

# epilepsy scotland

Scotland's voice for epilepsy

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## Men and epilepsy



**Helpline: 0808 800 2200**

**[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)**

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## Introduction

Some men don't like talking about their health. That's a safe starting point. This leaflet offers information. It also answers some of the questions men might have about epilepsy.

Each person's experience of epilepsy is unique. You might have some concerns about how epilepsy may affect your work. Or your love life. Or how to find support when you need it.

Epilepsy is complex. This leaflet is a general guide. If it raises more questions then health professionals and staff at Epilepsy Scotland can help.

This leaflet includes stories from experts. Just everyday men who live and work through the ups and downs of having this condition. They are proof you are not alone.

One in 20 people will have a seizure at some point in their life, but they might not have epilepsy. About one in every 130 people has the condition. It can affect anyone regardless of race, age, sex or ability. Around 40,000 Scots live with epilepsy. About 20,260 of them are men. Epilepsy Scotland is here to help. We have a confidential freephone Helpline on **0808 800 2200**. We can direct you to more information and answer questions. We can connect you with others living with epilepsy. You can also visit our website: **[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)** for more information.

## What is epilepsy?

Epilepsy is the most common, serious neurological condition. It is defined as having repeated seizures, not just one. These start in the brain. Our brain cells send tiny electrical signals to nerves all over our bodies. Sometimes the brain sends a burst of signals. These can overload the brain and cause a seizure.

The condition is common in childhood and in later life. Often there is no known cause. Some people can develop epilepsy after a head injury, dementia or stroke. No two people have identical experiences with seizures. Medication will vary from person to person. Some seizures end in seconds. Others last several minutes. There are different types of epilepsy. There are different kinds of seizures. Call our Helpline on **0808 800 2200** for a copy of our Seizures factsheet or view it online at **[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)**

There are some well known triggers for seizures. These include missing medication, illness or high temperature, too much alcohol or a hangover. Other triggers include lack of sleep, stress or anxiety, missing a meal or dehydration.

Men and boys tend to be slightly more likely to have the condition than girls and women. There is no known reason why this should happen. The stigma attached to epilepsy is slowly changing. Seizures are epileptic, not people.

Epilepsy is a long term condition, not a disease. Public understanding is improving, but there can still be some ignorance to deal with.

## **Coming to terms with epilepsy**

Being diagnosed with epilepsy can come as a shock. You may worry about how it will affect your life. Or that your lifestyle will need to change. Thanks to advances in medical science and better understanding epilepsy is getting easier to live with. You will learn what medication will best help you. And what activities could be dangerous if you take a seizure.

You're not alone if you've got concerns. A UK survey (Epilepsy Action 2007) was done with a small sample of men living with epilepsy. It found the condition extends into several areas of their lives. This includes work, family, driving and self-esteem.

Findings of respondents revealed:

- 77 per cent said the condition and its treatment affected their confidence
- 75 per cent indicated it influenced their ability to drive
- 72 per cent agreed there was an effect on their social life and activities
- 68 per cent connected it with their employment opportunities
- 54 per cent agreed it had an effect on other members of their family
- 37 per cent said their sexual relationships were affected
- more than a quarter said it affected the ability to be a good parent

You're not alone in having concerns and wanting to find a normal day-to-day life. Epilepsy shouldn't hold you back. You can lead a full and happy life with the help of friends, family and health experts. You know your body best. The more you understand about epilepsy, the more in control you might feel. Being open with others about the condition can help them know what to do if you have a seizure. It can also make you more comfortable with yourself.

And don't be afraid to ask for advice and help. Surveys might find men are more likely to avoid a doctor. However, epilepsy can't be ignored. It can be a serious condition, but you can live with it.

If you feel isolated or a bit down, Epilepsy Scotland has a Helpline on **0808 800 2200**. They may put you in touch with other agencies or individuals. No-one has your exact experiences. However, many men can benefit by chatting to others who live with the condition.

## Work life

Epilepsy can affect your work life. Some men have had to battle stereotypes and discrimination at work. Today, many employers realise that the condition doesn't stop the person from doing their job. They have to make changes to help the person if they need it. Ask yourself if there might be any risks with your job? Do your colleagues know what to do if you have a seizure? When and how often do seizures happen? How could that affect your work?

Some jobs have more risks than others if your seizures are uncontrolled. For example, working at heights or underground, near open water, or hot ovens or open fires. Operating heavy machinery, using chemicals, or working with high voltage or open circuit electricity carries a higher risk.

However, as most people find their seizures stop with medication this can mean their work is not affected.

The other big concern can be driving. By law, you can have an ordinary driving licence if:

- You are unlikely to be a danger to the public and
  - You have not had an epileptic seizure (with or without medication) for at least one year
- or
- You continue to have seizures while asleep but three years have passed with no seizures while awake.

About 60-70 per cent of people control their seizures with medication. You may only need to give up your licence for 12 months. This may entitle you to free bus travel during that time. There are more specific rules for other types of vehicles. More information is available from Epilepsy Scotland. Call our Helpline on **0808 800 2200** or view our Driving factsheet at [www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)

Epilepsy is considered a disability under the Disability Discrimination Act 1995. The Act protects your rights in the workplace. Employers need to make “reasonable adjustments”. This might including allowing you to work a late rather than an early shift because you can’t drive. Only the armed forces are free from this legislation.

Don’t focus too much on your epilepsy to your employer. Be positive and to the point. You want to let them know the realities of the condition. Explain about your specific needs and seizures. We can give employment information to you and your employer.

## Case study

Gary McGale died more than 30 years ago. For at least four minutes Gary was clinically dead after doctors failed to find a way to stop a three-hour seizure and body temperatures of 108F. They said there was a 95 per cent change his brain would not work properly. Despite this Gary survived and was well.

At 21, he was diagnosed with epilepsy. He had been having seizures that to others looked like he was staring into space. Years of school reports said he was daydreaming when the cause was really seizures. “ I just thought, ‘Oh, that’s what it was’, said Gary, now 35. ”I wasn’t angry with the medical people – I was upset I had epilepsy. It meant I lost my driving licence. My main thing was motor racing. I spent thousands of pounds trying to be a



racing driver and suddenly I was told I was not allowed.” Gary eventually took that frustration to Glasgow City Council and fought to gain a taxi-driver’s licence in 2001. “I argued for 45 minutes with a council lawyer about the legalities of the DVLA and council rules,” he said. “I won.”

Gary says he could have hidden his condition to get a licence. But he was, and still is very open about having epilepsy. “I never hid my epilepsy,” he explained. “If you need to fill out an application form, say you have got epilepsy. The more you tell, the less of a problem it is. I have a taxi licence because I was completely open about it.”

"I try to explain it to my wee boy Aedan. He is nearly five. He knows when daddy is different. I try to involve him. I'll ask him 'Can you get daddy's medication?' so he is not scared of epilepsy. I say 'It's not me, it's my medicine. And I explain I wear my medicare bracelet so he could tell people if I got sick."

It took Gary almost five years to get the right dose of that medication to treat his epilepsy. He has now been seizure free for more than 10 years. "But I will never stop my tablets," he said. "Men are more reluctant to see their doctor, but if someone with epilepsy doesn't see a doctor, it can be a matter of life or death."

Gary, who brings up Aedan and daughter Abbie with wife Marie, took up martial arts after he was diagnosed with epilepsy. He said the only thing he hasn't tried because of the condition is scuba diving. "There's really nothing you can't do," he said. "Having epilepsy has made me who I am today. I would be a completely different person otherwise, and I quite like the person I am."

## Social life

Epilepsy doesn't mean the end of going out with your mates or having a social life. Alcohol isn't forbidden, but it should be limited to moderate amounts (1-2 units) in a given day.

Alcohol affects how well your body absorbs epilepsy medication. This means saving your drinking for a binge at the weekend is not a good idea. Sometimes people can forget to take their medication when they've been drinking. This may trigger a seizure.

Call our Helpline on **0808 800 2200** for more information on alcohol and epilepsy. You can also log on to our website to view our Alcohol factsheet.

Most people with epilepsy are **not** photosensitive. They will not be affected by flashing or flickering lights. And should have no problems watching TV, using a computer, going to the cinema or out to a club.

## Case study



Dave Crozier had a seizure when he was seven years old due to a brain tumour. Doctors removed this before putting Dave on medication for two years. Just when doctors thought everything was fine, he stopped taking the drugs and started to have seizures again.

Now aged 21, Dave is happy to talk about having epilepsy. He has experienced medical ups and downs. He has experienced some of the stigma about the condition. "When I was growing up in high school in Fife, I always had someone in my group of friends who knew how to deal with it," he said. "I remember I was out with friends when I had a seizure. They were trying to support me but not restrain me. A couple walked past and scoffed at me. They shouted, 'That's what you get for being drunk'."

Dave is now studying community education at Strathclyde University. He is looking at how people deal with their disability, or are controlled by it. The idea stems from his own concern that sometimes he might let epilepsy control him. So he's keen to speak to others about how they adjust. Epilepsy has affected Dave in unique ways, just as any Scot with the condition.

As Dave was growing up, his seizures resulted in falls on his left side. His shoulder was damaged and he's unable to play rugby as he once did. Yet epilepsy hasn't prevented Dave from going out with his friends and having an active social life. "It's a learning process, and it's just a case of adjusting," he said. "Speaking to other people with epilepsy is great. You question who else is going through this? I think a woman would admit things in front of her sister or mum. More so than a guy would in front of his dad. A lot of my worries about my epilepsy I have kept to myself. But if you don't ask questions, you are never going to get results".

"People think I dwell on my epilepsy a lot. It does bring you down sometimes. Your family or best friends try to support you, but they don't know how you feel. I think there needs to be more support. I would take advantage of it, especially with a chance to socialise. Even if it doesn't work, you're not alone. Nobody is just like you. But there are people with epilepsy who understand."

## Family life

It's natural to worry how epilepsy will affect your home life. If you have a partner and any children, you will want to know how epilepsy can affect them. You'll want to know how you can explain the condition and the seizures you might have.

Many mums and dads with epilepsy successfully care for their babies and young children. If you follow sensible safety precautions, the risks that could harm your child are very small. Epilepsy Scotland or your doctor or epilepsy specialist nurse can offer more information if you have specific concerns and questions.

Epilepsy is not necessarily an inherited condition. The risk that a child will pick up epilepsy from their father is generally only slightly higher than someone without the condition.

## Sex life

Your sex life can be affected by any long term condition, including epilepsy. Persistent seizures and some epilepsy drugs can cause changes that affect hormones and sex drive. Stress and other outside factors can also have an effect on your sex drive. There is no universal rule but over 50% of men with epilepsy don't notice problems. You might also worry that a seizure could occur during sex. A seizure is no more likely to happen at this time than any other.

There is no evidence that taking epilepsy medication will affect any child you might father. Research is limited on fertility in men with epilepsy. While some studies have suggested it may be a problem for some men with epilepsy, most men have no difficulty fathering healthy children.

## Health care and medication

Nobody likes going to see the doctor, especially men. You know your body best, so it is important to involve experts such as doctors and specialist nurses to help you manage your epilepsy. People with epilepsy are now being invited for a yearly review with their GP or practice nurse. This is an opportunity to talk about your medication and how epilepsy affects you. If you have been seizure free for two to three years, you could talk to your doctor about slowly coming off your medication. The likelihood of this will depend upon the type of epilepsy you have.

It is important to think about the effects this might have on, for example, driving, employment and leisure activities. It is important that you do not come off your drugs without the supervision of your doctor. No one will try to force you to do this if you want to keep taking your medication. It would be your choice. Call our Helpline on **0800 800 2200** for a leaflet about this.

Seizures can be unpredictable. Sometimes you can recognise early feelings that a seizure may be about to happen. However, in an emergency, it is important that other people know how to help you. You can use epilepsy identification cards, necklaces or bracelets with medical details such as the type of seizures you have and your medication.

It is important to get enough sleep, reduce stress, and eat regularly. However, medication is the crucial tool to living with your epilepsy.

Antiepileptic drugs (AEDs) may control but cannot cure epilepsy. Doctors aim to use just one drug to treat seizures. More than one might be needed for some people. Working out the right medication and dose can take time so keep in contact with your epilepsy doctor or specialist nurse. All drugs can have side effects and your doctor or specialist will explain what could happen. People with epilepsy get free prescriptions.

**You should never** stop taking your medication or make any changes without first speaking to your doctor. Sometimes seizures can be life threatening or fatal. A small number of people with epilepsy die each year. In Scotland, around 100 epilepsy-related deaths are recorded annually. Nearly half of these are sudden and unexpected (known as Sudden Unexpected Death in Epilepsy – **SUDEP**). The risks are low for those whose seizures are well controlled. Overall the outlook for most people with epilepsy is very good. For more information see Epilepsy Bereaved's website at [www.sudep.org](http://www.sudep.org). You can also read about ways to reduce risk in our Safety factsheet.

Sometimes it is hard to remember to take epilepsy medication. You can get so used to your condition you forget about it. There are things you can do to help. Some men use pill organisers, often available from chemists. Others put a reminder on their mobile phone or watch alarm. Also if you live with someone, they can tell you when medication is due. No matter how careful you are, there is always a risk you might forget to take your AEDs. You can be better prepared. Talk to your doctor or epilepsy nurse at your next appointment. Ask about what to do if you miss a dose.

Surgery is an option for a small number of people with epilepsy. An MRI scan can show if it's possible to remove, for example, a tiny area of scarred brain tissue causing seizures. Vagal/Vagus Nerve Stimulation (VNS) involves putting a tiny generator with an electrode under the skin of the chest. This is attached to the vagus nerve in the neck. It is programmed to run on an electrical cycle every few minutes. In some cases, this can reduce the severity and frequency of seizures.

### **Complementary therapies**

There has been little research on the benefit of complementary therapies. Some people find certain essential oils (aromatherapy) or herbal remedies are helpful. However, they are not an alternative to your epilepsy drugs. Evening primrose oil, hyssop, St John's Wort, rosemary, sage and sweet fennel are harmful to people with epilepsy. They should be avoided. Please call our Helpline on **0808 800 2200** for our Treatment factsheet which has more information about complementary therapies.

## **Further information**

We hope this leaflet has offered some useful information. Epilepsy Scotland can give you more information for any specific questions you might have.

**We have fact sheets on:**

**Alcohol, Diagnosis, Driving, Employment (there are also leaflet for your employer), First aid for seizures, Leisure, Memory, Photosensitive epilepsy, Safety, Seizures and Treatment**

For further information and to talk over any concerns about epilepsy please call our Helpline on **0808 800 2200**.

You may also find the following organisations helpful:

**Breathing Space 0800 83 85 87** (open 6pm – 2am)

A free, confidential phonenumber to call when feeling down or stressed.

**[www.breathingspace.co.uk](http://www.breathingspace.co.uk)**

**Men's Health Forum**

An organisation working to improve men's health and wellbeing

**[www.mhfs.org.uk](http://www.mhfs.org.uk)**