



# Epilepsy

What you  
need to know

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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 children and young people.

# 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 (e.g. '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 older young people, talk with them about what their 'triggers' might be and how to recognise the signs of an impending seizure.

# Support Strategies For Your Group

- 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 the parents/carers (for younger children) or the child/young person (for older children) 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.

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)

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**This resource is just one 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.