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 donations like yours that make this life-changing work possible.

Please donate today.

Text ACT NOW to 70700 to give £5 (message will cost £5 plus your usual cost of sending a text, Epilepsy Action will receive 100% of your donation).

You can also join Epilepsy Action and add your voice to the UK’s biggest epilepsy movement. Together we can campaign for change, support each other and fight for a better future.

Find out more by calling the Epilepsy Action membership team on 0113 210 8800 or visit 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, which 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 how seizures are classified, and tells you about 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/training
Seizure classification

There are many different types of epileptic seizure. Seizure classification is a way of naming different types of epileptic seizures and putting them into groups. It’s important for healthcare professionals to all use the same names for seizures to avoid confusion. Being able to recognise and name a seizure accurately is also important, because some medicines and treatments can help some seizure types but not others.

How has seizure classification changed?

The International League Against Epilepsy (ILAE) is a world-wide organisation of epilepsy professionals. In 2017 they announced a different way of organising and naming seizures. Many of the
names for seizures are the same as before. But the ILAE has also introduced some new names for seizures, for example focal aware instead of simple partial. The new names don’t change what happens during seizures, but they do give doctors a more accurate way to describe them.

**How does the new seizure classification work?**

To name a seizure using the new classification, doctors look at three things:

1. Where in your brain the seizure starts
2. Your level of awareness during the seizure
3. Whether the seizure involves movement or not

**1. Where the seizure starts (the onset)**

**Focal onset** means the seizure starts in just one side of the brain. These seizures used to be called partial seizures. Sometimes, a seizure can start as a focal seizure and then spread to involve both sides of the brain. When this happens, it’s called a focal to bilateral tonic-clonic seizure (see page 13).

**Generalised onset** means the seizure affects both sides of the brain from the start.

**Unknown onset** means the beginning of the seizure is not clear. As doctors get more information about the seizure, they may be able to decide if it is focal or generalised in onset.

Rarely, doctors might be sure that someone has had an epileptic seizure, but can’t decide what type of seizure it is. This could be
because they don’t have enough information about the seizure, or the symptoms of the seizure are unusual. When this happens, it’s called an unclassified seizure.

2. The level of awareness

Focal onset seizures can be put into one of two groups depending on what level of awareness you have during the seizure.

Focal aware
During a focal aware seizure, you stay fully aware of what’s happening around you, even if you can’t talk or respond. These seizures used to be called simple partial seizures.
Focal impaired awareness

If your awareness is affected at any time during a focal seizure, it’s called a focal impaired awareness seizure. This replaces the term complex partial seizure.

Generalised onset seizures almost always affect your awareness in some way, so the terms ‘aware’ or ‘impaired awareness’ aren’t used for them.

3. Whether the seizure involves movement or not

Seizures can also be split into motor seizures, which means they involve movement, or non-motor seizures, which means they don’t involve movement.

Motor seizures

A motor seizure is any seizure that involves a change in your movement. For example, a tonic-clonic seizure – where all your muscles go stiff before making rhythmic jerking movements – is a type of motor seizure.

Focal seizures can also be motor seizures if the main symptom involves movement, for example automatic behaviour like plucking at clothes or repeated swallowing.

Non-motor seizures

A non-motor seizure is any seizure that doesn’t involve changes in movement. A focal seizure where your main symptom is a change in vision, smell or hearing is a type of non-motor seizure. Absence seizures are also non-motor seizures.
Focal seizures
When an epileptic seizure starts in one side of the brain, it’s called a focal onset seizure or a focal seizure. Both terms mean the same thing. Until recently these seizures were called partial seizures.

What are the main types of focal seizure?
There are two main types of focal seizure.

Focal aware seizures
During a focal aware seizure, you stay fully aware of what’s happening around you. This type of seizure used to be called a simple partial seizure.

Focal impaired awareness seizures
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.

What happens during a focal seizure?
What happens to you during a focal seizure depends on which part of the brain the seizure happens in. This is because different areas of the brain control movements, body functions, feelings and reactions. Some people experience just one symptom during a focal seizure, while others experience several.
The symptoms of focal seizures can be split into two groups. Symptoms that involve movement are called motor symptoms. Symptoms that don’t involve movement are called non-motor symptoms. Here are some examples:

**Motor symptoms**
- Part of your body, for example one arm, going stiff
- Part of your body going limp or ‘floppy’
- Rhythmic jerking in part of your body
- Brief, irregular jerks in part of your body
- Your head and eyes turning to one side
- Lip smacking, repeated swallowing or chewing
- A jerking movement that starts in one part of your body – usually your hand or face – and then spreads bit by bit to other parts of your body
- Having repeated movements such as rocking, pedalling or pelvic thrusting
- Undressing
- Running or walking

**Non-motor symptoms**
- Feelings of fear, anxiety, anger or pleasure
- Changes to your vision, hearing, smell or taste
- Having sensations of being hot or cold
- Seeing or hearing things that aren’t there (hallucinations)
- Feeling like your body is distorted
- Feeling like part of your body is missing or doesn’t belong to you
- Feeling or being sick
- Changes to breathing, heart-rate or skin tone
- Feeling like what’s happening has happened before (deja vu)
- Difficulty processing language
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.
**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. Or they can 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
- Your breathing may be affected, 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 (see page 14) 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.
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.

Epilepsy Action has more information about treatment and care for seizures that last more than five minutes.

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 used to be 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. 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 usually start in childhood or early adulthood.

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 are also called myoclonic jerks. They 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.
**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.
Status epilepticus

Most people have seizures that last for less than five minutes and stop without any treatment. However, some people have seizures that last longer than five minutes. Epileptic seizures that last longer than 30 minutes can cause damage to the brain, or even death. This is also the case for a cluster of shorter seizures that last for 30 minutes or more. In both cases, this is known as status epilepticus. Seizures lasting for more than five minutes need emergency treatment before they turn into status epilepticus.

Epilepsy Action has more information about treatment and care for seizures that last more than five minutes.
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. 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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Our thanks

Epilepsy Action would like to thank Professor Helen Cross for her contribution to this information. Professor Cross is The Prince of Wales’s Chair of Childhood Epilepsy and Honorary Consultant in Paediatric Neurology at UCL Institute of Child Health and Great Ormond Street Hospital for Children.

Professor Cross has declared no conflict of interest.
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.

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Please tell us how you think we can improve this information

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

Registered charity in England (No. 234343)
Ways to contact the Epilepsy Action Helpline

**Telephone:** freephone 0808 800 5050
We are usually open 8.30am to 5.30pm, Monday to Friday. 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.

**Email:** helpline@epilepsy.org.uk
Email us your question about epilepsy. We aim to reply within 48 hours (on work days)

**Text:** 0753 741 0044
Text us and we aim to send a text reply back to your phone within 24 hours (on work days)

**Twitter:** @epilepsyadvice
Tweet us with your question and we will tweet back (on work days)

**Post:** New Anstey House, Gateway Drive, 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:
freephone 0808 800 5050
epilepsy.org.uk

Epilepsy Action
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY
tel 0113 210 8800 email epilepsy@epilepsy.org.uk

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