



**SUDEP and seizure safety for people with
a learning disability and autistic people
with epilepsy**

A guide for families, carers and support workers

This is a guide for families, carers and support workers of people with a learning disability and autistic people with epilepsy. It describes how you could help them to reduce the risks linked to epilepsy and seizures and support them to make the right choices for them and their epilepsy.

The person you support should be involved in discussions about their epilepsy care, treatment, and any additional support they may need.

Easy read and plain english leaflets are available on the SUDEP Action website to help with this.



There are often lots of things that can be done to lower risks and improve safety. It is important to:

- ✓ Learn about epilepsy risks and how they may affect the person you support.
- ✓ Discuss and review these risks regularly with the person and their health professionals.
- ✓ Work together to plan how to lower these risks where possible (for example changes in treatment, lifestyle & support, or access to other services for help).
- ✓ Involve everyone in plans to lower risks (for example the person you support, family members, carers, health professionals, or care providers). This may include checking for risks at home, in care settings, at work or any locations they visit often eg: clubs/activities.

At least 21 people with epilepsy die each week in the UK. A common cause of these deaths is **SUDEP** (**S**udden **U**nexpected **D**eath in **E**pilepsy). This is when someone with epilepsy dies and no other cause is found. Other causes include seizure-related accidents (eg: drowning) and status epilepticus (prolonged seizures lasting 5+ minutes).

Over 50% of epilepsy deaths can be prevented, which means there are many positive things people with epilepsy can do to live more safely. Family, friends, carers, support workers and health professionals can also help people with epilepsy to live well.

If you have any questions or concerns about the care, treatment, or risks of the person with epilepsy who you support, please speak with their health professionals about this.



Seizure safety

Controlling seizures is the best way to lower risks linked to SUDEP/epilepsy deaths. The risk of SUDEP varies between people, and can change over time. Certain types of seizures put people with epilepsy at more risk, and should be discussed with their health professional:

- Generalised tonic-clonic seizures (seizures where the person is unconscious and their body shakes and moves).
- Status Epilepticus (a type of seizure that lasts more than 5 minutes).
- Cluster seizures (seizures one after another).
- Seizures at night/when sleeping (especially tonic-clonic seizures).
- Seizures that get worse (happen more often or are more severe).

Seizures are often unpredictable, happening anywhere, anytime and can cause accidents and injuries. For people with epilepsy, it can be difficult to balance safety with privacy and personal choice.



Discussing what might be a risk (and what can be done to live more safely) with the person you support is a positive thing to do if possible. This can help the person make the right choices for them and their epilepsy.

How you can help reduce risks from seizures:

1. Have a seizure management plan, including:
 - Regular medication to reduce seizures.
 - When/how to use emergency anti-seizure medication (prescribed for prolonged or cluster seizures).
 - How to prevent and care for accidents & injuries including:

Bathing – If a person is bathing, a plan should be put in place to lower the risk of drowning. Talk to the person you support about this plan.

Water safety – Take care around water (eg: the sea, lakes, rivers, ponds and pools). If the person you support is swimming, then have a plan for if there is an emergency.

Driving – See the Driving and Vehicle Licensing Agency (DVLA) for the latest regulations.

Risk of injuries during seizures eg: falling, burns and scalds. Have a plan for these risks to help the person to be independent and safe at home and places they often visit.

Risk during sport or other activities – People with epilepsy can take part in many activities with the right support, and if risks are positively managed.

First Aid – it is important that anyone supporting people with epilepsy knows seizure first aid to help during a seizure and in an emergency. You may be able to get first aid training local to you.

2. Discuss with health professionals the need for a nighttime monitoring plan, including:
 - If nighttime seizures are happening, and if so, do they increase risk for the person with epilepsy.
 - How to identify the seizures and whether devices might help eg: alarms, monitors.
 - How to respond to nighttime seizures eg: first aid, how long to wait with the person after their seizure ends.

3. Keep a record of seizures and be concerned about worsening seizures (in frequency or severity) and other changes such as:
 - New injuries.
 - Bruises.
 - Increased tiredness.
 - Changes in their sleep patterns or mood/behaviour.

An urgent epilepsy review may be needed.

Remember it is important to involve the person with epilepsy in these plans, and they should be supported to make the right choices for them and their epilepsy.



Medication



Anti-seizure medication controls seizures and reduces risks. Some people with epilepsy will need multiple anti-seizure medications and may take medications for other conditions too. These medications could be long-term. Regular regular reviews by a health professional (with expertise in epilepsy, learning disability and autism) are important.

Not everyone's epilepsy will be fully controlled with medication, so they may need more support to live safely. For some, surgery is can help control seizures.

It is important people with epilepsy don't stop taking their anti-seizure medication as this can cause seizures, injuries and in some cases death.

You can help the person you support by:

- ✓ Helping them take their medication regularly and as prescribed (to help reduce the number and severity of their seizures).
- ✓ Checking they are prescribed the same type/brand of medication (for some people, changing this affects how well the medication works).
- ✓ Supporting them with any new medications or any medication changes (in type or dose).
- ✓ Helping them speak to their GP about bone health (Vitamin D or medication may be needed).
- ✓ Encouraging them to share any questions or concerns with you and their health professional, about their medication or any side effects.

Managing mental health and other health conditions

People with epilepsy may also have other health conditions. It is important each health professional they see knows about all their conditions and any medications they take, so care and treatments are coordinated (also known as a 'multidisciplinary team approach').

People with epilepsy are more likely to have a mental health condition such as anxiety, or depression. Watch for:

- Changes in mood eg: if the person you support is more agitated, irritated, upset or distressed than usual.
- Changes in lifestyle, care or support which can increase stress eg: moving home/care setting.
- Changes in health eg: if their epilepsy or health worsens, or if side effects from medications are making them feel unwell.

Help the person you support to speak to their health professional if they or you notice any changes or are worried about their mental health, behaviour or any other health conditions they have.



Lifestyle risks

Drinking alcohol or taking recreational drugs can impact on how well epilepsy medication works, which can increase risk of seizures, injuries and dying prematurely.

If the person you support needs help with managing their alcohol/recreational drug use, help them to discuss this with their health professionals who can refer them to local services which can help.



Women with epilepsy may need extra support and information alongside their epilepsy care. This may include:

- Seizures worsening during their periods – talk to their health professional who may consider treatment changes.
- Any medication side effects which might affect the woman, or their unborn child (if they become pregnant). Women on Sodium Valproate/Epilim must have an annual review with an epilepsy specialist in line with government advice:
<https://www.nhs.uk/medicines/sodium-valproate/>
- If the person chooses to start a family, a safe pregnancy should be planned to lower risks. This can help:
 - Plan for any medication changes needed.
 - Lower risk to the baby from epilepsy medication.
 - People to take their epilepsy medication as prescribed.
 - Create a care plan during pregnancy so health professionals, and others who support the mother, know how to help her and her baby to stay safe.
 - Provide advice to help the mother with her own health after the birth, breastfeeding and looking after the baby (including safety during bathing or other activities in case the mother has a seizure).



Other risks to be aware of:

Research has shown that:

- Having had seizures for a long time, or them starting from a young age.
- Being male (research suggests men are at a 1.4 times increased SUDEP risk compared to women).

Can also increase risk of dying from epilepsy. These risks can't be changed, it is important to know about them alongside the other risks in this leaflet.

Epilepsy risk care plan

All people with epilepsy should have a personalised epilepsy care plan / risk assessment covering their care and treatment needs. How to reduce risks and improve their safety should also be included. This should be created by their health professionals, any care teams or care organisations who support the person and should involve the person themselves and their family members.

SUDEP Action's SUDEP and Seizure Safety Checklist supports health professionals to discuss, review and put actions in place to reduce epilepsy risks:

www.sudep.org/checklist

The EpSMon app helps people with epilepsy (and their family/carers) to keep track of their epilepsy risks:

www.sudep.org/epsmon

For extra information and support:

SUDEP Action's website has free information and resources about living well with epilepsy, reducing risks, and providing support to anyone bereaved by epilepsy:

www.sudep.org

The EpSMon app: www.sudep.org/epsmon

The Seizure Safety Checklist: www.sudep.org/checklist

Thanks to these organisations for their work on the My Life with Epilepsy project and helping to create this guide:



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