

Epilepsy and Occupational Health



Contents

Introduction	03
Why use this good practice guide?	04
About epilepsy	05
The Equality Act 2010	07
Your Risk Assessment	10
Privacy, Confidentiality and Data Protection	15
Appendix – Useful Resources	24

Introduction

From the Chief Executive

As human beings we all want to have a purpose in life and to feel valued. That applies to all aspects of our life including our work.

For someone who lives with epilepsy and is trying to gain employment these aims may seem incredibly difficult to achieve. The challenges in their daily lives combined with those encountered or anticipated in the workplace may seem insurmountable. Equally, for someone already in work who is newly diagnosed with the condition there may be some anxiety about how they will manage their continued employment.

We have learned from many calls to our Helpline, the need for up to date information is great. Although aimed at employers, this guide will also be helpful for employees in addressing the relationship that exists between epilepsy and employment.

Many people who have epilepsy enjoy a fulfilling work life. With this guide we hope to help achieve that for those whose condition may cause them some difficulties. This robust document contains up to date information and advice from experts in the field of occupational health medicine and epilepsy. It will assist employers and employees alike, inform decision making and ensure the best possible outcome for people with epilepsy in the workplace.

It will get the job done.



Leslie Young
CEO

Why use this good practice guide?

Epilepsy is one of the world's most common neurological conditions. **It affects 1 in every 97 people in Scotland and there are currently an estimated 251,169 people of working age with epilepsy in the UK¹.** It is likely you may interview and employ a person with epilepsy at some point, or you may already be doing so.

Around 56,000 people living in Scotland have epilepsy and on average eight people a day are diagnosed with the condition. The diagnosis of epilepsy is steadily on the increase. As it rises, so will the number of people with epilepsy in the workplace. The majority of people with epilepsy will have as many skills and competencies as those who do not so their condition should not be a barrier to most forms of employment.

Candidates are not obliged to tell a prospective employer they have epilepsy, unless there is a health and safety risk. Many people with epilepsy will require no additional support or adjustments in the workplace. Usually, the condition is disclosed once a job offer has been made, when the employee is requesting reasonable adjustments. An employee may develop the condition during their employment, and it is often disclosed during a discussion about illness arising at work or sickness absence. **As an employer, it's important not to make assumptions about someone's epilepsy and the impact it may have on their work.** There are many types of seizure and everybody's condition is different. By following good practice guidelines, employers can feel more confident in making reasonable adjustments, where necessary, to support people with this condition. In short, using this good practice guide can help your organisation to benefit most from their skills and ensure you comply with disability legislation.

In a minority of people, seizures may happen at work or work performance may be affected by anti-epilepsy drugs (AEDs). Employees may be reluctant to share their personal medical details with an employer but gathering accurate information on the person's seizures and looking closely at the nature of their job will help in deciding the best way to manage the individual. Occupational Health professionals provide a confidential service. They are trained to look at medical evidence and assess risk.

If necessary, they can also suggest the reasonable adjustments that may be required to help your employee maintain a productive working life. Our good practice guide is designed to tell you in plain terms what you need to know about epilepsy and the workplace and to help employers and employees get the most out of occupational health services. It also makes clear the legal responsibilities of employers according to anti-discrimination and Health and Safety at Work legislation. It includes a checklist to use when referring someone to an occupational health service, and details of where to get further support.



Epilepsy affects 1 in every 97 people in Scotland

251,169

people of working age with epilepsy in the UK.



56,000

people living in Scotland have epilepsy

¹ Office for National Statistics estimated labour market statistics February 2019; includes 31.3m employed and 1.3m unemployed, excludes 8.66m inactive (e.g. retired, students, those looking after family and home, and those temporarily or long-term sick or disabled.)

About epilepsy

What is epilepsy?

People can have an isolated seizure without having epilepsy. This could be for reasons like a high temperature or a head injury. People with epilepsy have a tendency to have **repeated seizures** and many people become seizure free with medication.

Billions of brain cells pass messages to each other to control what we say and do. The brain uses electrical activity to pass these messages on. If there is too much electrical activity, messages can get mixed up and cause seizures.

Seizures usually last a short time and the brain works normally between them. Some people find their seizures are triggered by certain things, such as not getting enough sleep or skipping meals.

Epilepsy is a very varied condition which can affect people in different ways. There are many types of seizures, and people may experience more than one kind.

Some people with epilepsy may only experience seizures while they are awake and fully aware. This might mean the seizure takes the form of an unusual taste or smell.

Some people with epilepsy may have seizures where they jerk, fall down and lose consciousness.

Others may only have seizures when they are asleep.

Up to 70% of people with epilepsy can be seizure free with optimal treatment. Therefore, the suitability of a job for a person with epilepsy will depend on the nature of the job and how seizures affect them.

Unfortunately, there are still a number of myths about epilepsy. **Epilepsy is a physical condition. It is not contagious.** People with epilepsy can lead a full and rewarding life.

Up to **70%** can be seizure free with optimal treatment.



If you would like to find out more about epilepsy and how it can affect people, please get in touch with

Epilepsy Scotland's freephone helpline on 0808 800 2200

or go to

www.epilepsyscotland.org.uk

About epilepsy

About seizures

Our brain controls our speech, movement, emotions, memory, vision, hearing. Different parts of the brain control different things. What happens during a seizure depends on which area of the brain is involved and what it controls. Seizures can be generalised or focal. Generalised seizures involve the whole brain. Partial seizures affect only part of the brain.

Focal seizures are either simple or complex.

A **focal aware seizure** (also known as simple partial) affects one small area of the brain:

- The person may experience an unusual taste or smell or twitching
- They know the seizure is happening but cannot stop it
- They will not have any loss of awareness.

A **focal seizure with impaired awareness** (also known as complex partial) affects a larger area of the brain:

- The person may experience strange or unusual feelings
- They may lose their sense of time and appear distant from what is happening and who is around
- They may behave in an unusual way. This could be smacking their lips, plucking at their clothes, or moving aimlessly around a room
- Unlike focal aware seizures, they will have a loss of awareness

Generalised seizures affect the whole brain.

The person will lose awareness during these. There are different types of generalised seizures. These include tonic-clonic, absence, tonic, myoclonic and atonic seizures. First aid for tonic-clonic seizures is given on [page 26](#).

See Epilepsy Scotland's 'Seizures Explained' and 'First Aid for Seizures' factsheets for more information at www.epilepsyscotland.org.uk.



Focal aware seizures (also known as simple partial) affect one small area of the brain



Focal seizures with impaired awareness (also known as complex partial) affect a larger area of the brain



Generalised seizures affect the whole brain.

The Equality Act 2010

Epilepsy was first defined as a disability under the Disability Discrimination Act of 1995, which was amended in 2003 and 2005. The Equality Act 2010 replaced and extended this legislation and gave people with disability greater rights.

Recruitment

■ Advertising a job

No job advertisement should discriminate against disabled people. This includes epilepsy. Discrimination can be direct and indirect. It is not always easy to spot indirect discrimination. An indirect way this could happen for a person with epilepsy is if a job advert asks for the person to hold a driving licence even if it is not a genuine requirement for the job. This unfairly discriminates against people who may not be able to drive due to their epilepsy. This should only be asked for if driving takes up a significant portion of the job and there is no way around this e.g. use of public transport or a support driver.

■ During recruitment

In the past, employers often asked candidates to complete a pre-employment health questionnaire, or ask particular questions about the candidate's previous sickness and absence record.

However, the Equality Act states that an employer must not ask about a job applicant's health until that person has been offered a job. Both written and oral questions are covered by the Act, so questions at job interviews must avoid the subject of health or fitness. Also, any request for a reference sent before a job offer is made must avoid asking these kinds of questions.

Employers can still ask about health in certain circumstances, such as to find out whether they need any reasonable adjustments to attend an interview or test. They may also ask questions in relation to specific skills which are essential to do the job. For example, it may be reasonable to ask a candidate for a job in a factory to confirm that they are medically fit to operate machinery safely. If the employer asks unlawful questions, the person can complain to the Equality and Human Rights Commission, who will investigate the matter.

Candidates are not obliged to disclose they have epilepsy during the recruitment period. As epilepsy is still a stigmatised condition, it is common for candidates not to tell a prospective employer about it unless they are requesting adjustments to the interview process or the role.

If the employer asks health-related questions and then rejects the applicant, they may be taken to an Employment Tribunal for potential unlawful discrimination.

Employers can ask more general health-related questions once they have offered the person a job. This is to find out if they need to make any reasonable adjustments to support the person in their post.

There are some exceptions to the rules on pre-employment health questions, such as those joining the armed forces and anyone being vetted for work for reasons of national security.

If you would like to find out more about the requirements of the Equality Act, see the Equality and Human Rights Commission website www.equalityhumanrights.com or call 08456 45510.

Also, ACAS can provide helpful and practical information, see www.acas.org.uk or call 08457 47 47 47.

The Equality Act 2010

Reasonable adjustments

The Equality Act requires employers to consider making reasonable adjustments to support people with a disability in the workplace. These adjustments can be very specific to the individual and help to enable the same quality of work to be undertaken.

Reasonable adjustments for people with epilepsy could include:

- allowing a person whose seizures occur while sleeping to start and finish later
- setting a fixed shift pattern for people who find their seizures are triggered by tiredness or varied shift work
- getting another employee to do part of the person's work they cannot do because of their epilepsy, e.g. climbing up a ladder to arrange files
- re-arranging working hours for a person who has lost their driving licence and cannot get in on time by public transport
- providing a quiet place where a person can rest after a seizure
- providing a support driver for some journeys where the person cannot drive because of epilepsy and public transport is not practical
- redeploying a person to an alternative job at a similar or higher level if they meet the essential criteria

A reasonable adjustment can also be temporary, for example until medication begins to control seizures in someone newly diagnosed with epilepsy or if someone is undergoing a medication change.

This is **not** an exhaustive list of **reasonable adjustments**. If you'd like to find out more about the kinds of adjustments which could help your employee, please call our freephone helpline on **0808 800 2200**.

What is reasonable?

What is reasonable for one employer/organisation may not be considered reasonable for another. It will depend upon factors like the size of the organisation and the cost. It also depends on the effect introducing the adjustment will have, such as any potential disruption to process or colleagues and staff time involved. **Financial support may be available from schemes such as 'Access to Work' which can cover up to 80% of the cost of an adjustment.**

Sometimes companies believe reasonable adjustments are too expensive. However, under the Equality Act 2010, this is less likely to be accepted as a reason for not implementing adjustments than in the past. Employers must take steps to explore and consider the actual costs and the practicability of adjustments, not simply jump to the conclusion that an adjustment will be unaffordable. Employers need to consider the risk of being taken to Employment Tribunal by a candidate or employee who believes they have experienced unlawful discrimination. This applies to recruitment, retention, training and promotion in employment.

Despite this, in some situations it will not be possible for the person to continue in the job and there may be no alternative post for them. An employer is not required to generate a post that does not already exist.

Disclosing epilepsy

Legally, if an employee discloses they have epilepsy to the human resources or occupational health department, or someone who could be reasonably expected to act on the issue, the employer is deemed to know of the person's condition. They are then under a duty to make reasonable adjustments and to address any associated health and safety concerns.

It may be an employee discloses their epilepsy but does not want their supervisor or co-workers to know. If the person needs a reasonable adjustment to be made (e.g. flexible working hours), the supervisor must be informed of the need for and nature of the adjustment but does not need to be told the medical diagnosis.

If the employee will need help from co-workers for adjustments to be successful, you may want to encourage them in being more open about their epilepsy. You could do this by making it clear any harassment or discrimination they face, such as bullying, will be dealt with quickly and stopped.

However, if the employee still wants their epilepsy to stay confidential, you must respect this.

Storage of health information

Health information, such as whether an employee has epilepsy, must be stored in accordance with the Data Protection Act 2018 and General Data Protection Regulations. Health information is defined as "special category" data so there are particular conditions which must be met before you can store this information. Your company must have a policy on confidentiality and how information about employees' health is to be handled.

For example, you will need to consider:

- Where will the information be kept? (e.g. In a personnel file)
- Who will have access to the information?
- Will it be stored on paper or digitally?
- Will it be stored securely?
- What is expected to be kept confidential and by whom?
- What happens in the event of a breach of confidentiality?
- When will the information be deleted?

The Equality & Human Rights Commission have several excellent publications on privacy, confidentiality and data protection in employment. You can find them at www.equalityhumanrights.com or call their **Scottish helpline on 0845 604 5510**.

The Information Commissioner has a code of practice which includes details of how health information should be stored, which is available at: www.ico.org.uk/media/for-organisations/documents/1064/the_employment_practices_code.pdf

Further information on the special category data is available at: www.ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/special-category-data

Your Risk Assessment

Why do you need a risk assessment?

According to the Health and Safety at Work Act 1974, employers have a duty to make sure the health, safety and welfare of all employees is looked after at work.

Under the Management of Health and Safety at Work Regulations 1999, employers also have a responsibility to:

- Carry out assessments of risks to employees and other people that arise from their work activities.
- Make arrangements to implement any controls and precautions found necessary by the risk assessment
- Appoint one or more competent people to help apply these measures
- Provide employees with clear and understandable information about the risks arising from their work activity and any precautions to be followed
- Provide employees with sufficient health and safety training to enable them to carry out their work safely
- Work together with other employers sharing the same workplace

Research shows the main concern employers have about employing people with epilepsy is safety in the workplace. In fact, studies have found people who have stable epilepsy have no increased likelihood of critical injury. Most jobs, such as in offices and shops, do not cause significant safety risks for people with epilepsy. If safety-related adjustments are needed for an employee with epilepsy, these can also benefit other workers.

In some situations, there may be legitimate concerns about a person with epilepsy doing certain tasks. The best way to ensure you take a fair and informed approach is to carry out an individualised risk assessment.



Example:

A factory worker tells her manager she has epilepsy, and the employer reviews the risk assessment. This identifies that she is working at times on a raised, unguarded platform out of sight of other workers. The risk of her having a seizure at work is low.

The employer chooses to install guards around the platform, remove an old piece of machinery to improve visibility and put in an emergency alarm in that working location. This benefits all workers doing the same job. Six months later another worker has chest pain at work in that location and uses the alarm to call for assistance.

Who would carry out the risk assessment and what does it involve?

Most employers will be familiar with carrying out a general, or 'generic', risk assessment for their company. The Health & Safety Executive recommends a 'five step approach' to such assessments:

- Identify the hazards
- Decide who might be harmed and how
- Evaluate the risks and decide on precautions
- Record your findings and implement them
- Review your assessment and update if necessary

However, it is important that risk assessments for employees with epilepsy are customised to the individual nature of the person's epilepsy, the demands of the particular job they do and the environment in which they work.

The nature of someone's epilepsy depends on a number of features, such as the type of seizures they experience (if any), any patterns to when seizures occur, whether they have a warning or 'aura' that a seizure is about to occur, and whether there are any specific triggers for their seizures.

It is worth keeping in mind, however, that many people with epilepsy can become seizure free with optimal treatment, some will also only experience seizures under specific conditions. It is not good practice to simply have a 'blanket ban' on all people with epilepsy carrying out particular activities.

For example, **working at heights may be unsuitable for some individuals with particular types of epilepsy** and variable seizure patterns. However, it may not necessarily be a problem for people who only have sleep seizures.

Similarly, it is important to take into account the particular nature of the environment an employee works in. There may be a considerable difference between working in an industrial quarry, to working in an office which may essentially be similar to a home environment.

As well as making sure any risk assessment is tailored to the person's specific circumstances, it is essential that the assessment is based on fact. It should reflect the reality of the person's epilepsy and not make assumptions about their condition. For many workers with epilepsy, the risk of injury at work is no different to the risks they face in their ordinary daily lives and no safety-related adjustments are needed. Generally, employers only need to assess those risks which are above and beyond those which an employee faces at home.

Working with an occupational health professional can be useful in helping to identify how an individual's epilepsy may or may not create risk in a particular employment setting. Occupational health professionals are also able to give guidance on reasonable adjustments which may be able to eliminate or manage any risks.

Your Risk Assessment

Reasonable adjustments

Occupational health assessment may suggest that the employee could benefit from adjustments such as:

- avoidance of unplanned overtime at the end of a shift to avoid fatigue,
- flexibility around starting times after a nocturnal seizure
- avoidance of night shift working
- a change in hours
- allowing the employee to attend appointments with their GP or hospital

It is for the employer to decide if these can be reasonably accommodated. It is important to find out how long they may be needed. For example, an employee may suffer side effects that make them more tired in the morning for a few weeks, whilst their medication is being increased or changed.

Specific Concerns

Medication and side effects

Many people with epilepsy are treated by either a single drug or by combination of medications. Information leaflets often mention a daunting list of possible side-effects, which can be hard to separate from the effects of the epilepsy itself, such as fatigue or lack of concentration. However, there is a wide variation in how people tolerate medication or experience side effects. Employers should not assume that someone will be affected by any side-effect but should take into account how the medicine affects the individual. Many people with epilepsy find that they tolerate their medicine without intrusive side-effects. Often people

report more problems when their medication is being changed or increased, which may settle down over a few weeks.

Everyone can benefit from good communication between occupational health and the doctor(s) who treat the person. This allows clinicians to have a better understanding of how the person's epilepsy and their work environment interact. They are then able to take it into account when planning treatment.

Shift work

Many people with epilepsy cope well with no additional problems when working on a rotating shift pattern. However, working night shifts can be a problem in some people with epilepsy. Lack of sleep or disrupted sleep patterns can be seizure-triggers. It is difficult to predict how susceptible any individual might be if introduced to a rotating shift pattern. Employers should not jump to the conclusion that an employee with epilepsy cannot work night shifts but instead seek expert, individual guidance.

Working with visual display equipment

For the vast majority of people with epilepsy using a PC should pose no additional risk of bringing on seizures. A small proportion of people with epilepsy (about 4%) have photosensitive epilepsy. This means that certain visual stimuli, such as flickering lights and repetitive patterns such as those in computer games, can trigger seizures. Older-style screens on computers and televisions carry a higher risk as they refresh the picture and flicker as they do so. Liquid Crystal Display (LCD) screens do not flash and flicker and so remove the trigger for people with this type of epilepsy. However, LCD screens do not protect from flashing and flickering content.

Working around hazards

Health care professionals have moved away from advising 'blanket' type restrictions for employees with epilepsy but there remain legitimate concerns about people working in situations where seizure activity could have a serious impact on the individual and/or colleagues or could result in damage to plant or equipment. In practical terms, the guidelines used by the DVLA for driving, which are based on assessments of risk, have often been applied to other broadly similar situations, such as working with machinery or in hazardous locations. It is good practice to seek expert Occupational Health advice where there is a concern over situations such as:

- Working at unprotected heights – e.g. climbing ladders or working on roofs
- Driving cars, lorries or buses, trains or planes or operating motorized equipment, such as forklift trucks, cranes etc.
- Working near unguarded machinery, deep water, fires, hot metal or furnaces
- Working for prolonged periods in isolated locations
- Operating a crane at high level

It is important the individual and management are aware of the importance of any advised restrictions. Also remember they may need to be reviewed if the situation changes, for example if the person becomes seizure free for a prolonged period or if their seizure patterns change.

Career choices

People with epilepsy should be able to undertake most types of job. Some career choices pose specific challenges. People who have experienced more than one seizure after the age of five or have had a single seizure less than five years before applying, will not be permitted to join the Armed Forces. This is because effective adjustments for people with epilepsy may require them to have regular medication and access to medical supervision and follow up. There are different rules for some forms of childhood epilepsy, and people who have had a single seizure within the last 5 to 10 years may be recruited for some restricted professions. Similarly, entry into some roles in the Police and Fire Service may be limited by the availability of adjustment options. Those seeking a career in driving must meet DVLA Epilepsy Regulations for holding group one and two licences. The added demands placed on group two (LGV and PCV) drivers is they must be free from seizures for ten years without treatment and not otherwise be a source of danger while driving. If there has been only one seizure episode, with no history of seizures and no treatment required, this period is reduced to five years.



Regulations for driving and epilepsy can be found at www.gov.uk/epilepsy-and-driving
Epilepsy Scotland has information on epilepsy and driving; anti-epilepsy medication; seizure triggers and epilepsy and safety available at www.epilepsyscotland.org.uk

Your Risk Assessment

What to do with the outcome of a risk assessment?

A careful risk assessment will help you develop a plan to manage any health and safety risks associated with an employee with epilepsy to an acceptable level. It will allow you to take reasonable precautions to protect both the individual and their co-workers. It may also identify one or more reasonable adjustments which can be made to enable the person to work safely and to the best of their ability.

Once a risk assessment is completed it is important to put in place any recommendations to manage risk. Employers should make sure the assessment is reviewed at regular intervals and updated if the situation has changed. Remember that a person's epilepsy may change over time.

However, if a significant risk remains, despite your best efforts to do what is reasonably practical to control it, you must not employ the person to do this work.

For more information on risk assessments, visit the HSE website at www.hse.gov.uk

There are a number of companies which provide Occupational Health services. These will be advertised in your local directory. For further information contact our helpline on **0808 800 2200**.



Privacy, Confidentiality and Data Protection

Working with Occupational Health Professionals

Occupational Health Professionals (OHPs) are doctors and nurses who specialise in applying health knowledge in specific organisational settings. They do this using an understanding of the hazards, risk and causes of ill-health associated with the specific circumstances of the workplace.

In the UK the NHS provides free health care for all eligible people. However, there is no parallel occupational health service to provide state-funded services to all UK organisations. Some organisations employ OHPs 'in-house', while others contract this out to private sector companies. For many employees working in small and medium sized businesses there may be no provision of such support.

It is not compulsory to involve OHPs regarding an employee with epilepsy. However, each person's epilepsy is unique and the specialist expertise of an OHP can help you to operate both within the law and using best practice. It is not mandatory to carry out the recommendations of an OHP, however refusing those without good justification may be considered unlawful discrimination against the employee with epilepsy.

SEQOHS is an organisation which sets standards in occupational health services. You can find a list of accredited occupational health services near you at www.seqohs.org/Accreditedunits.aspx

Alternatively, you can search for individual occupational health specialists and their areas of expertise who are members of the Society of Occupational Medicine at: www.som.org.uk/find-an-oh-professional

Occupational Health can help employers by helping to:

- Prevent work related ill health
- Promote the best wellbeing of workers
- Ensure that the work environment and work practices are assessed and modified to the needs of individuals, if necessary. This could include providing advice on issues such as suitability for night shift work, need for restrictions on work practices etc.
- Manage health related risks in the workplace from the potential for seizure activity occurring while at work

Occupational Health can help employees:

- Avoiding or minimising the risk from any specific work hazards e.g. working unprotected at heights, working beside dangerous environments
- Using work to optimise their own health and wellbeing by improving self-esteem and confidence
- Working in environments which are adapted to their specific health needs
- Liaising with doctors who treat the person to improve understanding of the links between the workplace and their medical condition

Occupational medicine is

“the branch of medicine most active in the field of occupational health. Its principal role is the provision of health advice to organisations and individuals to ensure the highest standards of Health and Safety at Work can be achieved and maintained”.

Faculty of Occupational Medicine: www.facocmed.ac.uk/about

Privacy, Confidentiality and Data Protection

There are a number of common points at which employers may find it beneficial to engage with OHPs concerning an employee with epilepsy. In many cases, it is when help is needed to conduct a customised risk assessment or to identify potential reasonable adjustments.

For example, this might be appropriate:

- After recruiting someone with epilepsy
- If an employee develops epilepsy or discloses epilepsy while carrying out their job
- If an employee with epilepsy has a change in duties or working environment which may increase or decrease risk
- If the nature of an employee's epilepsy changes in a way which may increase or decrease risk
- If an application is made for ill-health retirement

Communicating with Occupational Health

It may be helpful to think about and prioritise what it is you would like Occupational Health to help with and make sure this is feasible. If you are consulting with OHPs regarding an employee with epilepsy, there are rules which they will follow concerning the sharing of sensitive information about that person.

The employee should be aware of and have consented to involving Occupational Health in the process. The OHP and employer should make sure that the purpose of the assessment is clear and the employee understands why they are being assessed. It is normal for the referral information provided by the employer to be shared with the employee.

In some circumstances, the OHP may wish to liaise with the employee's GP or the hospital staff involved in their care. This might be to gather more information about the person's epilepsy or other health conditions, or to share information about the person's workplace with their GP.

However, an OHP will not disclose any confidential medical information to employers, unless the employee wishes them to do so. Instead they will give their independent opinion on non-medical issues, such as the person's fitness to do the job, how to look after his/her safety in the workplace, how to enhance attendance/ productivity in workplace and any appropriate reasonable adjustments.

The OHP must keep records of consultations with an employee. These form part of the person's Occupational Health records and will not be released to the employer except in the case of a Court Order. They must be treated in the same way as GP or hospital records. The employee can ask for a copy of all records held by the occupational health provider, who most supply this free of charge.

Employee concerns

Sometimes employees are anxious about the involvement of Occupational Health and may be apprehensive about undergoing assessment. They may perceive the OHP to be 'on the side' of the employer, since the employer is usually paying for the service. Also, referral to Occupational Health is often made once there is already an established problem with absence or performance.

Good communication can help in this situation. It is important to make clear that the guidance offered by the OHP is independent and impartial. It is also important to clarify issues about consent and what information will be shared with the employer. People often feel vulnerable when they have a medical condition and epilepsy can still carry a stigma that other conditions do not. You can help by explaining that OH assessment may identify measures to support the person in the workplace.

It is good practice for occupational health providers to offer a copy of the report that is sent to the employer and an employee can ask to see this before it is sent, so that they are aware of the contents.

Good Practice

Following on from the requirements of the legislation, there are a number of good practice measures which help enable employers and their employees to maintain a positive working relationship. Using good practice towards people with epilepsy can help your organisation to benefit most from their skills. Using good practice also helps to identify any issues early in order to avoid more significant problems developing later in a person's employment.

Healthy Working Lives

Useful forms for employers, including a health and safety policy, risk assessment forms, sickness absence and return to work forms including details of any reasonable adjustments are available free at: www.healthyworkinglives.scot/workplace-guidance

Communication

The most important element of good practice is for employers to listen to employees with epilepsy and to communicate clearly. People with epilepsy hold the best knowledge about their own abilities and the nature of their epilepsy. They are well placed to tell you what, if anything, they need in order to carry out the job effectively.

Sick leave

As an employer it is good practice to record disability and non-disability related work absences separately. With epilepsy some work absences may appear to be unrelated, e.g. headaches, tiredness, sore limbs, but they may actually be linked. After a seizure people with epilepsy can experience all of these symptoms and need time to recover.

A reasonable adjustment could involve a person with epilepsy being allowed more short-term work absences than are detailed in the general sickness policy. Sickness policies need to be flexible to take account of the unique nature of epilepsy. Despite this, research shows that people with epilepsy usually have no more work absences than people who do not have epilepsy.

Epilepsy awareness in the workplace

A practical way of supporting an employee with epilepsy is to encourage epilepsy awareness among their supervisors and co-workers. In particular, this can promote a positive attitude towards the employee from colleagues who help to implement reasonable adjustments. However, it is important to make sure the individual involved is comfortable with this, as some people wish to keep their condition confidential. Also, they may not feel it is appropriate if their seizures are controlled. The best idea is to ask the person how they feel about it and what would help most.

Epilepsy awareness in the workplace means giving employees an understanding of things such as:

- What epilepsy is
- Types of seizure
- Basic epilepsy first aid
- Common seizure triggers

Epilepsy often carries a social stigma, which is based on ignorance and fear. Understanding more about the condition and knowing what to do if someone has a seizure greatly helps reduce any anxieties.

Supported Employment

Supported employment is a flexible recruitment model which aims to help people with disabilities overcome employment barriers and access paid work. It usually follows a five-stage process which matches candidates to jobs and assists employers supporting people in the workplace. Welcoming supported employment to your business can bring several benefits including; a free recruitment process, access to a talented and committed pool of candidates and an enhanced recruitment process which will diversify your workforce.

To find out more about supported employment, visit:

Scottish Union of Supported Employment
www.suse.org.uk

Epilepsy, Emotional Wellbeing and CBT

It is completely normal for an employee to feel anxious, sad or angry when they are told they have epilepsy. They may worry about how other people view them, or feel that family, friends and colleagues now treat them differently.

Coming to terms with the diagnosis of a long-term condition is not easy. In the majority of cases the diagnosis will have a negligible impact on the person. However, a number of people will struggle to accept the way their lives may have changed. We all cope with life changing events differently. Over time, many find it becomes easier to accept the condition and move on to live full and active lives. Stress and anxiety can be a seizure trigger for some people with epilepsy. A number of those people may find that their seizures are less frequent once they begin to feel more positive.

Some people with epilepsy may have low moods which are linked to the condition itself.

For example:

- A side effect of anti-epileptic medication
- Linked to the cause of someone's seizures – such as scarring in a particular part of the brain
- Part of a person's seizures – some people find they feel very strong emotions before and after a seizure



If you would like to talk to Epilepsy Scotland about epilepsy awareness training and further information, please get in touch with

Epilepsy Scotland's freephone helpline on 0808 800 2200

or go to

www.epilepsyscotland.org.uk

Good Practice

There are several evidence-based tools that employees might use to successfully manage feelings of anxiety and depression.

These include:

Cognitive Behavioural Therapy (CBT)

aims to guide people into taking control over how they think and feel. Sessions are normally carried out weekly, with practice assignments given between sessions. The process introduces the person to a number of techniques by which they can ‘capture’ or ‘harness’ thoughts which may be causing them anxiety, panic, and depression. CBT helps people change how they think (cognitive) and what they do (behaviour). These changes help people feel better.

Mindfulness is another tool which may help people cope with how they are feeling. It aims to help people connect with their thoughts and feelings and bring them back to the present moment. It enables people to observe and let go of thoughts, changing negative thought patterns rather than being defined by them. There is evidence that mindfulness can prevent depression in some people.

Counselling is a form of talking therapy which involves a trained professional listening to a client and helping them work through their problems. Counselling is a type of support which helps people reach their own solutions to their difficulties. It can take various forms; face to face, group sessions, over the phone and via online methods.

Breathing Space and Living Life are two free NHS Scotland resources that provide mental health support to those who require it. They can be found at www.breathingspace.scot and www.breathingspace.scot/living-life.

Although there are various forms of mental health support, not all of them work for everyone. It is important that an individual finds the right support for their needs. This might take a completely different form to someone else experiencing the same kind of issues.

Workplace first aid

The first aid equipment and number of first aiders or appointed persons you are legally required to have depends both on whether work activities are considered high or low hazard and the size of the workforce. The HSE does recommend providing first aiders with extra training if you have employees with disabilities or particular health problems on site.

Employees whose epilepsy is not totally controlled may have a higher likelihood of seizures happening at work. Knowing basic epilepsy first aid can help colleagues respond calmly and confidently when dealing with someone having a seizure.

A summary of what to do when someone has a tonic-clonic seizure (formerly known as ‘grand-mal’) is on page 26. Whatever kind of epilepsy an employee has, it is good practice to have somewhere quiet and safe for them to recover following a seizure.

The HSE have guidelines for assessing workplace first aid needs at www.hse.gov.uk. Contact Epilepsy Scotland to learn more about epilepsy first aid training and further information on seizures.

Ill-health Retirement and Epilepsy

This section of the guide is designed to give some useful information to employers, trustees of pension funds and members of pensions departments. It may also help employees who are thinking of applying for ill-health retirement.

There are differences between the pension funds of different companies, but all funds have certain principles in common. For example, a doctor should assess the medical evidence in every application. The following is fairly broad advice but may help prevent wasted time and effort for everyone involved.

The rules of the individual pension scheme should guide any decision on whether someone is given ill-health retirement or not.

These rules should be clear and:

- Define the meaning of key words and phrases such as “**incapacity**”, “**permanent**”, and “**foreseeable future**”

- How important the difference is between what, in practice, is “**total**” or “**partial**” incapacity – even if these terms are not actually used.

Some pension trusts use terms like “**less demanding work**”, “**alternative gainful employment**”, “**with significant loss of earnings capacity**” and other terminology. Different rules apply to current members and former employees (called deferred members).

The trustees of some schemes may be able to grant or deny a pension based on their own views of the person’s fitness to work or not. They may not accept the opinion of the pensions medical adviser.

Ill-health retirement and the individual with Epilepsy

Causes other than epilepsy

Like the general population, people with epilepsy may be affected by heart problems, musculo-skeletal issues and other causes for ill-health retirement.

Co-conditions

Epilepsy may be associated with other problems such as cognitive impairment following brain damage due to illness, trauma or due to the effects of anti-epileptic drugs.

Epilepsy

This may be associated with physical and psychological problems. People with epilepsy may be more prone to depression and anxiety for various reasons. Also, their seizures may not improve with medication. The impact on the person may be physical, psychological and affect their cognitive and psychosocial function.

Good Practice

Factors considered when examining the evidence for or against Ill Health Retirement

Evidence is normally gathered by getting reports from the individual's GP, Specialist (such as their neurologist) or after an Independent Occupational Health Assessment. If the reports are not satisfactory, evidence is sometimes obtained by having the Pension Medical Advisor physically examine the person. However, this is not usually necessary. A copy of the job description should normally be available.

Secondly, no matter what the medical condition causing the possible ill-health retirement is, the following factors should be considered:

The severity of the medical condition.

This includes the impact on the individual's general health and wellbeing, physical or psychological health, cognitive ability (memory, thinking and concentration) or psychosocial function (social relationships).

The duration of the medical condition and of absence from work.

The range of treatment offered, for example, medication, counselling or specialist assessment and treatment, hospital inpatient treatment (including surgery). Normally, all appropriate forms of management of the underlying medical condition should have been offered, implemented and their benefits assessed before an application for ill-health retirement is made.

Any requirements of the Equality Act 2010, where appropriate.

This would include making reasonable adjustments to the job or working conditions, such as a phased return to work and modified duties.

The age of the applicant.

It might be significant that the younger applicant has more time to recover his or her health while the older applicant has less time to regain fitness to work before the date of normal retirement.

The medical assessor should have access to all relevant and up-to-date health reports which may have a bearing on the applicant's fitness or unfitness for work. In general, this should be based on their medical capability to do a job, rather than their training or previous job experience. For example, a labourer may be unable to do manual work, but could do a clerical job, though he or she may not have anticipated or be trained for clerical tasks.

The opinion of the person's GP and hospital consultants on ill-health retirement should be considered seriously. However, they may not always have full knowledge and understanding of the applicant's job as well as opportunities for rehabilitation.

Pensions legislation is very complex. If you need help with a particular pension query, you can ask for free advice from The **Pensions Advisory Service (TPAS)**. Information is available at: www.pensionsadvisoryservice.org.uk

If you believe that you have been treated unfairly, you can lodge a complaint with The Pensions Ombudsman. Information is available at: www.pensions-ombudsman.org.uk

The Ombudsman will normally only agree to investigate a complaint after all normal appeal processes available to the applicant have been exhausted.

Many people have medical conditions which necessitate ill-health retirement, either from their own job or, indeed, any job in the future. However, ill-health retirement is not always the best option. In particular, it can be a distressing and demoralising step for someone who has already prematurely lost many positive aspects of their life. Sometimes people suffer a type of bereavement reaction in losing the part of their lives associated with normal living and working. We know that work can be a great boost to our psychological wellbeing. Likewise, having no job may have the opposite effect.



It is widely accepted that after one year's absence from work, up to 5% of absentees may never work again.

By the time an application for IHR is made, it may be too late to make a meaningful intervention. This can be helped by early referral to and involvement of an occupational health service. By liaising with the person's GP and hospital specialist, a management plan for the individual's problems can be set out at an early stage. This gives quicker and greater benefits for the individual, his/her fitness and productivity, and the employer.



Appendix – Useful Resources

Further information and support

Personal Emergency Evacuation Plan

The aim of a Personal Emergency Evacuation Plan is to provide people who cannot get themselves out of a building unaided with the necessary information to be able to manage their escape to a place of safety and to give departments the necessary information to ensure that the correct level of assistance is always available.

Reasonable Adjustment Passport

The purpose of the Reasonable Adjustments Passport is to support discussions around removing or reducing any barriers to maximising the potential of each employee in the workplace.

To download further useful resources, such as a workplace Personal Emergency Evacuation Plan or a Reasonable Adjustment Passport, please visit the Information page of our website at www.epilepsyscotland.org.uk

ACAS (Advisory, Conciliation and Arbitration Service) provide information and advice on employment issues and work with employers and employees to resolve disputes.
Website: www.acas.org.uk
Telephone: **0300 123 1100**

The **Access to Work scheme** can provide practical information on overcoming difficulties for disabled people in the workplace. In some situations, financial support can be accessed through Jobcentre Plus to make this possible.
Telephone: **0141 950 5327**
Textphone: **0141 950 521**

Disability Information Scotland is Scotland's national disability information service
Telephone: **0300 323 9961**

The Employment Medical Advisory Service (EMAS) can help assess the suitability of particular types of work for disabled people. There are two EMAS offices in Scotland:
Edinburgh office - Telephone: **0131 247 2000**
Aberdeen office - Telephone: **01224 252500**

The Health and Safety Executive (HSE) provide information and advice on health and safety and risk assessments.
Website: www.hse.gov.uk
Telephone: **0845 345 0055**

Healthy Working Lives for information on workplace health, safety and wellbeing.
Website: www.healthyworkinglives.scot
Telephone: **0800 019 2211**

Safe Effective Quality Occupational Health Service (SEQOHS) is a set of standards and a voluntary accreditation scheme for occupational health services in the UK and beyond.
Website: www.seqohs.org
Telephone: **0203 116 6912**

Society of Occupational Medicine (SOM) is a UK organisation for all healthcare professionals working in or with an interest in occupational health.
Website: www.som.org.uk
Telephone: **0203 910 4531**

The UK Government Equalities Office has a number of resources including the information on the Equality Act 2010, which can be downloaded from their website:
www.equalities.gov.uk

There are a number of Occupational Health companies which provide paid for services in Scotland. These will be advertised in your local directory.

Referring an employee to Occupational Health

When referring an employee for Occupational Health Assessment, you may be given a form to complete, or you may have to write a referral letter. In either case, you will normally need to provide the following information:

- The employee's full name, home address and best contact number
- The name and designation of the referring manager and contact details to which the confidential OH report should be sent.
- The employee's job title, a description of duties, contracted hours, the structure of these hours (e.g. full or part time, shifts etc.) length of tenure and the date they started in their current post
- The reason for the referral, such as long-term sickness absence, repeated short-term sickness absence or concerns regarding behaviour and /or performance at work. If the referral is due to absence issues, you should state when the current absence began and the reasons for absence as stated on the employee's fit note, if there is one.
- Details of all action that has been taken so far to address the problems outlined

What you would like Occupational Health to address. For example:

- To report on ability to carry out current duties
- To report on likelihood of employee returning to work in the foreseeable future
- To report on rehabilitation into the work setting on return (e.g. restricted duties, reduced hours, timescale and adjustments recommended)
- To report on whether the Equality Act 2010 in relation to disability applies and advice on any areas where adjustments are recommended
- To report on whether the employee is permanently incapacitated
- To report on any workplace factors contributing to ill health
- To report on any further help or support that the employer can offer

It is essential the employee being referred is aware of the referral and the reason(s) for it. In order to avoid any misunderstanding, a written referral, rather than a verbal referral, will be necessary. It is useful to state who discussed the referral with the employee, and you should offer to provide the employee with a copy.

Appendix – Useful Resources

First Aid for tonic-clonic seizures

How do you know it's a tonic-clonic seizure?

The person will suddenly stiffen, fall and lose consciousness. The person will start to jerk and their breathing may be affected, turning blue at the lips. The person may make a grunting noise, produce saliva, bite their tongue and empty their bladder/bowels.

What should you do?

Usually, a seizure stops on its own, and there is normally no need to call an ambulance.

- Keep calm
- Check the time to see how long the seizure lasts
- Move any objects that could cause injury
- Put something soft like a rolled-up jacket or cushion under the person's head to prevent injury
- Loosen tight clothing around the neck
- Remove glasses
- Stop others from crowding around
- Turn the person onto their side into the recovery position as soon as the jerking stops
- Refer to the person's care plan if they have one
- Check for medical identification as this may have more information on the person's epilepsy
- Protect the person's dignity, particularly if they have emptied their bladder or bowels
- Speak softly and gently when you tell the person what has happened
- Remember they may be confused after a seizure

What NOT to do?

- Do not move the person unless they are in danger (i.e. on a busy road or at the top of stairs)
- Do not try to stop the jerking or restrain the person
- Do not put anything in the person's mouth or between their teeth
- Do not offer the person anything to eat or drink until they are fully conscious

First Aid for other types of seizures

How do you recognise other types of seizures?

Symptoms can include:

- staring into space/daydreaming
- a person experiencing unusual sensations or emotions
- sudden stiffening or loss of muscle tone with the person falling to the ground
- sudden jerks of arms, legs or head
- unusual or repetitive behaviour such as smacking lips, plucking at clothes or moving aimlessly around

What should you do?

- If the person has fallen down suddenly, check they haven't hurt themselves
- Keep the person safe during a seizure but do not restrain them unless they are in danger
- Let the seizure run its natural course
- Stay with the person until they have fully recovered
- Calmly and quietly reassure the person afterwards and tell them what's happened

When should you call an ambulance?

- If this is the person's first seizure (as far as you know)
- If the person has badly injured themselves
- If the jerking lasts for **five minutes** or a longer time than is usual for that person. If the person has a care plan, this will have information on their usual length of seizure
- If in doubt, call an ambulance

Epilepsy Scotland,
48 Govan Road, Glasgow G51 1JL
General enquiries: 0141 427 4911
Email: contact@epilepsyscotland.org.uk

Helpline: 0808 800 2200
Text: 07786 209 501
www.epilepsyscotland.org.uk

Epilepsy Action Scotland is a company limited by guarantee.
Registered in Scotland No 163987
Scottish Charity: No SC000067.

Copyright 2020



Production of this booklet is supported by Eisai Ltd. Eisai Ltd have no editorial control over the content of this booklet.

