epilepsy scotland

FACTSHEET

Epilepsy alarms

Although epilepsy alarms are not always 100% effective, as part of a general support package they can often provide additional peace of mind. Not all alarms are suitable for all types of seizures. Always seek medical advice from your epilepsy specialist nurse to make sure you get the type of alarm which will work for your type of seizures.

Getting an epilepsy alarm

Epilepsy alarms can be expensive to buy and maintain. Many people will need to rely on external funding for this. Below is a summary of your main options.

Social work funding

If you feel you, or someone you care for, would benefit from an epilepsy alarm, contact your local social work department in the first instance and ask for a community care assessment for an adult, or a section 23 assessment for a child. This assessment will be carried out in your own home, usually by an occupational therapist

Most local authorities in Scotland should provide funding for the purchase and installation of an epilepsy alarm but we are aware of some authorities in Scotland who currently do not provide this funding.

Your epilepsy specialist nurse can also help you liaise with your local authority to make sure you get the right type of alarm suitable for your type of seizures.

Telecare

Your local authority also provides a telecare service, which is a 24 hour response service. As part of this service, you can access a wide range of aids and devices which can help you or someone you care for stay safe, call for help and be as independent as possible in your own home.

Many epilepsy alarms can be linked up with telecare and will send a call once a seizure is detected to the telecare response team. They will then either call the emergency services or alert a designated emergency contact, such as a family member, on your behalf.

You may need to pay a monthly fee for telecare, but if you are, for example, on a low income, you may be exempt. Check out your local authority's website for more information on this service and charges.

Private purchase

If you are unable to get local authority funding, you may need to consider a private purchase. Always check all associated costs which includes the initial cost of buying the alarm and ongoing costs such as maintenance of the equipment, and any call centre/telecare costs if applicable. Even if you

have decided to privately purchase an alarm, always seek advice from your epilepsy specialist nurse to make sure the alarm you purchase is suitable for the type of seizures you or someone you care for has.

You may not have to pay VAT on an epilepsy alarm. For more information go to the UK Government's website page Financial help if you are disabled.

Contact your local housing association

If you rent a house or flat from a housing association, ask them about possible financial assistance for an epilepsy alarm. Some housing associations will provide that level of assistance to their tenants.

Grants

In some cases, especially if the alarm is for a child, you may be able to get a grant from a trust or charity to cover the cost of an epilepsy alarm.

To find a trust or charity, check out Turn2us 0808 802 2000 who can search a UK wide database.

Overview of epilepsy alarms

Epilepsy alarms can either be active or passive alarms.

Active alarms

An active alarm is one you operate yourself by pressing a button or pulling a cord to call for help. These types of alarm can be helpful if you, for example, get a warning before a seizure giving you enough time to activate

the alarm, or to call for help after a seizure if you have injured yourself. A child or someone else can also activate the alarm to call for help.

You can decide who the alarm will alert, for example a family member, a designated emergency contact, or a call centre.

You can wear an alarm as a neck pendant, watch, or belt clip. You can also have an alarm button in your home. These all work in the same way.

Please note, a pendant alarm worn around the neck may not be suitable depending on the type of seizure, as there could be a risk of being caught or tangled up during a seizure.

Passive alarms

A passive alarm works automatically, it does not need to be activated by a person.

Some of these alarms can also detect changes in your breathing pattern while asleep or pick up on specific noises indicating a seizure. Other types can detect body fluids.

Some alarms can detect a change in movement or body posture indicating a person may have fallen over or gone into a convulsive seizure. Some can pick up on a person getting out of bed or a chair, leaving the room or even leaving the house.

- **A listening device** may be suitable if you always make sounds before or during a seizure, and there is someone else living with you in the same

home. Many people purchase baby monitors as a cheaper option.

- **A fall alarm** can sense a change in body posture and should be able to distinguish between a sudden fall and normal movements, like bending over. The alarm is carried in a pocket, on a belt or as a neck and wrist pendant and can be set to dial a contact number or a telecare centre. If it is a false alarm or you don't need help, you can cancel the call.

  This type of alarm will usually not pick up on seizures which happen while sitting or lying down. They are also unsuitable for those types of seizure without a fall.

- **A movement detector** can pick up on different types of movements such as convulsions. Once a movement is detected, an alarm is raised by automatically calling a phone number or contact centre. The sensor should be able to tell the difference between normal movements and those relating to a seizure.

- **A moisture monitor** is fitted between a bed sheet and mattress and can detect moisture, such as urine. This type of alarm may be useful for anyone who loses control over their bladder during a seizure. If you or someone you care for wears absorbent pads, the alarm will not be suitable. You can also get sensors for inside a pillowcase picking up on excessive saliva produced during a tonic-clonic seizure.

- **A bed seizure monitor** placed under a mattress can detect the convulsive movements of a tonic-clonic seizures. It cannot be used for any other types of seizure. Apart from movement, some of these monitors can also pick up on sound, a change in heart rate, or if you get

out of bed. Sensitivity settings can often be adjusted to distinguish between normal sleep movements and seizures. Like all alarms, it may not always pick up on genuine seizures.

- **A breathing (apnoea) monitor** can be helpful for those whose breathing slows down or stops during a seizure. Sensor pads are placed under the sheet to monitor the person's vital signs. If you move off the sensor pad during sleep, an alarm will be triggered. Some systems combine breathing and bed seizure monitors. Or you can use individual monitors together.

- **A location monitor** clips onto your clothing and raises the alarm with a call centre if you go outside a certain area. Once an alarm is received by the call centre, they will contact your nominated emergency contact(s). The device uses satellites (GPS) to pinpoint your position on a map. You can set the area you can move about without triggering an alarm. The alarm can also be set for specific times of the day, or it can stay on all of the time.

  This type of alarm could be useful if you are prone to wandering during or after a seizure. Some of these devices can also work similar to a fall or movement monitor by detecting a fall or convulsions. A location monitor often has a help button you can push if you know you are about to have a seizure.

- **Pressure mats** are sensitive to pressure and can be placed on a bed or chair. These sensors can be put on a timer or can be active 24/7. They can also be programmed to include an absence time, which allows you to leave the bed or chair and return within a given time without an alarm

being triggered.

You can also get a pressure mat which is placed on the floor and triggers an alarm if you stand on it. The mats are available in different sizes and can be placed beside your bed or a chair. These types of alarm may be useful if you are prone to wandering after a seizure.

- **A motion sensor** uses passive infrared sensors (PIR) which detect movement which interrupts the beam. The alarm is triggered by movement, but it cannot usually tell the difference between seizures and other types of movement. It can be turned on and off as needed, some people may only switch it on at night. This type of alarm, for example, might indicate that you or someone you care for may have left their bed during or after a seizure.

- **A door exit alarm** can be fitted to any door. It is either triggered when the door is opened or if you go through the door wearing a bracelet linked to the alarm. It could, for example, detect if someone left the house during or after a seizure while confused. It can be set to work at specific times of the day, for example detecting if the exit door is opened at night.

- **TV or video monitoring** allows someone to watch for seizures without being in the same room. There are issues of privacy, and this type of monitor usually requires consent of the person if that person has capacity to make these decisions.

- **A heart rate monitor** can detect an increased pulse rate which can sometimes be a precursor to a seizure. Worn as a wrist sensor it can sometimes act as a useful warning of a seizure to come allowing yourself

to put yourself in a place of safety.

The monitor can also detect a change in pulse rate during a seizure triggering an alarm if the pulse rate decreases to a dangerously low level allowing for medical intervention.

- **Phone apps** may be able to detect seizures and work by sending messages to designated contacts on your phone. You may be able to cancel an alarm if a false alarm has been triggered. Motion sensors on smart phones may also be able to pick up on a change in movement or position such as a fall. You need to do your own research to make sure relying on an app provides you with the safety you are looking for.

- **Smart watches** often have a movement detector and can be linked to smartphones and tablets via bluetooth. The phone or tablet can be set to alert someone to a seizure. Some smartwatches can also measure heart rate. An increase in heart rate can be a precursor to a seizure for some people. There may also be a button you can press to raise the alarm if you know you are about to have a seizure.

- **Environmental Sensors** can detect extreme changes in temperature, smoke, flooding or an escape of gas. If, for example, you have a seizure while cooking using a gas cooker, inbuilt gas, temperature or smoke sensors can raise an alarm.

  Flood sensors can indicate an increase in water levels, for example if you have a seizure while running water. Some plugs have a valve that opens up when the water reaches a given height preventing the sink or

bath from overflowing. They may also be able to indicate if the water is too hot.

It is important to carry out a detailed risk assessment around bathing and showering as it only takes a couple of inches of water to drown. Usually having a shower in a level access shower or wet room tends to be safer than a bath, but it depends on the type of seizures, and the level of available supervision and support.

Alarm Suppliers

To help you start your research, we have pulled together a small selection of alarm suppliers. Your epilepsy specialist nurse or an occupational therapist may also be able to point you in the right direction. When you research alarm options, always make sure they are suitable for the type of seizures you or someone you care for has. Alarms are usually unable to pick up on absence seizures.

Please note inclusion in this list is not a recommendation:

- Disabled Living Foundation
- Sensorium
- Easylink UK
- Epilepsy Alarms UK
- Emfit
- Buddi
- Tunstall
- Alert-IT
- Health and Care
- Pulseguard
- Safety Systems Distribution Ltd

Contact us

If you have any further questions, please contact our helpline on 0808 800 2200 or get in touch with us via email contact@epilepsyscotland.org.uk and on our social media platforms.

Our resources are always free. If you would like to support our work, please text FACTS to 70085 to donate £3. Texts cost £3 plus one standard rate message.

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