

Seizure Guidance for Families

The following is a compilation of information from the NHS, Epilepsy Society and Epilepsy Foundation.

Sensitivity and Understanding

Everyone involved in a seizure episode will be scared by it, whether it's the person having the seizure or someone witnessing it, particularly if it's the first time it's happened. Children will be especially frightened, particularly if it is a parent having the seizure.

It is important that everyone shows sensitivity and it is helpful if everyone knows what is happening, what to expect, how to support and what to do. Whilst seizures are an intensely personal event being as open as possible will help everyone understand, be less fearful and be in the best position to help.

(It can also be embarrassing for the person having the seizure, as they may lose control of some parts of their body and pass wind, wet or soil themselves and need calm reassurance and privacy.)

This guide aims to give some practical ideas to address these points, including making an action plan so that everyone knows what to do and even practicing it, so it is clearly understood.



- What is happening during a seizure?
- Tracking Seizures
- Managing Seizures
- Seizure Action Plan
- Rehearsing the Action Plan
- Seizure Safety
- Seizure First Aid

What is happening during a seizure?

Although seizures can be caused by Epilepsy, many are not and may be caused by a variety of other conditions, or the actual cause may be unknown. Seizures happen when the usual activity in the brain becomes temporarily disrupted. The seizure can affect muscle control and movement, speech, vision and a person's awareness.

The Epilepsy Action website has helpful materials to explain seizures to children:

<https://www.epilepsy.org.uk/living/parents-and-children/just-for-kids>

Tracking seizures

Knowing what happens during a seizure, how often they occur and for how long, are three of the most important seizure details. Keeping track of seizures can help....



...your Doctor diagnose seizures:

- Seizures can look and feel different from one person to the next.
- A first-person report of what is going on will help the doctor tell if the events are seizures or not. And figure out what kind of seizure it is.
- Knowing the seizure type will help you and your family know: how to respond to a seizure, what to be concerned about, what NOT to worry about, and when to get emergency help.

...your Doctor choose treatments:

- Not all seizure medicines work for all types of seizures. Some are better for focal seizures than for generalized ones or in people with a specific epilepsy syndrome.
- Knowing the seizure type will help everyone decide which medicine or treatment to try.

...your Doctor know if a treatment works:

- Track if seizures happen less often or have changed after a new medicine or treatment is started.
- If seizures continue or get worse, this information will also help you and your team decide when to try a different treatment.

...you identify and manage side effects:

- Tracking side effects of medicines on seizure calendars can help you and your doctor know how you are tolerating the drug.
- See if side effects get better over time or go away when a dose is changed.
- If side effects don't go away, it's one more piece of information to use when deciding if other treatments should be tried.

...you identify triggers and modify lifestyle:

- Writing down when seizures occur and what happened around that time helps you recognize possible triggers.
- You may notice a pattern, such as seizures that occur only at a specific time of day.
- Or you can see if certain factors occur around the time of your seizures, such as not sleeping well, sick with fever or illness, stress or missing medicines.
- Use this information to make changes and help you get better seizure control.

Some people find that seizures may occur in a pattern or are more likely to occur in certain situations or under certain conditions. This is why tracking is important, because avoiding or managing any seizure triggers is something you and only you can do to lessen the chance that a seizure may occur under those circumstances. Parents can also do this for their children.

- Remember that not all people who have seizures have seizure triggers, and for those that do, triggers might be different from person to person. In other words, not all persons whose seizures can be triggered have the same seizure triggers.

- Triggers may be different from one person to the next. For example, seizures may occur only during sleep or when waking up. Some women may notice that they are more likely to have a seizure during certain parts of their menstrual cycle, while other people may notice seizures more often at times of high stress.

Some examples of triggers could be.....

- Missed medicine
- Sleep deprivation
- Stress
- Alcohol
- Drug abuse
- Menstrual cycle
- Nutritional factors
- Over-the-counter medicines
- Flashing lights

Managing Seizures

It will help everyone if there is a clear plan to manage the situation in the event of a seizure. The person having the seizure should be reassured that those around them know how to keep them as safe as possible and how to respond. Those around at the time will be reassured that although it might be frightening, they understand what is happening and what they can do to help. Creating a Seizure Action Plan will help you all discuss these issues and come up with a plan that meets everyone's needs and that they are comfortable with their part in. It might also help identify areas that need further attention, such as teaching a child to call 999 and give helpful information to the emergency services, or teaching them the Recovery Position.

(It may be helpful to consider when this call is made, most guidance says to call 999 if the seizure lasts more than 5 minutes, but if it is a child responding to the event, it might be worth considering making that call sooner, so that they have an adult on the line to reassure and support them. The call handler won't mind if the seizure is over before they can respond, as long as everyone is safe)



Seizure Action Plan

At the end of this guide you will find a template for a Seizure Action Plan to help you think through how your family will respond to a seizure, who will do what and when, and who needs to be contacted. This will help ensure that everyone understands what is happening and their part in it, which will help reduce anxiety and give reassurance. It might tell everyone.....

- how to protect the person having a seizure
- how long to expect the seizure to last
- any medical treatment that might be needed, such as medication
- if and when to phone for medical help
- what support might be needed as the person having the seizure recovers



The template is only a guide and your family might want to add extra steps or information to suit the circumstances.

Rehearsing the Action Plan



It might sound silly, but rehearsing the Action Plan regularly might be useful, to remind everyone of their role and give them a chance to practise any tasks they are not comfortable with. This could be particularly important for children and help them overcome any anxieties about their part in the plan.

Seizure Safety

Safety Proof Your Environment

Arrange your home, and if possible, work or study space, to be safe should you have a seizure. For example, pad sharp corners, use non-slip carpet, avoid scatter rugs, and put barriers in front of fireplaces or hot stoves.

If you wander or are confused during or after a seizure...

- Pay special attention to heights, railings and nearby pools or bodies of water.
- Shut your door when you are home alone, so you don't wander outside or into dangerous areas.
- Make sure someone else (neighbour, friend) has a key to get in and check on you!

If you fall during seizures, "fall-proof" your home and other areas. Put in carpets, cover sharp corners, and avoid glass tables.



Fire Safety



- If you have uncontrolled seizures, be very careful around heat or flames.
- Sit far back from open flames, such as a campfire.
- Electric stoves may be safer than gas (due to flames). Using a microwave is even better!
- Cook on the back burner - you are less likely to lean on the burner or spill hot foods on yourself or others during a seizure.
- Set the maximum hot water temperature in your house to 43° C/110° F.
- Put guards on open fireplaces, wood stoves or radiators.
- Don't smoke or use matches when you're alone. A fire could start if you drop it during a seizure.

Child Care Safety

- Baby proof the house early!
- If you have uncontrolled seizures, think about the best way to carry your child. Your type of seizures will affect this. For example, women who fall forward should avoid carrying their child in their arms or in a sling frequently when they are alone.
- Use a small stroller to carry a baby around the house or outside.
- Change the baby on the floor.
- Do not bathe the baby in a tub when you are alone. Make this family time and share the job!
- Feed an infant sitting in the middle of the bed or couch to support the baby more easily.
- Have an enclosed safe play area.



Seizure First Aid



Not everyone who suffers with seizures experiences the same symptoms, so it is important that everyone understands the way your symptoms usually affect you, so they know what is normal and what is not.

These are general steps to help someone who is having any type of seizure:

- Stay with the person until the seizure ends and they are fully awake. After it ends, help the person sit in a safe place. Once they are alert and able to communicate, tell them what happened in very simple terms
- Comfort the person and speak calmly
- Check to see if the person is wearing a medical bracelet or other emergency information
- Keep yourself and other people calm

When most people think of a seizure, they think of a generalized tonic-clonic seizure, also called a grand mal seizure. In this type of seizure, the person may cry out, fall, shake or jerk, and become unaware of what's going on around them.

Here are things you can do to help someone who is having this type of seizure:

- Ease the person to the floor
- Turn the person gently onto one side, (known as the Recovery Position). This will help the person breathe
- Clear the area around the person of anything hard or sharp. This can prevent injury
- Put something soft and flat, like a folded jacket, under their head.
- Remove eyeglasses
- Loosen ties or anything around the neck that may make it hard to breathe
- Time the seizure. Call 999 if the seizure lasts longer than 5 minutes, or as decided in your Action Plan
- As the seizure comes to an end move them back into the recovery position to help their breathing



The Recovery Position

Knowing what **NOT** to do is just as important for keeping a person safe during or after a seizure.

Never do any of the following things...



- Do **not** hold the person down or try to stop their movements
- Do **not** put **anything** in the person's mouth. This can injure teeth or the jaw. A person having a seizure cannot swallow their tongue
- Do **not** try to give mouth-to-mouth breaths (like CPR). People usually start breathing again on their own after a seizure
- Do **not** offer the person water or food until they are fully alert

Seizure Action Plan



Keep this Action Plan handy at all times. It will also be useful for emergency responders should the information be needed.

Name: _____ Date of Birth: _____

Address: _____

Postcode: _____

1st Emergency Contact

Name: _____

Relationship: _____

Phone Number: _____

2nd Emergency Contact

Name: _____

Relationship: _____

Phone Number: _____

Cause of seizures suffered (if cause/condition is known)

Type of seizure suffered (describe the symptoms usually displayed and the usual length of a seizure)

Known Triggers (this information may help, if a trigger source can be removed from the situation, e.g. flashing lights)

Specific Treatment (is there any medication that should be given, including dose, is there anything to avoid, i.e. allergies?)

When to call 999 (instructions specific to your situation, note previous comment regarding children supporting seizure)

After Care (is there anything specific that helps recovery?)

First Aid for any Seizure

- ☑ **STAY** calm, keep calm, reassure and begin timing the seizure
- ☑ Keep me **SAFE** – remove harmful objects, don't restrain, protect my head
- ☑ **SIDE** – turn on my side if not awake, keep airway clear, don't put objects in mouth
- ☑ **STAY** until recovered from seizure
- ☑ **WRITE** down what happened and for how long

When to call 999 (General guidance)

- ➔ Seizure with loss of consciousness longer than 5 minutes, or if not responding to medication
- ➔ Repeated seizures longer than 10 minutes, with no recovery between them, or not responding to medication
- ➔ Difficulty breathing after seizure
- ➔ Serious injury occurs or is suspected, seizure in water