It can last from a few minutes up to 36 hours, before going away.



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### **Tonic-clonic seizures**

Tonic-clonic seizures are the type of epileptic seizure most people recognise. In the past they were called grand-mal seizures.

Tonic-clonic seizures can have a generalised onset, meaning they affect both sides of the brain from the start. When this happens, the seizure is called a generalised tonic-clonic or bilateral convulsive seizure.

Some seizures start in one side of the brain and then spread to affect both sides. When this happens it's called a focal to bilateral tonic-clonic seizure.



# What happens during a tonic-clonic seizure?

There are two phases in a tonic-clonic seizure: the 'tonic' phase, followed by the 'clonic' phase.

#### During the tonic phase:

- You lose consciousness, so you won't be aware of what's happening
- All your muscles go stiff, and if you're standing you fall to the floor
- Air might push past your voice box, which can make a sound like you're crying out
- You may bite down on your tongue or inside your mouth

#### During the clonic phase:

- Your limbs jerk quickly and rhythmically
- · You may lose control of your bladder and/or bowels
- You might have difficulty breathing, causing a blue tinge around your mouth

#### Focal to bilateral tonic-clonic seizures

If the seizure starts on one side of the brain and spreads to affect both sides, it's called a focal to bilateral tonic-clonic seizure. If you have this type of seizure, you might get the symptoms of a focal seizure immediately before you lose consciousness. Examples of these symptoms are feeling frightened, having a rising sensation in your stomach or smelling something that's not there. This can act as a warning that you're about to have a tonic-clonic seizure. Some people call this warning an aura.

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# How long do tonic-clonic seizures last?

Most tonic-clonic seizures last between one and three minutes. If a tonic-clonic seizure lasts longer than five minutes you may need emergency medical treatment (see page 20).

# What happens after a tonic-clonic seizure?

After a tonic-clonic seizure, you might have a headache and feel sore, tired and very unwell. You might feel confused, or have memory problems. You might go into a deep sleep. When you wake up, minutes or hours later, you might still have a headache, feel sore and have aching muscles.

The length of time it takes to recover after a tonic-clonic seizure is different from one person to the next. Some people feel better after an hour or two, but for some people it can take several days to feel 'back to normal'.

Some people find they have temporary weakness or can't move part of their body after they've had a seizure. This is called Todd's paresis or Todd's paralysis. It can last from a few minutes up to 36 hours, before going away.

# **Absence seizures**

Absence seizures are a type of generalised onset seizure, meaning both sides of your brain are affected from the start. In the past, absence seizures were called petit-mal seizures.

The two most common types of absence seizure are typical and atypical.

# What happens during an absence seizure?

#### **Typical absences**

If you are having a typical absence seizure, you will be unconscious for a few seconds. You will suddenly stop doing whatever you were doing before it started, but will not fall. You might appear to be daydreaming or 'switching off' or people around you might not notice your absence seizure. Your eyelids might flutter and you might have slight jerking movements of your body or limbs. In longer absences, you might have some brief, repeated actions. You won't know what is happening around you, and can't be brought out of it.

Some people have hundreds of absences a day. They often have them in clusters of several, one after another, and they are often worse when they are waking up or drifting off to sleep. Typical absence seizures almost always start in childhood before the age of 14.

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#### **Atypical absences**

These absences are similar to, but not the same as, typical absences. They last longer, and they start and end more slowly. You might be able to move around, but your muscles might go limp or 'floppy', making you clumsy. You may be able to respond to someone during an atypical absence seizure.

People who have atypical absences usually have learning disabilities or other conditions that affect the brain. Atypical absences can happen at any age.

# How long do absence seizures last?

A single typical absence seizure usually lasts less than 10 seconds. But some people have clusters of absences one after another.

Atypical absence seizures last longer, up to 30 seconds.

#### What happens after an absence seizure?

After an absence seizure, you're normally able to go straight back to what you were doing beforehand. If you've had a cluster of several absence seizures you might feel confused.

# **Myoclonic seizures**

Myoclonic seizures can be generalised onset, meaning both sides of the brain are affected from the start, or they can be focal onset, meaning just one side is affected.

# What happens during a myoclonic seizure?

Myoclonic seizures are sudden, short-lasting jerks that can affect some or all of your body. They are usually too short to affect your consciousness. The jerking can be very mild, like a twitch, or it can be very forceful. Sometimes if the jerk is very forceful it can make you throw something you're holding, or make you fall over.

# How long do myoclonic seizures last?

Myoclonic seizures usually only last for a fraction of a second. However, some people have them in clusters of several seizures over a period of time.

# What happens after a myoclonic seizure?

After a myoclonic seizure you're usually able to get back to what you were doing straight away.

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# **Tonic seizures**

Tonic seizures can be generalised onset, meaning they affect both sides of the brain from the start. Or they can be focal onset, meaning they start in just one side of the brain.

# What happens during a tonic seizure?

If a tonic seizure starts in both sides of the brain, all your muscles tighten and your body goes stiff. If you're standing, you may fall to the floor. Your neck will extend, your eyes open wide and roll upwards. Your arms may raise upwards and your legs stretch or contract. You may cry out and stop breathing during the seizure.

If a tonic seizure starts in one side of the brain your muscles tighten in just one area of the body.

# How long do tonic seizures last?

Tonic seizures usually last less than 60 seconds.

# What happens after a tonic seizure?

Once a tonic seizure has ended your muscles relax. You might feel sleepy or confused afterwards.

# **Atonic seizures**

Atonic seizures can be generalised onset, meaning they affect both sides of the brain from the start. Or they can be focal onset, meaning they start in just one side of the brain. Atonic seizures are sometimes called drop attacks.

# What happens during an atonic seizure?

If you have atonic seizures, usually all your muscles go limp and you drop to the floor. This can result in injuries to your head, nose or face. Sometimes you might not completely fall, but your head may drop forward or you might sag at the knees.

#### How long do atonic seizures last?

Atonic seizures are very brief, usually lasting just one or two seconds.

#### What happens after an atonic seizure?

Your muscle tone returns as soon as the seizure is over. If you've fallen, you can get up again straight away.

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# **Status epilepticus**

Most people with epilepsy have seizures that last a short time and stop by themselves. But sometimes, a seizure can last too long and become status epilepticus. Status epilepticus happens when a seizure doesn't stop in the usual time, or when someone has seizures one after another without recovering in between.

Status epilepticus can happen with any type of seizure, but convulsive (tonic-clonic) status epilepticus is the most dangerous. Convulsive status epilepticus is when a tonic-clonic seizure lasts for five minutes or longer, or when one tonic-clonic seizure follows another without regaining consciousness in between. Convulsive status epilepticus is always a medical emergency.

Contact Epilepsy Action for more information about status epilepticus and emergency treatment.



# **About this publication**

This booklet is written by Epilepsy Action's advice and information team, with guidance and input from people living with epilepsy, and medical experts. If you would like to know where our information is from, or there is anything else you would like to say about this booklet, please contact us.

To find out why you can trust Epilepsy Action's information, please contact us or visit **epilepsy.org.uk/trust** 

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Epilepsy Action would like to thank Dr John Paul Leach, consultant neurologist at the Queen Elizabeth University Hospital, Glasgow, for his contribution to this information. Dr Leach has declared no conflict of interest.

### **Disclaimer**

Epilepsy Action makes every effort to ensure the accuracy of information in its publications but cannot be held liable for any actions taken based on this information.

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# First aid for tonic-clonic seizures

The person goes stiff, loses consciousness and falls to the floor.

#### **Do...**

- Protect the person from injury (remove harmful objects from nearby)
- Cushion their head
- Aid breathing by gently placing the person on their side (in the recovery position) when the seizure has finished (see picture)
- Stay with them until recovery is complete
- Be calmly reassuring



#### Don't...

- Restrain the person's movements
- Put anything in their mouth
- Try to move them unless they are in danger
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

### Call 999 for an ambulance if...

- You know it is the person's first seizure or
- The seizure continues for more than five minutes or
- One seizure follows another without the person regaining consciousness between seizures **or**
- The person is injured **or**
- You believe the person needs urgent medical attention

# First aid for focal (partial) seizures

The person is not aware of their surroundings or of what they are doing. They may pluck at their clothes, smack their lips, swallow repeatedly or wander around.

#### Do...

- Guide the person away from danger
- Stay with the person until recovery is complete
- · Be calmly reassuring
- · Explain anything that they may have missed

#### Don't...

- Restrain the person
- Act in a way that could frighten them, such as making abrupt movements or shouting at them
- Assume the person is aware of what is happening, or what has happened
- · Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

#### Call 999 for an ambulance if...

- You know it is the person's first seizure or
- The seizure continues for more than five minutes or
- The person is injured **or**
- You believe the person needs urgent medical attention

Epilepsy Action has information on what to do if someone has a seizure in a wheelchair.

# **Further information**

If you have any questions about epilepsy, please contact the Epilepsy Action Helpline.

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Information is available in the following formats: booklets, fact sheets, posters, books and DVDs.

# Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue. Or download a copy at epilepsy.org.uk/catalogue

# **Epilepsy Action's support services**

**Local meetings:** a number of local branches offer support across England, Northern Ireland and Wales.

**Coffee and chat groups:** these give people living with epilepsy the chance to meet new people, share experiences and learn more about life with epilepsy.

**forum4e:** our online community is for people with epilepsy and carers of people with epilepsy. You have to be aged 16 or over to join. Go to forum.epilepsy.org.uk

**Epilepsy awareness:** Epilepsy Action has a number of trained volunteers who deliver epilepsy awareness sessions to any organisation that would like to learn more about epilepsy. The volunteers are able to offer a comprehensive introduction to epilepsy to a range of audiences.

If you would like more information about any of these services, please contact Epilepsy Action. Contact details are at the back of this booklet.

# **Epileptic seizures explained**

We would like to know if you have found this booklet helpful.

As a result of reading the information, please let us know if you agree (tick yes) or disagree (tick no) with any of the following statements.

Yes	No	
		I feel more informed about issues to do with epilepsy
		I feel more confident about talking to my GP/epilepsy specialist/epilepsy nurse/other (cross out those that don't apply)
		I have talked to my employer/colleague/teacher/family/ other (cross out those that don't apply) and they have improved how well they support me
		I have used other Epilepsy Action services, such as the website, the Epilepsy Action Helpline, support groups or forum4e

Please tell us how you think we can improve this information							

Please return the completed form to:

FREEPOST RTGS-LEYK-XGCK, Epilepsy Services, Epilepsy Action, New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY

You can also give us feedback online. Visit epilepsy.org.uk/feedback

Thank you.

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# **Ways to contact the Epilepsy Action Helpline**

#### freephone 0808 800 5050

We are usually open 8.30am to 8pm, Monday to Thursday, 8.30am to 4.30pm on Friday and 10am to 4pm on Saturday. Our helpline staff are Text Relay trained and we are able to offer advice and information in 150 languages. To ensure the quality of our service, we may monitor calls.

#### M helpline@epilepsy.org.uk

Email us your question about epilepsy. We aim to reply within 48 hours (on work days)

#### 0753 741 0044

Text us and we aim to send a text reply back to your phone within 24 hours (on work days)

# @epilepsyadvice

Tweet us with your question and we will tweet back (on work days)

New Anstey House, Gate Way Drive, Yeadon, Leeds, LS19 7XY Write to us and we aim to reply within seven working days

# **About the Epilepsy Action Helpline**

#### We do:

- Provide confidential advice and information about epilepsy to anyone
- Give general medical information
- · Give general information on legal and welfare benefit issues related to epilepsy

#### We do not:

- Tell people what to do
- Offer a medical diagnosis or suggest treatment
- Take up people's legal cases on their behalf

If we cannot help you directly with a query, we will do our best to provide details of other organisations that may be able to help. In doing this, Epilepsy Action is not making a recommendation.

We welcome feedback, both positive and negative, about our services.







# **Epilepsy Action Helpline:**

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#### **Epilepsy Action**

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