



***Safety & Seizures***

# Contents

|   |    |
|---|----|
| Preventing Seizures                     | 1  |
| Triggers                                | 2  |
| Reducing Risks                          | 3  |
| The Seizures Wheel                      | 7  |
| The Path To Independence                | 10 |
| First Aid For Seizures                  | 11 |
| The Seizure Smart Home                  | 13 |
| Personal Safety Planning                | 16 |
| Sports Activities                       | 20 |
| Leisure: Night Clubs, Cinemas, Concerts | 23 |
| Summer Camps                            | 24 |
| Holidays and Travel                     | 26 |
| Alarms and Seizure Supports             | 32 |



Epilepsy Ireland  
249 Crumlin Road, Dublin 12

Tel: 01 455 7500  
Email: [info@epilepsy.ie](mailto:info@epilepsy.ie)  
Web: [www.epilepsy.ie](http://www.epilepsy.ie)

Facebook: [www.facebook.com/epilepsy.ie](http://www.facebook.com/epilepsy.ie)  
Twitter: [@epilepsyireland](https://twitter.com/epilepsyireland)

Charity Number: 6170 CRA Number: 20010553  
Date of Print: August 2017



## ***Preventing Seizures***

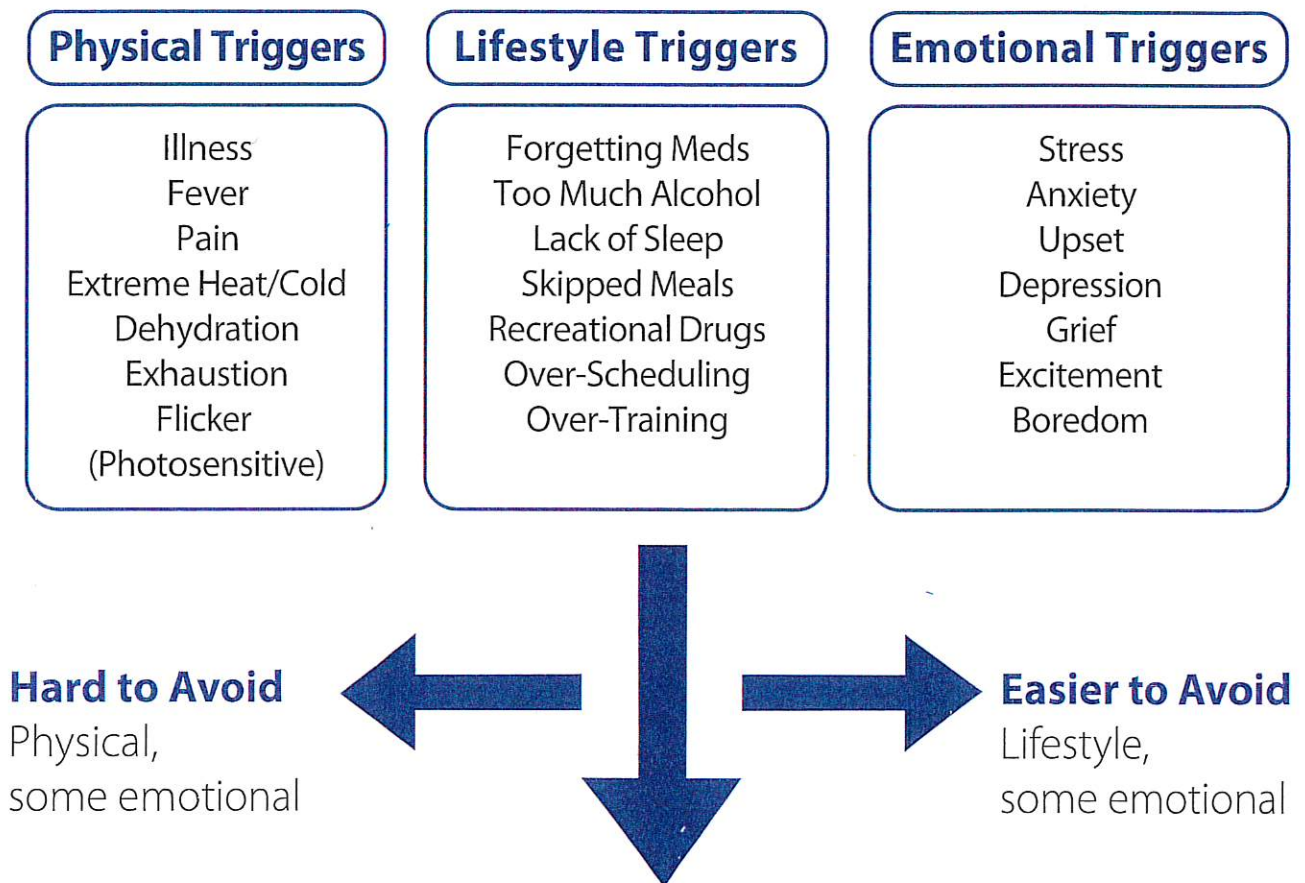
Most people with epilepsy can look forward to becoming free of seizures. With anti-epileptic drug treatment, up to 70% of people with epilepsy will not have seizures on medication. A small number benefit from epilepsy surgery which, in some cases, can manage the condition completely. However, for up to 30% of people with epilepsy, seizures are difficult to control despite treatment. Seizures by their nature can pose risks to safety. The best way to lower your safety risk is to get the best control possible of your seizures. Getting a diagnosis of epilepsy is the first step. Working with your medical team to find the right treatment for you is the next stage. Regular follow-up with your medical team is important too.

Anti-epileptic drug treatment is still the way most people are treated. For the right drug to be given at the right dose, the medical team will need to have good information about your seizures. They need to know what happens during a seizure, how many seizures you have had and how often you have them. If you haven't seen a consultant neurologist and you continue to have seizures, ask your GP to refer you to an epilepsy specialist for a review of your treatment options.

A common reason why some people continue to have seizures is because they may not take their medication exactly as prescribed. Sometimes side effects of a particular medication may be hard to cope with. Epilepsy specialists can explain if other treatment options are more suitable for you if you are finding it hard to take the medication, or if you find it hard to deal with side effects. It's important to get the best seizure control you can. While seizures continue the risks are raised.

# Triggers

A diary can help you to identify some triggers, such as lack of sleep, too much alcohol, stress or forgetting tablets. Sometimes there is no obvious trigger, seizures just happen. It may help to think of which triggers are easier or harder to avoid and make a plan around them. Epilepsy can be considered a disability if it impacts on a person's day to day functioning but not everyone feels it affects them this way.



## Sample plan to avoid or reduce triggers

| Physical                           | Lifestyle  | Emotional                                 |
|------------------------------------|--|---|
| Treat illness, pain or fever early | Regular Sleep and Meals<br>Reduce Alcohol Intake<br>Pace Exercise and Training | Seek Support<br>Relaxation<br>Counselling |

## ***Reducing Risks***

The more you know about your own epilepsy the more you can make better and safer choices. There are booklets, leaflets, and posters about all aspects of epilepsy from Epilepsy Ireland's offices and more resources on our website [www.epilepsy.ie](http://www.epilepsy.ie). Our Community Resource Officers around the country run Toolkit programmes for those with recent diagnoses and STEPS self-management programmes for adults and parents of children with epilepsy.

Carrying identification is important. It gives information about what someone needs to do if you have a seizure. If you are concerned about how people who know you will manage your seizures you can share our information resources with them. Epilepsy Ireland can also give talks for schools, workplaces and groups.

### ***Reducing risks from seizures***

Risk is part of daily life for everyone, whether they have epilepsy or not. However, for a person with epilepsy there are some important safety precautions. People whose seizures are frequent and unpredictable will need to be safety aware, especially if they are likely to have a sudden loss of consciousness or a fall. Thinking about safety risks can be difficult and it's understandable that you may feel some anxiety about it, but in the long run it could keep you safer.

As with other long term conditions such as asthma and diabetes, having epilepsy can also carry with it associated health risks. People who continue to have seizures are more at risk of injury, status epilepticus and SUDEP. We need to know the risks in order to make safer decisions. Statistics show that rates of injury and mortality are higher in people with uncontrolled seizures in particular. Studies show that the most injuries happen at home. Unfortunately, it is a fact that there is a risk of death also with epilepsy. Up to 50% of these deaths relate to SUDEP (Sudden Unexpected Death In Epilepsy). Other deaths relating to epilepsy can happen due to accidents that can happen through seizures. Having a seizure in the bath is the next most common risk of death in epilepsy.

In Ireland, there are approximately 80-130 reported deaths due to epilepsy each year, which represents around 0.2% of the nearly 40,000 people with epilepsy in the country.

Some risks are easy to remove whereas others might be less so. It is easy to place a fireguard in front of an open fire but stairs are fixed and need to be worked around. Try to think about what possible risks there are in the layout of your home which might be hazards for your seizure type (such as stairs and falls, balconies and wandering). How can these risks be reduced with careful planning? Is epilepsy your only condition? Do you have other illnesses or disabilities which need to be included in safety decisions? If you have mobility issues or sensory issues you will need your safety plan tailored to these needs.

## ***Injury***

Types of injury risk will obviously depend on the type of seizure and where seizures happen, particularly if they affect awareness or if they involve falling without warning. Fractures can be linked to falls especially among those with bone health issues. Bone health can be affected by some epilepsy medications so speak to your nurse or team about whether you need to take calcium.

## ***Status Epilepticus***

This is not common and refers to seizures that are prolonged or occur one after another in quick succession. In some seizure types status, if untreated, can cause brain damage and can be life threatening. It follows that it is important your doctor knows if you have experienced a seizure that is longer than normal. Many people with epilepsy are prescribed emergency medication to prevent status epilepticus.

## ***SUDEP***

Sudden Unexpected Death in Epilepsy is uncommon. It occurs when a person with epilepsy dies suddenly and no other cause of death is found, this is called SUDEP (Sudden Unexpected Death in Epilepsy). Between 21-44 people are believed to die from SUDEP each year in Ireland. SUDEP is connected to seizures but what exactly causes it is unknown. The most likely explanation is

that a seizure interferes with the part of the brain that controls breathing or the heart.

## ***Who is most at risk?***

The risk of SUDEP varies from low to very low but for a small number of people the risk may be higher. It is important to understand the person's epilepsy and how best to manage it. The most significant risk factor for SUDEP is having seizures (particularly tonic-clonic). Therefore the better epilepsy is controlled, the more the risk is reduced.

## ***Keep perspective on risk***

It's important to put safety risks in perspective. The overall SUDEP risk relates to frequency of seizures and varies from up to 1:100 (for those at highest risk) to a general risk of about 1:1000 (similar to the risk of smoking 10 cigarettes a day). SUDEP can affect any age group. Although SUDEP is known to have occurred in some children under 16 it is still rare among that age group.

## **The main risk for SUDEP is frequent tonic clonic seizures**

### ***Summary of risk factors for SUDEP***

- having frequent tonic clonic seizures
- having sleep seizures
- having seizures when alone
- untreated epilepsy
- abrupt changes in epilepsy medication
- not taking medication as prescribed

### ***Summary of advice to reduce your own risk***

- Know your triggers and if they can be avoided or reduced
- If you aren't sure, check what type of epilepsy you have
- If you are not seizure-free, seek a referral to a neurologist

- Take your medication and never change or stop taking it without your doctor or epilepsy specialist nurse's guidance
- Let your doctor know about the number, frequency and type of seizures and any medication side effects. Ask witnesses to document your seizures or take a video clip
- For sleep seizures use a seizure alarm.
- Raise SUDEP questions with consultant or specialist nurse.

### ***Advice for Carers to reduce the risk of SUDEP***

- Consider using seizure detection alarms and monitoring
- Although there is little research on ventilated pillows and SUDEP many people might opt to use them
- Stay with the person after a seizure has finished and check their breathing is regular and their colour is back to normal
- Put them into the recovery position when the seizure is over
- Follow any Care Plan that may have been drawn up with the epilepsy team exactly. It will state what is to be done and when and the Care Plan will be tailored to the person's epilepsy needs

### ***Other reasons to call an ambulance can include:***

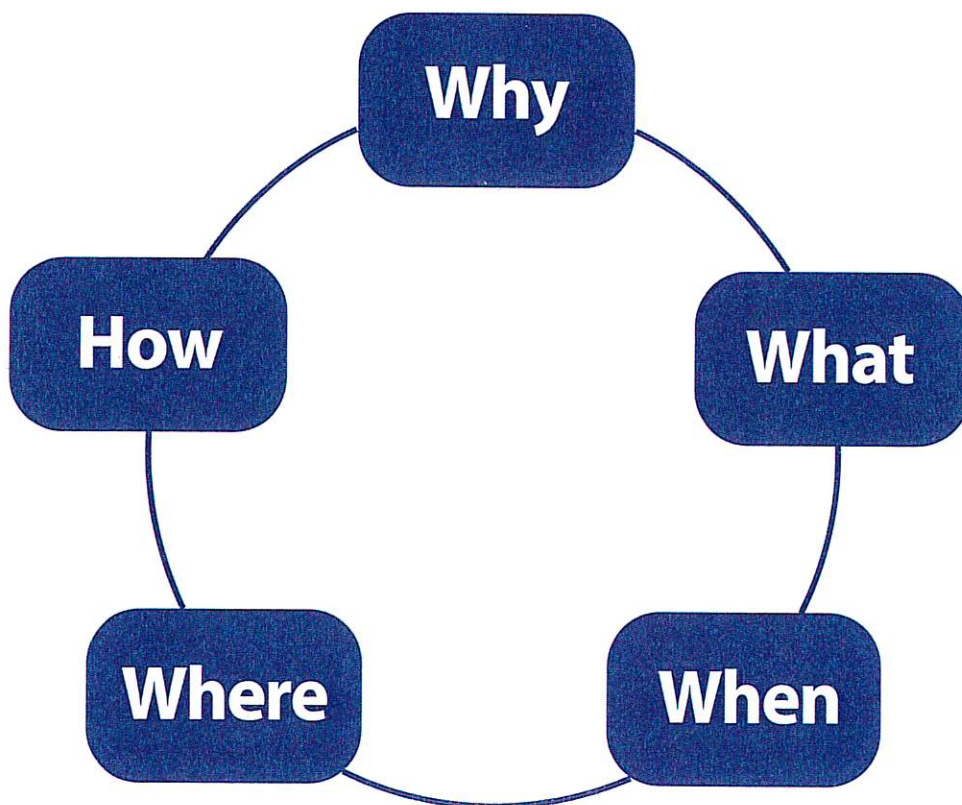
- If the person is injured
- If the seizure does not stop after a few minutes
- If one seizure follows another without recovery
- If the person is having trouble breathing
- If the person has a complicating medical condition





## *The Seizures Wheel*

Every person with epilepsy is different. The safety measures suggested depend on each person's type of seizure, their triggers, patterns of seizures, and individual factors. It can help to use the "Why, What, When, Where, and How" prompts in the Seizures Wheel below to think about how seizures happen for you.



### ***WHY do the seizures happen?***

Are there known triggers such missed doses, stress, flashing lights, illness, missed sleep or lifestyle factors.

### ***WHAT happens during a seizure?***

Do you lose consciousness, are falls likely, is wandering is a feature?

### ***WHEN might they happen?***

Is there a pattern? Morning, sleep, anytime

### ***WHERE might they happen?***

In bed, at home , anywhere.

### ***HOW often do they happen?***

Daily, weekly, monthly, variable pattern.

### ***HOW long do they last for?***

Under 2 minutes, 2-5 minutes, 5 minutes, over 5 minutes. What is usual for you?

## *Main points of my seizures*

**Why** \_\_\_\_\_

**What** \_\_\_\_\_

**When** \_\_\_\_\_

**Where** \_\_\_\_\_

**How often** \_\_\_\_\_

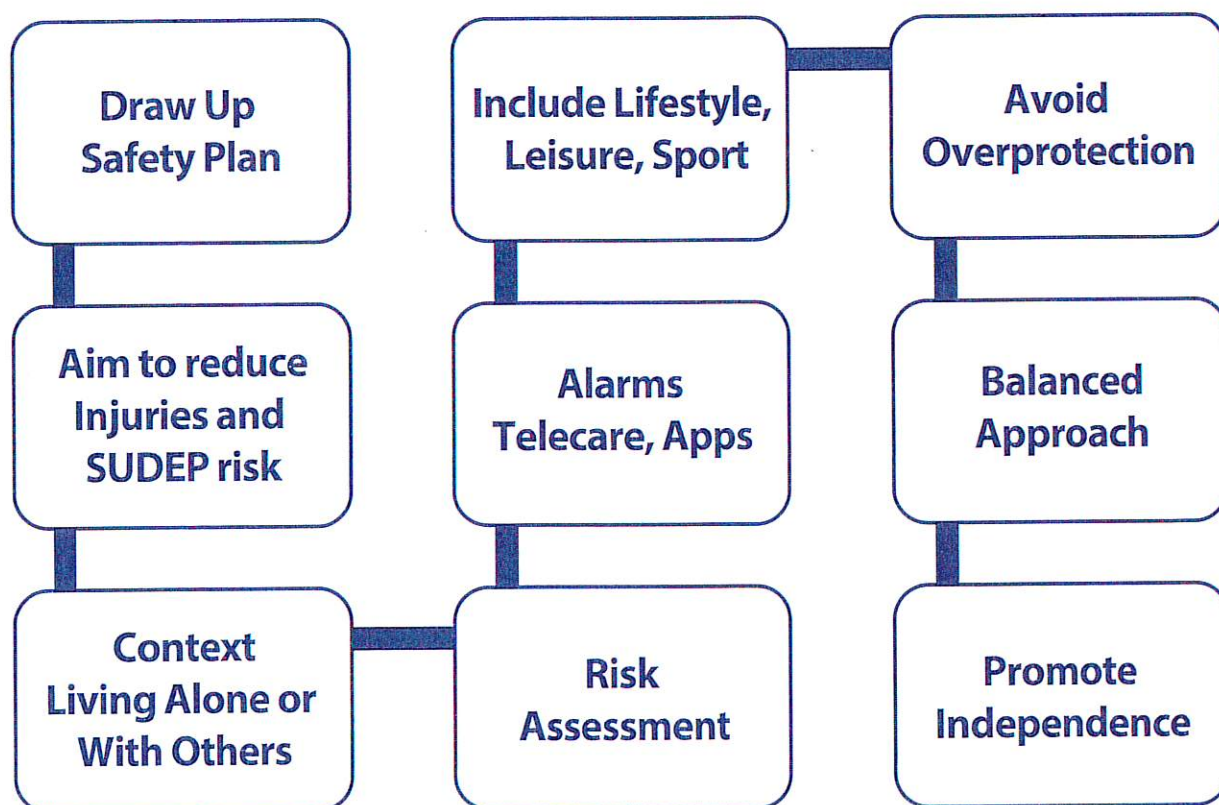
**How long** \_\_\_\_\_

**Other** \_\_\_\_\_



## The Path to Independence

Sometimes a diagnosis of epilepsy leads to overprotection in the family and limits are placed on the person with epilepsy. Over protection can harm self-confidence. A person with epilepsy is encouraged to lead as full and active a life as possible. Safety Plans will help you to reduce your risk of injury and SUDEP, make choices about equipment, leisure, lifestyle decisions and help you make your home and daily life safer. A risk assessment is recommended if you live alone. Balancing safety with promoting independence can be difficult but must be done with the person with epilepsy in mind. It's best to think of ways to support the person, and not to limit them too much. The chart below shows explores stages on the path to independence.



# First Aid For Seizures

It is important for people around you to know what to do when a seizure occurs. Health professionals can advise about individualised first-aid and more information and training is available from Epilepsy Ireland on administration of emergency medication. Epilepsy Ireland's First Aid posters on Tonic Clonic seizures and Focal Non Aware (Complex Partial) seizures are easy to follow.

## First Aid for Complex Partial (focal) seizures

including temporal lobe seizures

Non-convulsive seizures in which awareness is affected but consciousness is not lost

**KNOW THE SIGNS**

|   |   |  |
|---|---|--|
|   |   |   |
| Wandering aimlessly   | Fidgeting with clothing   | Agitated behaviour   |
|  |  |  |
| Chewing & smacking of lips  | Confused or slurred speech  | Staring trance-like  |

**KNOW WHAT TO DO**

|   |   |  |
|---|---|--|
|  |  |  |
| DO time the seizure   | DON'T restrain or grab  | DO guide gently from danger  |
|  |  |  |
| DO calmly reassure  | DO stay until seizure ends  | DO explain what happened   |



**When to call an ambulance**

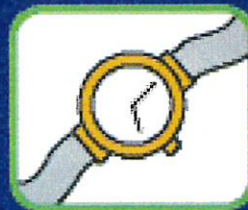
- If the seizure is longer than 5 minutes
- If the person has more than one seizure
- If you know it is the person's first seizure
- If the person is injured
- If you are in any doubt



247 Cummin Road, Dublin 12.  
T: 01 4557500. info@epilepsy.ie  
www.epilepsy.ie  
Facebook.com/epilepsy.ie  
@epilepsyireland

## First Aid For Tonic Clonic Seizures

Convulsive seizures where the body stiffens (tonic phase) followed by general muscle jerking (clonic phase)



1. **DO** time the seizure



2. **DO** remove any harmful objects



3. **DO** cushion the head



4. **DO** look for Epilepsy I.D.



5. **DON'T** put anything in the person's mouth



6. **DON'T** restrain the person or move unless in danger



7. **DO** turn the person on side (into recovery position) when seizure stops



8. **DO** stay with the person until the seizure ends and offer assistance



### When to call an ambulance

- If the seizure is longer than 5 minutes
- If one seizure follows another without stopping
- If you know it is the person's first seizure
- If the person is injured
- If you are in any doubt

#### Complex

#### Partial Seizures

(also convulsive seizures with confusion, wandering, unusual behaviour)

- Stay with the person
- Time the seizure
- Guide away from any danger
- Speak gently and calmly to reassure the person
- **DON'T** restrain the person unless in danger

# ***The Seizure Smart Home***

## ***Fires***

Open fires are a hazard if a person might fall and lose consciousness. Sturdy fireguards like those used for young children are essential. These should be securely fixed to a wall or floorboards so that they cannot be knocked over during a seizure. Stoves can become very hot and need to be guarded in the same way as open fires.

## ***Heaters***

Lightweight, freestanding heaters are easily knocked over. Open element electric heaters and gas heaters are dangerous to someone who might fall across them. Radiator guards may help protect from heat injuries but edges and corners shouldn't be too sharp. Radiators which are too close to the floor may cause a person to become wedged in a seizure and it's best if these are mounted higher up to prevent this. Hot pipes can be covered to reduce risk of burns also.

## ***Electric flexes***

Trailing electric flexes are potentially dangerous, as they can result in an appliance being pulled over during a seizure, which could cause a fire or entanglement in the flex.

## ***Glass and Mirrors***

Safety glass can be used for glass doors and windows so it doesn't shatter on impact. Alternatively, rolls of safety film can be applied to glass surfaces to prevent dangerous splintering. Avoid using glass tables and freestanding glass or mirrored items where possible. Mirrors can be mounted securely on walls.

## ***Cookers***

Pot handles should always be turned away so that pots are less likely to be accidentally knocked over during seizures. A cooker guard or rail is recommended. Avoid carrying dishes of hot food or liquid. Using a food trolley is helpful to move hot dishes. If cooking for a number of people use several small dishes instead of one large one to reduce the risk from lifting a large dish of hot food from the oven. Using a microwave cooker reduces the risk of burns from direct heat sources.

## **Kitchens**

Built in presses and secured appliances are less likely to become loose during seizures. Cordless appliances with automatic cut-off switches are preferable. Try to secure appliances to walls or counters where possible. Keeping water levels lower in kettles reduces the risk of scald injuries in seizures. Depending on the frequency and nature of seizures consider avoiding or reducing the use of sharp kitchen tools.

## **Flooring**

Hard tiled surfaces can lead to impact injuries during falls. Coarse carpets can lead to friction burns. Safety matting helps reduce risks.

## **Baths**

Water, even at low levels, is a potential hazard and taking baths isn't recommended especially for someone on their own with uncontrolled seizures. Drowning in the bath is the most common accidental death among people with epilepsy. For someone with uncontrolled seizures bathing is a greater risk. If there is only a bath available it's safest to keep water to the very lowest level and turn off the taps before getting in. It would be safer though to simply attach a shower hose for washing and keep the plug out to allow drainage. Sitting in the bath and using the shower hose reduces risks of falling and sinking in water. Avoid using very hot water to reduce the risk of scalding. Let someone in the home know if you are using the bathroom.

## **Showers**

Showers are generally safer than baths and while they are not risk free they are easier to adapt. Avoid shower bases with high sides where water could be trapped if a fall occurred. If the seizures are frequent and unpredictable always let someone know that you are taking a shower. A shower chair reduces the risk of falling from a standing position. Shower curtains can be an entanglement risk so safety glass or perspex may be better. Make sure that water temperature is controlled. A water timer can ensure water is cut off at a pre-set time.

## **Bathrooms**

If possible, it is best to hang the door so that it opens outwards then the door would not be blocked if a person fell against it. Locks are best avoided so that help can be quickly at hand if needed. Some people use special safety



locks that can be operated from outside in an emergency. Others find that an “engaged” notice hung over the outside door handle is all that is needed. Tight spaces between sinks and toilets can be a risk if the person becomes wedged. Place some safe items in these spaces which will not pose a risk. Remove glass shelving and attach mirrors to walls.

## **Bedrooms**

Seizures during sleep are not so different from waking seizures except for where they happen so it is helpful to consider bedroom safety. Use low good sized beds with padded headboards. Many people prefer to avoid soft pillows, use instead a ventilated pillow or no pillow at all. Smoking in bed is very unsafe for a person and should be avoided. Keep heavy furniture and lockers away from bedside to prevent injury during a fall. Built in furniture is preferable to freestanding which could be knocked over in some kinds of seizures. Consider using a safety mat on the floor if the person tends to fall out of bed during seizures. This will prevent carpet burn from coarse carpets. Such mats are similar to those used in gyms or to foam mats. Top bunks aren’t safe for people with active seizures. Wall mounted lamps pose less risks than bedside lamps which are easily knocked over. Hanging the door to be opened from outside will allow access to someone in a seizure.

## **Gardens**

If a parent has epilepsy and there are young children in the family it is important to make sure that the children cannot wander off unsupervised. Garden gates need good locks. Hard landscaping and ornamental features can be a risk in falls. Remove those that can be taken away. Ponds and open water are best covered with mesh. Grass and decking are safer than hard surfaces if falls are frequent. Coarse gravel may cause skin injuries in falls. Wooden fencing may be safer than metal railings.

## **Storing medication**

Remember that medication is dangerous for small children. Pills and tablets are easily mistaken for sweets and the child who has watched a parent take medication may try to copy them. Anti-epileptic drugs and other medications should be securely locked away and you need to be safety conscious about pills carried around in pockets and bags if there is a child about.

# Personal Safety Planning

Step 1. Consider what risks might apply to you at home and out and about. Some changes are easy to make but others may be less easy. Everyone's epilepsy is individual to them and needs to be looked at in this way. The table below lists safety points and tips to reduce risk.

| Context                  | Hazzard                | Suggestion to reduce risk           | Action Needed<br>Yes/ No |
|--------------------------|------------------------|-------------------------------------|--------------------------|
| <b>Throught the Home</b> | Glass Panels           | Safety glass or clear contact film  | <input type="checkbox"/> |
|                          | Coarse Carpet          | Cover with safety matting           | <input type="checkbox"/> |
|                          | Loose Appliances       | Mount on walls where possible       | <input type="checkbox"/> |
|                          | Loose Flexes           | Tack to wall or boards              | <input type="checkbox"/> |
|                          | Hot Pipes              | Conceal with heat resistant foam    | <input type="checkbox"/> |
|                          | Tight Spaces           | Enclose to prevent getting wedged   | <input type="checkbox"/> |
|                          | Candles/ Cigarettes    | Avoid using especially if alone     | <input type="checkbox"/> |
|                          | Hard Flooring          | Cover with safety matting           | <input type="checkbox"/> |
|                          | Sharp Edges            | Use child-proof covers or replace   | <input type="checkbox"/> |
|                          | Heights                | Avoid ladders, attics etc.          | <input type="checkbox"/> |
|                          | Other                  |                                     | <input type="checkbox"/> |
| <b>Living Room</b>       | Open fires/ stoves     | Large secure fireguard              | <input type="checkbox"/> |
|                          | Freestanding TV        | Wall mounted is safer               | <input type="checkbox"/> |
|                          | Glass tables           | Remove table or replace glass       | <input type="checkbox"/> |
|                          | Trailing flexes        | Attach to skirting board            | <input type="checkbox"/> |
|                          | Radiators              | Covers                              | <input type="checkbox"/> |
|                          | Light bar/ gas heaters | Remove in case of fall on appliance | <input type="checkbox"/> |
|                          | Freestanding lamps     | Secure or wall mount                | <input type="checkbox"/> |
|                          | Other                  |                                     | <input type="checkbox"/> |
| <b>Kitchen</b>           | Ovens                  | Microwaves are safest               | <input type="checkbox"/> |
|                          | Hobs                   | Use cooker guard or rail            | <input type="checkbox"/> |
|                          | Saucepans              | Cook on rear rings                  | <input type="checkbox"/> |
|                          | Hot dishes             | Turn handles to rear of hob         | <input type="checkbox"/> |
|                          | Glasses/ ceramics      | Limit carrying, use a trolley       | <input type="checkbox"/> |
|                          | Sharp cutlery          | Use unbreakable crockery            | <input type="checkbox"/> |
|                          | Electrical appliances  | Limit use of steak knives           | <input type="checkbox"/> |
|                          | Hot liquids            | Use cordless where possible         | <input type="checkbox"/> |
|                          | Other                  | Keep levels low                     | <input type="checkbox"/> |

| Context       | Hazard                                  | Suggestion to reduce risk   | Action Needed |    |
|---------------|---|---|---------------|----|
|               |   |   | Yes           | No |
| Bedroom       | Bed                                     | Low level, no bunks   |               |    |
|               | Headboard                               | Choose soft padding   |               |    |
|               | Soft pillows                            | Firm ventilated type or none  |               |    |
|               | Locker position                         | Move from bedside to limit risk of injury   |               |    |
|               | Lamps                                   | Wall mounted is safest  |               |    |
|               | Undetected seizures                     | A bed alarm can help  |               |    |
|               | Doors                                   | Re-hang to open out, leave unblocked  |               |    |
|               | Other                                   |   |               |    |
| Bathrooms     | Baths/showers                           | Avoid baths. Showers are safer  |               |    |
|               |   | Use a shower chair  |               |    |
|               |   | Shower when someone is around   |               |    |
|               |   | Don't bathe children alone  |               |    |
|               |   | If using bath leave plug out & wash with shower hose  |               |    |
|               | Shower doors                            | Safety plastic rather than glass  |               |    |
|               | Shower curtain                          | Leave open to prevent entanglement  |               |    |
|               | High shower trays                       | Lower or flat tray  |               |    |
|               | Doors                                   | Keep unlocked and hang to open outwards   |               |    |
| Loose mirrors | Attach to walls                         |   |               |    |
| Hot water     | Use a thermostat to control temperature |   |               |    |
| Other         |   |   |               |    |
| Hall          | Stairs                                  | Limit use of stairs if seizures are frequent<br>Use stair gates if wandering is a feature<br>Ground level may be best |               |    |
|               | Other                                   |   |               |    |
| Outdoors      | Gates                                   | Need to be secure to prevent wandering  |               |    |
|               | Paving                                  | If possible reduce areas of sharp hard surfaces   |               |    |
|               | Gravel                                  | Reduce areas in favour of grass   |               |    |
|               | Pools/ ponds                            | Fill in or cover with mesh  |               |    |
|               | Sharp railings                          | Consider adapting or covering sharp features  |               |    |
|               | Flicker and glare                       | Check if photosensitivity (PSE) applies<br>Follow PSE guidelines if needed  |               |    |

| Context    | Hazard                                   | Suggestion to reduce risk                                       | Action Needed<br>Yes/ No |  |
|------------|--|---|--------------------------|--|
| Leisure    | Exercise                                 | Stay healthy but know your limits                               |                          |  |
|            | Cycling                                  | Wear protective headgear  |                          |  |
|            | Walking                                  | Carry epilepsy ID and contact details                           |                          |  |
|            | Events                                   | Check if strobes / fireworks are used                           |                          |  |
|            |  | (PSE only)  |                          |  |
|            |  | Avoid known lifestyle triggers                                  |                          |  |
|            | Salons/ Spas                             | Seek medical advice about safe treatments                       |                          |  |
|            | Travel and Holidays                      | See guidelines on travel with epilepsy                          |                          |  |
|            |  | Keep to regular medication schedules                            |                          |  |
|            |  | Keep medication in hand luggage                                 |                          |  |
|            | Carry prescription separately            |   |                          |  |
|            | ID, EHIC card (EU only) travel insurance |   |                          |  |
| Other      |  |   |                          |  |
| Daily Life | Trigger factors                          | Learn which triggers might apply,                               |                          |  |
|            | Missing medication                       | alcohol, stress, etc.   |                          |  |
|            | Losing medication                        | Use a pill dispenser with a timer and alarm                     |                          |  |
|            | First aid for seizures                   | Programme a mobile phone reminder                               |                          |  |
|            |  | Store medications and scripts safely                            |                          |  |
|            |  | Give key people first aid information                           |                          |  |
| Other      |  |   |                          |  |
| Sport      | Gyms                                     | Take medical advice on safe equipment use                       |                          |  |
|            | Swimming                                 | Never swim alone  |                          |  |
|            |  | Swim in a pool with a lifeguard on duty                         |                          |  |
|            |  | Avoid high diving   |                          |  |
|            | High risk sports                         | Avoid boxing/ climbing/ bungee jump/ caving/ sky & scuba diving |                          |  |
|            | Water sports                             | Take medical advice on safety                                   |                          |  |
|            |  | Don't put others at risk  |                          |  |
|            |  | Wear a lifejacket at all times                                  |                          |  |
|            |  | Don't do the activity alone                                     |                          |  |
|            | Winter sports                            | Don't ski alone or go off piste                                 |                          |  |
| Training   | Know what is safe, don't overdo it       |   |                          |  |
| Other      |  |   |                          |  |

## Priority To-Do List

Review your Personal Safety Plan/Summary. Where you have decided action is needed list the safety suggestions in order of most urgent

| Hazzard | To do list for Safety Points and Suggestions | Completed                |
|---------|--|--------------------------|
| 1       |  | <input type="checkbox"/> |
| 2       |  | <input type="checkbox"/> |
| 3       |  | <input type="checkbox"/> |
| 4       |  | <input type="checkbox"/> |
| 5       |  | <input type="checkbox"/> |
| 6       |  | <input type="checkbox"/> |
| 7       |  | <input type="checkbox"/> |
| 8       |  | <input type="checkbox"/> |
| 9       |  | <input type="checkbox"/> |
| 10      |  | <input type="checkbox"/> |

## ***Sports Activities***

Exercise and sports are important for many people with epilepsy. It is important to remember that once off accidents can happen to anyone. If a seizure occurs during an activity, this does not have to mean that the person must stop the activity. It is often better to try find a way to support the person continue the activity safely.

Adults and children with epilepsy should be included in the full range of low risk team sports and activities, if it is safe for them. Blanket restrictions aren't helpful and may even be based on outdated ideas. Simply knowing that a person has epilepsy isn't enough reason to prevent them taking part in an activity. Decisions need to be taken on a case by case basis based on knowledge of the person's seizures, being informed about the risks and advice from their doctor.

Exercise and sport can benefit everyone and most activities are open to people with epilepsy. If you aren't sure about any activity think about what risks it could pose and whether there are ways of adapting those to allow you take part. The list of activities below, are those that are most often asked about. Some anxiety is normal where seizures may happen, but sensible steps can go a long way towards making many activities safe. The Seizure Wheel can help you understand your seizures and think about any activity you might wish to do. The main things to consider are how well controlled your seizures are, what happens during them and what the activity involves.

### ***Cycling***

If your seizures are controlled there should be no increased risk. Many people who have epilepsy may cycle when they are off the road from driving but if your seizures are frequent you may need to take your doctor's advice about continuing to cycle. Busy roads present obvious risks and a helmet is essential to reduce risk of head injury.

## ***Horse Riding***

Normal hard riding hats should be worn by all riders. The temperament of the horse can affect how they respond to sudden events. If your seizures are poorly controlled a doctors opinion is advisable.

## ***Boxing, Field and Contact Sports***

Boxing is generally not advised due to the risks from blows to the head. If you are long term seizure free this may be reviewed. Field and contact sports involving possible injury to the head need assessment for each individual by your doctor or specialist. Soccer, hockey, volley ball, basketball, golf, rounders, etc are normally low risk but where there are concerns about injuries to the head protective headwear should be worn. High impact sports like rugby, karting, kickboxing and hurling should be assessed on an individual basis.

## ***Climbing***

Rock climbing and mountain climbing pose risks for someone with uncontrolled seizures. A medical opinion is essential in such cases. Sailing and canoeing require competent supervision. It's not recommended to sail alone. Always wear a life jacket.

## ***Gyms ,Yoga and meditation***

Many people with epilepsy use gyms safely but it is important to let staff know you have epilepsy. Choose activities and equipment that will pose least risk and pace yourself to avoid extreme training. Gentle yoga and Mindfulness meditation can be helpful

## ***High risk sports***

**Boxing**

**Solo hang gliding and solo parachuting**

**Unsupervised potholing/caving**

**Solo hill walking, rock or mountain climbing, abseiling**

**Full contact karate**

**Bungee jumping**

**Scuba diving**

**Aviation and motor sports**

**Sports involving heights/ free running**

**Unsupervised skiing**

**Unsupervised sailing, water sports, swimming, surfing**

## ***Swimming***

There is no reason why people with epilepsy shouldn't swim as long as they take certain precautions. Consider the degree to which your seizures are controlled and whether you get a warning of a seizure. Consider any trigger factors for you which might be likely to occur while swimming, such as dappled light on water for a photosensitive person.

- Never swim alone but with a lifeguard present, or a companion who can handle seizures in water.
- Wear a bright swimming cap so you can be spotted quickly in the pool.
- Swim in a pool rather than open current where rescue is more difficult.

## ***Dealing with a seizure in water – advice for companion swimmers***

Close monitoring of someone who may have any kind of seizure in water is vital. Even in the briefest of seizures the swimmer may suddenly disappear below the surface. Flotation devices may help but they are not fool proof.

Once the companion realises a seizure is starting they need to react quickly and keep the person's head supported and their face above water all the times during the seizure. It may be easier to support the person in place from behind the head. If possible, gently ease the person to shallower water and continue to hold the head so that the face is above water at all times. Once the seizure is over, the swimmer may be moved gently to the poolside keeping the head supported and the face above water.

Medical attention is needed in the event of inhaling water or any concerns about breathing or recovery.

**For more information about water sports and safety see The Irish Water Safety site [www.iws.ie](http://www.iws.ie)**



## ***Leisure: Night Clubs, Cinemas, Concerts***

Over 95% of people with epilepsy are not affected by flashing lights and don't need to unduly avoid venues. However, people diagnosed with photosensitive epilepsy on an EEG may find flashing lights, fireworks, even natural light or glare, could trigger a seizure. Covering one eye with a hand helps to reduce risk of a seizure.

### ***Social Drinking***

Some people with epilepsy choose not to drink alcohol at all but for most an occasional drink should cause no great problems. It is well known, however, that too much alcohol may trigger seizures and 'binge drinking' should be avoided.

### ***Videogames, computers and TV***

Again for over 95% of people with epilepsy flicker and glare don't trigger their seizures. If you aren't sure if this applies to you, ask your team about your EEG record to check for the results of the photic stimulation test, where lights are flashed to see if the person has the photosensitive response. Computers are safe to use for the vast majority of people with epilepsy, even many people with Photosensitivity. Computers are required by law to have anti-glare screens built in. Unlike the older analogue TV sets, modern digital flatscreen TV's like LCD and plasma screens are flicker free but if glare is still a problem they may need to be adjusted for that.

The set is best placed at eye level, at least three metres away from the viewer with good background lighting. Use a remote control for changing channels.

## **Summer Camps**

Summer camps are often provided in the local community and may be themed such as sports or arts based camps. There may be camps in some areas for children with special needs. In general most Irish children with epilepsy should attend local mainstream camps in their own community.

### ***Do I need to tell Camp Staff about My Child's Epilepsy?***

Most camps will ask about medical conditions on the application form. The staff in charge of your child will need to know about the seizures and what happens during them; how they are to be handled and any safety restrictions that may apply.

Safety restrictions may be needed in some activities but where possible the child should be encouraged to take part in activities suitable for them. There may be insurance implications of not disclosing your child's epilepsy. It is a good idea to contact the camp organiser before applying and discuss the needs of the child. In this way you can gauge their response. It also gives the camp provider time to plan for camp staff to get training if that is required.

### ***Are all camp staff trained to give emergency medication ?***

Some camp staff may be familiar with epilepsy and the use of emergency medication but this can't be assumed. Staff can be trained in using the emergency medication and if the camp provider and their insurer is supportive of this there may not be any issue. Sometimes there may be insurance and liability concerns that need to be addressed first. Training in epilepsy awareness can be provided by Epilepsy Ireland and training in administration of Emergency Medication can sometimes be provided by the Public Health Nurse or GP or sometimes through the prescribing hospital.

### ***What do I look for in a Summer Camp?***

Health and Safety Policy : Adequate level of staff training including first aid.

Levels of supervision must be adequate.

Up to date Child Protection Policy.

Openness to supporting a child with epilepsy.

Open to giving emergency medication or be trained in it's use.

Full Insurance is essential.

## ***What activities can my child do in Summer Camp?***

There are activities of all kinds from art to drama which don't usually hold any major safety concerns. Sports based camps doing sports that the child is already doing in school are unlikely to post an extra risk - provided the camp is well supervised and follows a safety policy. Adventure centres that offer a range of water based and outdoor climbing activities that would need individual assessment. Each child will vary in terms of their seizure pattern and degree of control of seizures. In the multi activity camps the child may be offered activities of different risk levels and this is where individualised assessment is again recommended - preferably with input for the child's neurology team where needed.

## ***Residential Camps***

If a residential camp is chosen then thought needs to be given to day to day safety and self-care. The same advice applies as would apply at home, showers instead of baths for example. Medication reminders can be programmed into mobile phones. Those with sleep seizures can take their ventilated pillows with them to camp and sleep on bottom bunks instead of top bunks. Regular patterns of sleep and meals are as important away as it would be at home. Others sharing rooms may need to know what to do in the case of a seizure.

## ***Before booking a place on Summer Camp***

- Put together a pack of basic information about epilepsy for the camp organisers. Information leaflets, books and posters can be obtained from Epilepsy Ireland
- Prepare a written outline of how your child's seizures occur, how to recognize them and what needs to be done, who is to be contacted and other relevant details. This can be used as a training tool for staff and kept on file
- Seek the opinion of the child's medical team regarding camp activities offered in terms of high, medium or low risk. Call the nurse helpline if there is one at the clinic
- Familiarise yourself with the camp Health and Safety Policy and Child Protection procedures

## ***Holidays and Travel***

Extremes of heat can trigger seizures. Here are some tips to reduce risks of heat related seizures

- Keep in the shade as much as possible
- Keep well hydrated but avoid taking energy drinks with caffeine or other stimulant drinks. Your pharmacist can advise on re-hydration solutions if you need them
- If glare is a trigger for photosensitive seizures wear wraparound shades with polarised lenses and a wide brimmed hat to give shade
- Be careful around water and water based activities. Seek medical advice if you are not sure if an activity is safe
- During holidays it's easy for regular routines to slip – try to keep to regular medication schedules even if routine alters
- Paths and tarmacadam can get very hot and could cause burn injuries for someone in a seizure. Using a towel or picnic rug to ease under the head or bare skin when placing someone in the recovery position will help reduce the risk. However, moving the person is not recommended unless they are in immediate danger
- Make sure to use suncream and aftersun lotion if needed. Sunburn could lead to sleep loss which can trigger seizures
- If you find it difficult to get to sleep in the warm weather make sure the room is well ventilated, reduce bedding and if you still can't sleep speak to your GP
- Alcohol is a trigger for seizures and combined with heat might be more problematic so be sensible in how you use it

- Some people on medications such as Lamictal may find their skin more sensitive to the effects of sunlight and may need to take care or use a higher factor sunscreen. This effect can happen with medications for other conditions too. Your pharmacist can advise if any type of medication that you are on would be likely to increase your sensitivity to sunlight

## ***Before you go....and when you get there***

Here are some tips for making your holiday at home or abroad as problem free as possible. It's advisable to discuss travel plans with your doctor especially if travelling long haul, to areas requiring vaccinations, or where malaria occurs, as well as deciding which activities may be suitable for you. Travelling and all the preparation for it can be tiring in itself so try to make sure you are well rested before the journey. When you arrive taking some time to rest first before unpacking and exploring the area will give you a chance to recharge after your journey.

## ***Checklist for Holidays***

- European Health Insurance Card for EU countries (formerly E111) available from the HSE free of charge at [www.ehic.ie](http://www.ehic.ie)
- Travel Insurance – needed in the EU due to variable cover under EHIC and outside EU where EHIC cover does not apply
- Enough supply of daily medication for your trip in it's original packaging kept in hand luggage, allow extra for any delays
- Emergency medication (if prescribed)
- Airline guidelines on carrying liquid medications
- Letters from doctors stating medication is for your epilepsy
- Copies of prescriptions (Pharmacists in EU can dispense on EU prescriptions but outside EU they can be re-prescribed)
- Copy of Travel Handbook (travel advice document available from Epilepsy Ireland website)
- Contact details of epilepsy groups or medical services in the country you are travelling to.
- Updated Epi-Alert bracelet (within Republic of Ireland), Tap2Tag, wearable ID jewellery, card with local translation

- Ventilated pillow for sleep seizures (or if one is used. alternatively, use no pillow.)
- 2 watches to track time gap 1 on Irish time, 1 on local time
- Medication reminders programmed into mobiles or watches
- Letter of seizure freedom (for car hire) - driving laws vary
- Flotation devices and a bright coloured swim cap
- Up to date vaccinations if needed – discuss with doctor in advance

### ***Managing tonic clonic seizures on planes***

- Passengers in surrounding seats should be moved where possible to leave space around the person
- Armrests should be raised
- Protect the head with pillows, blankets or rolled up coats
- Place nothing in the mouth
- Let the seizure run its course
- Note the length of time the seizure lasts. Some people may carry emergency medication to stop the seizure and those accompanying them need to know how to use it.
- Lone travellers need to inform the crew in advance if they have epilepsy and carry ID with their first aid details on it.
- When a seizure lasts more than 5 minutes, or longer than normal for the person, or more seizures follow without recovery in between, this is a medical emergency. The cabin crew need to know in case a diversion is needed. If a person is injured or has another medical condition they may need medical attention.
- After the seizure allow the person lie across seats on their side in the recovery position to facilitate their breathing. If the person has vomited during or after the seizure, take special care. They should not be lifted up or moved onto their back, the recovery position is best.

### ***Managing tonic clonic seizures on buses and trains***

- Passengers in surrounding seats should be moved if possible to leave space around the person
- Armrests should be raised
- Protect the head with pillows, blankets or rolled up coats

- Place nothing in the mouth
- Let the seizure run its course
- Monitor the length of time the seizure lasts. Some people may carry emergency medication to stop the seizure and those with them need to know how to use it.
- Lone travellers: wear ID or carry cards with first aid details
- When a seizure lasts more than 5 minutes, or longer than is normal for the person, or more seizures follow in a cluster without recovery in between this is a medical emergency. The bus driver or rail staff need to know in case an emergency stop is needed. If a person is injured or has another complicating medical condition they may require medical assessment.
- After the seizure allow the person lie across seats on one side in the recovery position to facilitate their breathing. If the person has vomited during or after the seizure take special care. They should not be lifted up or moved onto their back, the recovery position is best.

### ***Tonic Clonic Seizures In Wheelchairs Or Buggies***

- Remain calm and note the time of the seizure.
- Apply the brake and ensure the chair is secure.
- Don't restrain the person or attempt to stop the seizure.
- DO NOT put anything into the person's mouth.
- Wipe away any saliva that may collect around the mouth.
- Let the person stay in the chair during the seizure – this is safer than moving them which could lead to injury.
- Move objects that could cause injury to the person.
- The seat belt or harness should prevent falling from chair.
- If there is no belt you may need to support (not restrain) the person to prevent them from falling out of the chair.
- Cushion the head area using a rolled up coat or a cushion.
- At the end of the seizure the person can be moved gently from the chair and placed in the recovery position. If they have vomited take special care. Do not lift them up or put them on their back, leave them seated or ease gently them onto their side in the recovery position.
- There is no need to call an ambulance unless the seizure is prolonged (5 minutes or more), there is injury, it's the first seizure or the person has a complicating medical condition.

## ***Air travel for children and adults with special needs***

If you are travelling by air with children and adults who may be anxious, or who have special needs, some airports have booklets with pictures explaining the air travel step by step from check in to lift off.

## ***Choosing locations and accommodation***

When booking accommodation ground level is safer especially with frequent seizures.

If seizures involve wandering ask to see a plan or layout of accommodation. Apartments and hotels often have balconies and easily accessible pools. Knowing the layout in advance helps you plan to reduce risk.

If you won't be driving on holiday choose accommodation served by public transport.

Remember the same safety advice that applies at home applies on holiday too with regard to cooking, bathing, sleeping and being out and about.

To try to ensure a restful night's sleep you may wish to choose a less lively location

Try choose a location with ready access to medical services should you require them.

## ***While on holiday***

Take your medication at the required intervals.

Keep your patterns of sleep and meals similar to that at home.

Be mindful of extremes of heat and cold and the effects these can have.

Keep alcohol intake low to moderate.

Choose activities that will not put you at unnecessary risk.

Take care around water

If you are photosensitive you may need to take care around discos and other visual triggers, wraparound sunglasses, polarized lenses and covering one eye with your hand are often helpful.

Pace yourself – take activities at a pace that doesn't leave you struggling to keep up.

Relaxation is an important part of any holiday – make sure to factor it in!



## ***Air travel for children and adults with special needs***

If you are travelling by air with children and adults who may be anxious, or who have special needs, some airports have booklets with pictures explaining the air travel step by step from check in to lift off.

## ***Choosing locations and accommodation***

When booking accommodation ground level is safer especially with frequent seizures.

If seizures involve wandering ask to see a plan or layout of accommodation. Apartments and hotels often have balconies and easily accessible pools. Knowing the layout in advance helps you plan to reduce risk.

If you won't be driving on holiday choose accommodation served by public transport.

Remember the same safety advice that applies at home applies on holiday too with regard to cooking, bathing, sleeping and being out and about.

To try to ensure a restful night's sleep you may wish to choose a less lively location

Try choose a location with ready access to medical services should you require them.

## ***While on holiday***

Take your medication at the required intervals.

Keep your patterns of sleep and meals similar to that at home.

Be mindful of extremes of heat and cold and the effects these can have.

Keep alcohol intake low to moderate.

Choose activities that will not put you at unnecessary risk.

Take care around water

If you are photosensitive you may need to take care around discos and other visual triggers, wraparound sunglasses, polarized lenses and covering one eye with your hand are often helpful.

Pace yourself – take activities at a pace that doesn't leave you struggling to keep up.

Relaxation is an important part of any holiday – make sure to factor it in!

## **Theme Parks**

Contact the park in advance to find out their supports for persons with disabilities

Parks may have special passes such as easy access cards so you may not need to queue for long if you have a disability or illness (not just mobility problems). This can be a real help as tiredness and heat can trigger seizures.

If tiredness is a problem parks usually have large buggies and wheelchairs available.

By arrangement in advance Park staff may be on hand to provide assistance and support.

Some rides may be unsuitable and warnings may be displayed at the entrances to these.

If you are unsure you or a support person can ask for a preview of the ride to assess it.

Seizures are often unpredictable so you need to consider what could happen if you have a seizure on an attraction – safety is the main concern.

Excitement and fear can trigger seizures for some people too so bear this in mind when assessing rides.

Finally, keep the balance between safety and being able to enjoy your holiday. Safety measures are suggested to help you have fun safely not to be a source of worry in themselves.



## ***Alarms and Seizure Supports***

Technology can help detect seizures. There are numerous models of seizure alarms on the market and there are some apps for detecting seizures too. Seizure alarms can give peace of mind especially for people living alone. Alarms can be costly so it is best to look at the range of products available to find what suits your needs and budget best. To decide on the best device for you will need to think about:

- 1. Your seizure type** is it a tonic clonic seizure, another seizure with movement, do you get a warning or not, does the seizure feature saliva, urine, breathing changes or wandering.
- 2. How will you benefit?** Anyone with epilepsy can benefit but especially those who live alone or parent alone, people with sleep seizures, people with uncontrolled tonic clonic seizures, prolonged seizures, those with history of injuries, people who wish to live independently of family.
- 3. Which alarm is best suited** not all alarms are the same they capture different seizure types in different situations. A bed alarm can detect seizures in bed but a separate alarm is needed to detect waking/daytime seizures.
- 4. What kind of support do you need?** Someone living alone may need an alarm which detects the seizure and contacts a monitoring centre or nearby trusted key-holder. Those living with family might choose an alarm to alert a carer in the home.

Epilepsy specific alarms are designed to detect seizures with rhythmic movements, electrical changes in the skin, and other physiological features. Other alarms monitor position, falls, wandering, breathing and heart rate. Alarms can be used alone or combined to detect a wider range of features.

## **Main Types of Epilepsy Alarms and Seizure Detection Apps after Alarms**

**Costs** for epilepsy alarms vary from €100 - €1400 depending on alarm types and packages. Some companies may offer payment plans. HSE funding is on a case by case basis and medical letters are needed.

1. Tonic clonic seizure alarms detect tonic clonic seizures with falls in people who get no warning and they can dial out to get help. They are fixed alarms and detect seizures in or around the home. They are not effective outside a certain radius.
2. Bed alarms come in 2 main types. Mattress sensors detect seizures with movement, urine or saliva and can alert a carer in the home or dial out using an auto-dialler. SAMI sleep monitor, a camera/motion sensor which works with Apple devices and detects a wide range of seizures, records them and alerts a carer in the home. Sami monitor only works with Apple devices.
3. Smart Watches: detect tonic clonic seizures with movement. The Epicare Watch and the Embrace Watch can be worn outdoors, in the home and in bed. Trials of Embrace watches are ongoing.
4. Apps: There is a range of apps (see next page). Epdetect and Openseizuredetect are free. SeizureDetect is for Pebble watches (Pebble are being discontinued but the app should be usable for Pebble owners). Trials of the Apple watch and some related apps are ongoing.
5. Wearable Monitoring: PulseGuard monitors pulse rates in seizures.

### **Do these alarms work?**

It has been found in studies to date, that no alarm detects seizures 100% of the time and 'false alarms' do occur. Alarms may aid in lowering risk but can't be guaranteed to prevent SUDEP. Nonetheless people surveyed reported largely positive feedback about their use of epilepsy alarms.

## Epilepsy Alarm and Suppliers

| Company                        | Products   | Description   | Location |
|--------------------------------|--|---|----------|
| Tunstall<br>Emergency Response | EpiCare Free Wrist Sensor<br>Bedside Companion<br>Epilepsy Monitor<br>Companion Mini<br>Bed Guardian | Tonic clonic sensor<br>Bed movement<br>Sensor<br>Portable sensor<br>Bed monitor | Wexford  |
| Task                           | Ep-IT Companion Monitor<br>EpIT Guardian Monitor   | Tonic clonic monitor<br>Movement sound and exit<br>monitor                      | Meath    |
| Independent Living<br>Ireland  | Companion Epilepsy<br>Monitor<br>Companion Mini<br>Guardian Monitor                                  | Tonic clonic bed sensor<br>Portable sensor<br>Multi-detection                   | Galway   |
| Homecare<br>Technologies       | Emfit<br>Medpage MP5<br>Medpage MP2  | Tonic clonic bed sensors  | Cork     |
| Epilepsy Solutions             | SmartWatch PT  | Seizure movement detector   | UK       |
| Easylink                       | Medpage MP5  | Bed senso   | UK       |
| Adris                          | Pulseguard   | Wrist/ankle worn pulse<br>sensor  | UK       |
| SAMI                           | SAMI monitor   | Camera sensor   | US       |
| Empatica                       | Embrace Watch  | Seizure monitoring  | US       |

## Seizure Detection Apps

| App                 | For                | Google Play              |
|---------------------|--------------------|--------------------------|
| OpenSeizureDetector | Android/Pebble     | pebbleseizuredetect.com  |
| PebbleSeizureDetect | Android phones     | www.epdetect.com         |
| Epdetect            | iPhone,Apple Phone | iTunes, seizurealarm.com |
| SeizAlarm           | Android            | Google Play              |
| Soterra             | Phone & smartwatch | www.watchaware.com       |
| Neutun              | Android            | Google Play              |
| BioLert             | Apple Watch        | iTunes Apple             |
| EpiWatch            |                    |                          |

## Checklist for choosing alarms

Where and when do I need it, at home, outdoors or in bed?

Is the alarm to be worn or is it to be in a fixed place?

Do I need a landline for a fixed alarm base unit?

Which mobiles will the alarm work with?

How far is the range of detection for a fixed alarm?

Will GPS be needed to locate me outside of home?

Does the alarm need to autodial for help?

Do I need a monitoring service?

Do I have trusted key-holders nearby who will respond?

Is there a mobile phone app to support the alarm?

Is there technical back up from the supplier?

Is it mains or battery operated?

If battery powered how much charging is required?

If mains powered will it work during a power failure?

What are the costs? Are rental options available?

Is it easy to install?

Can I try the alarm before buying?

What is the returns policy if I am not satisfied?

Check online reviews for user feedback

Check the Alarms Survey on [www.epilepsyresearch.org.uk](http://www.epilepsyresearch.org.uk)

## ***More Safety Supports***

Safety helmets are recommended for people with frequent seizures with falls and atonic and tonic seizures (drop attacks). These helmets help to protect the head and face from further injury. They differ somewhat from sports helmets in their design and construction. They can be made of a hard shell or of leather. They can offer protection in the area most vulnerable to injury.

Safety Pillows are firm foam pillows with holes in them like a cot mattress. Soft pillows are a theoretical safety risk if a person turned their face into them during a seizure. Safety pillows allow air to circulate. Although there is no research to date on the effectiveness of these pillows, people with sleep seizures might prefer to use them.

ID Jewellery can be useful if you are out and have a seizure. Details you choose to give are available to paramedics and A&E staff. This is important if you are taken to hospital on our own. Epilepsy Ireland provides free bracelets with our 2 year membership and our ID cards are free to all.

Seizure alert dogs differ from assistance dogs. Alert Dogs are said to detect the onset of seizures and signal this. Assistance dogs do other things even helping with household tasks. Research on seizure alert dogs is mixed and more studies are needed. Epilepsy Ireland is not aware of accredited training services currently supplying trained dogs in the Republic of Ireland but it has been possible to have pet dogs trained.

While Epilepsy Ireland staff are aware of many products and services that might be of help they do not have expertise in alarms, equipment or training of alert dogs, and will not be able to recommend or prescribe devices or services. If you have access to an Occupational Therapist they would be in a position to recommend equipment. However, many people with epilepsy don't have access to Occupational Therapy services and wait lists in the community are lengthy. Often the technical staff from alarm companies are well placed to match you with the best alarm for your needs and some companies do their own assessment based on the information you give them. Social media might also be helpful if you wish to ask others what has worked for them.

## **Suppliers in Ireland**

Emergency Response, Ryland Road, Bunclody,  
Co Wexford  
Telephone: 1850 232324  
[www.emergencyresponse.ie](http://www.emergencyresponse.ie)

Home Care Technologies, Classis Business  
Centre, Ovens, Co. Cork.  
Tel: 1890 480 480  
[www.homecaretechnologies.ie](http://www.homecaretechnologies.ie)

Task Ltd, Unit 1 Block 3, CityNorth Business  
Campus, Stamullen Co. Meath.  
(01) 8435901 K32 V008  
[www.taskltd.com](http://www.taskltd.com)

Independent Living Ireland, Old church street,  
Athenry, Co. Galway. [www.independentliving.ie](http://www.independentliving.ie)  
Info@independentlivingireland.ie  
091 877 007

Alarm companies and seizure detection  
products - outside Ireland:-

Easylink UK: [www.easylinkuk.co.uk](http://www.easylinkuk.co.uk)  
Sami Alert Sleep Seizure Monitor:  
[www.samialert.com](http://www.samialert.com)  
Adris Technologies: [www.pulseguard.org](http://www.pulseguard.org)  
Epilepsy Solutions: [www.epilepsysolutions.co.uk](http://www.epilepsysolutions.co.uk)

Apps and watches from the US  
Pebble watch app can be downloaded from:  
[https://github.com/PebbleSeizureDetect/  
PebbleSeizureDetect](https://github.com/PebbleSeizureDetect/PebbleSeizureDetect)  
Embrace watch: see [www.empatica.com](http://www.empatica.com)  
Apple watch: see [www.apple.com](http://www.apple.com)

### **List of suppliers for helmets**

Glencar Medical  
Unit 2 Redleaf Business Park  
Turvey, Donabate,  
Co Dublin  
Telephone: 01 8900201  
Website: [www.glencar.ie](http://www.glencar.ie)

Glencar Medical (Northern Ireland)  
6 G Milltown Industrial Estate  
Greenan Road  
Warrenpoint  
BT 34 3 FN  
Telephone: 048 417 54854  
Trulife  
3103 Lake Drive  
City West Business Campus  
Tallaght  
Dublin 24  
Telephone: 01 4511755  
Website: [www.trulife.ie](http://www.trulife.ie)

Orthocare Ltd  
Unit 5 Cedar Estate  
Killarney Road  
Bray  
Co Wicklow  
Telephone : 01 2762770

### **Disability Products and Suppliers Directory**

Assist Ireland  
Citizens Information Board  
George's Quay House  
43 Townsend St  
Dublin 2  
Tel: 0761 07 9200  
Text: 086 383 7644  
Email: [support@assistireland.ie](mailto:support@assistireland.ie)  
Web: [www.assistireland.ie](http://www.assistireland.ie)  
Membership Form





**Web:** [www.epilepsy.ie](http://www.epilepsy.ie)  
**Facebook:** [facebook.com/epilepsy.ie](https://facebook.com/epilepsy.ie)  
**Twitter:** @epilepsyireland  
**YouTube:** [youtube.com/BrainwaveEpilepsy](https://youtube.com/BrainwaveEpilepsy)

---

#### Head Office

249 Crumlin Road, Dublin 12  
**Tel.:** 01 455 7500  
**Email:** [info@epilepsy.ie](mailto:info@epilepsy.ie)  
**Specialist Nurse Helpline Tel.:** 01 455 4133  
Monday 9.30am – 1pm  
**Transitional Care Advice Line Tel.:** 01 455 4133  
Monday 2pm – 5pm

---

#### North West

**Covering:** Donegal, Leitrim & Sligo  
**Community Resource Officer:** Agnes Mooney  
Letterkenny Office, Grand Central Complex, Floor 2B,  
Canal Road, Letterkenny, Co. Donegal  
**Tel.:** 074 9168725  
**Email:** [amooney@epilepsy.ie](mailto:amooney@epilepsy.ie)  
**Tel.:** 071 9141858

---

#### West

**Covering:** Galway, Roscommon & Mayo  
**Community Resource Officer:** Edel Killarney  
Westside Resource Centre, Seamus Quirke Road,  
Westside, Galway  
**Tel.:** 091 587640  
**Email:** [ekillarney@epilepsy.ie](mailto:ekillarney@epilepsy.ie)

---

#### Mid-West

**Covering:** Limerick, Clare & Tipperary North  
**Community Resource Officer:** Veronica Bon  
Social Service Centre, Henry St. Limerick  
**Tel.:** 061 313773  
**Email:** [vbbon@epilepsy.ie](mailto:vbbon@epilepsy.ie)

---

#### Kerry

**Covering:** Kerry  
**Community Resource Officer:** Kathryn Foley  
9/10 The Paddocks, Ballydowney, Killarney, Co. Kerry  
**Tel.:** 064 6630301  
**Email:** [kfoley@epilepsy.ie](mailto:kfoley@epilepsy.ie)

---

#### Cork

**Community Resource Officers:**  
South Lee & West Cork: Niamh Jones  
North Lee & North Cork: Loretta Kennedy  
35 Washington Street, Cork  
**Tel.:** 021 4274774  
**Email:** [njones@epilepsy.ie](mailto:njones@epilepsy.ie) /  
[lkennedy@epilepsy.ie](mailto:lkennedy@epilepsy.ie)

---

#### South East

**Covering:** Kilkenny, Wexford, Carlow, Waterford &  
Tipperary South  
**Community Resource Officer:** Miriam Gray  
C/o HSE, St. Joseph's, Waterford Rd, Kilkenny  
**Tel.:** 056 7789904  
**Email:** [mgray@epilepsy.ie](mailto:mgray@epilepsy.ie)

---

#### Midlands

**Covering:** Offaly, Longford, Laois & Westmeath  
**Community Resource Officer:** Cliona Molloy  
The Charleville Centre, Church Avenue, Co. Offaly  
**Tel.:** 057 9346790  
**Email:** [cmolloy@epilepsy.ie](mailto:cmolloy@epilepsy.ie)

---

#### East

**Covering:** Dublin, Kildare & Wicklow  
**Community Resource Officer:**  
Dublin North, West & Kildare: Edel Curran  
Dublin South & Wicklow: Carina Fitzgerald  
National Information Officer: Geraldine Dunne, 249  
Crumlin Road, Dublin 12  
**Tel.:** 01 4557500  
**Email:** [gduenne@epilepsy.ie](mailto:gduenne@epilepsy.ie) /  
[ecurran@epilepsy.ie](mailto:ecurran@epilepsy.ie)  
[cfitzgerald@epilepsy.ie](mailto:cfitzgerald@epilepsy.ie)

---

#### North East

**Covering:** Louth, Meath, Monaghan & Cavan  
**Community Resource Officer:** Mary Baker  
Unit 1a, Partnership Court, Park St. Dundalk, Co.  
Louth  
**Tel.:** 042 9337585  
**Email:** [mbaker@epilepsy.ie](mailto:mbaker@epilepsy.ie)

---

#### Training for Success

**Manager:** Honor Broderick  
Institute of Technology Sligo, Ballinode, Sligo  
**Tel.:** 071 915 5303  
**Email:** [Broderick.honor@itsligo.ie](mailto:Broderick.honor@itsligo.ie)

---

#### Epilepsy Specialist Nurse HELPLINE

Monday 9.30am – 1.00pm  
**Tel.:** (01) 4554133

---

#### Transitional Care Information Advice Line

Monday 2pm - 5pm  
**Tel.:** (01) 4554133