Work and epilepsy

epilepsy.org.uk
Epilepsy Action Helpline: 0808 800 5050
Epilepsy Action – together we can change lives

Together we can help more people gain the knowledge and confidence to live better with epilepsy. We can raise awareness, so that more people understand epilepsy.

Together we can:

• Provide expert information and advice, so everyone affected by epilepsy can get the support they need to live better with epilepsy
• Run local events and support groups, so that fewer people have to face epilepsy alone
• Campaign to help make sure health services and national policies take into account the needs of everyone living with epilepsy

It’s only donations like yours that make this life-changing work possible.

Please donate today.

Text ACT NOW to 70700 to give £5 (message will cost £5 plus your usual cost of sending a text, Epilepsy Action will receive 100% of your donation).

You can also join Epilepsy Action and add your voice to the UK’s biggest epilepsy movement. Together we can campaign for change, support each other and fight for a better future.

Find out more by calling the Epilepsy Action membership team on 0113 210 8800 or visit epilepsy.org.uk/join

Thank you.
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Work and epilepsy

This information is about looking for and staying in work. It looks at your rights in the workplace and ways the workplace can become more epilepsy friendly. This might be down to reasonable adjustments being made after you have had a health and safety risk assessment (see page 17). Or it might be by changing employer or employee attitudes to epilepsy. It also tells you how you can take action if you feel you are being treated unfairly at work.

Am I considered to be disabled if I have epilepsy?

You are classed as disabled by the equality laws if you have epilepsy that has a substantial effect on your day-to-day activities, or would have a substantial effect, if you were not taking your epilepsy medicine.

If you have a type of epilepsy that is not currently causing any problems and doesn’t need epilepsy medicine, but could be triggered by specific circumstances, then you are likely to be covered. Some common triggers for epileptic seizures are:

- Feeling tired
- Not getting enough sleep
- Stress

Epilepsy Action has more information about things that trigger seizures
The equality laws are called the Equality Act in England, Scotland and Wales and the Disability Discrimination Act in Northern Ireland. They apply to you whether or not you take epilepsy medicines.

The equality laws cover everything to do with work including:

- Job adverts
- Training
- Application forms
- Promotions
- Interviews
- Dismissal
- Job offers
- Redundancy
- Conditions of employment

**What type of work can I do?**

It depends on how your epilepsy affects your daily life, and what skills and experience you have.

**Which jobs might not be open to me because of my epilepsy?**

Very few. Employers shouldn’t use your epilepsy as a reason not to give you a job, unless they have very good reason. Here are some possible reasons.

**Health and Safety**

An employer can legally refuse to give you a job if your epilepsy poses a health and safety risk to you or somebody else. For example, if you are still having seizures, they could refuse to give you a job where climbing ladders is a substantial part of the job.
**Driving**

An employer can refuse to give you a driving job if you don’t hold the right type of driving licence. For example, if you have had seizures in the last 10 years, legally you are not allowed to hold a licence that allows you to drive heavy goods vehicles. So, an employer can refuse to employ you as a lorry driver.

**Armed Forces**

Jobs in the Armed Forces are not covered by the equality laws. This means the Armed Forces can refuse to employ you because you have epilepsy or a history of epilepsy.
Can I be asked questions about my health before I’m offered a job?

It depends. If you apply for a job, employers aren’t generally allowed to ask you questions about your health before they offer you the job. This includes questions about your previous sickness absence. And, at this stage, they can’t refer you to an occupational health adviser or ask you to fill in a questionnaire provided by an occupational health adviser.

However, employers are allowed to ask questions about your health or any medical conditions before they offer you a job, if they have a good reason. This might be because they need to make a reasonable adjustment for your job interview or for an assessment. Or, the employer might need to know if there are health and safety reasons why you couldn’t do the essential duties of a specific job, such as working at heights.

If, without good cause, the employer asks questions about your health before offering you a job, they can’t rely on this information when making a decision about the job. If they do, this would be disability discrimination.

Application forms

Employers should only ask you to fill in a medical questionnaire before offering you a job when this is essential. And the questions must be targeted on the essential duties of the job. So, if an application form includes questions about your health, and you don’t feel this is relevant, you can choose to ignore them.
However, they could ask if you need any reasonable adjustment to be made for an interview. For example, they could ask if you need extra time to do a test.

**Job interviews**

During an interview, an employer is only allowed to ask questions about your health if they are directly linked to an essential aspect of the job you are applying for. As an example, they could ask how your epilepsy could affect your ability to do that job safely.

If your ability to do the job safely and effectively is not affected by your epilepsy, you don’t need to mention it. An example of this could be if you only have seizures when you are asleep, or your seizures are well controlled.

Epilepsy Action has more information about the equality laws.
Sources of help and support when looking for work

Jobcentre Plus work coaches

A work coach can help you in your search for work, or to gain new skills. They can also tell you about disability friendly employers in your area.

To have an appointment with a work coach, you need to be already receiving certain benefits, or be disabled. See page 5, 'Am I considered to be disabled if I have epilepsy?'

You can find contact details for your local Jobcentre Plus in the Phone Book, or search for 'Jobcentre Plus' online. If you live in Scotland, you can also get help from Fair Start Scotland.

Disability Confident

When you’re looking for work, look for the ‘disability confident’ logo on adverts and application forms. The logo means the employer is committed to employing disabled people. If a job advert displays the logo, you’ll be guaranteed an interview if you meet the basic conditions for the job.
Work programmes and grants

The Work and Health Programme
If you live in England or Wales, the Work and Health Programme can help you find and keep a job if you’re out of work.

Work Clubs
Anyone who’s unemployed can join a Work Club. They’re run by local organisations like employers and community groups, and give you the chance to share knowledge, experience and job hunting tips.

Specialist Employability Support
Specialist Employability Support is intensive support and training to help you into work if you’re disabled. You’ll usually get Specialist Employability Support for 12 months.

Information about all these programmes is available from Jobcentre Plus.
Telling people at work about your epilepsy

Telling your employer

Once you have been offered a job, you don’t automatically have to tell your employer about your epilepsy. This is as long as you don’t believe it will affect your ability to do your job safely and effectively. This could be, for example, if your epilepsy is well controlled, or you only ever have seizures when you are asleep.

If you don’t tell your employer about your epilepsy and it does affect your ability to do your job safely, your employer may be able to dismiss you. To do this, they would have to prove that:
• You have been given the opportunity to tell them how your epilepsy could affect your job and
• You haven’t given them this information

If you are not sure whether to tell your employer about your epilepsy, here are some things to think about.

Reasonable adjustment
If your employer doesn’t know about your epilepsy, they can’t make any reasonable adjustments to help you (see page17).

Health and Safety at Work Act
The Health and Safety at Work Act (1974) is a law that says that all employers have to provide a safe workplace. They must protect all their employees from any possible danger to their health, while they are at work. As an employee, you also have a responsibility to take reasonable care of your own and other
people’s health and safety at work. If your epilepsy could cause a health or safety risk to you or anybody else, you must tell your employer about it. This is the law.

More information about the Health and Safety at Work Act is available from the Health and Safety Executive (HSE): hse.gov.uk (for England, Scotland and Wales); nidirect.gov.uk (for Northern Ireland).

**Employer’s insurance**
Your employer’s insurance may pay you compensation if you are injured at work, or if you become ill because of your work. If you don’t tell your employer about your epilepsy, you will not be fully covered by their insurance. So, you may not receive any compensation if you have an accident related to your epilepsy.

More information about employer’s insurance is available from the Health and Safety Executive (HSE): hse.gov.uk (for England, Scotland and Wales); nidirect.gov.uk (for Northern Ireland).

**When to tell your employer about your epilepsy**
If you decide to tell your employer about your epilepsy, it’s useful to do it before you start the job. This gives them time to make any reasonable adjustments you need. If you don’t tell them about your epilepsy before you start a job, you can change your mind and tell them at any time. As soon as your employer knows about your epilepsy, they have to make any reasonable adjustment that could be helpful for you.
Telling people you work with

It’s your decision whether you tell the people you work with about your epilepsy. But if you do, they will probably feel more confident about helping you if you have a seizure.

If you think it would help, you could ask your employer to arrange some epilepsy awareness training for your colleagues. Contact Epilepsy Action for more information.

Can my employer tell other people about my epilepsy?

Yes, if you give them permission, and sign a consent form. But they can’t tell other people about your epilepsy without your permission. This is to comply with the Data Protection Act.
Care plans for seizures at work

If there’s a chance you will have seizures at work, it’s a good idea to prepare a care plan with your employer. This can include what happens when you have a seizure and how people can help you during and afterwards. This information collected at your risk assessment can be used to help you do this. Here are some more suggestions.

• If you usually recover quickly after a seizure, you might be able to get straight back to work. Or, you might just need a quiet place to rest, before returning to work. The care plan should say where this rest should take place.

• If you normally take a long time to recover from a seizure, you might need to go home. Your care plan should show how you will get home, and who will travel with you, if necessary. This should be in line with company policies and procedures for anyone becoming unwell at work.
What is a health and safety risk assessment?

It’s an assessment your employer must do to make sure you can carry out your duties safely. Some questions that might come up during your health and safety risk assessment are:

• What happens to you when you have a seizure?
• Are your seizures controlled?
• How often do you have seizures?
• Do they happen at a particular time of day?
• Do they happen when you are awake, asleep, or both?
• Is there anything that makes your seizures more likely, such as lack of sleep, tiredness, stress, hormonal changes, flashing or flickering lights or patterns?
• Do you get a warning before a seizure?
• How long do your seizures last?
• How do you feel afterwards?
• How long does it take you to recover?
• Do you need any first aid/specific care during/following a seizure?

What is a reasonable adjustment?

It’s something that your employer could do to help you at work, such as:

• Make changes to your working pattern and duties
• Provide training or mentoring
• Make alterations to their building
• Make sure they provide information in a format you can use
• Change or get different equipment
• Allow you extra time to do selection ‘tests’
• Make sure you don’t work alone, or there is a ‘regular check in’ process for you.

Reasonable adjustments have to be reasonable to the employer and to you.

Many reasonable adjustments involve little or no cost. If there are costs involved, funding might be available from Access to Work. See page 20.

**People with epilepsy talk about their reasonable adjustments at work**

“My seizures are always first thing in the morning. I am allowed to start and finish work two hours later than other people.”

“I have a poor memory, so my boss always writes down instructions as well as talking to me about them.”

“There’s a three shift system where I work. I don’t do the night shift, as my seizures can be triggered by not having a regular sleep pattern.”

“I’m a community nurse. When I lost my licence after a seizure, I was given clinic work instead.”

“My usual work is delivering post. After my recent seizure, I was given work in the sorting office, rather than my usual walking round.”
“I’ve recently qualified as a chef and work in a large company. My seizures are not fully controlled, so I work well away from the ovens and stoves.”

“We have children between the ages of 0-3 years in our nursery. I work with the older children, as they don’t need carrying around. That could be risky if I had a seizure.”

“Our sales teams work in various offices around the country. Since I lost my driving licence, I’ve been moved to our local office, rather than travelling to head office.”

“I need regular hospital appointments during my usual working hours. My employers do their best to accommodate them.”

“My boss records my epilepsy sickness separately from sickness for other reasons. This means it doesn’t look too bad on my sickness record.”
Employers can decide themselves how much sickness absence they will allow before your absence from epilepsy is considered excessive.

If your employer doesn’t make reasonable adjustments to help you, this could be illegal, unless they have significant justification. But sometimes it might not be possible to make a job safe, even with adjustments, if you have uncontrolled seizures. Not making reasonable adjustments in this instance would not be illegal.

If your epilepsy changes (for example, you get better or worse seizure control), you should ask your employer to do a new risk assessment for you. Generally speaking, if you’re allowed to drive a car, then there are few jobs you can’t do.

**No reasonable adjustment needed**

It may be that you won’t need any adjustments to be made in the workplace. This could be if you are completely seizure free, or you or others wouldn’t come to any harm if you had a seizure at work.

**Access to work**

If the help you need at work is not covered by your employer making reasonable adjustments, you may be able to get help from Access to Work. You need to have a paid job, or be about to start or return to one.
You'll be offered support based on your needs, which may include a grant to help cover the costs of practical support in the workplace.

An Access to Work grant can pay for:
• Special equipment, adaptations or support worker services to help you do things like answer the phone or go to meetings
• Help getting to and from work

The money does not have to be paid back and will not affect your other benefits.

You might not get a grant if you already get certain benefits. Contact Access to Work to find out if you’re eligible.

Access to Work is available in England, Scotland and Wales. Access to Work NI offers a similar scheme in Northern Ireland.

To find out more, search for ‘Access to Work’ at gov.uk or nidirect.gov.uk
What can I do if I feel I have been treated unfairly at work?

Three important things to do are:

1. **Talk to people**
   Talk to the people involved. This might be your colleagues, your line manager or your employer. If you’re a member of a union, you could ask them to support you when you are talking to them. If not, you could ask to bring a colleague or friend with you to meetings when you are discussing your work situation.

2. **Keep notes**
   Keep notes of any actions, or comments made, that you are concerned about. Also, keep a note of attempts you have made to try and sort the situation out. This can be useful information if you later decide to take more formal action, such as raising a grievance or getting legal advice.

3. **Know your rights**
   Check your contract, in particular the terms and conditions and the grievance procedure.

   If your employer wants information from your doctor, they can only get this with your consent. They should only ask for information that is relevant to your epilepsy.
How do I take legal action against someone who has treated me unfairly at work?

Seek advice as soon as possible. This is because there are strict time limits for bringing cases to Employment Tribunals and courts.

You can get advice from different organisations, including Citizens Advice, ACAS, or your trade union. You can also take legal advice from a solicitor. Taking legal action can be very expensive. Depending on your financial circumstances and the issues involved, you might be eligible for the Legal Aid scheme. This can cover some, or all, of your costs. You might consider opting for legal expenses insurance cover, for example when taking out house contents insurance. This is usually inexpensive and can be valuable if you have problems at work.
If you decide to employ a solicitor, it’s important to check at the beginning how they will expect to be paid. You should also check that they have a contract to provide advice and representation through the Legal Aid scheme, if you qualify for it.

See page 25 for details of organisations that can offer help, support and advice in the UK, if you feel you are being unfairly treated.

**Staying in work**

If you are having problems at work because of your epilepsy, here are some thing you could do that might help.

**Talk to your employers**

Keep your employer up-to-date with any changes to your health that could have an effect on your work. Make a note of your discussions and of any changes to your working conditions that are made as a result. This would be useful if your work situation became really difficult and you needed to raise a grievance.

If your epilepsy has changed, you could ask your employer to arrange a new risk assessment for you. And if you are off sick because of your epilepsy, keep them up-to-date with your situation.
Sources of further advice and information

The information in this section is about epilepsy and working in the UK. If you live outside the UK, you can find out about working and epilepsy in your country by contacting your local epilepsy group.

Citizens Advice
Citizens Advice help people to resolve their problems, from debt and employment to consumer and housing, plus everything in between.
Tel. 03444 111 444 (England) 03444 772 020 (Wales)
Website: citizensadvice.org.uk

Equality Advisory Support Service (EASS) (England, Scotland and Wales)
EASS gives free advice, information and guidance to individuals on equality, discrimination and human rights issues.
Tel. 0808 800 0082  Website: equalityadvisoryservice.com

Equality and Human Rights Commission (EHRC) (England, Scotland and Wales)
EHRC provides advice and guidance on rights, responsibilities and good practice, based on equality law and human rights.
Website: equalityhumanrights.com

The Equality Commission (Northern Ireland)
The Equality Commission (Northern Ireland) provides advice and information about the Disability Discrimination Act in Northern Ireland.
Tel: 028 90 500 600  Website: equalityni.org
Law Centres (England, Scotland and Wales)
Law Centres provide free legal advice and representation to disadvantaged people.
Tel: See your local Phone Book
Website: lawcentres.org.uk

Advisory, Conciliation and Arbitration Service (ACAS) (England, Scotland and Wales)
ACAS aims to improve organisations and working life through better employment relations. They offer free advice about employment rights.
Tel: 0300 123 1100
Website: acas.org.uk

Disability Law Service
Disability Law Service offers advice and information about employment law to disabled people.
Tel: 020 7791 9800
Website: dls.org.uk

Jobcentre Plus
Jobcentre Plus is an organisation that helps people to get either jobs, benefits or both.
Tel: See your local Phone Book
Website: gov.uk (search for Jobcentre Plus)

The Health and Safety Executive (HSE)
HSE can provide general information and guidance for employers about work-related health and safety issues. They also offer a free leaflet, *Controlling risks in the workplace*, which
aims to help employers do their own risk assessments. This can be downloaded from their website. There is also a specific section about employing disabled people on the HSE website. Website: hse.gov.uk

**Employment Medical Advisory Service (EMAS)**

EMAS is part of the Health and Safety Executive. It is staffed by specialist occupational health professionals who give health related advice for people with medical conditions. Website: hse.gov.uk
Our thanks

Our thanks to Epilepsy Action’s Huddersfield Branch for funding this publication.

Epilepsy Action would like to thank Professor Sayeed Khan, Specialist in Occupational Medicine, Chief Medical Adviser to EEF, the manufacturers’ organisation, and Judith Hogarth, Solicitor, Excello Law, for their contributions.

About this publication

This booklet is written by Epilepsy Action’s advice and information team, with guidance and input from people living with epilepsy, and professionals. If you would like to know where our information is from, or there is anything you would like to say about this booklet, please contact us.

Epilepsy Action makes every effort to ensure the accuracy of information in its publications, but cannot be held liable for any actions taken based on this information.

Date: August 2018
Due for review: August 2019
Code: B135.05
First aid for tonic-clonic seizures

The person goes stiff, loses consciousness and falls to the floor.

Do...
• Protect the person from injury (remove harmful objects from nearby)
• Cushion their head
• Aid breathing by gently placing the person on their side (in the recovery position) when the seizure has finished (see picture)
• Stay with them until recovery is complete
• Be calmly reassuring

Don’t...
• Restrain the person’s movements
• Put anything in their mouth
• Try to move them unless they are in danger
• Give them anything to eat or drink until they are fully recovered
• Attempt to bring them round

Call 999 for an ambulance if...
• You know it is the person’s first seizure or
• The seizure continues for more than five minutes or
• One seizure follows another without the person regaining consciousness between seizures or
• The person is injured or
• You believe the person needs urgent medical attention
First aid for focal (partial) seizures

The person is not aware of their surroundings or of what they are doing. They may pluck at their clothes, smack their lips, swallow repeatedly or wander around.

Do...
• Guide the person away from danger
• Stay with the person until recovery is complete
• Be calmly reassuring
• Explain anything that they may have missed

Don’t...
• Restrain the person
• Act in a way that could frighten them, such as making abrupt movements or shouting at them
• Assume the person is aware of what is happening, or what has happened
• Give them anything to eat or drink until they are fully recovered
• Attempt to bring them round

Call 999 for an ambulance if...
• You know it is the person’s first seizure or
• The seizure continues for more than five minutes or
• The person is injured or
• You believe the person needs urgent medical attention

Epilepsy Action has information on what to do if someone has a seizure in a wheelchair.
Further information

If you have any questions about epilepsy, please contact the Epilepsy Action Helpline.

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Information is available in the following formats: booklets, fact sheets, posters, books and DVDs.

Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue. Or download a copy at epilepsy.org.uk/catalogue

Epilepsy Action’s support services

Local meetings: a number of local branches offer support across England, Northern Ireland and Wales.

Coffee and chat groups: these give people living with epilepsy the chance to meet new people, share experiences and learn more about life with epilepsy.

forum4e: our online community is for people with epilepsy and carers of people with epilepsy. You have to be aged 16 or over to join. Go to forum.epilepsy.org.uk

Epilepsy awareness: Epilepsy Action has a number of trained volunteers who deliver epilepsy awareness sessions to any organisation that would like to learn more about epilepsy. The volunteers are able to offer a comprehensive introduction to epilepsy to a range of audiences.

If you would like more information about any of these services, please contact Epilepsy Action. Contact details are at the back of this booklet.
# Work and epilepsy

We would like to know if you have found this booklet helpful.

As a result of reading the information, please let us know if you agree (tick yes) or disagree (tick no) with any of the following statements.

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Please tell us how you think we can improve this information

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Please return the completed form to:
FREEPOST RTGS-LEYK-XGCK, Epilepsy Services, Epilepsy Action, New Anstey House, Gateway Drive, Yeadon, Leeds LS19 7XY

You can also give us feedback online. Visit epilepsy.org.uk/feedback

Thank you.
Epilepsy Action
FREEPOST RTGS-LEYK-XGCK,
New Anstey House,
Gate Way Drive,
Yeadon,
Leeds LS19 7XY

Registered charity in England (No. 234343)
Ways to contact the Epilepsy Action Helpline

**Telephone:** freephone 0808 800 5050

We are usually open 8.30am to 5.30pm, Monday to Friday. Our helpline staff are Text Relay trained and we are able to offer advice and information in 150 languages. To ensure the quality of our service, we may monitor calls.

**Email:** helpline@epilepsy.org.uk

Email us your question about epilepsy. We aim to reply within 48 hours (on work days)

**Text:** 0753 741 0044

Text us and we aim to send a text reply back to your phone within 24 hours (on work days)

**Twitter:** @epilepsyadvice

Tweet us with your question and we will tweet back (on work days)

**Post:** New Anstey House, Gateway Drive, Leeds, LS19 7XY

Write to us and we aim to reply within seven working days

About the Epilepsy Action Helpline

We do:

• Provide confidential advice and information about epilepsy to anyone
• Give general medical information
• Give general information on legal and welfare benefit issues related to epilepsy

We do not:

• Tell people what to do
• Offer a medical diagnosis or suggest treatment
• Take up people’s legal cases on their behalf

If we cannot help you directly with a query, we will do our best to provide details of other organisations that may be able to help. In doing this, Epilepsy Action is not making a recommendation.

We welcome feedback, both positive and negative, about our services.
Epilepsy Action Helpline:
freephone 0808 800 5050
epilepsy.org.uk

Environmental statement
All Epilepsy Action booklets are printed on environmentally friendly, low-chlorine bleached paper. All paper used to make this booklet is from well-managed forests.