



for parents of ch

Epilepsy in the Workplace

An Employers Information Resource



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Welcome



It is my pleasure to present Epilepsy Ireland's *Epilepsy in the Workplace - An Employers Information Resource* booklet. Thank you for taking the time to read this booklet which aims to assist employers' understanding of epilepsy and considerations relating to employment. Epilepsy Ireland believes that people with epilepsy make just as good (if not better) employees.

Peter Murphy CEO, Epilepsy Ireland
Studies show that because they can find it difficult to obtain employment, they tend to be more motivated in seeking and retaining employment. It is important to remember that most people with epilepsy have been able to stabilise their condition through a medical regime, therefore, for many people, it is unlikely to impinge on their working lives.

Many myths and misconceptions still exist about the condition and I hope this booklet will allay any concerns that colleagues or employers may have. The key to understanding epilepsy is awareness and openness. This booklet endeavours to address misconceptions about epilepsy, allay any concerns colleagues or employers may have, and provide the information for employers to feel confident addressing the condition.



We are delighted to be involved in the *Epilepsy Ireland – Epilepsy in the Workplace* employer's handbook. We are committed to creating a diverse and welcoming workplace where all employees are given the opportunity to achieve their goals. Rachel Ashe is a perfect example of this. Five years ago, Rachel joined Hays and together we have managed her

Richard Eardley Managing Director, Hays Ireland
epilepsy. Open communication helps both employer and employees understand how epilepsy impacts Rachel and potentially her work. Armed with this information we made practical changes to her work space and Rachel engaged her colleagues on the subject of her epilepsy.

Her openness eroded misconceptions and her colleagues became more confident in the event of a seizure. Rachel has experienced seizures in the Hays offices, each time we have ensured her safety and swift recovery, thanks to Rachel and her colleague's proactive approach to epilepsy. Coupled with a positive approach, this booklet will make a big difference for employers when working with people with epilepsy.

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About Epilepsy

What is epilepsy?

The word 'epilepsy' is derived from the Greek word meaning 'to be seized, to be overwhelmed by surprise'. To have epilepsy is to have a tendency to have recurring seizures. Anyone can have a seizure, if the brain is exposed to a strong enough stimulus. We know that about 1 in every 20 people will have a single seizure at some time during their lives. There are 37,000 people over the age of 5 living with epilepsy in Ireland. The significance of having a tendency to have seizures will vary from person to person, and will depend on many things. For most people, epilepsy will only affect them for a short period in their lives. For some, however, the consequences can be more lasting.

Are there different forms of epilepsy?

Yes. Epilepsy is divided into categories according to seizure type:

Generalised seizures these occur when seizures involve the whole brain.
Partial (Focal) seizures these occur when seizure activity starts in one part of the brain.

What happens during a seizure?

There are many different types of seizures, these can range from simple twitching in one limb to a full-blown convulsive seizure. There are four main types of seizure:

- » **Tonic-Clonic** seizure: (once known as the major or ‘grand-mal’ seizure) involves convulsions and loss of consciousness, the person becomes rigid, falls to the ground and jerking can be seen in all limbs. It usually lasts a few minutes.
- » **Absence** seizure: loss of consciousness also occurs in an absence seizure (sometimes known as a minor or ‘petit-mal’ seizure), but it is so brief that it appears like daydreaming and the person does not fall or convulse.
- » **Simple Partial** seizure: seizure activity will depend on which part of the brain is affected, consciousness is not interrupted and the seizure is limited perhaps to the rhythmical twitching of a limb, or to unusual sensations, such as pins and needles in a specific part of the body.
- » **Complex Partial** seizure: the person although appearing fully conscious will not be aware of surroundings.

The seizure is sometimes pre-empted by a strange feeling welling up from the stomach and/or some other sensory disturbance – known as an **Aura**. This may be followed by a change in awareness, erratic movements and general confusion.

Although a tonic-clonic seizure can be disconcerting to see, the person having the seizure is not in pain and will have little or no memory of what has happened. A major seizure will last a few minutes. The attacks cannot

be stopped or altered so you should not try to rouse the person until the seizure ends.

What are the causes of epilepsy?

Just as there are many different forms of epilepsy, there are also many different causes including brain infection, tumour, stroke, head injury and genetic influences. However in most cases, there is no actual brain damage or brain disease, and the cause of the condition is unknown.

What causes seizures to occur?

Seizures are usually spontaneous events without a clear cause. In a few people, seizures can be triggered by specific stimuli, such as strobe lights, lack of sleep, boredom, anxiety, abrupt cessation of anti-epileptic treatment and drinking too much alcohol may also bring on a seizure. It is important to note that up to 70% of people have the potential to control their epilepsy and rarely experience seizures.

Treatment

In most cases epilepsy is treated with medication, and over recent decades new epilepsy drugs have become available allowing many people to live virtually seizure-free lives. While some people are suitable for surgery, there is also the Vagal Nerve Stimulator option. This is a pacemaker like device which can help a person achieve seizure freedom.

Why is epilepsy a hidden condition?

Epilepsy, even though it is common, is a well-hidden condition. This can be attributed to two reasons:

- a. It does not physically manifest itself continually in the way that other physical disabilities do.

- b.** Many people choose not to inform others about their epilepsy due to the stigma and discrimination that people can attach to the condition.

Why are people reluctant to disclose their condition?

There are many reasons, depending on the individual, the most common being a fear of discrimination or being treated differently. As the majority of people with epilepsy lead normal active lives, they don't wish to run the risk of not being considered for a job if they disclose their disability.

Many feel it would be better to get the job on their own merit and then disclose their epilepsy. Again the fear of how a future employer might react can still prevent them disclosing their condition.

It is also worth noting that many people with epilepsy do not fully understand their own condition. Sometimes they have been brought up in a very protective environment, parents and family may be reluctant to discuss the issue. The family may think it better to avoid the subject as it might lead to others knowing their situation and the fear of possible discrimination can then be avoided.

When a person with epilepsy chooses to disclose their condition, often they are placing a great trust in the person to whom they disclose. The person receiving this information should bear this in mind when responding. They should do their utmost to reassure the individual that epilepsy is something the person has, it does not define them. They should also communicate that the individual is respected and accepted for who they are.

Seizure Management

First Aid /Healthcare: If a person has a tonic-clonic seizure at work, an ambulance should always be called if it is the person's first seizure or if the seizure lasts longer than 5 minutes. In other circumstances, if a person has

discussed their epilepsy with the employer there should be an agreement between them as to what constitutes an emergency for the person and how to manage their particular seizures.

The following measures are recommended for tonic-clonic seizures accompanied by falling and unconsciousness:

Do not panic - Do not move the person unless there is danger.

To protect the person during the seizure – be a “TEAM” player



- » **T.** Take care to protect the person
- » **E.** Ensure you stay with them
- » **A.** Allow the seizure to run its course
- » **M.** Move the person onto their side when the seizure is over

- » Do not put anything under the person’s head to protect him/her from injury.
- » Do not put anything in the person’s mouth



- » After regaining consciousness the person can be asked if/ what type of, help is desired.
- » Professional medical help during a seizure is only necessary when:
 - The seizure lasts longer than 5 minutes.
 - Seizures come in a series and the person does not regain consciousness between the seizures.
 - The person has injured him/herself during the seizure and needs medical treatment.

If seizures are likely to occur at work, the employer should help the employee to talk about his/her epilepsy to workmates, and some first aid training or other information should be provided for those who might be involved should

a seizure occur. For Seizures Involving - Altered Consciousness or Behaviour
Non-convulsive seizure with outward signs of confusion/ unresponsiveness:

Do

- Note time seizure started
- Guide the person from danger
 - Stay with them until recovery is complete
- Calmly reassure • Explain anything that they may have missed

Do Not

- **DO NOT** restrain the person
- **DO NOT** assume the person is aware of what is happening or what has happened
- **DO NOT** give them anything to eat or drink until they are fully recovered

Frequently Asked Questions

This section contains the questions employers frequently ask about epilepsy and employment.

1. What do I do if I find out that a person I have recently hired has epilepsy?

Use the opportunity to inform yourself about epilepsy. You'll be amazed at how little it interferes with day-to-day living. Bear in mind that you or anyone of your employees could become disabled in the future due to accident or illness.

2. Are persons with epilepsy obliged to disclose their condition to employers?

They are only obliged to disclose their condition if they are specifically asked. They can only be asked as part of a medical examination.

3. Is it true that people with epilepsy have more absenteeism?

No. Evidence would suggest that, on average, people with epilepsy have fewer accidents at work than other employees, take less time off work and have good job loyalty records. It is important to note that people with epilepsy who are stable on medication may have very few or no seizures.

4. Can people with epilepsy work with machinery?

Yes. Epilepsy does not restrict a person from operating guarded machinery. If changes need to be made, there are grants available for adapting workplace equipment. See

www.welfare.ie/en/Pages/WorkplaceEquipment-Adaptation-Grant.aspx

5. Do people with epilepsy have more accidents?

No. There is evidence to suggest they have fewer accidents, because they are more aware of potential hazards. Epilepsy does not usually force the employer to take extra safety precautions in the work place. People with epilepsy are generally very careful about their own well-being and are no more prone to accidents than anyone else.

6. Are people with epilepsy less productive?

No. People with epilepsy, being aware of employers' concerns over productivity, are often keen to prove that they are productive, reliable and valuable employees. The difficulty for them is securing the job in the first place. If an employee has a seizure at work, they usually only need a short rest, after which they can resume work as normal.

7. Are there higher work cover premiums for people with epilepsy?

No. It is often assumed that employing someone with epilepsy is ultimately going to result in an increased premium. This is not the case. No special insurance is required for a worker with epilepsy. At a basic level, employers should ensure that they are covered by *Public Liability Insurance and Employers' Liability*. Premiums are only affected by claims,

and there is no evidence to suggest claims increase by employing someone with epilepsy.

8. What do I do if someone has a seizure at work? See Section One: 'About Epilepsy'

9. Is job accommodation for people with epilepsy expensive? No. Most often, employers do not need to make any adjustments, and if changes need to be made, financial support is available.

10. Are people with epilepsy allowed to drive?

Yes, if seizure free for one year a person would be legally entitled to drive a car. For further information see link below.

www.epilepsy.ie/index.cfm/spKey/info.rights_entitlements.html

11. How do I reassure my customers if an employee has a seizure at work?

Although observing a seizure can be disconcerting, the customer is likely to appreciate an employer who reacts with understanding and fairness towards an employee with epilepsy. Indeed, providing staff with first aid information could be advantageous in the event of a customer having a seizure.

12. Are people with epilepsy able to handle management positions?

Yes, if they have the job qualifications and skills for doing so.

13. What do I tell co-workers if I employ a person with epilepsy?

Anything to be said should be done in the presence of the employee with epilepsy. It might be a good time to have an open discussion about epilepsy and other disabilities in general. First Aid measures should also be dealt with. Epilepsy Awareness Training is available from Epilepsy Ireland.

14. Is stress in the work place a particular risk for people with epilepsy?

Stress is a very individual factor for anyone, regardless of whether they have epilepsy or not. For some people with epilepsy it can be a factor. Everyone is affected by stress to some degree, and everyone has to learn how to cope with it in his or her working life. As with all employees, a supportive working environment benefits everyone with their stress levels.

15. Are there any guidelines or principles for employing people with epilepsy?

Yes, but they have more to do with good practice rather than employing someone with epilepsy per se. The Employment Commission of the International Bureau for Epilepsy (IBE) have produced a document entitled *Principles for Good Practice in the Employment of People with Epilepsy*. www.ibe-epilepsy.org/employing-people-with-epilepsy-principles-for-good-practice/

16. Where should people with epilepsy go to get support?

People with epilepsy may get support and advice from their GP, pharmacy and from Epilepsy Specialist Nurses connected to most main hospitals.

Epilepsy Ireland provides a comprehensive range of support. We have Community Resource Officers who are available in all regions across Ireland offering individual support and advice in hospital and community settings as well as courses, programmes and seminars about managing epilepsy and specialised sessions for the newly diagnosed.

17. What are the myths about epilepsy?

A number of myths have grown up around epilepsy, probably dating from times when medical treatment was not as successful in treating

the condition and from common historical portrayals of epilepsy and seizures.

Contrary to popular belief, people with epilepsy can drive cars and use visual display units (VDUs). In fact, people with epilepsy can work in the vast majority of jobs, and have the same aspirations as other employees. Furthermore, employers rarely, if ever, incur extra costs through employing someone with epilepsy.

One of the most common myths concerns the belief that extra insurance is needed when employing a person with epilepsy. It is often assumed that employing someone with epilepsy is ultimately going to result in an increased premium. This is not the case. No special insurance is required for a worker with epilepsy. Employers must also be aware of the implications of current legislation in relation to Employment Equality.

18. What is the relevant legislation relating to epilepsy in the workplace?

Employment Equality Act 1998 - 2005

An act to make further provision for the promotion of equality between employed persons.

Equal Status Acts 2000 - 2015

Equal status act 2000 was an act to promote equality and prohibit types of discrimination, harassment and related behaviour. The Act has been amended by the Equality Act 2004, the Disability Act 2005 and the Civil Law (Miscellaneous Provisions) Act 2008. They are known collectively as the Equal Status Act 2000 - 2015

Copies of relevant acts are available from Government Publications and on the internet at www.irlgov.ie

Finding the most suitable employee for the job

Most people with epilepsy have effectively stabilised the condition and can lead full and active lives. People with epilepsy can also perform the vast majority of jobs.

Despite this many people with epilepsy are still reluctant to disclose their condition for fear of discrimination. They may also feel inadequate in effectively communicating their condition.

Should a person choose to disclose, they may do so:

- a. On the application form.
- b. At the interview.
- c. Having been offered the job.
- d. After starting work.

An employer of course may never discover a person has epilepsy until after the person has a seizure.

Care must be taken in handling this delicate issue of disclosure.

a. On the application form

When assessing whether someone with epilepsy should be considered for interview, an employer should consider first and foremost whether the person is a suitable candidate for the job.

- **Does the person have the right training/qualifications?**

- **Does the person have previous relevant work experience and/or the necessary skills?**

b. At the interview

While continuing to assess the above an employer must also consider:

- **Is the person competent?**
- **Is the person motivated?**
- **Does the person demonstrate a capacity for work?**

In other words employers should apply the same criteria to assess a person with epilepsy as are used to assess every other candidate for the job. Interviews should focus on the capabilities of the individual with epilepsy and not on his/her real or assumed limitations. This means that suitability for the job should be decided before any implications arising from the job applicant's epilepsy are considered. A person with epilepsy will sometimes wait to disclose.

c. Having been offered the job

Feeling they have got the job on their merits and ability.

d. After starting work

Having proven their ability by their performance.

There are of course people who never disclose, believing that they will still be discriminated against, despite having a proven work record.

When job applicants decide to reveal that they have epilepsy, or the person's condition has been revealed as a result of having a seizure, the following questions will help an employer assess the severity of the individual's condition and how seriously it might affect their work.

- 1. What kind of seizures does the person have?**
- 2. How often do they occur?**
- 3. What exactly happens when the person is having the seizure?**
- 4. Do the seizures occur randomly or is there a pattern?**
- 5. Is there anything in particular which triggers the seizure?**
- 6. After the seizure how long does it take before the person can carry on with their work?**
- 7. What should be done if the person has a seizure at work?**

The details revealed through this line of discussion will also help establish the support measures that an employer may need to put in place to ensure the well-being of the person with epilepsy, their colleagues and of course the company's clients.

Reasons for employing a person with epilepsy:

- 1.** People with epilepsy often find it difficult to obtain employment so they tend to be more motivated in seeking and retaining jobs.
- 2.** It is good practice to create a workforce inclusive of all sections of the population. Often people with epilepsy are afraid to disclose their condition, as they may not be called for interview or feel that the employer's view will hinder them in the workplace. Open tolerant workplaces encourage people to disclose health issues.
- 3.** By employing someone with epilepsy, employers will become better informed, not only about disability, but also about their own work place. Employers rarely have to implement any changes in their work practices, as the safety, legal and insurance structures needed for someone with epilepsy apply for all employees.
- 4.** By including people with disabilities in their search to find the right employee, employers will gain access to a broader base of people with the specific skills that they will need for their work place.

5. Most employers find they do not need to make any adjustments in employing a person with epilepsy. However, if they do, the organisational, financial and legal supports are in place to help them do so.

I See Beyond

The I See Beyond campaign is a joint initiative of Headway and Epilepsy Ireland, national charities working to support people with two common types of hidden disability, acquired brain injury and epilepsy. The campaign is funded by the Department of Justice and Equality's Disability Awareness Raising Grant Scheme.

Creating and maintaining an inclusive workplace that promotes and supports diversity is a key element of our I See Beyond campaign. We have listed some information here that we hope will guide you to finding how to deliver for all. We encourage you to aim to implement best practice for all your employees, whether they are a person with a disability or not. In relation to employing people with disabilities, best practice includes:

- Providing disability awareness training
- Ensuring premises are accessible
- Providing accessible technologies
- Ensuring that company policies are inclusive and accessible (Handbook, PEEP / Health and Safety)
- Recruiting a diverse and inclusive workforce

It is good practice to set out in written policies the steps you will take if an employee discloses a hidden disability or acquires a disability.

Organisations that can help you and your company with advice on different policies are

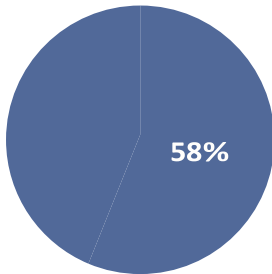
- Employer Disability Information (EDI) employerdisabilityinfo.ie
- Irish Small & Medium Enterprises Association (ISME) isme.ie
- Irish Business and Employers' Confederation (IBEC) ibec.ie
- Chartered Institute for Personnel Development (CPID)

See also www.iseebeyond.ie

Survey: Epilepsy in the workplace

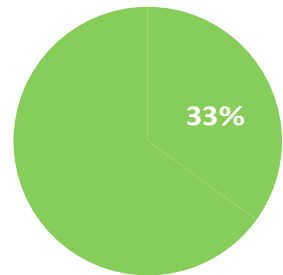
Epilepsy Ireland recently announced results of a survey conducted among 337 people with epilepsy on their experience of the condition within the workplace.

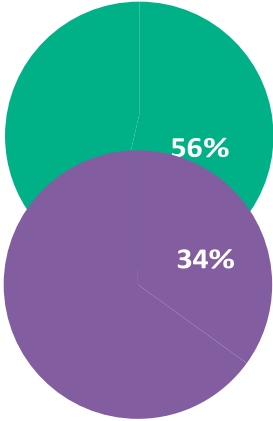
The positive results showed that:



58% of people with the condition who are in employment now feel comfortable telling their employer and work colleagues that they have epilepsy – an increase of 14% when compared to a 2012 Epilepsy Ireland survey

Just **33%** of people with epilepsy found that their employers and work colleagues attitudes towards them changed after they told them of their epilepsy, when compared to 50% in 2012

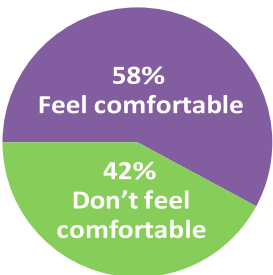
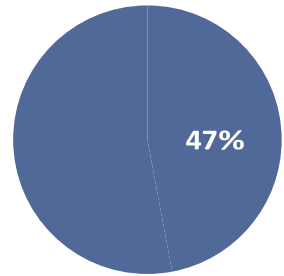




56% said their epilepsy gave them a greater motivation to succeed in their career. However, not all the figures are encouraging:

34% stated their epilepsy has prevented them from fulfilling the responsibilities of their job

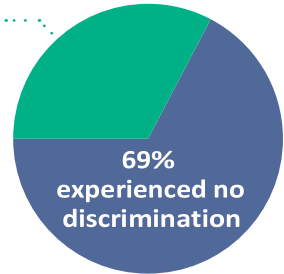
47% said their epilepsy prevented them from applying to a new job



Percentage of people with the condition who are in employment who feel comfortable telling their employer and work colleagues that they have epilepsy

Percentage of people with epilepsy have experienced discrimination in the workplace as a result of their condition

31% have experienced
discrimination



Supports for Employers

“People with disabilities are often confronted in the workplace with preconceived ideas or myths about their disability, such as their ability to do the work, and what they might need to do the job. Often these misconceptions and myths disguise an underlying discomfort or embarrassment on the part of those without a disability, when they come into contact for the first time with people with disabilities”.

(IBEC’s Guideline on employing people with a disability)

For an employer who is interested in bringing people with epilepsy into the workforce or for those who have employees with epilepsy, Epilepsy Ireland can offer the following support.

Epilepsy Awareness Training, which can provide guidance on:

What is Epilepsy ?

- » A look at the facts concerning the condition as opposed to some of the commonly held misconceptions.

What is a Seizure ?

- » Epilepsy is a condition that is unique to each individual. This section looks at the major classifications of seizures.

Do’s and Don’ts

- » This section looks at the things people should/should not do if they are in a situation where a person has a seizure.

For details Contact Paul Sharkey, Training Manager, Epilepsy Ireland, 249 Crumlin Road Dublin 12 – 01-4557500 or email psharkey@epilepsy.ie



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Twitter: [@epilepsyireland](https://twitter.com/epilepsyireland)

CHY: 6170



Support for employers is available from a range of national organisations: *for parents of ch*

Employer Disability Information

17 Kildare Street, Dublin

Tel.: +353 1 676 2014

Email: info@employerdisabilityinfo.ie

Web: www.employerdisabilityinfo.ie Confidential Advice and Information for Employers on the Recruitment, Employment and Retention of People with Disabilities

It assumes the roles and functions previously carried out by the National Employment Rights Authority (NERA), Equality Tribunal (ET), Labour Relations Commission (LRC), Rights Commissioners Service (RCS), and the first-instance (Complaints and Referrals) functions of the Employment Appeals Tribunal (EAT).

Workplace Relations Commission

Lansdowne House, Lansdowne Rd, Dublin 4

Tel.: +353 1 613 6700

Web: www.workplacelrelations.ie The Workplace Relations Commission (WRC) is an independent, statutory body which was established on 1st October 2015 under the **Workplace Relations Act 2015** (No. 16 of 2015).

Irish Human Rights and Equality Commission

4th Floor, Jervis House, Jervis Street, Dublin 1

Lo-call: 1 890 245 545

Tel.: + 353 1 8589601

Email: info@ihrec.ie

Web: www.ihrec.ie

11. **Wissenschaftliche Mitarbeiter**
11.1. **Wissenschaftliche Mitarbeiter**

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