

# DISCLOSURE

## FACT SHEET



Disclosure

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## Disclosure is the act of making something known

Deciding when to tell others about your epilepsy can be one of the most challenging decisions for both people with epilepsy and parents of children with epilepsy.

Many people worry about stigma, rejection, or discrimination. Should you tell people about your epilepsy before a seizure happens in front of them?

Unfortunately, epilepsy is still often misunderstood, and some outdated beliefs persist.

In this section, we look at the things to think about when deciding whether to share your epilepsy diagnosis and offer practical tips on how to have these conversations.



### Deciding to tell others

Talking about your epilepsy with others can have practical and emotional benefits.

Practically, it means people will be less likely to panic and will know how to help if you have a seizure, creating a safer environment and giving you peace of mind.

Emotionally, choosing to share your diagnosis in your own way can help you feel more in control and increase your chances of being accepted and supported.

Issues to think about

Your decision to tell others may depend on:

- the type of seizures you have,
- your need for help during or after a seizure,
- when and how often your seizures happen,
- the type of activities or work you do,
- if your seizures may affect others.



Ask yourself:

- Will my epilepsy affect my ability to do activities safely?
- Could a seizure put others at risk?
- Are people likely to find out, whether I disclose or not?
- Do my friends or colleagues need to know in case I have a seizure in their presence?
- What will be the consequences if I don't tell?
- Who do I tell?
- What will your telling involve or result in?

Why tell?

- It can reduce people reacting in fear
- Increases awareness about what to do
- Reduces unnecessary ambulance calls
- It may reduce your own fears and concerns



**It's your choice who to tell, whether it be friends, distant relatives, or colleagues at work or school**

# WHEN YOU NEED TO DISCLOSE

## Driving

When someone is diagnosed with epilepsy or has a seizure, it is a legal responsibility of the holder of a driver's license to notify the appropriate road transport authority in their state or territory.

A doctor may also notify the authorities if they have a suspicion that a person is having seizures or not taking their medication as prescribed and continues to drive.

## Applying for health, life or travel insurance

If epilepsy or recent seizures are not disclosed in your insurance application and you lodge a claim for medical treatment because of a seizure, your claim will be checked against medical records and may be invalidated.

## Employment

Some jobs may require disclosure – such as if it would be unsafe for yourself or others if you had a seizure. Examples include, commercial driving, working near water, working at heights or using heavy machinery.

### Telling your employer

Deciding whether to tell your employer (or future employer) about your epilepsy is a personal choice. Some people worry that if they share this information, they may be treated unfairly or lose their job. But in some cases, it can be helpful – and even necessary – to let your employer know.

In Australia, you don't have to tell your employer about your epilepsy *unless it affects your ability to do your job safely or meet its core requirements*. If your seizures could create a safety risk for you or others at work, it's important to think about whether disclosing will help you and your workplace stay safe. Your employer also has a legal duty to keep the workplace safe under the Work Health and Safety Act (WHS Act 2011).

For an employer to fulfil their obligations under the WHS Act, they need to be aware of any condition that may require them to change working practices or environment, to improve safety. This may mean making reasonable adjustments to keep a person employed if they have or develop epilepsy.

Telling your employer means they can:

- Make safety adjustments if needed
- Be prepared in case you have a seizure
- Support you better at work

If you do choose to disclose, your employer must:

- Keep the information private
- Get your written permission if they need to share it with someone else



**Think about your job, the risks, and what makes you feel most comfortable.**




# APPLYING FOR A JOB

## When should I tell them?

There's no right or wrong time. You can choose to disclose at one of the following stages:

### 1. In Your Job Application

You might want to be open from the start. Some employers may appreciate your honesty - but be aware that it could also affect your chances of getting an interview. If you do disclose, you could mention that you're happy to talk more about it during the interview.

 *Tip: You may wish to apply for jobs where epilepsy is less likely to affect your ability to work safely.*

### 2. At the Interview

Telling your employer face-to-face gives you the chance to explain things clearly and answer any questions. You can focus on your skills and how you manage your epilepsy.

 *Tip: Think about the questions they might ask, practice what you want to say, and you could also bring a letter from your doctor*

### 3. After You're Hired

Some people wait until they've started work to disclose. This gives you time to show your abilities first. But keep in mind that if you have a seizure at work before telling anyone, it might affect your employer's trust, and you may not get the right help.



## What if I experience discrimination?

In Australia, the Disability Discrimination Act 1992 (DDA) protects people with epilepsy from discrimination in various areas, including employment, education, and access to services.

While not everyone with epilepsy identifies as having a disability, the DDA's broad definition of disability covers those who may not consider themselves disabled.

If you feel you have been discriminated against, firstly take steps in the workplace:

### 1. Document the discrimination: Gather evidence and keep a record.

Note down the date, time, location, and details of each incident, including what was said or done, who was involved, and how it made you feel. If possible, collect any relevant documents, emails, or other evidence that supports your claim.

### 2. Speak to your employer or HR:

If you feel comfortable, inform your manager or HR department about the discrimination you've experienced. Explain the situation and what actions you would like them to take. You are allowed to take a support person with you – either from work or outside of work

If informal discussions don't resolve the issue, you may need to submit a formal written complaint.

### 3. Seek Advice and Support:

- [Speak with an Epilepsy Nurse](#) at Epilepsy Action Australia
- Talk to your union or engage a legal professional.
- Submit a formal complaint to the [Human Rights Commission](#).
- You can also contact the [Fair Work Ombudsman](#) or the Equal Opportunity Commission in your state.

# SUMMARY

Disclosing epilepsy involves deciding whether and how to share your diagnosis with others, particularly in professional or social settings. Key reasons include the type of epilepsy, seizure control, and potential risks.

The decision to disclose epilepsy is a personal one, but it is essential to consider potential impacts on safety, workplace adjustments, and legal obligations. While not always mandatory, disclosing can be beneficial, especially if seizures require workplace accommodations or if there is a need for colleagues to understand how to assist during a seizure.

You need to weigh-up when is a good time, where is a good place to bring up the subject, and who needs to know about your epilepsy.



**Not everybody needs to know you have epilepsy. Who you tell is up to you, most of the time.**

## Further information

[Know Your Rights](#): Familiarise yourself with the legal protections available under the DDA and other relevant anti-discrimination laws

[Disability Rights](#)

[Complaints](#) under the Disability Discrimination Act

[Fair Work Ombudsman](#)

[Safe Work Australia](#)

[How2Tell](#) from Epilepsy Ireland

Contact us on:

Phone: 1300 37 45 37

Email: [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au)

[Make a booking with an epilepsy nurse](#)

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