

Epilepsies in children, young people and adults

Information for the public

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Epilepsy: the care you should expect

The epilepsies are a group of conditions affecting the brain. People with epilepsy have repeated bursts of abnormal electrical activity in the brain that lead to epileptic seizures. Usually, a seizure lasts for a few seconds or minutes and then brain activity returns to normal.

Epileptic seizures can take different forms. Some involve movements that the person cannot control, such as jerking or twitching, going stiff, or falling to the floor and shaking. Others involve becoming confused or having unusual sensations. Some people lose awareness while others remain aware of what is happening.

Epilepsy can start at any age, but most commonly starts in childhood or in later life. Some people have epilepsy for just a period in their life while others live with it for many years or all their life.

People with epilepsy are usually offered medicines called antiseizure medications (previously called antiepileptic drugs or AEDs) that aim to stop or reduce seizures. There are other treatment options for some people, such as epilepsy surgery, if medicines do not work.

We want this guideline to make a difference by making sure that:

- people see an epilepsy specialist within 2 weeks of a suspected first seizure for assessment and diagnosis, and more urgently if a type of seizure called infantile spasms is suspected
- people are offered further investigations promptly if epilepsy is likely, such as an EEG (which records brain activity) and an MRI scan, if appropriate
- people with epilepsy know what type of epilepsy or epilepsy syndrome they have and the type of seizure they have experienced
- people with epilepsy and their families and carers have an information and care planning session with an epilepsy specialist nurse and know how to contact them for support and information
- people with epilepsy and their families and carers are given opportunities to discuss the risks of epilepsy, including sudden unexpected death in epilepsy (SUDEP), and how to reduce their risk
- people with learning disabilities get extra support to manage their epilepsy and are offered the same treatments as everyone else
- women and girls with epilepsy who are planning pregnancy or are pregnant have a review of their antiseizure medication and understand the risks and benefits of different options
- people who need extra care for their epilepsy have regular reviews
- people with epilepsy can be seen by a specialist in a tertiary epilepsy service if they need further investigations or additional expertise to manage their seizures.

Making decisions together

Decisions about treatment and care are best when they are made together. Your healthcare professionals should give you clear information, talk with you about your options and listen carefully to your views and concerns.

To help you make decisions, think about:

- What matters most to you – what do you want to get out of any treatment?
- What are you most worried about – are there risks or downsides to the treatment that worry you more than others?
- How will the treatment affect your day-to-day life?
- Whether you are likely to get pregnant now or in the future?
- What happens if you don't want to have treatment?

If you need more support to understand the information you are given, tell your healthcare professional.

Read more about [making decisions about your care](#).

Where can I find out more?

The [NHS website](#) has more information about epilepsies.

The organisations below can give you more advice and support.

- [Dravet Syndrome UK](#), 01246 912 421
- [Epilepsy Action](#), 0808 800 5050
- [Epilepsy Research UK](#)
- [Epilepsy Society](#), 01494 601 400
- [Epilepsy Wales](#), 0800 228 9016
- [Matthews Friends](#), 07884 054 811
- [SUDEP Action](#), 01235 772850; 01235 772852 (support line for bereaved families)
- [The Daisy Garland](#)
- [The UK Infantile Spasms Trust](#)
- [Young Epilepsy](#)

NICE is not responsible for the content of these websites.

To share an experience of care you have received, contact your local [Healthwatch](#).

We wrote this guideline with people who have been affected by epilepsies and staff who treat and support them. All the decisions are based on the best research available.

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