

A photograph showing a woman with dark hair tied back, wearing a brown ribbed sweater and blue jeans, crouching over a person lying on the ground. The person on the ground is wearing a bright yellow long-sleeved shirt. The background is a lush green park with trees and sunlight filtering through the leaves. The overall mood is one of care and support.

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**RESOURCE**

# Epilepsy

Effective support for  
young people with  
additional needs

# Epilepsy

Young people with epilepsy tend to have recurrent seizures, which can display high visibility symptoms such as convulsions and loss of consciousness, or may be much less noticeable. These seizures occur when excess electrical energy in an area of the brain causes a temporary disruption in its function. This disruption results in the brain's messages becoming halted or mixed up.

The brain is responsible for all of the functions of the body, so what is experienced during a seizure will depend on where in the brain the epileptic activity begins and how widely and rapidly it spreads. For this reason, there are many different types of seizure and each person will experience epilepsy in a way that is unique to them.

There are over 450,000 people in the UK with epilepsy, many of them being young people.

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## Key issues

- There are many different kinds of seizure and it is often difficult for young people with epilepsy to articulate what is happening to them.
- There are some common 'triggers' that can increase the likelihood of a seizure, e.g. *lack of sleep, missing medication, flashing or flickering ('strobe') lighting, illness/high temperature.*



# Support strategies for your group

- **Talk to the young person's parents/carers to get a better understanding** of the specific form of epilepsy that the young person has. This is information that can be vital in the event of a seizure.
- For young people, **talk with them about what their 'triggers' might be** and how to recognise the signs of an impending seizure.
- **Avoid situations where a young person is told, publicly, that they are "not allowed" to take part** in an activity "because of your epilepsy".
- **Always ask young person for permission** before discussing their condition with others.
- Assuming you have sought permission first, **make sure that your team know what to do** to ensure the safety of a young person in the event of them having a convulsive seizure:
  - Remove anything nearby which may cause injury and cushion their head.
  - Ensure an ambulance is called.
  - Time how long the seizure lasts.
  - Contact the young person's parents/carers.
  - Once the seizure has stopped, put them in the recovery position.
  - Stay with the young person to reassure them.
- **If a young person has had a convulsive seizure during your group activity**, they are likely to feel embarrassed or feel that the other young people will avoid them. Try to reassure them that they are still accepted in the group and encourage them to come back, but don't overly fuss over them next time they come (or this may add to their embarrassment).
- **One type of epilepsy, photosensitive epilepsy, means that the young person reacts to flashing or flickering light.** Make sure all fluorescent lighting is working correctly and has effective diffusers. Also, try to avoid using flashing or flickering (e.g. 'strobe') lighting for visual effects. If this is not possible due to the requirements of a specific event, give clear warning well in advance.
- **Some people have misused passages about healing in the Bible** to suggest that people with epilepsy are demon-possessed. This is, of course, highly offensive and could be very distressing and frightening to young people. As always, any teaching relating to disability using Bible references should be done very sensitively.

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Thanks to **Epilepsy Action** for much of the material used in writing this article.

**Further Information:** Epilepsy Action: [epilepsy.org.uk](http://epilepsy.org.uk)

Research shows that young people with additional needs are more likely to be abused than their peers (NSPCC) This increased vulnerability is due to a number of factors including communication differences, increased dependence on caregivers, social isolation and a higher likelihood that warning signs would be missed or misinterpreted. As a youth leader it's therefore important to be especially alert to changes in behaviour and wellbeing and discuss any concerns with a safeguarding lead at the earliest opportunity.



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of the many ways we're  
here to walk with you!**

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[urbansaints.org](http://urbansaints.org)

This resource has been adapted from our Invited to Belong Team Training Kit.



If you're interested in helping your team become more aware and welcoming of young people with additional needs, you can explore our Invited to Belong Team Training Kit at [urbansaints.org/resources](http://urbansaints.org/resources)

The original content of this resource was created in partnership with **Youthscape** as part of the Invited to Belong resource.