

# **Self-management**

The unpredictability of seizures can make people with epilepsy sometimes feel powerless and out of control. Identifying potential triggers for seizures can, however, be the first step towards better seizure control, as it is often possible to avoid, reduce or manage a trigger. The following chapters list common seizure triggers, giving you the knowledge and power to work on these triggers, and hopefully regaining a sense of control.

## Keeping a seizure diary

Keeping a seizure diary is usually the starting point for trying to identify possible triggers. Not everyone though has their seizures triggered by certain events; in many cases, they simply happen. We can send you a free seizure diary to record your seizures.

Start by recording any seizure you have and anything that happened in the run up to the seizure. Did you forget to take your medication? Where you particularly tired? Did you skip your meals? Where you stressed or anxious about something? All of these are possible triggers for seizures, which are described in more detail below.

# **Missing medication**

The most common reason for a seizure is forgetting to take your anti-epileptic drug (AED) or deliberately not taking it. Seizures can also be triggered if you take your AED much later than advised (find out in advance from your medical team what constitutes 'too late' as this differs from drug to drug). Your body is used to having a certain level of drugs in your system, which prevents any seizures from happening. The level of your AED in your body can quickly fall so low that it stops working effectively to control your seizures. If you do not top up your medication when it is time to do so, you may react by having a seizure.



This trigger is one of the easiest to manage. Get into a routine to make sure you take your medication exactly as prescribed. If necessary set your mobile phone alarm or use an electronic pill box which can be set to send you an alarm reminder. Or you can link it to a daily routine, such as brushing your teeth. Never skip your drug, no matter what the reason is, this can put you at risk of having a seizure which can be worse than normal. Even forgetting just once can trigger a seizure.

#### **Alcohol**

Moderate drinking (one to two units a day) is usually fine. Many doctors, however, advise not to drink alcohol when on anti-epileptic drugs because alcohol can sometimes make these less effective. If you have many seizures, it may be worth your while staying off alcohol to see if this makes a difference to your seizure control. Avoid binge drinking as this can trigger a seizure, even in those who do not have a diagnosis of epilepsy.

Beware the after effects of a hangover. Lack of sleep, being dehydrated, sleeping in, forgetting to take your drugs or taking them much later than usual, not eating anything or low blood sugar are all potential triggers for seizures. For more information on this, please read our factsheet on 'Alcohol'.

# **Recreational drugs**

There are no regulations to control the quality and strength of recreational drugs including legal highs. Many of these drugs are stimulants which can affect brain chemistry potentially triggering a seizure. As each person reacts differently to each drug, there is no way of knowing in advance if a particular drug is 'safe'. Even people who do not have epilepsy can have a seizure after taking recreational drugs. For more information on this, please read our factsheet on 'Recreational drugs and seizures'.



#### **Caffeine**

High concentrations of caffeine can be found in many energy or fizzy drinks, caffeine shots and pills, and even over-the-counter cold and flu remedies. As caffeine is a stimulant, it can trigger seizures in some people. Even drinking large amounts of tea or coffee can give you more than the daily recommended amount of caffeine and this could trigger a seizure if you have already a lower seizure threshold. To find out more on this, please read our factsheet 'Recreational drugs and seizures'.

## **Food triggers**

There is some anecdotal evidence that **Aspartame**, (an artificial sweetener found in many diet food and drinks), also known as E951, and **Monosodium Glutamate** (a flavour enhancer used in processed food), also known as E621, can trigger a seizure in some people. Keeping a food diary alongside your seizure diary for a few weeks may allow you to identify anything you consume that could trigger a seizure. Get medical advice from your doctor, specialist nurse or a dietician before you start cutting out any food groups. This is important as this could lead to vitamin or mineral imbalances, which can sometimes make seizures worse.

# Lack of sleep / tiredness

This is one of the biggest triggers for seizures. People with epilepsy generally should avoid working night shifts as this can be the cause of sleep problems which may increase seizures. If you are affected by insomnia, ask your doctor or specialist nurse for advice as improved sleep could make a difference to seizure control.

Establish a good sleep routine; avoid caffeine in the evening, give your brain some time to switch off after watching television and switch off electronic devices an hour before you go to bed. Many of the electronic devices we use give off a blue light which interferes with the production of melatonin, a hormone essential for sleep. There is more on sleep in our factsheet 'Lack of sleep'.



#### Stress / anxiety

Stress and anxiety can sometimes trigger a seizure in people with epilepsy. Not all sources of stress can, of course, be avoided but you may be able to change how you respond to stressful situations which could lower the potential to have a seizure. There are so many different ways of combatting stress. Simple things like going for a walk, meeting up with friends or listening to music can help you step back from a stressful situation. Breathing techniques, yoga, or meditation can also be useful tools to help you cope with stress.

Knowing that stress can trigger a seizure would perhaps allow you to take some precautions such as telling those around you that you may be more likely to have a seizure, and watching out for any other potential trigger factors. Stress can also affect your sleep, which is another potential trigger for seizures. Seek professional help if stress or anxiety becomes a problem in your life particularly if it interferes with seizure control. For more information on stress, check out our factsheet 'Epilepsy and stress / anxiety'.

#### **Boredom**

For a small number of people with epilepsy, their seizures can be triggered by being bored or doing nothing. Some people find that keeping themselves busy or using some distraction techniques when they feel a seizure coming on can sometimes avert a seizure.

# Feeling unwell

If you feel unwell or get a cold or the flu, you may be more likely to have a seizure. Running a temperature or fever can lower your seizure threshold. Vomiting and diarrhoea can stop your drugs from being fully absorbed by your body allowing the level of the drugs go below that which is required to prevent a seizure. This can also make you more dehydrated or affect your sleep, which can be seizure triggers. It is, of course, not always possible to avoid getting a cold or flu, but being aware of the



fact that some symptoms can make you more likely to have a seizure will allow you to take some precautions. This could, for example, be ensuring you keep yourself hydrated with water and getting plenty of rest.

Epilepsy does not entitle you to the free annual flu jab. Normally, this is only offered to people who have a condition which affects a person's immune system. This is not the case with epilepsy, as the condition does not make you more likely to catch the flu or a cold. Many doctors will, however, offer the flu jab to those with epilepsy as the consequences of getting the flu can be more severe for people with epilepsy, such as having a breakthrough seizure or increased amount of seizures.

If you have not been offered the jab, ask your doctor for it. If you cannot get the jab at your GP practice, you may be able to pay for it at your local chemist.

#### **Skipping meals**

Low blood sugar can sometimes trigger a seizure in people with epilepsy. Eating regular meals can help your seizures stay controlled. If you are thinking of going on a weight loss diet, seek advice from your doctor or specialist first about the safest way to do this.

## **Dehydration**

Keep your fluids topped up all the time. Dehydration can make it more likely for you to have a seizure. This is particularly important when you are exercising, when it is hot outside or you are on holiday in a hotter climate, or when you are unwell with vomiting and / or diarrhoea (see above).

### **Hormonal changes**

Some women have more seizures at a particular point in their menstrual cycle, as monthly hormonal fluctuations can make it more likely to have a seizure. These fluctuations also occur after child birth and in the run up to the menopause, making a



woman with epilepsy more susceptible to seizures at these times. If you suspect that your seizures are linked to your menstrual cycle keep a diary for a while. Your specialist may be able to prescribe additional medication you can take around this time of the month to give you added protection against a possible increase of seizures.

# Flashing / flickering lights

This is a well known but relatively rare seizure trigger. Only around 2-3% of people with epilepsy are photosensitive, which means their seizures tend to get triggered by flashing or flickering lights. Light effects created by sunlight streaming through trees or a fence can create a similar flicker effect potentially triggering a seizure. Modern technology has made screens a lot safer by eliminating the refresh rate flicker which used to trigger seizures. However, the content of a television programme or computer game can still trigger a seizure if this involves flicker effects or fast moving patterns.

If you are photosensitive and suddenly find yourself faced with flashing or flickering lights, try covering one eye with one hand before you either turn away from the source or switch the TV or other device off. This can sometimes interrupt a process in the brain avoiding a seizure. For more information and useful tips on how to minimise risks of a seizure if you have photosensitive epilepsy, read our factsheet 'Photosensitive epilepsy'.