# Epilepsy

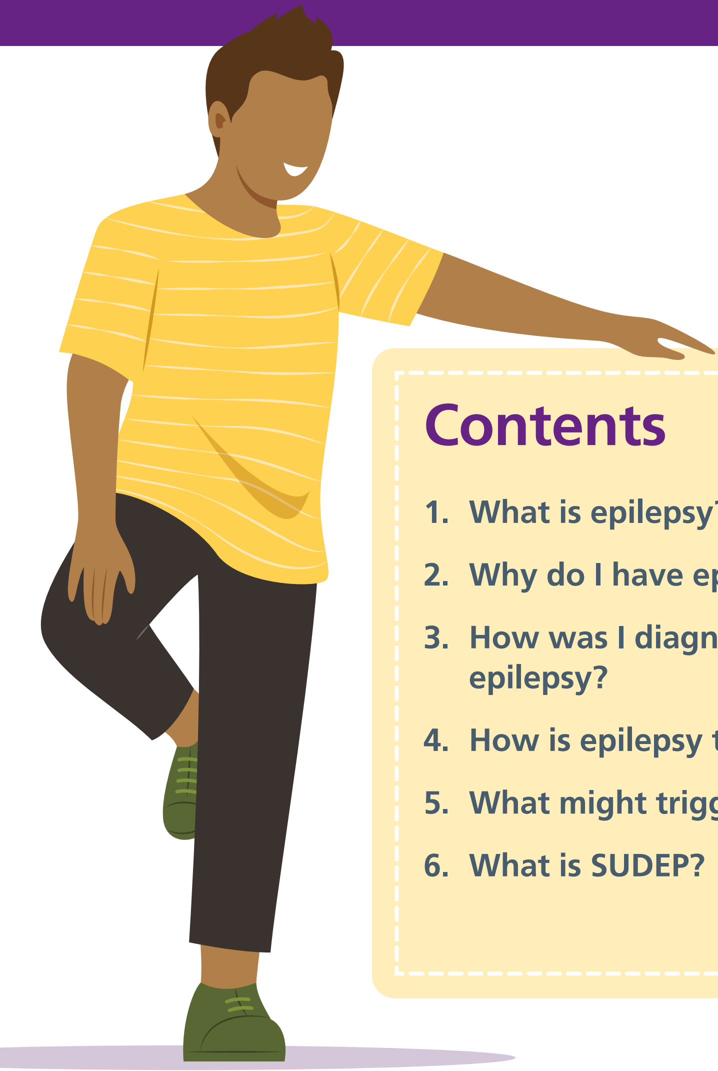
## Teenage Transition 1

# Welcome to your first teenage clinic.

## How is this clinic different?

When you reach 16 your epilepsy care will be managed by the adult neurology team.

To make sure you are ready for this we have made 3 booklets, and you will be invited to special teenage (transition) clinics. This will help you understand more about epilepsy, how epilepsy might affect you, and how to manage your epilepsy.



## Contents

# 1

# What is epilepsy?

Epilepsy is a condition that affects your brain. When you have a seizure, your brain stops working properly. Your brain has lots of neurones which pass electrical messages along them. A seizure happens when the electrical messages misfire causing the information to be jumbled.

Sometimes this can happen in a small bit of your brain called a lobe (a focal seizure); sometimes it is in the whole of your brain (a generalised seizure). To work out what sort of seizures you have we will ask you and the people who saw it what happened and what it looked like.

## My seizures look like this

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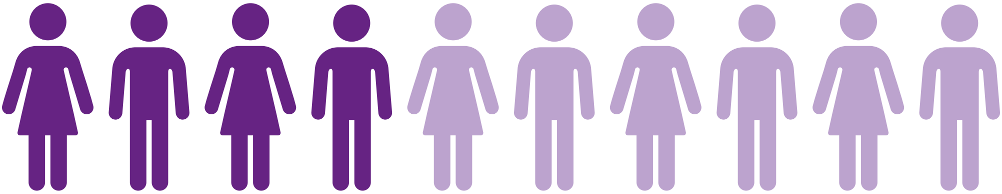
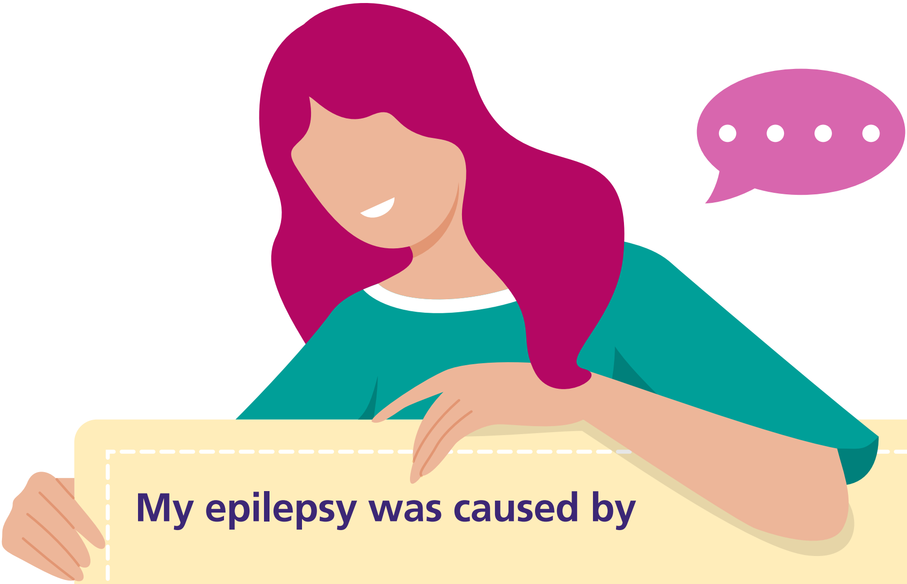
# Why do I have epilepsy?

Epilepsy is a common condition: 1 in 240 children have epilepsy. It is even more common in adults. We only know what causes epilepsy in 4 out of 10 children.





### My epilepsy was caused by

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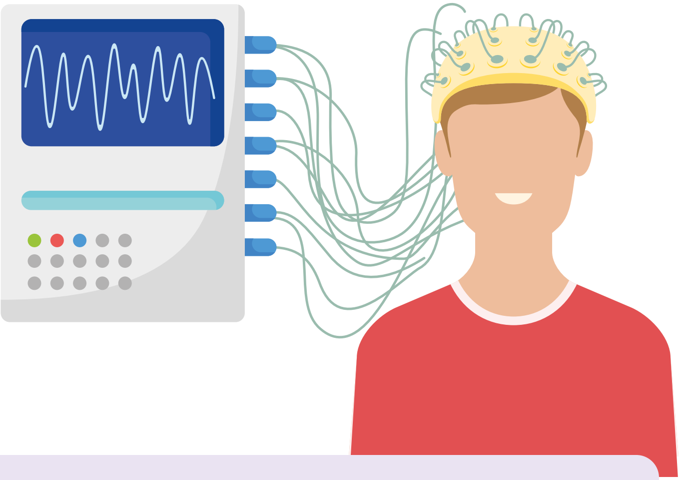
Sometimes it helps to know why you have epilepsy so the doctors know what medication to use, or they might try another sort of treatment. Knowing why you have epilepsy can also help us decide if you will still have epilepsy as an adult.

# 3 How was I diagnosed with epilepsy?

Your epilepsy diagnosis was made following a discussion with:

A discussion with yourself, your parents, carers, or your teachers who might have witnessed you having a seizure. We often ask your carers to make a video of your seizures so we can use that to pick out all the little details that are important.

The doctors or nurse may ask for other tests to help them try and make sure they have your diagnosis of epilepsy correct. These tests may be an EEG, an MRI, an ECG or blood tests to test for genetic condition.



## My epilepsy was diagnosed by

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# 4 How do we treat your epilepsy?

There are different medications to treat specific types of seizures. These can be sometimes be taken in a liquid, tablet or granule form.

Your medication has two names – the drug name (for example paracetamol) and the brand name (for example Calpol). There can be different brand names for the same drug. For some epilepsy drugs, it is important to try and take the same brand each time because it can help reduce your chance of having a seizure. For other epilepsy drugs it does not matter if you change brands.

Sometimes you can have other choices as well – epilepsy surgery, a Vagus Nerve Stimulation (VNS) or a special diet (ketogenic diet) but this depends on your specific sort of epilepsy.

**My medication is called**

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**I take how much?**

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**How many times a day?**

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It is important to remember to take your medication every day. If you forget, it can make your seizures worse. One way to remember might be to set an alarm on your phone. If you forget to take it and go to school make sure you take your evening dose a couple of hours early. The leaflet in your box will tell you more about this and what to do if you take too much by accident.

## How do I remember to take my medication?

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Your hospital consultant or nurse is the person who recommends your epilepsy medication, but it is your GP who prescribes this medication regularly for you. Missing doses because you have run out of medication could cause a withdrawal seizure.

## Where do I order my medication from and where do I collect it from?

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Medication can sometimes make you feel different (side effects). There is an information leaflet in your medicines box to explain this. You need to tell the doctor or nurse if you get any side effects because they might be able to do something about it.

# 5

# What might trigger a seizure?

Taking medication reduces the risk of you having a seizure, but it does not always stop them. Sometimes seizures can happen because:

- You are taking your medication at the wrong time or missing a dose
- You are not taking enough medication
- Not eating regular meals
- Being tired or not getting enough sleep
- Photo sensitivity (where you seeing flashing lights)
- Being stressed or bored
- Being unwell or getting too hot

**My seizure triggers are:** ..................................................................

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**Lack of sleep is a big trigger. How much sleep do you get?**

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# What is SUDEP?

The best way to reduce the risks associated with epilepsy and SUDEP is to have as few seizures as possible and to build healthy habits to manage your condition.

SUDEP stands for Sudden Unexpected Death in Epilepsy. It is extremely rare but every year, approximately 1 in 4,500 children with epilepsy die each year with no obvious cause found. This risk increases if you have a more complex, rare form of epilepsy, for example, Dravet Syndrome.

Having a long-term condition like epilepsy does not mean you can't take part in everyday activities, but it does mean you might need to take some extra steps to make sure you keep as safe as possible. Seizures often happen unexpectedly so you need to take care around very hot things like fires, when climbing, or when you are in water like a bath or swimming.

## 7

# How to look after me when I have a seizure

Seizures can happen at any time in any place. It is important that people near you know how to look after you.

You will probably have an individual epilepsy plan which we would like you to share with your school, family or friends. The epilepsy nurses can help you share this information. The plan has information about what your seizures look like and what someone should do if you have a seizure.

**Talk to your nurse about how your epilepsy can affect you.**

# We are Young Epilepsy

**Epilepsy can be frightening, and it can feel lonely. Sometimes people just don't understand what you are dealing with.**

Young people living with epilepsy have told us how important it is for them to understand their condition, and how making connections with other young people, and hearing their experiences, really helps.

From trusted information and real stories about living life with epilepsy, to support services and opportunities to have your say and influence the world around you, we're here for you.

**youngepilepsy.org.uk**

Young Epilepsy is the operating name of The National Centre for Young People with Epilepsy Charitable Trust. Registered Charity number 311877 (England and Wales)

GO PURPLE

GET TALKING ABOUT EPILEPSY

For more information about epilepsy, what it is, and how it is managed can be found on these websites:

**www.epilepsy.org.uk**

**www.youngepilepsy.org.uk**

**www.youngminds.org.uk**

**www.howareyoufeeling.org.uk**
(Hull)

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