

20. EPILEPSY

People with epilepsy have seizures.



Reviewed September 2023. Free to use for personal use and with people you support. **This checklist can be downloaded from www.surreypb.org.uk**

About one in three people with learning disabilities have epilepsy.

People with severe learning disabilities are more likely to have epilepsy.



A seizure happens because of a sudden burst of electrical activity in the brain.

There are different types of seizures. It is important that supporters learn to notice these.

Seizures can affect people in different ways.



- They may stare ahead of themselves for a few seconds.
- Their arms, legs or head may move about in a jerky way.
- Their body may become still, making them fall to the floor.



People with learning disabilities who have epilepsy often have more than one type of seizure and complex seizure patterns.

If there have been changes to the pattern or number of seizures you have you should talk to your doctor.

Status epilepticus

This is when you have a series of seizures one after the other without any time to recover in between.



Status epilepticus is a medical emergency because the longer a seizure lasts, the less likely it is to stop on its own. It's important that supporters know to call an ambulance when someone is having Status epilepticus.

THINGS TO CHECK

1 If you have epilepsy do you need more support to help manage it?

Support you may need includes:



Keeping an accurate record of the number, type and length of your seizures.



Having regular reviews of any medication you take for your epilepsy. Taking your medication at the right times.



Having an epilepsy review every year at your doctor's surgery.

A healthy lifestyle helps to manage your epilepsy.

- Don't drink too much alcohol.
- Try not to miss meals.
- Do things that help you relax.



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Do your supporters need help to understand your epilepsy better?



Supporters may need the following things:



Up to date guidelines about how to support you with your seizures.



Help to understand what things can trigger your epilepsy.

Things like hot weather, stress and sleeping badly can be triggers.

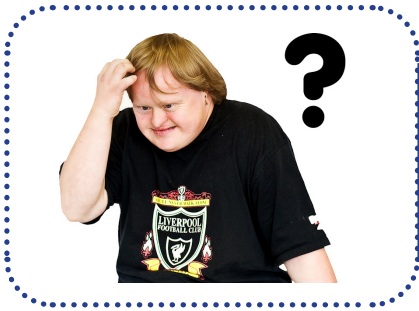


Training about how to support you with your epilepsy.

Your local Community Learning Disability Team may have Learning Disability nurses that have skills or a special interest in epilepsy.



Changes in behaviour.



Supporters need to notice changes in behaviour like being sad more often and seeing or hear things that are not there.

Changes in behaviour can be related to epilepsy. Your doctor will give you support and advice.

Other health issues.

People with epilepsy are more likely to have :

- Mental health problems like depression.
- Challenging behaviours.
- Physical health problems like headaches.



3 Does anyone think you should talk to your doctor about epilepsy?

If you are not diagnosed with epilepsy but people think you might be having seizures it's important to talk to your doctor.



Epilepsy Action

The Epilepsy Action website has advice and information about epilepsy and the support you can get.



www.epilepsy.org.uk

Easy Health

Easyhealth is run by an organisation called Generate Opportunities Ltd.

There are Easy Read leaflets and videos about epilepsy designed by many different organisations.

Look in the 'Health Videos' and 'Health Leaflets' section.



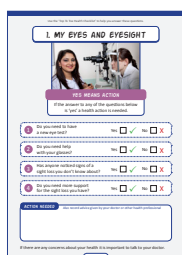
www.easyhealth.org.uk

USING THIS CHECKLIST

This checklist is a part of The Health Action Planning toolkit available from www.surreypb.org.uk

The Health Action Planning toolkit is free to use.

- There are 20 other checklists in the series covering a wide range of health issues.
- There is a Health Action Plan template for your checklist answers.



The Health Action Planning Toolkit was developed by Mike Leat from The Clear Communication People Ltd in partnership with Surrey & Borders Partnership NHS Foundation Trust health professionals and other health professionals in Surrey.

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The Health Action Planning Toolkit is intended as a aid to support people with learning disabilities to access the support and advice of qualified health professionals. The Clear Communication People Ltd take no responsibility for medical diagnosis, advice and treatment given in conjunction with the use of this checklist.

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The **Clear Communication** People Ltd

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