

7 Minute Briefing

7. Questions to consider

Where might I come across children or young people with a diagnosis of epilepsy?

How can I support them to manage their epilepsy and to stay safe?

Would I know what to do if they had a seizure?

6. Support resources

RCPCH Advice Leaflet for parents & carers: Following a first seizure without fever

RCPCH Advice leaflet for children & young people: Following a first seizure without fever

Epilepsy Action: https://www.epilepsy.org.uk/

Young Epilepsy: https://www.youngepilepsy.org.uk/

5. What can continue?

A diagnosis of epilepsy can lead to a wide range of emotions in children, young people and their families; it is important that there is support to continue safely in school and in all normal activities, with access to sports and leisure facilities with the right support and safety precautions in place.

Understanding epilepsy, medication and risks along with a good support network are really important in learning to live with the diagnosis.

1. Background

Epilepsy is a condition affecting the brain, causing seizures. Most children with epilepsy are treated with anti-epileptic drugs. Epileptic seizures can lead to harm if they last for a long time, or if they occur in certain high risk circumstances.

When children and young people are given a diagnosis of epilepsy, they and their families should receive information about how to manage their seizures, what to do in an emergency, and how to stay safe.

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2. Why it matters

Every year, between 40 and 80 children (in the UK) die as a result of their epilepsy. Some of these deaths are as a result of preventable accidents or injuries; having a seizure can put individuals at greater risk of accident or injury, especially if they occur in a hazardous setting.

Epilepsy can come with some risks to safety, but these can be reduced by awareness of the risk, and taking steps to minimise the risk.

3. Key Messages

It is important that families, children and young people are fully aware of the risks and safety advice, so that they can make informed choices to balance quality of life and staying safe.

Not everyone with epilepsy has the same level of risk; someone with good seizure control may be at less risk than someone experiencing unpredictable seizures.

4. What needs to change?

For a child or young person of any age with epilepsy, the following advice will help keep them as safe as possible:

- Bathing: showers are safer, supervision at all times if having a bath. Always leave the bathroom door unlocked & don't bathe in the house alone.
- Climbing: supervision & harness if climbing above their own height.
- Cycling: wear a helmet, be supervised, avoid busy roads.
- Swimming: always supervised with a responsible adult, tell the lifeguard you have epilepsy.
- Driving: for the rules about driving and epilepsy visit www.gov.uk/epilepsy-and-driving.

Seizure control can change over time, and continuing to be aware of and assess risk is important. Alcohol, tiredness and forgetting to take epilepsy medication can all increase the risk of having a seizure.