

epilepsy scotland

Scotland's voice for epilepsy

# Epilepsy and employment



**Helpline: 0808 800 2200**  
**[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)**

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People with epilepsy tend to have repeated seizures. These start in the brain. Some people may have one or two seizures during their life. These could be because of a high temperature or a head injury. It does not necessarily mean they have epilepsy.

Forty thousand people in Scotland have epilepsy. This is one in 130 people. It is the most common serious brain (neurological) condition. Anyone can develop epilepsy at any age. However, it is most common in childhood, teenage years and later life.



# Epilepsy and employment

Many people are worried about their jobs or finding a new one when they are diagnosed with epilepsy. However, to a good employer it matters more that you have the right qualifications, skills and experience.

Most people have well controlled epilepsy thanks to medication. If you are one of them, you will be able to do most jobs.

Even if you continue to have seizures, you should be able to work. You will need to think more carefully about the kind of work you do or want to do. This is particularly important if your seizures are unpredictable.

Ask yourself:

**The job** - are there any risks in this job for you or your colleagues if you have a seizure? Will you be working alone?

**Your seizures** - how frequent are they? Do you have warnings? Do they happen at a certain time of day?

Some jobs have more risks than others. These can include working:

- at heights or underground
- near open water
- operating heavy machinery or moving vehicles
- with chemicals
- with hot ovens or open fires
- with high voltage/open circuit electricity.

The risk to you depends on the types of seizures you have, particularly if you fall suddenly or lose awareness of what is going on around you.

If you drive as part of your job, you need to know about the driving laws for people with epilepsy. For more information on this, see our factsheet on Driving. You can also phone our Helpline on **0808 800 2200** if you are worried about driving.



## “Epilepsy has not stopped me from doing a good job”

**Lee McNulty** was seven years old when his first seizure happened just after a family party. It took more than two years before epilepsy was diagnosed. He’s only ever had seizures when he’s asleep, never when awake. After a seizure, he usually feels sore and tired the next morning. This affected his attendance at school as some of the seizures were quite serious and required hospitalisation. However, he still managed to pass all his exams with high grades.

Now, aged 24, he works as an IT consultant with a small company. His employers only have a workforce of 11 people. Lee started as an IT engineer eight years ago. Today, after working his way up to being an IT consultant, he covers the whole of Scotland.

Lee says that his employers have been extremely supportive from the very beginning:

“When I went in for the interview, I was asked if I had any disabilities or anything that I felt would restrict me from working in IT.

“I explained about my epilepsy. I was then asked if I thought this would affect me doing the job and I said ‘no’. The panel were okay with that.”

The first time Lee had a nocturnal seizure after he started working there, his employers bought a book on epilepsy to learn more about it. “My boss was asking me if different things affected me, and at the time he actually knew more about it than I did!”

Lee needs to drive as his job covers the whole of Scotland. Since his seizures only happen when he’s asleep, he has a licence and is allowed to drive. A couple of years ago there was a mix-up at his GP’s surgery. They mistakenly sent a letter to DVLA (Driving Vehicle Licensing Authority) giving wrong information that Lee had taken a seizure when he was awake. His licence was revoked and it took five months before he got it back. His neurologist wrote to DVLA explaining that there was no medical and legal reason why Lee couldn’t drive.

Lee says that his employers were really good during this time. “They understood that because of this mix-up I wouldn’t be able to drive. One of the bosses each took turns to drive me around during the day. So for five months, I basically was chauffeured about.”

On another occasion, while his parents were on holiday, Lee took a seizure and fell and hurt himself. He phoned his work in the morning to let them know that he wasn’t coming in. Lee says that his boss then phoned him back to see if he could manage on his own at home. “When my manager heard I had hurt myself, he sent one of the other bosses to pick me up and take me to hospital for an x-ray. For the next few days, they phoned me every hour from work or asked me to phone in so that they could be sure I was okay.”

Lee takes two or three seizures a month, but sometimes he can go six months without one. He knows he can feel quite disorientated for hours after a seizure. Sometimes he does not even recognise people including his own parents.



When he goes into work in the morning after a seizure, he does routine tasks like making phone calls until he feels better. If he can’t make it into work for the regular time, the company has an arrangement to phone him and check that he is alright.

Lee knows he is lucky to have such good employers. “To be honest, I can’t think of anything else that they could do for me. They do things like taking me to a hospital appointment, waiting for me, and running me home. They are more than willing to give me time off if I need it and I don’t have to justify myself. Epilepsy is just not a hassle for them.”

# Disability Discrimination Act (DDA) 1995

The good news is there is no blanket ban on any kind of job apart from the Armed Forces. You cannot join the Armed Forces if you have a diagnosis of epilepsy or if you have had more than one seizure after the age of five.

If you have epilepsy, you are very likely to be covered by the Disability Discrimination Act (DDA) 1995 even if your seizures are well controlled with medication.

This means that it is unlawful to discriminate against you because of your epilepsy. The Act protects you whether you are looking for a job or whether you are already in employment. For example, it is unlawful not to offer you a job just because you have epilepsy. If this happens, see a solicitor or go to your local Citizens Advice Bureau.

If you are already in a job, and you are diagnosed with epilepsy, you should talk to your employer. You could ask, for example, for your work hours to be changed to help you cope with the initial side effects of your epilepsy medication. This is called making a "reasonable adjustment". The DDA gives you the right to ask for adjustments and your employer is required to consider making these. Examples of reasonable adjustments are:

- Changing your starting and finishing times to allow you to catch a bus to and from work if you cannot drive because of your epilepsy.

- Allowing you to start later in the day if your seizures usually happen first thing in the morning.

- Allowing you more regular breaks than your colleagues if your seizures are triggered by being tired.

- Arranging for someone to drive you if you need a car as part of your job to get from one place to another. Or you may be allowed to use taxis.

- Allowing flexible working, such as working from home or reduced hours if you take anti-epileptic medication and experience side effects such as tiredness, lethargy, nausea or anxiety. This could be a permanent or temporary adjustment.

- Ensuring that you do not work on your own when you are most likely to have seizures.

The Access to Work scheme at your local Job Centre may be able to offer help with any extra costs to your employer, for example paying the additional cost if you need to use taxis for work.

If you cannot drive because of your epilepsy you can apply for a free bus pass. Please see our Driving factsheet for more information. You can also phone our Helpline.



Some careers have their own rules. These include fire fighters, police officers, train drivers, doctors, nurses, teachers and nursery nurses. However, the DDA still applies to them. This means that they must not reject a job application from you just because of your epilepsy. If you are the best candidate for the vacancy, they should look at your epilepsy and consider making reasonable adjustments, so that you can do the job safely and to the best of your abilities.

For more detailed information on this or any other questions, you can contact our Helpline.

## How can I find work?

Job vacancies are usually advertised in newspapers, your local job centre or employment agencies. Most employers also advertise vacancies on their own websites.



You can also get help from:

### Disability Employment Advisers (DEAs)

DEAs are based at Job Centres. They can help you look for work. They can also help you gain new skills if you have been out of work for a long time, or if you have little or no work experience. Once you have found a job, DEAs can also help employers make reasonable adjustments at your work place.

### Employment organisations

Supported employment organisations can help you find work. They can also support you during the first few weeks in your new job. Your local Citizens Advice Bureau (CAB), Job Centre, or Social Work Department should be able to tell you if there are any supported employment organisations in your area.

## How can I improve my skills?

To improve your chances of getting a job, there are a number of things you can do:

### Work experience

Work experience can last around one to eight weeks. If you are interested, find out more from your local Job Centre.

### Voluntary work

There are a lot of opportunities for voluntary work. You should be able to find something that interests you. You can contact Volunteer Centre Network Scotland [www.volunteerscotland.org.uk](http://www.volunteerscotland.org.uk) or find the details of your nearest volunteer centre in your local phonebook.

### Further Education

You may feel that further education or training would be helpful. For information on courses in your area, contact your local further education college, library or careers office. You can also visit Careers Scotland's website on [www.careers-scotland.org.uk](http://www.careers-scotland.org.uk)

### Learn Direct Scotland

[www.learnirectscotland.com](http://www.learnirectscotland.com) can give you details of courses available in your area. Their freephone helpline number is **0808 100 9000**.

# Should I tell my employer I have epilepsy?

Like some people you may prefer to tell your employer so colleagues know how to keep you safe in case you have a seizure. Telling your employer will also allow them to make any reasonable adjustments. This could make it easier for you to do your job and keep seizures under control.

Other people prefer not to mention that they have epilepsy. If your epilepsy is well controlled and you have not had a seizure for a number of years, you may decide not to tell. This is because you are unlikely to have a seizure at work.

When deciding whether to tell or not to tell, ask yourself:

- How likely am I to have a seizure?
- What type of work will I be doing?



**However it is very important to tell your employer you have epilepsy if the job you do carries a health and safety risk.**

This could be working at heights on a construction site. If you have a seizure while on top of scaffolding, you could fall and injure yourself. You could also injure a work colleague. Not telling your employer could make you personally liable for injuring a colleague.



## A perfect employer

**Mary Nicol** developed epilepsy at the age of 38. Her first seizure happened out of the blue. "It was quite a shock. I was chairing an interview panel and I started to babble and rock back and forward in my seat. Fortunately, the candidate had left the room." Mary had tests but was not put on medication. Then following a couple of seizures nine years later, she finally was diagnosed with epilepsy.

"My seizures settled down for a while after being on different drugs, but then started to come back again." Mary's employer's health scheme paid for her to see a consultant privately. "I was really pleased with my employer for doing this, as it brought forward an appointment with a neurologist by several months."

Mary is now Deputy Head of Personnel at the Scottish Parliament. Everyone in her office has been trained in epilepsy and how to recognise it. The Parliament also organised a general awareness session for all staff. A refresher course is planned.

Mary explains that every new member of staff in the Personnel office is told with her permission that she has epilepsy. They also get a one-to-one on what to do if she has a seizure. This is just one of the many ways the Parliament supports Mary.

"When colleagues from other departments come into my office for the first time, they quite often comment on how dark it is. I tell them that very bright light can make my epilepsy worse. I have my own room with natural light. And I am allowed to have uplighters instead of fluorescent lighting.

**"people check on me regularly"**

"Because I am in a room on my own, people check on me regularly. The last person to leave the office makes sure we go together. If I do want to work in the office on my own I have to report to the security staff and let them know where I am. I also have a personal emergency evacuation plan. If the fire alarm is activated, a designated person will make sure that I get out of the building."

After a seizure, Mary says she feels very confused for days afterwards. She has a bad headache and usually has to go to bed. "If it happens in the office, I am sent home in a taxi with someone to accompany me, and they will sit with me until I feel comfortable to be left on my own."

Her epilepsy has affected her confidence quite a bit. She says this seems to be getting worse as she gets older. She stresses that there is nothing else her employer could do to support her at work. "I am already allowed to work reduced hours. I can work from home. I am allowed to come in late if I wake up in the morning and don't feel too great."

One of the other side effects of her seizures is that it affects Mary's short term memory. "Everyone here including senior managers knows about this. They make allowances for it, and I don't get criticised when I forget things."

**"It hasn't stood in the way of my promotion"**



She is quick to point out that her experience at the Parliament has only ever been positive. "It hasn't stood in the way of my promotion. I consciously tell everyone, including the senior management team and the directors. Even the Chief Executive knows I have epilepsy.

"I feel comfortable about disclosing this to colleagues. I have never been treated any differently from anyone else here who works in the Parliament".

## When do I tell my employer?

This is your decision. Some people prefer not to mention it on an application form. You could talk about this at the end of an interview when you would normally be asked if you have any questions.

Other people prefer to tell an employer about their epilepsy after being offered the job. At this point, you may want to discuss how your epilepsy affects your work, if at all. You can also ask at this stage for any reasonable adjustments to your job, in line with the DDA. Sometimes, having a doctor's letter explaining your epilepsy and how it would or would not affect your work can also be helpful.



## What should I say to my employer?

Don't over-emphasise your epilepsy. Be positive and to the point. There are two main things you would want your employer to know:

**General information about epilepsy** - what it is and what it isn't. Many employers falsely assume that most people with epilepsy cannot use computers. Epilepsy Scotland has leaflets which can help inform your employer.

**Information about your epilepsy and your seizures** - how frequent are they? Does anything trigger them? What do your seizures look like? How long do they last? What first aid is needed? How long do you need to rest?



## I think I am being treated unfairly. What can I do?

Coping with rejection is difficult but staying positive is important. There could be many reasons why you may find it hard to find a job. If you are worried about any of these things, speak to your local Disability Employment Adviser. It is their job to help identify your skills and experience and help you find work. They can also help you gain more qualifications to improve your chances of finding employment.

If you think you have been treated unfairly because you have epilepsy, there are organisations you can contact for advice and help:

If you are in work, and are a member of a union, contact your union representative for advice.

**ACAS** (Advisory, Conciliation and Arbitration Service) [www.acas.org.uk](http://www.acas.org.uk) can also help. Their Helpline number is **08457 47 47 47**.

The **Equality and Human Rights Commission** [www.equalityhumanrights.com](http://www.equalityhumanrights.com) can give you information on your rights in relation to the Disability Discrimination Act. Their Helpline number is **0845 604 5510**.

Other sources of help include your local CAB, lawyer or law centre.

You can also phone Epilepsy Scotland's Helpline for further information.

## Further information

Epilepsy Scotland can give you further information on:

Factsheets:	Guides:
<ul style="list-style-type: none"> <li>• Diagnosis</li> <li>• Driving</li> <li>• First aid for seizures</li> <li>• Leisure</li> <li>• Memory</li> <li>• Safety</li> <li>• Seizures</li> <li>• Treatment</li> <li>• Triggers (includes information on alcohol and photosensitive epilepsy)</li> </ul>	<ul style="list-style-type: none"> <li>• A guide to epilepsy - what you need to know</li> <li>• A parent's guide to epilepsy</li> <li>• A woman's guide to epilepsy</li> <li>• An employer's guide to epilepsy</li> <li>• Epilepsy and later life</li> <li>• Guidelines for teachers</li> <li>• Looking after someone with epilepsy and learning difficulties</li> <li>• Men and epilepsy</li> </ul>

We also have information leaflets designed for people with learning difficulties. These include:

- All about epilepsy
- Safety and epilepsy
- Living with epilepsy

If you have questions after reading this leaflet, please call our Helpline. Our trained staff are available during office hours and until 6pm on Thursdays.

If you would like this leaflet in a different format or language, please call **0808 800 2200**.

# epilepsy scotland

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Epilepsy Action Scotland is a company limited by guarantee.

Registered in Scotland No 163987

Scottish Charity: No. SC 000067

A member of the Joint Epilepsy Council of the UK and Ireland

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