



EPILEPSY IN THE WORKPLACE

A TUC guide

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About the author

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Kathy had epilepsy as a child, as did two of her three children. She no longer has epilepsy, but does have several long-term health conditions.

Introduction by the TUC General Secretary

I am delighted that the TUC has worked with Epilepsy Action to produce this new guide for trade unionists on supporting members with epilepsy. The author is a specialist and a trade unionist so this briefing will be an authoritative aid to union reps, officers and members on dealing with the issues facing members with epilepsy in the workplace. Despite legal protection, workers with epilepsy still encounter ignorance, prejudice and discrimination. Trade unions challenge all such attitudes and behaviour and this guide will help them to do so from a position of strength. I welcome it and commend it to unions.

Frances O'Grady
March 2015

1 | THE SOCIAL VERSUS THE MEDICAL MODEL

There are different ways of understanding disability. The two main ones are:

- ▶ the social model
- ▶ the medical model

This section explains the two and how they apply to epilepsy. The rest of this handbook uses the social model to understand epilepsy in the workplace and trade union strategies for taking up issues around epilepsy.

The social model of disability

The trade union movement uses the social model of disability. The social model looks at the barriers that our society puts in the way of disabled people's participation (in this case, people with epilepsy), including both attitudes and practical barriers. It aims to remove unnecessary barriers that prevent disabled people accessing work and services and living independently.

The social model identifies the problems faced by disabled people because of external factors. For example, flickering lights in a workplace might trigger seizures in a person with epilepsy who is sensitive to them.

The social model distinguishes between impairment and disability. Impairment is described as a characteristic or long-term trait, which may, or may not, result from an injury, disease or condition. For example, a person with epilepsy may have some cognitive, memory or concentration problems (explained in section 2).

Disability is the difficulty experienced by people with an impairment by society not taking sufficient measures to take account of their needs. For example, an individual is not prevented from carrying out a sudden change in working practices by having epilepsy: but they may be prevented by an employer not giving enough consideration to how these changes could have an impact on the working life of the person with epilepsy.

The social model identifies attitudes that may block disabled people's participation and equality. There is prejudice and ignorance surrounding epilepsy. There are also workplace practices, procedures, cultures, unwritten rules and forms of communication that do not take account of people with epilepsy.



The medical model suggests epilepsy in itself is a barrier to employment - trade unions reject this

The medical model of disability

The medical model presents the impairment as the cause of disabled people's disadvantage and exclusion. An employer who decides that a person cannot work for them because they have epilepsy, rather than considering how to make the workplace suitable for them, is probably being influenced by this model. Unfortunately, the medical model dominates much political and legal decision-making.

“The medical model presents the impairment as the cause of disabled people’s disadvantage and exclusion.”



Unions are fighting to change workplace environments and conditions that disable the worker with epilepsy

“The social model looks at the barriers that our society puts in the way of disabled people’s participation (in this case, people with epilepsy), including both attitudes and practical barriers.”

The trade union response

The trade union movement supports the social model of disability. In individual representation, collective bargaining, drawing up demands and campaigning for them, the most effective approach for trade unions to follow is to identify the factors in the workplace environment and working conditions that disable the worker with epilepsy. Then the union can identify and fight for the changes that would remove these factors.

In the UK, there are over 600,000 people with epilepsy. Around seven in every ten people with epilepsy can have their seizures controlled with the right dose of the right drug. However, uncontrolled seizures, or even a single breakthrough seizure, can have a huge impact on a person’s working life. This guide aims to provide an insight into what epilepsy is and how you can understand some of the needs of people with epilepsy in the workplace.

2 | WHAT IS EPILEPSY?

If someone has epilepsy, it means they have a tendency to have epileptic seizures. Epilepsy is not necessarily a life-long diagnosis, and doctors may consider that someone no longer has epilepsy if they go without seizures for a long enough time.



After a focal seizure, it is common to feel confused and have difficulty in speaking for a short time

What is a seizure?

Electrical activity is happening in our brain all the time. A seizure happens when there is a sudden burst of intense electrical activity in the brain. This is often referred to as epileptic activity. The epileptic activity causes a temporary disruption to the way the brain normally works, so the brain's messages become mixed up.

The brain is responsible for all the functions of the body. What happens during a seizure will depend on where in the brain the epileptic activity begins, and how widely and quickly it spreads. For this reason, there are many different types of seizure, and each person will experience epilepsy in a way that is unique to them.

Some common types of seizures

Focal (partial) seizures

In focal seizures, epileptic activity starts in just part of the brain. The person may or may not be aware of what is going on around them. Different areas of the brain (the lobes) are responsible for controlling all of our movements, body functions, feelings or reactions and seizures can start in any of these lobes. What happens during a seizure will differ depending on which lobe, and which part of the lobe, the seizure starts in. Each person will have their own experiences and symptoms during a focal seizure.

During a focal seizure, the person with epilepsy might:

- feel frightened
- have a déjà-vu experience – that is, a feeling that what's happening has happened before
- experience a strange taste, or smell something that isn't there
- have a rising sensation in the stomach
- have automatic behaviours such as staring, lip smacking, repeated swallowing, chewing, and dressing or undressing
- not be aware of their surroundings, or have difficulty speaking
- scream, swear or laugh
- have repeated movements, such as rocking, pedalling or pelvic thrusting
- have feelings of numbness, tingling, heat, pressure, electricity and (rarely) pain
- see things that are not there, or see things differently from how they really are: for example, objects might seem too close, too far away, too large, too small, slanted, moving or otherwise not right
- have difficulty understanding spoken words or language, reading or doing simple maths
- not see as well as usual, or not be able to see at all
- have fluttering eyelids.

After a focal seizure, it is common to feel confused and have difficulty in speaking for a short time. Some people feel very tired.

Focal seizures that act as a warning of a generalised seizure

The epileptic activity that causes a focal seizure can sometimes spread through the brain and develop into a generalised tonic-clonic, tonic or atonic seizure (explained below). In this case, they may be called an 'aura' or warning.

Warnings can be very useful. They might allow someone to get to a safe place or to let someone else know that they are going to have a seizure. Sometimes the epileptic activity becomes generalised so quickly that the warnings are not recognised.

Generalised seizures

If someone has this type of seizure, they will have epileptic activity in both hemispheres (halves) of their brain. It's usual to lose consciousness during these types of seizure, but sometimes it can be so brief that no one notices. The person's muscles may stiffen and/or jerk. They may fall down.

These are different types of generalised seizures.

Tonic-clonic seizures

This is the most recognised type of seizure. It has two phases: the 'tonic' phase, followed by the 'clonic' phase. If someone has this type of seizure, they will lose consciousness, their body will go stiff, and they will fall to the floor. They may cry out. During the clonic phase, their limbs jerk, they may lose control of their bladder or bowels, bite their tongue or the inside of their cheek, and clench their teeth or jaw. They might stop breathing or have difficulty breathing, and could go blue around their mouth.

After a tonic-clonic seizure, it's common to have a headache and for their whole body to feel sore, tired and very unwell, or to feel confused, or to have memory problems. Some people go into a deep sleep. When they wake up, minutes or hours later, they might still have a headache, be feeling sore all over and have aching muscles.

Tonic seizures

Some people have only the first parts of a tonic-clonic seizure. This is called a tonic seizure. The symptoms of a tonic seizure are like the first part of a tonic-clonic seizure but there is no jerking stage (clonic). The person might cry out.

Atonic seizures

The opposite of a tonic seizure is an atonic seizure. In this type of seizure the person will lose all muscle tone and drop to the floor. These seizures are very brief and it will usually be possible to get up again straight away. However, the person concerned might have injuries to their face, nose or head from the fall.

Myoclonic seizures

These are usually isolated or short-lasting jerks that can affect some or all of the body. They are often too short to affect a person's consciousness. The jerking can be very mild, like a twitch, or it can be very forceful, and can cause some people to fall to the floor. Some people have a single jerk; others have a cluster of several jerks.

Absence seizures

Absence seizures usually develop in children and adolescents, but can last into adulthood. If someone has absence seizures, they will be unconscious for a few seconds. They will stop doing whatever they were doing, but will not fall. They might appear to be daydreaming or 'switching off'. It can be difficult to spot an absence seizure.

Epilepsy Action has more information about the different types of seizures: www.epilepsy.org.uk/info/seizures-explained

To sum up, there are many different types of seizures. Some appear as unusual behaviour and some, like the tonic-clonic seizures, are very easy to spot. Some people have only one type of seizure, but some people have a range of different seizure types. For example, people with juvenile myoclonic epilepsy might have myoclonic, tonic-clonic and absence seizures.

Epilepsy Action has some e-learning materials that describes the different types of seizures, and the relevant first aid.

3 | MYTHS AND FACTS

Myth: People with epilepsy can't drive

FACT: Many people with epilepsy can't drive if they are still experiencing seizures. However, just having a diagnosis of epilepsy doesn't always prevent a person from driving. Whether they can drive or not depends on the types of seizures they have and when they last had one. There are different rules for people who have seizures only when asleep, when awake, or both.

Epilepsy Action has up-to-date information about the driving regulations in the UK:
www.epilepsy.org.uk/driving

Myth: You can tell someone is having a seizure because they fall down on the floor

FACT: Not always. The most common type of seizure is the tonic-clonic seizure, and you can usually identify this seizure if someone falls to the floor and starts jerking. Six out of ten people with epilepsy have this type of seizure, but there are many more types, such as absence seizures, where an onlooker might not notice it was happening.

Myth: People with epilepsy can't use computers

FACT: Most people with epilepsy can use computer screens without any problems. But around three people in every hundred with epilepsy will have photosensitive epilepsy. This is a type of epilepsy in which all, or almost all, seizures are triggered by flashing or flickering light. It's unusual for modern computer screens to trigger seizures but it can happen, depending on the type of screen you are using. If you have photosensitive epilepsy, the current advice is to use an LCD screen.

Epilepsy Action has more information about photosensitive epilepsy:
www.epilepsy.org.uk/photosensitive

Myth: People with epilepsy can't become teachers or nursery nurses or work as carers

FACT: People with epilepsy can, and do, work in nursery nursing, teaching and other caring professions. Epilepsy itself is not an automatic barrier to working in any career or profession, except the armed forces. Decisions on recruiting someone should be made on an individual basis. A failure to do so might amount to disability discrimination.



People with epilepsy can, and do, work in nursery nursing, teaching and other caring professions

Having epilepsy is not just about having seizures

There is more to epilepsy than having seizures. Epilepsy may limit someone's ability to work at the time of a seizure itself and during recovery. But the impact on memory, concentration, cognition, anxiety, depression, stigma and isolation may last longer and have a constant impact on the individual. Seizures can be unpredictable and can have a huge impact on someone's life. On a day without seizures, they may lead a 'normal life', but having a seizure can mean having to change plans at the last minute. This affects all areas of life, not least because of the constant fear of having a seizure.

4 | EPILEPSY IN THE WORKPLACE

Health and safety risk assessment

If someone has epilepsy, an employer must carry out an individual health and safety risk assessment to make sure that person can carry out their duties safely. Some questions that might come up during a health and safety risk assessment:

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

Reasonable adjustment

Once the answers to these questions are known, an employer might need to make 'reasonable adjustments' to allow the person with epilepsy to start or continue in their role or to take part in training or a work placement. This is a requirement of the Equality Act (England, Scotland and Wales) and the Disability Discrimination Act (Northern Ireland). Financial support to fund reasonable adjustments might be available from Access to Work (see page 16).



Risk assessments are designed to protect the worker with epilepsy and ensure they can carry out their tasks safely

Here are some quotes from people who have had adjustments made to their working times or environment:

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

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

“There’s a three shift system where I work. I don’t do the night shift as my seizures can be triggered by irregular sleep patterns.”

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

“My usual work is delivering post. After my recent seizure, I was given work in the sorting office rather than my usual walking round.”

“I’ve recently qualified as a chef and work in a large company. My seizures are not fully controlled, so I work well away from the ovens and stoves.”

“We have children under 3 in our nursery. I work with the older children as they don’t need carrying around, which could be risky if I had a seizure.”

“I teach middle school children and, although my seizures are well controlled, the school has arranged for another adult to be available, should I feel unwell.”

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

No reasonable adjustment needed

Some people with epilepsy will not need any adjustments in the workplace. This could be people who are completely seizure free, or people who wouldn't come to any harm should they have a seizure at work.

5 | HOW WORKPLACES CAN CREATE DIFFICULTIES FOR WORKERS WITH EPILEPSY

Workplaces and employers make work difficult for workers with epilepsy in the following ways:

DISCRIMINATION: *Treating the person with epilepsy differently from or less favourably than others, for a reason relating to their epilepsy.*

RAJ

Raj had frequent seizures until his meds were changed recently. He has now been seizure-free for two months. He works in a call centre and his absence level is assessed on a 12-month rolling cycle, so was considered too high. He says:

"My epilepsy-related absences have been included into the Bradford factor and I have been in for a warning. I did argue that this was unfair as, at the time, I had no control over my seizures. Also, they think I'm lying because I don't 'look sick'. I was asked for my medical records, which I refused, but I have shown my epilepsy clinic appointment card. I spoke with my union rep, and the company took notice of what he said. It wasn't easy to make it happen, but they have now said they will not include epilepsy-related absences in the Bradford factor thing."



There is no reason to treat workers with epilepsy any differently to other workers in terms of their duties and career opportunities

BARRING: *Preventing a person with epilepsy from carrying out duties or using equipment when there is no valid reason to do so.*

SAM

"I was interviewed for a position in a call centre. In that role, I would be talking to people on the telephone and inputting information into a database. The interview went well, and I was offered a job. However, when I filled in the medical form and told them about my history of epilepsy, the job offer was withdrawn. I was told that people like me (with epilepsy) were not allowed to use computers. I was gutted, particularly as I have never had any problems with flashing or flickering lights."

BULLYING: *Causing loss of self-confidence due to discrimination or bullying.*

MAX

"I've worked at the same company for many years – some of them good, and some not so good, but I enjoy my work, and try hard not to let people rattle me.

"Today, I started on a new project with three colleagues from other departments. One of them was a bloke I worked with years ago – a bit of a loudmouth sometimes. He upset me a lot when I was younger with his comments about people who 'couldn't control themselves' (when I had a seizure).

"Anyway, at coffee time we were all having a natter when he told a joke. I didn't get it (as often happens), then I overheard a joke aimed at me. Here's a supposedly mature guy, who talks about someone behind their back (but literally), so you can hear everything.

"'Too much medication, you know' he says to the girl beside him, and points, I guess, at me. He wasn't facing me, but very close. I wait, had time to realise what had been said, then shouted back 'Tom, you watch it, mate'".

"He replies 'Yes, Max, I'M BACK", as though he knows exactly how he used to upset me all those years ago, and I am to expect more!!!

"I'm gutted. It took me a long time to get over his 'jokey' bullying last time we worked together and he's senior to me, so I really don't know what I can do to get him off my back. I can't ask to be taken off this project, as my manager wants me to get more experience, so I can go up a grade. I just don't know what to do about him."

LACK OF COMMUNICATION AND SUPPORT: *Acting on assumptions and without investigating the facts can lead to discrimination that may be unlawful.*

CALVERT v JEWELGLEN

Mr Calvert, an experienced care assistant, was employed by a nursing home as a care assistant. He declared that he had epilepsy and that, due to his medication regime, he had remained seizure free for the last 18 years. Only senior management were aware of his medical history and were happy to employ him.

As a side effect of his medication, he often experienced dizzy spells, which would pass very rapidly. However, on one occasion a dizzy spell persisted and he reported it to the night sister, who sent him home. She was previously unaware of his epilepsy.

Based on assumptions and without any investigation, she told him that he was not required and that he was to call the owner who might relocate him to a clerical position. However, on speaking to the owner it became apparent that he was not prepared to employ Mr Calvert at all.

Mr Calvert was dismissed purely on the basis of the night sister's concerns, without any further investigation. The reason given for his dismissal was his past medical history and the amount of sedatives he was currently prescribed.

The tribunal held that Mr Calvert was disabled under the remit of the DDA and that his dismissal was unlawful, as the decision to dismiss was taken without further investigation of the night sister's concerns, or proper inquiry as to the real facts.

Calvert v Jewelglen Ltd [1997]
IT/2403989/97

LACK OF COMMUNICATION

AND SUPPORT: *Sacking a worker who has had a seizure without seeking expert advice and considering adjustments has been found to be unlawful.*

HOLMES v WHITTINGHAM & PORTER

Mr Holmes worked as a labourer for Whittingham & Porter for 31 years, during which he had epilepsy and occasional seizures with robotic movements. On the one and only occasion when he collapsed during a seizure, his employer suspended him while awaiting a report from his GP.

This report was sent to the employer's medical adviser, whom the tribunal noted was a specialist in neither occupational medicine nor epilepsy. The employer's medical adviser expressed concern that part of Mr Holmes' job involved walking around the factory where there was hot metal and forging hammers and that he might be a danger to himself and others. After a meeting with Mr Holmes to discuss this advice, the employer dismissed Mr Holmes.

The tribunal noted that if Mr Holmes had not had epilepsy he would not have been dismissed. Mr Holmes had been treated less favourably for a reason related to his disability and the question therefore remained, 'can the employer justify this?'

The tribunal held that it could not, because the company's medical adviser was inadequately qualified, not having any particular knowledge of epilepsy. An epilepsy specialist might have been able to suggest a change in medication, or an occupational health specialist could have considered adjustments. The employer had not really given Mr Holmes any time to see whether the seizure recurred in this form.

Holmes v Whittingham & Porter
(1802 799/97)

EXPLOITATION: *An employer may think they can 'get away with' treating an employee with epilepsy badly.*

JAMES

James takes epilepsy medicine and has very few seizures – probably about four a year – during his sleep. He is an electrician. Here is his story:

"When I was first diagnosed with epilepsy, I lost my driving licence. As I couldn't drive, work 'grounded' me to an office doing data input, on a lower pay scale than before. It nearly drove me mad. Once I got my licence back, they should have put me back on my electrician duties. Instead, I had to see occy health and have a medical report before they would allow me to drive my van, even though the DVLA had cleared me to drive. Work wanted to stop me working at heights and with high voltage, even though I had never had a seizure when I was awake.

"I'm still with the company, as I have worked for them for 36 years, and have a good pension, but I do think they try to treat me worse than other workers, just because they know I have epilepsy."

UNEMPLOYMENT AND PAST

EXPERIENCES: *People with epilepsy are more likely to be unemployed, often due to losing or leaving a job because of unsuitable conditions. These experiences can have a huge impact when applying for new jobs.*

ELAINE

Elaine is 51 and was diagnosed with epilepsy at the age of 23 following a tonic-clonic seizure at work. Following tests, she was told she had scar tissue on her brain that needed to be removed. She had successful surgery in September 2000 and was seizure free for five years. However, her seizures started again and in June 2008 she had further surgery. She has had a few seizures since but all went very well with her operation.

Following this surgery, she was eager to get back to work so she went for an interview as a teaching assistant for the learning support department of a school. She would be assisting in a class to support children with epilepsy, learning disabilities and other needs.

Following the interview, the school called Elaine and offered her the job. She was delighted and started soon after. She was very open and honest about her epilepsy in the interview, which she believes helped her get the job.

She was also very open about her epilepsy with the other staff and explained what happened and what to do if she had a seizure. One day, Elaine had a complex partial seizure in the classroom. There was another teacher in the classroom at the time so she was not on her own with the children. However, following this the school told her she wasn't good enough to do the job, and asked her to leave. Elaine was devastated.

Continues right

"I have lost several jobs, and successfully taken one company to tribunal. The equality laws exist, but employers ignore them! I have experienced many rude comments in general from people and employers."

Elaine is still looking for work but her confidence is at an all-time low, and she isn't confident she will get another job.

LACK OF ACCESS TO TRAINING:

Not training people with epilepsy in new work processes, when other employees are given that opportunity.

SANDRA

Sandra has had epilepsy for years. She takes epilepsy medicine, but still has the occasional focal seizure, particularly when she is stressed. She works for a large store, handling money and serving customers. An opportunity came along recently for volunteers to train to sell foreign currency. Thinking it would be another skill, she applied. However, she wasn't successful as her supervisor said it would be too stressful for her. Sandra was disappointed but did not want to 'rock the boat' or upset her employer, and she did not have the confidence to take it any further.

PERFORMANCE MANAGEMENT:

Procedures may cause undue stress and pressure to workers with epilepsy.

MANDY

Mandy is 36, and has occasional focal seizures. She was diagnosed with epilepsy when she was 25. She has been working in the same supermarket since before her diagnosis.

Mandy's managers have changed on several occasions, and several of them have caused problems. She describes how one set of managers gradually took away some of her duties and responsibilities. This had a serious impact on her confidence and self-esteem and made her very stressed. The increase in stress led to an increase in seizures. At this point, she felt like resigning from work, but as a single parent she couldn't.

However, to her delight, her manager changed yet again. And the new manager had a son with epilepsy and worked with Mandy to reduce her stress levels. This had the effect of reducing her seizures, which meant she could go back to doing some of her previous work, although she needed some adjustments to be made.

Mandy is still having seizures, but these are very rare, and she knows this manager will support her, so she is regaining her confidence and beginning to enjoy her work again.

CAREER PROGRESSION: *People with epilepsy are often under-employed, that is, employed to do work that does not fully use their skills and abilities.*

ALAN

Alan is 25 and lives alone in Birmingham. He has a degree. He was diagnosed with epilepsy at the age of 16, following one absence and two tonic-clonic seizures; he is not seizure free. He is now looking for permanent employment in the UK and has started many employment contracts, often for very junior admin work. However, at the end of his 'probation period' he has not been taken on permanently.

He believes his failure to gain permanent employment is due to his employers' lack of understanding and is losing confidence in his abilities. He has experienced managers who resented time off from work to attend medical appointments, and managers who were embarrassed when they witnessed his seizures. He is still looking for a permanent job.

KAREN

Karen has had epilepsy for most of her life, but has a seizure only once each year, usually in her sleep. Having recently qualified as a nursery nurse she applied for a job in a playgroup. She was told she wasn't fit to do the work as she was 'too much of a risk around young children'. This is despite the fact that she is a single parent of three young children, who have never been neglected or harmed by her seizures.

6 | MAKING WORKPLACES EPILEPSY-FRIENDLY

Many employers believe they do not need to make any changes until a worker identifies themselves as having epilepsy and requests adjustment. However, an employer can make many changes so that the workplace is epilepsy-friendly before someone requests it. The advantages of doing this are:

- ▶ A workplace that is epilepsy-friendly is one that recognises diversity, and therefore is a workplace that is better for all workers.
- ▶ The issue is approached as a collective rather than an individual issue – and collective action is what trade unions are all about.
- ▶ Having possible adjustments for individuals listed in a collective policy or agreement will make it easier for individuals to ask for, and receive, them when the need arises.

Whether or not there is an identified person with epilepsy in the workplace, the union may ask the employer for:

- ▶ a place to rest and relax, for example, a quiet room
- ▶ all changes to working practices to be negotiated with the union, and proper notice given before they are introduced
- ▶ all lights, fans and machinery that flashes or flickers to be maintained regularly, and attended to immediately if they malfunction, to make sure they don't flash or flicker
- ▶ the company's welfare, occupational health service and first aiders to be equipped to provide assistance
- ▶ training for managers and staff about epilepsy
- ▶ the provision of paid time off for trade union representatives to attend trade union training and events about epilepsy
- ▶ all instructions and policies to be written and communicated clearly and accurately
- ▶ a variety of tools to assist personal work organisation, for example visual timetables and organiser apps

- ▶ only objective criteria to be used for assessment/promotion
- ▶ adherence to work schedules
- ▶ the inclusion of epilepsy in harassment and bullying policies to:
 - minimise harassment and bullying of workers with epilepsy
 - make sure that any manager or worker who bullies or discriminates against a worker with epilepsy is dealt with appropriately.

Reasonable adjustments for individual workers with epilepsy might include:

- ▶ paid time off when needed
- ▶ fixed hours rather than variable shifts
- ▶ a change of work location, for example to be nearer home, or nearer support facilities
- ▶ extra breaks to avoid becoming overtired
- ▶ providing a mentor
- ▶ providing extra time for training, if needed
- ▶ adjusting the way assessments are carried out, and allowing extra time, if needed
- ▶ having a clear routine and work schedule
- ▶ having a personal workstation that is made as safe as possible for someone who is still having seizures
- ▶ relaxation of triggers for disciplinary action for matters such as sickness absence or bonus targets
- ▶ allowing additional time off for treatment/appointments, as part of a policy of disability leave
- ▶ exchanging some work with colleagues, with their agreement.

Access to Work funding may be available for some of these measures. Access to Work is a government fund that finances a range of different adjustments to enable disabled people to obtain or remain in work, see www.gov.uk/access-to-work

7 | 'NOTHING ABOUT PEOPLE WITH EPILEPSY WITHOUT PEOPLE WITH EPILEPSY'



The experts on disability are disabled people; unions must listen to members with epilepsy when discussing adjustments they may need

The UN Convention on the Rights of Persons with Disabilities, Article 4.3, states that: *"In ... decision-making processes concerning issues relating to persons with disabilities, State Parties shall involve persons with disabilities, including children with disabilities, through their representative organisations."*

The same principle should apply to how trade unions organise their members. In the workplace, the practical application of this idea is that a worker with epilepsy needs to be involved in any discussion around adjustments to overcome barriers that may have been identified.

The trade union movement supports the demand of the disabled people's movement: 'Nothing about us without us'.

Many trade unions have structures for disabled members; if they do, it may be useful to invite and welcome the involvement of people with epilepsy in these.

There are organisations of people with epilepsy, and trade unionists may benefit from their expertise.

8 | EPILEPSY AND PARLIAMENT

Since 1995, as a leading member of the Joint Epilepsy Council (JEC), Epilepsy Action, the leading UK member-led epilepsy organisation, has been working with the All Party Parliamentary Group (APPG) on epilepsy.

This APPG is a cross-party group made up of MPs and peers with an interest in epilepsy. Its aim is to increase awareness of the nature of epilepsy among parliamentarians and to raise the political profile of epilepsy and its related problems.

The APPG is not part of government and does not have any powers to introduce new laws. However, it does play an important role in stimulating political discussion about epilepsy and issues associated with the condition.

The APPG has asked questions of government about public services for people with epilepsy and lobbied for change. In the past, it has conducted its own inquiry into the human and economic cost of the under-funding of epilepsy services in England. The inquiry resulted in written reports to lobby government for improved health care services for people with epilepsy. The evidence highlighted the main issues caused by poor service provision, including the influence of epilepsy on employment opportunities and education, as well as the social stigma.



The All-Party Parliamentary Group on epilepsy has lobbied government for better services for people with epilepsy

“The APPG has asked questions of government about public services for people with epilepsy and lobbied for change.”

9 | USING THE RIGHT LANGUAGE



Using the wrong words can reinforce negative stereotypes

See the TUC briefing, *Words Can Never Hurt Me?* for a detailed explanation of how the choice of language can help or hinder our campaigning for disabled rights.

The language we use can reinforce negative stereotypes of people with epilepsy, or it can challenge them. If a trade union uses terms that insult or demean people with epilepsy, it will suggest to them, and professionals working with people with epilepsy, that the union does not understand or empathise with them, and that if they get involved in the union they may face prejudice.

In using the term 'disabled people', the TUC follows most of the British disability movement. In the USA, the term 'person with disabilities' is more common, and some British and Irish disabled people follow this American usage. The TUC does not regard 'people with disabilities' as offensive.

Epilepsy language

Words to avoid

Illness: epilepsy is a condition, not an illness.

An epileptic: it is important to look at the person before the medical condition, therefore it is more appropriate to say "a person with epilepsy".

A victim, a sufferer: these words imply that someone is helpless.

Words that are okay to use

Fit: although the term 'seizure' or 'epileptic seizure' is preferred by many people, some people with epilepsy choose to use the word 'fit'.

Brainstorming: Epilepsy Action is often asked about the use of this term. Our view is that it depends on how the word is used. If the word is being used to describe a meeting where people are suggesting ideas, then its use is not offensive to people with epilepsy. However, it should not be used to describe what happens in the brain during a seizure.

Trade unionists should aim for a natural and relaxed style of speaking and writing, which avoids giving unnecessary offence.

10 | CRIME AGAINST PEOPLE WITH EPILEPSY

People with epilepsy often feel vulnerable when out and about, particularly if they still have seizures. Here are three examples of people who have had crimes committed against them during seizures.

PURSE STOLEN BY 'HELPERS'

A Birmingham woman had a seizure in the city centre. The police said two women went to the aid of the 25-year-old after she 'blacked out' and collapsed. When she regained consciousness, she found her purse was missing. Police have released CCTV images of two women they want to speak to in relation to the incident. They said it was "not clear if the two women were together" and that one of them may have genuinely tried to help.

This was a callous and terribly sad case where a woman was taken ill just yards from her place of work, only to then become a victim of crime when she was defenceless.



People with epilepsy have been victims of crime while having seizures

ENGAGEMENT RING STOLEN

A 'despicable' thief snatched a diamond engagement ring off the hand of a bride-to-be while she was having an epileptic fit.

Charlotte, aged 23, had a seizure when walking through North Park in Bootle. As she lay defenceless on the ground, a man pretended to comfort her, but while holding her hand he slipped the white gold ring off her finger.

Charlotte made an emotional appeal for her ring to be returned. She said: "I feel really violated and upset. During and after a seizure I'm at my most vulnerable and someone has taken advantage of that."

ROBBED SIX TIMES OVER THE YEARS

Thieves snatched a wallet belonging to a pensioner with epilepsy while he was having a fit in a town centre. The crooks at first pretended to help John Bostock, as he lay paralysed on the pavement in Kidsgrove. But they then rifled through his pockets and stole his wallet containing £10 in cash, bankcards and his free bus pass. Now the 66-year-old has revealed it was the sixth time he has been targeted while suffering seizures since his illness was diagnosed 20 years ago.

Although not currently classed as a crime, some people with epilepsy have had photos or videos taken of them when they have had seizures in public; and these often appear on social media. Here is one story:

SOCIAL MEDIA BULLYING

Maggie O'Connor, aged 26, was walking her dog in the grounds of St Botolph's Priory in Colchester when she had a fit. When she came to, she was being filmed by 'two lads, poking fun' at her. She posted her own Facebook account of her experience, which attracted, she said, 'hundreds' of responses from epilepsy sufferers.

"My aim completely changed from when I initially put that status up, when I was angry," she told BBC Essex.

"I wanted to find the boys and for them to get into trouble, but as time's gone on I've had hundreds and hundreds of messages from people saying they have the same epilepsy as me and they don't go outside.

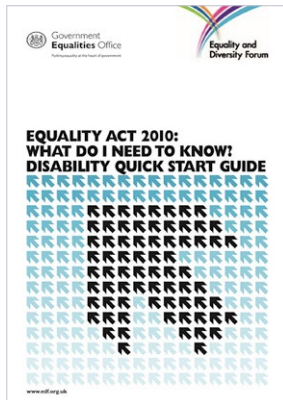
"I never realised how many people are stopped by their epilepsy," she said.

"It shocked me, and I thought my focus now is to get some more awareness of the condition and help these people feel safe outside."

"People with epilepsy often feel vulnerable when out and about, particularly if they still have seizures."

11 | A GUIDE TO THE LAW

People with epilepsy are defined as disabled people for the purposes of the Equality Act 2010. The legal definition of a disabled person is someone "with a physical or mental impairment that has a substantial adverse impact" on their ability to carry out "normal" day-to-day activities. It must have lasted, or will last, at least 12 months.



The following actions by an employer are outlawed by the Equality Act.

Direct discrimination: treating a disabled employee less favourably than other employees.

Indirect discrimination: this may occur when the application of a provision, criteria or practice to everyone has particular disadvantages for people with a disability compared to people who do not have that disability, and where the provision, criteria or practice cannot be justified as meeting a legitimate objective.

Discrimination arising from disability: this occurs when a disabled person is treated less favourably because of something connected with their disability, and where the discrimination cannot be justified.

Failure to make a reasonable adjustment: the requirement on an employer to make a reasonable adjustment where a disabled worker would be at a substantial disadvantage compared to non-disabled colleagues is the lynchpin of the law. It covers "provisions, criteria and practices", "physical features" and "provision of auxiliary aids". Once it has been established that the adjustment is reasonable, failure to comply is a breach of the law and cannot be justified. What defines "reasonable" is (a) whether the adjustment is effective in removing the obstacle, (b) whether the adjustment is practical (c) the cost of the adjustment in relation to the resources of the organisation and (d) the availability of financial support (such as Access to Work). The Equality and Human Rights Commission guidance lists a range of possible adjustments that fit the criteria. Advice is also available in the TUC's Disability and Work publication.

Harassment: is specifically outlawed by the Equality Act.

12 | EPILEPSY AND TRADE UNIONS: WHAT THE UNION CAN DO

Trade unions will have members with epilepsy and they need to be in a position to offer the same protection and assistance as to any other member. It is therefore recommended that this guidance be made available to union officers, representatives and members.

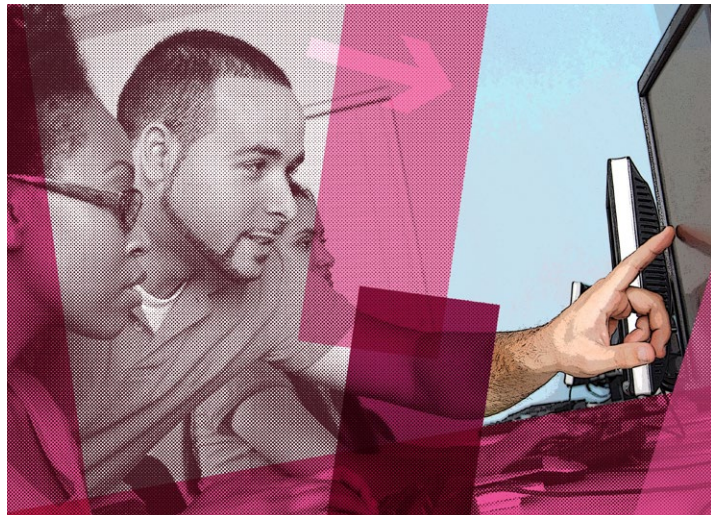
The most effective approach for a trade union will be to negotiate with the employer to persuade them to adopt a social model approach to disability, then to see this through in practice by discussing all the steps that can be taken to make the employer's premises, services, provisions and practices free of the barriers that may disadvantage disabled people. This will also make them accessible to many other groups of people, as well as creating a positive workplace environment and a more committed workforce.

As part of this, the union may identify the kind of obstacles that could impact adversely on workers with epilepsy (see sections 4, 5 and 6) and the measures needed to remove them. These could include both physical changes and changes to working practices to enable workers with epilepsy or other impairments to continue to work.

Training will be an important element of a union's strategy. Negotiate time off for union representatives to train on disability rights and on the social model, and to learn in more detail about dealing with workplace issues around epilepsy. Encourage the employer to organise training for managers.

Epilepsy Action can provide training for employers. Contact the National Coordinator for Volunteers on 0113 210 8777.

The reaction of work colleagues can be very important. If it is known that a member has epilepsy and may be liable to have seizures at work, it may be important – with the agreement of the member – to also train the member's work colleagues.



This guide and training will help unions offer the right assistance to members with epilepsy

Obtain information from organisations such as Epilepsy Action that can be displayed on workplace notice boards. Invite a speaker to address a meeting.

Where negotiation has failed to achieve a practical solution, unions will be aware that the Equality Act (see section 11) offers protection from discrimination, including failure to make a reasonable adjustment. Reminding employers of their legal obligations may help bring about a suitable outcome, not least to avoid the risk of exposure in an employment tribunal.

13 | RESOURCES AND USEFUL WEBSITES

Epilepsy Action

Epilepsy Action provides advice and information, online, in print and directly through the Epilepsy Helpline. It also offers e-learning – with tips for living with epilepsy – as well as videos and interactive quizzes. Its UK-wide network of groups is growing all the time and gives people a great chance to share experiences and support each other. Its online forum has members around the world, all supporting each other, alongside its Facebook page.

Helpline (freephone): 0808 800 5050

Text: 0753 741 0044

Email: epilepsy@epilepsy.org.uk

Website: www.epilepsy.org.uk

Epilepsy Action publications

- ▶ Epileptic seizures explained
www.epilepsy.org.uk/info/seizures-explained
- ▶ Epilepsy and driving
www.epilepsy.org.uk/info/driving/applying-for-your-licence
- ▶ Photosensitive epilepsy
www.epilepsy.org.uk/info/photosensitive-epilepsy/computer-television-screens
- ▶ Epilepsy and work
www.epilepsy.org.uk/info/employment/workplace
- ▶ Epilepsy, employment and the law
www.epilepsy.org.uk/info/employment/legal-matters

Other publications about epilepsy and disability

- ▶ Elwes RD *et al* (2014). *Epilepsy and Employment: a community based survey in an area of high unemployment*
- ▶ Business Disability Forum. *A Practical Guide for Employment Adjustments for People with Epilepsy*

- ▶ Epilepsia (2003). *Employment: living with epilepsy*
- ▶ TUC (1998). *Words Can Never Hurt Me?*
- ▶ TUC (2011). *Disability at Work: a trade union guide to the law and good practice*
- ▶ TUC (2008). *Representing and Supporting Members with Mental Health Problems at Work*
- ▶ TUC (2015). *Trade Unions and Disabled Members: why the social model matters*

(All TUC publications are available from TUC Publications or are downloadable from the TUC website www.tuc.org.uk).

Sources of further advice and information

Acas (Advisory, Conciliation and Arbitration Service) (England, Scotland and Wales)

Acas aims to improve organisations and working life through better employment relations. It offers free advice about employment rights.

Tel: 0845 747 4747

Website: www.acas.org.uk

Disability Law Services

Disability Law Services offer advice and information about employment law to disabled people.

Tel: 020 7791 9800

Website: www.dls.org.uk

Employment Medical Advisory Service (EMAS)

EMAS is part of the Health and Safety Executive. It is staffed by specialist occupational health professionals who give health-related advice to people with medical conditions.

Website: www.hse.gov.uk

Equality Advisory and Support Service (EASS) (England, Scotland and Wales)

The Equality Advisory Support service gives free advice, information and guidance to individuals on equality, discrimination and human rights issues.

Tel: 0808 800 0082

Website: www.equalityadvisoryservice.com

Equality and Human Rights Commission (England, Scotland and Wales)

The Equality and Human Rights Commission (EHRC) provides advice and guidance on rights, responsibilities and good practice, based on equality law and human rights.

Tel: 0808 800 0082

Website: www.equalityhumanrights.com

Equality Commission (Northern Ireland)

The Equality Commission provides advice and information about the Disability Discrimination Act in Northern Ireland.

Tel: 028 90 500 600

Website: www.equalityni.org

Health and Safety Executive (HSE)

The HSE can provide general information and guidance for employers about work-related health and safety issues. It also offers a free leaflet – *Five Steps to Risk Assessment* – that aims to help employers do their own risk assessments. This can be downloaded from its website. There is also a specific section about employing disabled people on the HSE website.

Tel: 0300 003 1747

Website: www.hse.gov.uk

Jobcentre Plus

Tel: see your local phone book

Website: www.direct.gov.uk
(search for Jobcentre Plus)

Law Centres (England, Scotland and Wales)

Law Centres provide free legal advice and representation to disadvantaged people.

Tel: see your local phone book

Website: www.lawcentres.org.uk

TUC

Tel: 020 7636 4030

Website: www.tuc.org.uk



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