

**epilepsy action**

# Understanding epilepsy: One hour briefing


## Welcome

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## Housekeeping



- Please mute your microphone
- Feel free to ask any questions in the chat and I'll answer them at the end

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## Who we are

We are Epilepsy Action.

We fight for a better, fairer future for all people with epilepsy.



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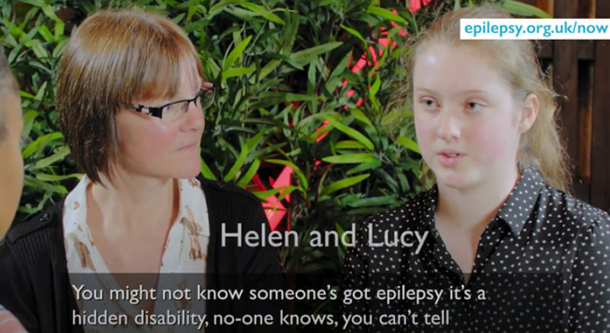
## What we will talk about today

- What is epilepsy?
- What causes a seizure?
- How many people have epilepsy?
- How can I help someone having a seizure?
- Epilepsy is more than seizures
- How can I help someone live well with epilepsy?
- Where can I get more information?

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[epilepsy.org.uk/now](http://epilepsy.org.uk/now)

Helen and Lucy

You might not know someone's got epilepsy it's a hidden disability, no-one knows, you can't tell

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# What is epilepsy?

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- **An epileptic seizure**
  - is caused by a sudden burst of intense electrical activity in the brain.
- **Epilepsy is...**
  - a tendency to have recurrent seizures.



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**Epilepsy can appear very different**



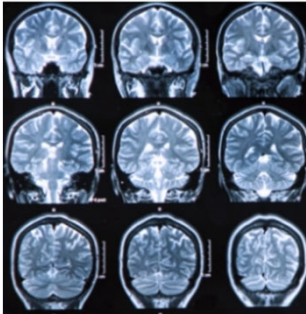
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**Seizure types**

Each has different symptoms depending on

- Which part or parts of the brain are affected
- How far and fast it spreads



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**Focal seizures**

Focal seizures start in just one part of the brain.

Two main categories

- Focal aware
- Focal impaired awareness




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**Generalised onset seizures**

- Generalised seizures affect both sides of the brain
- During this type of seizure the person is usually unconscious
- Absence and tonic-clonic seizures are generalised seizures



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**What causes a seizure?**

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Epilepsy can start at any age

It can be a result of:

- Brain damage
- Brain tumours
- Problems with brain development
- Genetic factors

Over half the people with epilepsy don't know what caused it

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What can trigger seizures?

Only 3 out of every 100 people with epilepsy have photosensitive epilepsy



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What can trigger seizures?

- Missing doses of epilepsy medicine
- Stress
- Feeling tired/lack of sleep
- Alcohol
- Missing meals
- Menstrual cycle

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How many people have epilepsy?

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How many people have epilepsy in the UK?



**1 in 103**  
people have epilepsy

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Every day, 87 people receive diagnosis of epilepsy

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## How can I help someone having a seizure?

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### First aid for focal seizure

- Be calm and reassuring
- Keep them safe, guide them from any danger
- Let the seizure take its course
- Stay with them until recovery is complete
- Only offer them something to drink or eat after they have recovered

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### First aid - tonic-clonic seizures

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**A** Assess  
**C** Cushion  
**T** Time  
**I** Identity  
**O** Over  
**N** Never

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

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

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### After the seizure...

- The person may be confused or have memory problems
- The person may need to sleep
- The person may have a headache and aching limbs
- Recovery time varies depending on the person

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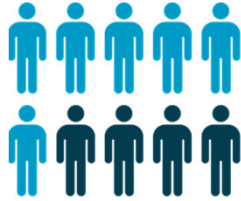
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# Epilepsy is much more than seizures

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**60%**  
For about 60% of people with epilepsy, taking epilepsy medicine controls their seizures

These often come with side effects

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## Wellbeing can be impacted

- Exhaustion
- Memory problems
- Frustration
- Uncertainty
- Fear or anxiety
- Independence

Epilepsy doesn't just affect the person with epilepsy but also their friends, family and carers

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Everyone's epilepsy is different

- Different
  - Seizures
  - Triggers
  - Recovery
  - Frequency
  - Side effects



Seizures are rarely predictable

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# How can I help someone live well with epilepsy?

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## Living well with epilepsy

- Be understanding
- Listen to how epilepsy presents itself in an individual
- Be aware of their seizure triggers
- Ensure a care plan is in place
- Conduct risk assessments
- Make any relevant reasonable adjustments
- Help them keep a seizure diary

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## Employer toolkit

Supporting employees with epilepsy in the workplace <https://employers.epilepsy.org.uk/>

Supporting employees Recruitment

About epilepsy Issues in the workplace Safety

Reasonable adjustments First aid for seizures F8Ds

The workplace

Solutions action plan  
Risk assessment  
Education plan  
The workplace

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# Where can I get more information?

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## Support is available

- Epilepsy Action Helpline
  - Freephone 0808 800 5050
  - helpline@epilepsy.org.uk
- Virtual and face to face groups
  - Meet others for peer support
- Online courses
  - Epilepsy and you
  - My child and epilepsy

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## Information

- About epilepsy
- Diagnosis
- Treatment & medicines
- Wellbeing
- Daily life
- Children

[www.epilepsy.org.uk](http://www.epilepsy.org.uk)

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

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## Summary...

- Epilepsy is a complex condition
- It can affect people in many different ways
- There are some occasions when people with epilepsy might need extra support and understanding
- In other situations, people might not need any extra support
- Many people can, and do, live well with epilepsy

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# Thank you

## Any questions?

Epilepsy Action Helpline  
Freephone 0808 800 5050

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