

Drivers Medical Enquiries

Telephone: 0300 790 6806 (car or motorcycle),

Telephone: 0300 790 6807 (bus, coach or lorry)

Public Transport

If you have a diagnosis of epilepsy, you are entitled to apply for a free bus pass, and a pass for discounted rail travel. You may need a letter from your doctor to apply. Application forms can be picked up from your bus or train station.

EPILEPSY AND EMPLOYMENT

For most people, a diagnosis of epilepsy will not affect their ability to work. Even if a person with epilepsy continues to have seizures, employers are required by law, under the Disability Discrimination Act to make reasonable accommodations so that the person can continue to work.

When should I disclose that I have epilepsy?

It can be an anxious decision when to disclose to your employers that you have epilepsy. However, it may be necessary to discuss this so that accommodations can be put in place to protect both yourself and potentially your colleagues. Before you attend a risk assessment, however, it is sensible for you to have as much knowledge as possible about your epilepsy.

Considerations may include:

- *How often you have seizures*
- *Potential triggers*
- *What first aid may be required*
- *Whether you get a warning, or 'aura' before a seizure*
- *How long it usually takes for you to recover*
- *If there is someone that you would like to be contacted if you have a seizure*

It is your decision whether or not to tell your colleagues about your epilepsy. It is also illegal for your employer to disclose this information without your consent.

What constitutes discrimination?

Everyone has the right to be free from harassment at work, regardless of disability. However, it is also discrimination to make employment decisions based on criteria unrelated to performance. Epilepsy must not be a factor in decisions about recruitment, training and promotion, if it does not affect your ability to work. If a person believes that they have been discriminated against, they can contact the Equality and Human Rights Commission in Wales:

www.equalityhumanrightscommission.com/wales

What jobs can I not do?

There are some jobs where accommodations cannot be made to minimise risk. These normally include jobs where seizures would endanger the lives of others, for example, airline pilots and certain military professions.

RISK AND SAFETY

For some people, it can be a difficult balance between minimising risk of accidents, and minimising the impact of epilepsy on their lives. A risk-assessment should be done on an individual basis, and whether at work, at home, or out and about, all that is usually required is recognising risk and applying common sense.

For example, a common risk for many people with epilepsy is drowning. So precautions might include not swimming unsupervised, or taking a shower rather than a bath. Social Services can provide you with a risk assessment for your home if you feel this is necessary. Remember, you can always discuss risk and safety with your specialist.

It is also very important to know what may trigger your seizures, and how to avoid these triggers. Again, this is likely to depend on the individual, but common triggers include stress, excessive alcohol consumption and missed medication.

SUDEP

SUDEP stands for **SUDDEN UNEXPECTED DEATH IN EPILEPSY**. Thankfully, this condition is rare, however, it is important to be aware of it so that the risks can be reduced.

SUDEP is said to have occurred when a person with epilepsy dies suddenly, and no cause can be found. Known risk factors include:

- *Uncontrolled tonic-clonic seizures, especially during sleep*
- *Frequent or sudden changes in medication*
- *Missed medication*
- *Where more than one anti-epileptic-drug is needed to control seizures*

SUDEP usually occurs at night, and is thought to be linked to seizures. Precautions that may help to reduce risk include anti-suffocation pillows and seizure alarms.

WOMEN AND EPILEPSY

Epilepsy and contraception

If you are given a diagnosis of epilepsy, it is important that you have a discussion with your doctor about contraceptive methods and pregnancy. Some contraceptive methods, for example the Pill, may have an effect on your anti-epileptic medication. This may make it more likely that you will have seizures, and therefore your dosage may need to be adjusted. It is also true that certain anti-epilepsy medications may reduce the effectiveness of particular contraceptive methods, and make it more likely that you will become pregnant.

Epilepsy and pregnancy

If you have epilepsy, you should take care to avoid unplanned pregnancy. Although most women with epilepsy have perfectly normal pregnancies, there is an increased risk that having seizures, or taking some anti-epileptic medications can affect your health or that of your baby. If you are planning to have a baby, you should discuss this with a specialist to minimise the risk as much as possible. However, if you should become pregnant accidentally, it is very important that you do not stop taking your anti-epileptic drugs, as this could pose a serious risk to yourself and that of your baby. You should arrange an appointment with your doctor as soon as possible.

REVIEW

It is very important that a doctor or specialist nurse reviews your epilepsy. This review can be every year, or every three to six months by arrangement. Depending on your circumstances, you may have a review with your local GP, or a specialist such as a neurologist, paediatrician, GP with specialist interest, or specialist nurse. A review is important to ensure that you are on the right treatment and that your seizures are as well controlled as they can be. It is also a chance to discuss any lifestyle issues related to your epilepsy, such as depression, side effects from drugs, pregnancy and conception, employment, driving etc. If your doctor does not have the answers to all your questions, they should provide you with information on who else can help.

GET THE FACTS ABOUT EPILEPSY

Registered Charity No.: 1059067

EPILEPSI CYMRU
EPILEPSY WALES

WHAT IS EPILEPSY?

Epilepsy is defined as a tendency to have recurrent, usually unprovoked epileptic seizures. Anyone can have a single epileptic seizure, but only those people that go on to have more than one will get a diagnosis of epilepsy. Epilepsy is not a psychological illness. Seizures are caused by a physical problem in the brain, leading to abnormal electrical activity. When this activity starts in a particular part of the brain, this is called focal epilepsy; if it affects the whole brain at once, it is generalised epilepsy. There are over forty different types of seizure under these two main divisions. **For more information, please contact Epilepsy Wales.**

What causes epilepsy?

Anyone can develop epilepsy at any stage of life. It can be caused by damage or malformation to a part of the brain, for example a head injury, a tumour, a viral illness, or because of changes to the brain as part of the ageing process. There are also genetic causes for some epilepsies.

How is epilepsy diagnosed?

There is no definitive test for epilepsy. Your doctor will reach a diagnosis based on your account, or that of eyewitnesses. When diagnosed, you may have an MRI scan of the brain to look for any areas of damage. However, this damage is often so small that a scan cannot find it. In cases where a cause cannot be found, this is called 'ideopathic epilepsy'. You may also have an EEG to help the doctor reach a diagnosis. This is a painless test which reads electrical activity in the brain.

How common is epilepsy?

Epilepsy is a very common condition and there are many different forms, some of which can affect quality of life more than others. It is believed that for every 94 people in Wales, one person will have epilepsy.

Is epilepsy inherited, and can I pass it on?

There are genetic causes for some types of epilepsy. If you have a focal epilepsy, caused by damage to a particular part of the brain, it is unlikely that your children will have an increased risk of having epilepsy. If you have a generalised epilepsy, the risk is slightly greater.

TREATMENTS FOR EPILEPSY

There are several options for treating epilepsy, with the most common being anti-epileptic drugs, or AEDs. Up to 70% of people with epilepsy could have their seizures completely controlled on the right treatment.

Anti-Epileptic Drugs

This is usually the first treatment that your doctor will try to control your seizures. The aim is to control seizures as fully as possible, whilst minimising the side effects of the drugs. There are many drugs available, and if you experience a bad reaction to a particular drug, or if your seizures are not as well controlled as they could be, there are others that can be used.

What are the side effects?

Drugs can affect different people in different ways, but all drugs can have side effects. You should discuss this with your doctor before taking a new drug, or if you believe you are experiencing any side effects.

Will I always have to take my AEDs?

Most people that take drugs to control their seizures have to take them for life, however some people may decide, with the help of a specialist doctor, to slowly reduce and then stop taking AEDs. There is always an increased risk of seizures when coming off a drug, and it may also affect whether or not you will be able to drive.

The Ketogenic Diet

The Ketogenic diet is usually considered for people, most commonly children, when AEDs have not had a good effect on controlling seizures. It involves strictly controlling fat, protein and carbohydrate levels, and should always be done with the supervision of a specialist dietician. For further information, please visit www.matthewsfriends.org

Vagus-Nerve Stimulation (VNS) Deep Brain Stimulation (DBS)

Both VNS and DBS involve implanting devices to attempt to suppress the abnormal electrical activity that causes seizures. They can be considered for people when anti-epileptic drugs have failed to give control.

Surgery

For certain people, there are various surgical procedures that can be used to try to control seizures. There are risks involved with any surgery of this kind, but surgery can be a good option for some people and improve quality of life.

First Aid

There are over forty different types of seizure, and most are not a medical emergency. However, it is important that you know the first aid steps to take if they are needed. You can then pass on this information to partners, family members or friends if you feel it necessary. Epilepsy Wales can provide first aid advice, and also first aid training to family members, or in the workplace

First Aid for focal seizures where awareness is lost:

- *Be ready to guide the person away from potential dangers*
- *Be calm, quiet and reassuring*
- *Stay with the person until they have fully recovered*

First Aid for a convulsive seizure where consciousness is lost:

- *Protect from danger, by cushioning the head with a jacket or your hands, and removing nearby objects*
- *When possible, roll the person onto their side, to help their breathing*
- *Stay with the person until they are recovered. The convulsions usually do not last more than a few minutes, but a person may be disorientated and confused after a seizure.*
- *Be calm and reassuring, and maintain the person's dignity and privacy*

DO NOT:

- *Try to restrain movements*
- *Attempt to put anything in the person's mouth*

Call an ambulance in the following situations:

- *The seizure lasts more than five minutes*
- *The person has further seizures without regaining consciousness*
- *The person injures themselves as a result of the seizure, or is having difficulty breathing*
- *It is the person's first convulsive seizure*

Remember, most seizures are not a medical emergency, however, if you are unsure if a person needs medical help, it is always better to call an ambulance.

WILL EPILEPSY AFFECT MY LIFESTYLE?

Driving Regulations

Having epilepsy does not necessarily mean that you will never be able to drive, however there are strict regulations in place for those at risk of seizures. Having your licence taken away can be very upsetting for many people, but the legal consequences of ignoring regulations can be serious, not counting the risk to yourself and other members of the public.

For full information on driving regulations, please contact DVLA: www.dvla.gov.uk

**WANT TO FIND OUT MORE?
PLEASE CONTACT
EPILEPSY WALES ON
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