

Epilepsy and Occupational Health

A GOOD PRACTICE GUIDE FOR EMPLOYERS

*
A positive work experience for people with Epilepsy

HELP WITH THINGS LIKE RISK ASSESSMENT AND EQUALITY LEGISLATION.
INFO ON EPILEPSY AND THE WORKPLACE

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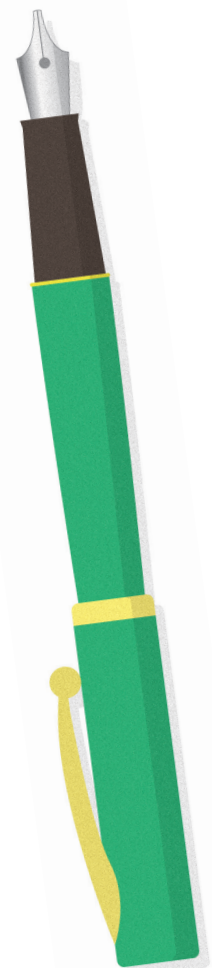
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INTRODUCTION

From the Chief Executive

Lesslie Young,
Chief Executive,
Epilepsy Scotland

Feeling valued, having a purpose in life and a reason to get up every morning is important for everyone. Consistent employment helps to achieve all of these aims.

For anyone who is living with epilepsy and trying to gain employment, the challenges in their daily life combined with those encountered or anticipated in the work place may seem insurmountable. Equally, for someone already in work who is newly diagnosed with the condition there may be anxiety about how they will maintain their employment.

It was through the many calls to Epilepsy Scotland's Helpline from people in these situations, concerned about work and career, that I saw the need for more and better information about epilepsy in the workplace. This guide is aimed at employers, but will be helpful to both employers and employees in addressing the complex relationship that exists between epilepsy and employment.

Many people who have epilepsy enjoy a fulfilling worklife. On the occasions when the condition causes difficulties this robust document offers information and advice from experts in the fields of occupational health medicine and epilepsy. It will assist employers and employees alike to ensure the best possible outcome for people with epilepsy in the workplace. It will get the job done.

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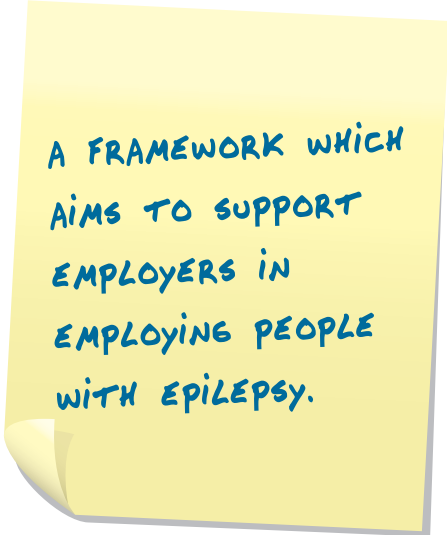
Work and good health

Dr Freddie Westbrook,
Consultant Occupational Physician,
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There is an increasing recognition of the important positive relationship between being in work and good health. It is now accepted that this applies both to those with and without disabilities. Getting into and staying in the right type of work plays an important part in how we see ourselves and also how others see us. A positive work experience can lead to improved emotional function through increased self esteem and self fulfilment. Physical function can also improve by remaining active.

Over recent years there has been a profound shift in how we consider the link between work and health. In particular, people with disabilities and health problems are encouraged to show their productivity, creativity and add organisational value. However evidence suggests that this situation varies widely across the country. Individuals with epilepsy are known to have a much lower level of employment than average in the UK, resulting in a lack of further opportunity for development. Additionally, low self esteem arising from not working can compound their reduced chances of gaining and remaining in long term employment.

Employers face many challenges in an ever-shifting economic environment. They may be concerned about the impact of employing people with disabilities. This booklet sets out a framework which aims to support employers in employing people with epilepsy.



A FRAMEWORK WHICH
AIMS TO SUPPORT
EMPLOYERS IN
EMPLOYING PEOPLE
WITH EPILEPSY.

¹ Black, C - "Working for a healthier tomorrow", London, 2008

Why use this good practice guide?

Epilepsy is one of the world's most common neurological conditions. It affects one in every 130 people and there are currently an estimated 241,692 people of working age with epilepsy in the UK. It is likely you may interview and employ a person with epilepsy at some point, or you may already be doing so.

40,000 people in Scotland have epilepsy and a further 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.

An employee may disclose they have epilepsy during the recruitment process, or develop it while employed by your organisation. As an employer, it is important not to make assumptions about someone's epilepsy - there are over forty types of seizure and epilepsy syndromes and everybody's condition is different.

In a minority of people, seizures may happen at work or work performance may be affected by anti-epilepsy drugs (AEDs). Gathering accurate information on the person's seizures and looking closely at the nature of their job will help in deciding the best way forward with each individual. Occupational Health professionals 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.

Many people with epilepsy will require no additional support or adjustments in the workplace, but others will require some changes to do their job. By following good practice guidelines, employers can feel more confident in making reasonable adjustments, where necessary, to accommodate people with this condition. In short, using good practice towards people with epilepsy can help your organisation to benefit most from their skills.

² Office for National Statistics labour market statistics September 2010; includes 26.16m employed and 2.47m unemployed, excludes 9.26m inactive (eg. Retired, looking after family or claiming incapacity benefit)

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 the majority are able to stay seizure-free with the right 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 can affect people in different ways. There are over 40 types of seizure and epilepsy syndromes, 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 have no seizures while taking medication. 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.

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 0800 800 2200 or go to www.epilepsyscotland.org.uk

About seizures

Our brain controls all our speech, movement, emotions, memory, vision, hearing and much more. 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 partial. Generalised seizures involve the whole brain. Partial seizures affect only part of the brain.

Partial seizures are either simple or complex.

A simple partial seizure 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 complex partial seizure 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 simple partial seizures they will have a loss of awareness.

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

Generalised seizures affect the whole brain.



The person will lose consciousness. 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 25](#).

Equality and confidentiality

The Equality Act 2010

The Disability Discrimination Act came into force in 1995 and was amended in 2003 and 2005. The Equality Act 2010 replaced and extended this legislation and gave people with disability greater rights.

Equality in 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 eg use of public transport or a support driver.

FIND OUT MORE ABOUT
THE EQUALITY ACT
WWW.EQUALITYHUMANRIGHTS.COM
OR CALL 09456 45510.

ALSO, ACAS CAN PROVIDE
HELPFUL AND PRACTICAL INFORMATION,
SEE WWW.ACAS.ORG.UK OR CALL
08457 47 47 47.

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 have to 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 in relation to specific skills which are essential to do the job, or to find out whether they need any reasonable adjustments to attend an interview or test. However, if the employer asks unlawful questions, the person can complain to the Equality and Human Rights Commission, who will investigate the matter.

If the employer asks these questions and also rejects the applicant, they may be taken to an Employment Tribunal for 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.

Just an overview!
Find out more
about the kinds of
adjustments which
could help your
employee, call helpline
0808 800 2200.

Reasonable adjustments

The Equality Act requires employers to make reasonable adjustments to support disabled people 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 that 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.

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 that 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 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

It is best practice for your company to have a policy on confidentiality and how information about employees health is to be handled. For example, you may wish 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?



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 that an employee discloses epilepsy but does not want their supervisor or co-workers to know. If the person needs a reasonable adjustment to be made (eg. flexible working hours), the supervisor **must be informed of the nature of the adjustment, but does not need to be told the nature of the health condition.**

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 that **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.

Your risk assessment

Risk assessment

Why do you need a risk assessment?

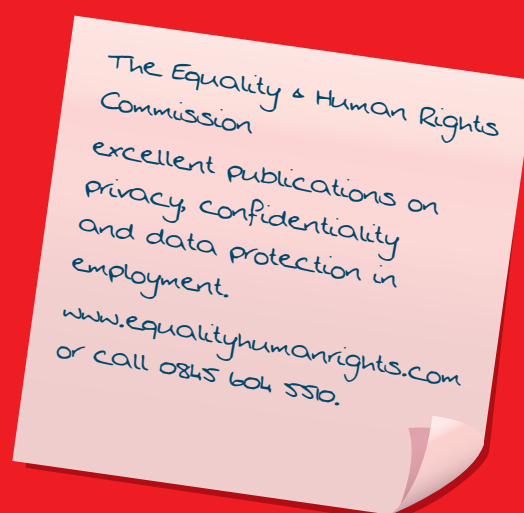
According to the Health and Safety at Work Act 1974, employers have a duty to make sure the health, safety and welfare of all employees is looked after at work.

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 persons 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 that the main concern employers have about employing people with epilepsy is safety in the workplace. In fact, studies have found that people who have their seizures well controlled have no increased likelihood of critical injury.

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





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 up to 70% of people with epilepsy are able to become seizure-free with medication, and many others will only experience seizures under specific conditions. It is not good practice and potentially unlawful 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.

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.



REGULATIONS FOR DRIVING AND EPILEPSY
CAN BE FOUND AT WWW.DFT.GOV.UK/DVLA
EPILEPSY SCOTLAND HAS INFORMATION
ON EPILEPSY AND DRIVING; ANTI-EPILEPSY
MEDICATION; SEIZURE TRIGGERS AND
EPILEPSY AND SAFETY AVAILABLE AT
WWW.EPILEPSYSCOTLAND.ORG.UK

Specific concerns

Medication and side effects

Many people with epilepsy are treated by either a single drug or by a combination of drugs. Some of these drugs can have particular side-effects which can be hard to separate from the effects of the epilepsy itself, such as fatigue. There is a wide variation in how people may experience side-effects, such as lack of concentration or drowsiness. This is important to take into account when conducting individual risk assessments.

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

Lack of sleep and disrupted sleep patterns can make seizures occur more frequently in some people with epilepsy. We do know that many people with epilepsy cope well with no additional problems when working on a rotating shift pattern. However working night shifts can be a factor in triggering seizures in people with epilepsy for whom fatigue is a seizure-trigger. This is because of the significant effect on sleep patterns. It is difficult to predict how susceptible any individual might be if introduced to this type of shift pattern.

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 specific concerns about people working in situations where seizure activity could have a serious impact on the individual and/or colleagues. 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.

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 motorised equipment, such as forklift trucks, cranes etc.
- working around unguarded machinery
- working near deep water, fires, hot metal or furnaces
- working for prolonged periods in isolated positions, such as operating a crane at high level.

It is important that both the individual and management are aware of the importance of any advised restrictions. Also remember that 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 ten 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. 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 (HGV & LGV) drivers is that they must be free from seizures for ten years without treatment and not otherwise be a source of danger while driving.

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 in spite of 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**.

Contacting Occupational Health

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.

Occupation 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



Occupational Health can help employers by:

- preventing work related ill-health
- promoting the best wellbeing of workers
- ensuring 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.
- managing health related risks in the workplace in order to avoid the potential for seizure activity.

Occupational Health can help employees by:

- avoiding or minimising the risk from any specific work hazards eg. 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 that 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.



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 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.

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.

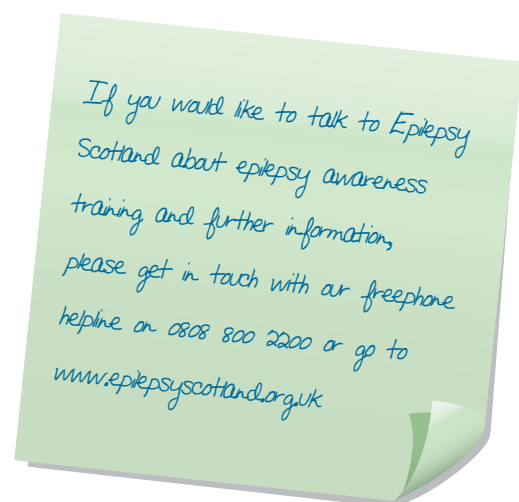
However, an OHP will not disclose any confidential medical information to employers, unless the employee wishes them to do so. Instead they will give their independent opinion on non-medical issues, such as the person's fitness to do the job, how to look after his/her safety in the workplace, how to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

The OHP may keep records of consultations with an employee. These form part of the person's Occupational Health records and are not released to the employer. They must be treated in the same way as GP or hospital records.

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.



Good practice measures

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.

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, eg 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 work absences than are detailed in the general sickness policy. 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.

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.

Epilepsy, emotional wellbeing and CBT

Dr Robert Sharpe, Consultant Chartered Psychologist

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:

- as a side effect of anti-epileptic drugs (AEDs)
- 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 seizures cause very strong emotions before and after a seizure.

You may discover that an employee with epilepsy is undergoing some Cognitive Behavioural Therapy (CBT) to help with low moods. CBT is now a leading way of helping and guiding people to take control of how they think and feel. Sometimes CBT can be recommended for an employee as the result of an Occupational Health assessment, if it is appropriate. Alternatively, other approaches, such as person-centred counselling, may be suggested.

The process of CBT 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. CBT focuses on the 'here and now' problems and difficulties.

Other talking treatments focus on past events, whereas CBT looks for ways to improve an individual's current state of mind.

CBT usually involves a series of structured sessions that focus on the techniques themselves and how the person can relate these to their areas of distress or emotional discomfort. The time frame over which the work is carried out is usually a few weeks. Sessions are normally carried out weekly, with practice assignments being given between sessions. It is a highly practical therapy and the person learns also how to apply the same techniques to other issues which might arise in the future.

The desired outcome of CBT is that the person thinks and feels in a more proactive way. It helps the person to take a more considered approach to challenges.

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 25. 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

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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 pensions 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.



Types of ill-health retirement (IHR)

Generally, most company IHR schemes have two tiers. These are either based on:

- total incapacity - where the person is judged to be permanently unfit to do any paid employment, that is until he/she reaches normal retirement age
- partial incapacity - where the person is permanently unfit to perform their current job, but may be fit to do some form of paid employment before reaching normal retirement age.

Some pension trusts use terms like 'less demanding work', 'with significant loss of earnings capacity' and other terminology. The above IHR pensions only apply to active members of the scheme, e.g. current employees.

Terminal illnesses

Epilepsy is not considered a terminal illness. However, people with epilepsy can develop terminal conditions in the same way as anyone else. In cases of terminal illness, for example when someone is dying of cancer, the specialist (e.g. the oncologist) may state that on the balance of probabilities, the individual may have less than one year to live. This opinion should be passed on to the trustees by the pension medical advisor as the individual may be given a much larger lump sum to compensate for the fact that he or she will receive their pension for a very short time.

This subject should always be handled with great sensitivity as the individual may not be fully aware of exactly how serious their medical condition is.

Preserved members

People who are entitled to remain in the scheme after leaving their employment within the organisation are known as 'preserved' members. They may apply for early payment of their preserved pension on grounds of ill-health. There are many variations on how someone qualifies for this pension. Possibilities include:

- An individual is unfit to perform the job they carried out while they worked for the company.
- An individual is unfit for their current job.
- There may be a rather vague statement about 'unfitness for most work'.

The trustees of some schemes may still be able to grant or deny a pension based on their own views of the person's fitness to work or not. This can be one of the most difficult areas regarding ill-health retirement pensions.

Factors to consider when examining the evidence for or against IHR

Evidence is normally gathered by getting reports from the individual's GP, Specialist (such as their neurologist) or after 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.

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). 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 status 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 rather than their suitability to perform a job. For example, a labourer may be physically fit to perform a clerical job, though he/she may not have anticipated or trained to do that kind of work.

The opinion of the 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. Generally, they should always be given a copy of the individual's job description before being asked their opinion on a person's fitness or unfitness for work.

The above should be regarded as a minimum requirement in the assessment of ill-health retirement applications or appeals. However, in some cases other factors may need to be considered and these are described in the table below and following section on IHR and the individual with epilepsy.

Stumbling blocks to IHR applications

Problem

Explanation

Insufficient evidence

Sometimes the reports submitted by doctors are not sufficient. This may be because:

- they have not been asked the right questions
- the report has not been completed at the right time/stage
- the quality of the report is poor.

Condition not permanent enough

The condition(s) involved may improve significantly before the person reaches normal retirement age.

Application is premature

The person's treatment has not had sufficient time to take effect and its benefits assessed.

Not all of the appropriate forms of management of the condition have been put in place

It is important that all of the appropriate ways of managing someone's condition have been tried. For example, referral to a pain management clinic for some individuals with musculo-skeletal or other disorders.

Sometimes psychological help has not been accessed when it could be useful. Approaches such as Cognitive Behavioural Therapy (CBT) can be beneficial in some forms of work related stress, anxiety and depression. For more information see page 19.

Ill-health retirement and the individual with Epilepsy

Non-epileptic causes

Like the general population, people with epilepsy may suffer from heart problems, musculo-skeletal issues and other causes for ill-health retirement. All of the steps above should still be taken in assessing the application.

Co-conditions

Epilepsy may be associated with other causes of problems such as cognitive impairment following brain damage associated with illness or trauma. There are also many other reasons, some of which may be related to the effects of anti-epilepsy 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. Again, all the steps outlined above should be followed.



Making the decision – things to remember

Look at the requirements of the Equality Act. Potential reasonable adjustments to the person's work should be carefully considered, such as time of work, hours of work, and adjustment of duties. Please read the sections on [specific concerns \(page 13\)](#) and [career choices \(page 14\)](#) for more information.

If the person's epilepsy is not controlled, it is important that all treatment options are reviewed. This includes a review of their medication within the SIGN guidelines (NICE in England and Wales) to ensure that every opportunity is given to control an individual's seizure activity.

The role of Cognitive Behavioural Therapy and other forms of psychological intervention can be beneficial in helping restore a person's psychological and, often, physical wellbeing.

Conclusion

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.

Secondly, in dealing with applications for ill-health retirement, it is very important that the pension medical advisor has a good relationship with the referring personnel, who may be HR Managers, Case Managers or other occupational health personnel. This ensures that every aspect of the application can be scrutinised in depth.

Finally, the pension medical advisor should be well prepared for the distress or anger which the decision to deny an application for IHR may cause and be sure of his or her arguments to support their recommendations. This also helps in avoiding the involvement of the Pensions Ombudsman. For many companies, an experienced occupational physician acts as the pension medical advisor.

Useful resources

Further information and support

To download further useful resources, such as a workplace Personal Emergency Evacuation Plan for employees with a disability, please visit the Occupational Health Guide pages of our website at www.epilepsyscotland.org.uk

Epilepsy Scotland's freephone helpline: **0808 800 2200**

Helpline text: **07786 209501**

Email: enquiries@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: **08457 47 47 47**

Textphone: **08456 06 16 00**

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**

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**

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

The Employers' Forum on Disability is an organisation focused on making it easier to recruit and support disabled people in the workplace.

Website: www.employers-forum.co.uk

Telephone: **020 7403 3020**

Textphone: **020 7403 0040**

Update is Scotland's national disability information service

Telephone: **0131 669 1600**

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

Referring 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 (eg. 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 (eg 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 that the employee being referred is aware of the referral and the reason(s) for it. Therefore, you should confirm that this is the case. It is useful to state who discussed the referral with the employee and the date this took place.

First aid

REMEMBER
CHECK IF THE PERSON IS WEARING
ANY MEDICAL ALERT JEWELLERY.

First Aid for tonic-clonic seizures

How do you know it is a tonic-clonic seizure?

The person will suddenly stiffen, will fall and will lose consciousness. The person will start to jerk and their breathing may be affected. Their lips may turn blue. 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 other people 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.

First Aid for other types of seizures

How do you recognise other types of seizures?

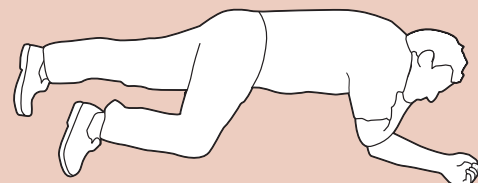
Symptoms can include:

- 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 have not 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 has happened.

Recovery Position



What NOT to do

- **Do not** move the person unless they are in danger (ie 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.

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 Rd, Glasgow G51 1JL

Helpline: 0808 800 2200 (free phone)

Helpline Text: 07786 209501

Enquiries: 0141 427 4911

Email: enquiries@epilepsyscotland.org.uk

Web: www.epilepsyscotland.org.uk

Twitter: twitter.com/epilepsy_scot

Also find us on Facebook!

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