

Reducing Seizure-Related Risk

Plain English information for people with epilepsy

This leaflet shares important information to help you to live safely with your seizures.

You may need someone to support you to go through this information, to make sure you understand it. This person could be someone from your family, a carer, a friend or a professional.

People with epilepsy experience seizures (fits) and most types of seizures do not need emergency help. However, there are risks linked to having epilepsy; some of these risks can be dangerous, and sometimes people are at risk of dying. This could be because of things like seizures that go on for too long, getting injured during a seizure, having lots of seizures in a row or SUDEP (Sudden Unexpected Death in Epilepsy) – which is when someone with epilepsy dies and there is no other reason.

There are often lots of things you and those around you (family, friends, carers and health professionals, etc.) can do to lower any risks you may have. It is important you know about these risks so you can live as safely with epilepsy as possible. You can live a good life with epilepsy, and these things can help you do this.

How to live safely with epilepsy

Things you can do:

Keep a seizure-diary or ask a care-provider to keep one on your behalf:

It helps you to remember how many seizures you are having, when you are having them and how they make you feel. This will help your health professional advise on medication and how to reduce your risks.

It is important for the people who support you to know what type of fits you have as some fits are more dangerous than others. For example fits that make your body shake or put you to sleep. These fits are called tonic clonic seizures.

Never stop taking your anti-seizure medication and make sure you take it at the right time every day:

Not taking your anti-seizure medication can be dangerous. It could mean that you have more seizures which could also get worse.

If you are worried or have questions about your epilepsy medication, speak to your family, carers or your health professional:

Sometimes medications can have side effects. It might be your body getting used to the medication, but let your family, carers or health professional know if you continue to feel unwell.

Make sure you are prescribed the same type or brand of anti-seizure medication (for some people, changing this affects how well the medication works).

If you take Sodium Valproate, your health professional will need to speak to you yearly about the medication's side effects and what this means for you.

Tell friends and supervisors at clubs, groups of other social settings you go to that you have epilepsy:

Let them know what to do and who to contact if you have a seizure, or in an emergency, for example if you hurt yourself or your seizure lasts a long time.

Understand and follow your epilepsy care-plan:

Some people with epilepsy will have a care plan to share important information about your epilepsy, medications, care and support, what to do when you have a seizure or are in an emergency, and how best to keep you safe. Your care plan is unique to you and your epilepsy. You should be involved in making your care plan. Ask your family, carer or health professional if you have a care plan, and if they can talk to you about it so you know what you can do to keep yourself as safe as possible. You need to make sure this care plan is regularly updated.

Eat well:

It is important to eat a healthy and balanced diet. Drinking a lot of alcoholic drinks and/or taking illegal drugs can increase your risk of having a seizure.

Visit the link below for more information:

www.nhs.uk/live-well/eat-well

Sleep well:

Sleep is very important – try to get 7–9 hours of sleep each night if you can. Not getting enough sleep or not sleeping well can increase your risk of having seizures. Tell the family members, carers or health professionals who look after your epilepsy if you are not sleeping well, or if you are often feeling tired in the morning.

If you are a driver, understand the law in relation to epilepsy and driving:

Having a seizure whilst driving could be very dangerous and put your life and others at risk.

Visit the link below to learn more about the law in relation to epilepsy and driving:

www.gov.uk/epilepsy-and-driving

How your health professional can help you to live safely with epilepsy

Speak to your health professional if your seizures get worse, happen more or less often, or if they make you feel different:

Speak to a health professional, carer, support worker, or family member if your fits get worse, happen more or less often, or if they make you feel different. Changes in your seizures could mean that you need more help to control them and to lower your risk.

Lowering your risk of seizures can also help you live happy and well.

Tell your health professional if you often feel sad, worried or hopeless or if you find you have little interest or pleasure in doing things:

Your feelings about your epilepsy are as important as the control of your seizures.

Discuss night-time seizure safety with your health professional:

You may have signs of night-time seizures, if you feel different in the morning with no other reason, or wake up with unexplained injuries, these could include tongue-bites and bruising. If you have seizures at night or when asleep, you might need extra support or care to help you.

Speak to your health professional about how to avoid accidents or injuries during seizures:

Many people with epilepsy can have accidents or get injured when they have a seizure. It is important to think about what you and your family or carers can do to make your home, work or places you often visit as safe as possible in case you have a seizure. For example, how to avoid falls, getting burnt or how to stay safe around water. This is especially important for people who have epilepsy. You can read more at the following website, and your health professional will be able to advise on how best to lower these risks:

www.nhs.uk/conditions/epilepsy/living-with

Pregnancy

If you are thinking about starting a family then speak to a health professional. They can give you advice to keep you and your baby as safe as possible.

Speak to your health professional if you are taking medication for another health condition or illness:

Some medications can have side effects and may change how other medications work. It is important that your health professional is aware of all the medications you take for your epilepsy and other health conditions.

Don't keep worries to yourself:

Health professionals are there to help you, and it is important that they know about any worries you may have about your epilepsy or your care-plan. If you are worried about anything, speak to your family, carer or health professional.

Researchers and health professionals are always learning more about risks for people with epilepsy, and what can be done to lower these risks to help people to live safely with epilepsy.

There are a lot of things you can do to manage your own risks, your family, carers and health professionals involved in your care can help you to do this.



SUDEP Action (an epilepsy charity) have made a free app to help people with epilepsy to learn about their epilepsy risks. Information on how to access this app can be found at the following link:

www.sudep.org/epsmon

This app helps you understand what risks you might have, so you can get help to lower these. It can be taken with you to your epilepsy appointments to help you talk about this.

For more information, visit: www.sudep.org

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