

Disability Insight

Take a look around you

International Day of Epilepsy Awareness 26 March 2014

6 facts you need to know about epilepsy

- Epilepsy is the tendency to have recurrent seizures that start in the brain.
- Epilepsy is a neurological condition.
- Epilepsy can affect anyone, at any age. Many people who develop epilepsy below the age of 20 will 'grow out of it' in adult life.
- Many people with epilepsy can take part in the same activities as everyone else, with the help of simple safety measures where appropriate.
- People who have been seizure-free for a year can re-apply for their driving licence.
- Many people with epilepsy are still discriminated against due to ignorance about the condition. Epilepsy is covered by the Disability Discrimination Act in Northern Ireland.

Sources:

www.epilepsysociety.org.uk/epilepsy-did-you-know

www.epilepsy.org.uk/press/facts

en.wikipedia.org/wiki/List_of_people_with_epilepsy

Someone you know may have epilepsy

1 in 20 people will have a one-off epileptic seizure at some point in their life (although this does not necessarily mean that they have epilepsy). **1 in 103** people has epilepsy.

Some famous people with epilepsy include: Julius Caesar, Vladimir Lenin (Politicians), Danny Glover (Actor), Neil Young, Lindsey Buckingham, Prince (Musicians), Maggie McEleney (Paralympian), Paul Wade, Leon Legge (Footballers).

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Seizures

- Not all seizures are due to epilepsy
- Most seizures happen suddenly without warning, last a short time and stop by themselves.
- Not all seizures involve convulsions. Some people appear vacant, wander around or seem confused during a seizure.
- Some people have seizures when they are awake; others have seizures while they are asleep.
- Injuries can happen during seizures, but many people don't hurt themselves and don't need to go to hospital or see a doctor.

Sources:

www.epilepsysociety.org.uk/epilepsy-and-seizures

www.epilepsysociety.org.uk/epileptic-seizures

How does epilepsy affect a person?

From people who have epilepsy, we know that some of the ways in which they may be affected includes:

- feeling uncertain and afraid (when there are delays in diagnosis and appropriate treatment or from any unhelpful reactions of colleagues)
- feeling powerless at not knowing when the next seizure will occur
- being bullied and stigmatised by the behaviour of others
- memory problems
- tiredness
- side effects of medication.

Others feel that at times it has no significant impact on their day-to-day living.

Here is an opportunity to **listen** to some people talk about their experience of living with epilepsy. Click on any of the links below, produced by Epilepsy Action:

[Christina I \(1min 32s\)](#)

[Christina II \(2min 31s\)](#)

[James \(2min 14s\)](#)

[Graham \(2min 44s\)](#)

[Barbara \(1min 30s\)](#)

[Memory problems \(1min 43s\)](#)

[Being positive \(1min 59s\)](#)

To **read** some other personal stories click on any of the following links produced by the Epilepsy Society: [Daniel](#), [Rob](#) and [Jane](#).

How best to support a person who has epilepsy?

There are a number of practical things you can do to support a colleague who has epilepsy. A lot of it is common sense. It starts with the language you use. There are also useful first aid tips if somebody in the workplace has a seizure.

The language you use – Terms to avoid:

- **Illness:** epilepsy is a condition, not an illness.
- **Fit:** although the term 'seizure' or 'epileptic seizure' is preferred by many people, some people with epilepsy choose to use the word 'fit'.
- **An epileptic:** it is important to look at the person before the medical condition, therefore it is more appropriate to say 'a person with epilepsy'.
- **A victim, sufferer:** this implies someone is helpless.
- **Grand Mal or Petit Mal:** terms previously used to describe types of seizure. There are many types of seizures so these terms are too general and are now considered outdated.
- **Brainstorming:** it depends on how the word is used. If it is to describe a meeting where people are suggesting ideas, then its use is not offensive to people with epilepsy. However, it should not be used to describe what happens in the brain during a seizure.

Source: www.epilepsy.org.uk/press/facts

First Aid for Seizures - What to do

1. **Stay calm.**
2. **Look around** - is the person in a dangerous place? If not, don't move them. Move objects like furniture away from them.
3. **Note the time** the seizure starts.
4. **Stay with them.** If they don't collapse but seem blank or confused, gently guide them away from any danger. Speak quietly and calmly.
5. **Cushion their head** with something soft if they have collapsed to the ground.
6. **Don't hold them down.**
7. **Don't put anything in their mouth.**
8. **Check the time again.** If a convulsive (shaking) seizure doesn't stop after 5 minutes, call for an ambulance (dial 999).

9. **After the seizure has stopped**, put them into the recovery position and check that their breathing is returning to normal. Gently check their mouth to see that nothing is blocking their airway. If their breathing sounds difficult after the seizure has stopped, call for an ambulance.
10. **Stay with them until they are fully recovered.** If they are injured, or they have another seizure without recovering fully from the first one, call for an ambulance.

Source: www.epilepsysociety.org.uk/10-first-aid-steps-when-someone-has-convulsive-seizure

As a line manager - You should speak to the individual and to Human Resources to consider what reasonable adjustments you can make. This could include, for example, flexible working or support for memory problems – such as combining emails with talking to the individual face-to-face.

Are you a carer of a person who has epilepsy?

You can find further information for carers, including on what support is available in the community, from [the Epilepsy Society](#) and from [Carers Northern Ireland](#).

Are you a person who has epilepsy?

If you are considering whether or not to tell your employer about your epilepsy, you may find this information useful, by [Epilepsy Action](#) and the [Epilepsy Society](#). You may also find it useful to speak directly to your line manager, your Human Resources Directorate or the BSO Equality Unit.

For information used from Epilepsy Action: Copyright 2014 Epilepsy Action, www.epilepsy.org.uk, Epilepsy Helpline: freephone 0808 800 5050. Please note: this information was correct at the time of printing. Please visit the Epilepsy Action website epilepsy.org.uk for the latest information.

