

## Navigating disclosure

Possibly one of the most difficult dilemmas people with epilepsy and parents of children with epilepsy have to face is if, who, when, and how to tell others about epilepsy and seizures. There is often a fear of stigma and rejection but there is a need to reveal seizures before they reveal themselves.



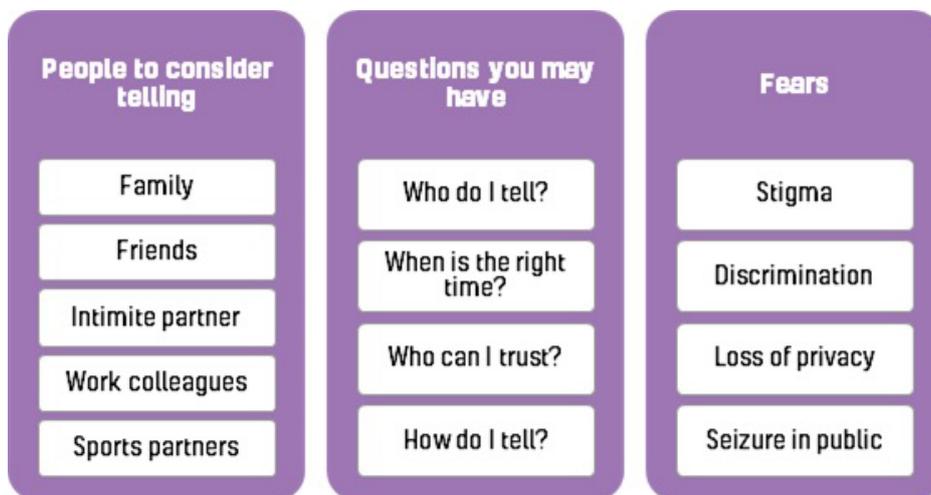
**Here we explore the issues and considerations when deciding on whether to reveal epilepsy and seizures, and offer some practical advice when having this discussion.**

Telling others is the way of taking control of the disclosure and making sure that you have the best chance of acceptance and support from others.

## What is disclosure?

Originally it referred to telling others about yourself. Today it is used to define the process of communicating personal health information about you or your child to another person.

## Issues to consider



Who do you tell? What will your telling involve or result in? Every person with epilepsy faces this question in many situations day-to-day.

## Making the decision to disclose

On the practical side, talking to people about your epilepsy means others are less likely to panic and know how to help if a seizure occurs. This can help to foster a safer environment that will give you peace of mind. Emotionally it can also be a turning point for you to take control by making the epilepsy known in a manner you choose, to achieve the greatest possibility of acceptance and support<sup>1</sup>.

But preparation is vital. Think about<sup>2</sup>:

<sup>1</sup> "How (and Why) to Tell Others about Your Epilepsy", Robert J Mittan, PhD, Seizures & Epilepsy Education [S.E.E.] [www.theseeprogram.com](http://www.theseeprogram.com) in Exceptional Parent magazine, Vol 39, Issue 4, pgs 40-42, April 2009

<sup>2</sup> "Psycho Social Aspects of Disclosure - Issues for People with Bleeding Disorders & Living with HIV," Alex Coombs, Social Work Dept, Alfred Hospital, October 2009

<b>Who</b>	<ul style="list-style-type: none"><li>-Who are you going to tell?</li><li>-Who can help you?</li></ul>
<b>Where</b>	<ul style="list-style-type: none"><li>-Where will you disclose?</li><li>-Where can I feel comfortable, private and emotionally safe?</li></ul>
<b>What</b>	<ul style="list-style-type: none"><li>-What support do you or they need?</li><li>-What supports are available?</li><li>-What do you want to say and how much?</li></ul>
<b>Why</b>	<ul style="list-style-type: none"><li>-Why do you want to tell them?</li><li>-Do they need to know?</li></ul>
<b>How</b>	<ul style="list-style-type: none"><li>-How are they likely to react?</li><li>-How can you prepare yourself?</li></ul>

### When is disclosing epilepsy a legal requirement?

**Driving** - When someone is diagnosed with epilepsy or has a seizure, it is the 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 with uncontrolled seizures is driving or not taking their medication as prescribed.

**Applying for health, life or travel insurance** - If recent seizures were not disclosed in your insurance application and you lodge a claim for medical treatment as a result of a seizure, your claim will be checked against medical records and may be invalidated.

**Some jobs** - when it would be dangerous to yourself or others if you had a seizure for e.g. commercial driving, nautical work, using heavy machinery. At other times disclosing to your employer is a matter of personal choice.

### Why tell?

Fear of seizures is one of those emotions pre-programmed into our subconscious. People who are not familiar with seizures commonly react to seeing a seizure with fear.

As in all situations when you tell others about your epilepsy, a main goal is to reduce the fear that person might experience when they see a seizure. An important step in reducing fear is telling others what to expect and what they should do for you when you have a seizure. This makes them aware of your seizure behaviours and appropriate actions to take. This empowers the person to take control of the situation, which further reduces fear and a sense of helplessness during seizures. It also helps prevent unnecessary ambulance call outs.

Another reason for telling others you have epilepsy is less fear and worry for you about having a seizure in public.

### Who to tell?

From a safety point of view, someone needs to know. For most people with epilepsy that someone (or more than one person) is usually a family member. People in the family can learn about epilepsy, how to help if a seizure happens, and how their observations can help you and your doctors understand more about your condition.

It's your choice about disclosing to other people in your life, whether they are friends, distant relatives, or colleagues at work or school. Many people with infrequent or well-controlled seizures choose to only disclose to people they are close to. If seizures are poorly controlled, you may find it more practical to tell those who may witness a seizure so they can help you stay safe and so that they are not afraid to act properly.

### Disclosing in the workplace

The possibility of experiencing discrimination at work is an understandable concern when disclosing epilepsy to an employer. This is not helped by the fact that the workplace is where we spend a lot of our time, and work is central to our financial security.

The decisions you make about disclosing at work depends on how your epilepsy, or any other medical conditions or disabilities, may affect the safety of you and your colleagues. Critical factors are the requirements of the job, the workplace environment, whether you work alone or with a group and whether you will need specific accommodation made for your epilepsy.

Legally in Australia you are under no obligation to disclose your condition unless it affects your ability to meet the inherent requirements of your job. Unfortunately, there are circumstances when someone may lose their job because of their seizures, particularly if there are safety concerns. An employer has a duty of care to provide a safe working environment for all employees as per the Occupational Health and Safety Act [OH&S]. Where there is serious conflict between the Disability Discrimination Act [DDA] and OH&S laws, OH&S law may override the **DDA**.<sup>3</sup>

Even so, it can be useful to discuss epilepsy with a potential or current employer. For an employer to be able to fulfil their obligations under the OH&S 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.

Disclosing epilepsy to your employer can also increase your peace of mind, knowing your condition is out in the open and your co-workers can now respond appropriately if a seizure happens at work.

If you do choose to disclose that you have epilepsy, your employer is required by law to keep the information confidential and must obtain your written consent to share the information with others.

### When to disclose

There are different stages when you could choose to reveal epilepsy in the workplace:

#### 1. In your application

Your honesty may impress prospective employers, but they may also dismiss your application without seriously considering it, even if you are the best candidate for the job. You could be honest and state that you have epilepsy, but that your seizures are controlled (if this is true). You could also add that you would be willing to discuss your seizures at interview.

People who disclose at this stage find securing a job can be difficult, but once hired they experience fewer problems related to their epilepsy. It may help to limit your applications to those roles not likely to be affected by your epilepsy. Examples of situations to avoid would be working around water, at heights, or shift work if sleep pattern change is likely to affect your seizure frequency.

#### 2. At the interview

Disclosing face to face could still lead to your application being passed over. However it will give you the opportunity to personally address any of your employer's concerns such as the chance of increased sick leave, greater potential for accidents, and occupational health and safety issues. Beforehand it would help to think of answers to questions the interviewer may have, focusing on your abilities and skills, and even rehearse what you are going to say. You could also provide the potential employer with a letter from your doctor to support your application.

<sup>3</sup> <http://www.findlaw.com.au/articles/2157/disability-discrimination-act-review.aspx>

### 3. After you are hired and start work

This gives you a chance to prove yourself to your employer and colleagues before disclosing. However, your seizures could unexpectedly reveal your epilepsy anyway. Your trustworthiness could be called into question if your employer thinks you withheld important information relevant to your employment, and you also risk not receiving the correct first aid.

### Combating discrimination

#### What if you experience discrimination after disclosure?<sup>4</sup>

Most people with epilepsy do not see themselves as having a disability and therefore do not always think that they can experience discrimination. Discrimination occurs when a person with a disability or a medical condition – or their relative, friend, carer, co-worker or associate – is treated less fairly than anyone else. The federal Disability Discrimination Act protects the rights of people with a disability or a medical condition. It aims to ensure that everyone has an equal opportunity to participate in and make a contribution to Australian life.

The law prevents people discriminating against you in areas including:

- Employment, such as getting a job or applying for a promotion
- Education at school, university, TAFE
- Access to public premises like shops, libraries or hospitals
- Getting goods and services, including taxis, banks accounts and legal services
- Accommodation whether renting units or houses, buying or selling property or land
- Activities of clubs or associations, such as joining a sports club or RSL
- Commonwealth Government laws and programs, like voting
- Playing sport

Call the **Human Rights and Equal Opportunity Commission (HREOC) Complaint InfoLine on 1300 656 419** for advice on what constitutes discrimination and the simple steps to make a complaint.

The website – [www.hreoc.gov.au](http://www.hreoc.gov.au) – is a comprehensive source of information. There are also a number of State and Territory Anti-discrimination and Equal Opportunity Agencies that can help.

### Having that conversation

#### The origin and role of stigma

Stigma in our culture can be traced back to ancient times when various afflictions were ascribed to evil spirits or demons. Yet the sense of shame and negativity about epilepsy persists in society. Misconceptions colour the way people with epilepsy or whose children have epilepsy will feel about the condition, and also how others react. Opening up about epilepsy can help to begin combating these cultural misunderstandings.

In some instances disclosure may bring personal freedoms and enhance social interactions and self-esteem.

Hiding that you have epilepsy can perpetuate the feeling that it is bad and unacceptable.<sup>5</sup> Fear of rejection can lead to withdrawing from relationships, in turn prompting others to hold back, and feeding a cycle of growing withdrawal and isolation. On the flipside, telling close friends you have epilepsy means you trust that person(s) and it will build their self-esteem too, and foster a closer relationship.

### General tips when telling others

- Allow a relationship to develop before telling someone – if you can talk about personal issues together you are probably ready to mention epilepsy.
- Often dealing with other people's fear of seizures is the biggest part of managing disclosure. Detailed and correct information reduces fear by preparing others to recognise and predict your seizure behaviour, and take positive action to help you.
  - Try this: a short outline of epilepsy (it's common, seizures are occasional, injury is rare); what your seizures or child's seizures look like, how long they may last, and instructions about what to do.

<sup>4</sup> Human Rights and Equal Opportunity Commission  
<sup>5</sup> "How (and Why) to Tell Others about Your Epilepsy", Robert J Mittan, PhD, Seizures & Epilepsy Education (S.E.E.) [www.theseeprogram.com](http://www.theseeprogram.com)

## Fact Sheet: Disclosure

- When disclosing, aim to be a good friend yourself by thinking about the other person and their needs, not just your epilepsy. When you initially bring up the subject, consider leaving it at saying that you have epilepsy and describing your seizures. You may like to wait for another time to give them further information unless they ask for more. Most often, disclosure leads to many questions as it is something personal about you so your friend will probably want to know all about it.
- Work at keeping your voice matter-of-fact. Remember epilepsy is a medical condition just like diabetes or asthma not something you should apologise for. Your tone will convey as much about what you are saying as what you are feeling.
- Others knowing seizure first-aid can be as good for them as it is for you. Being able to help you during a seizure gives them confidence and can be satisfying to help you when you are in need.
- Negative reactions may be a person's default response to the news but this is based on our common cultural conditioning - try allowing time for the information to sink in, after which a positive reaction may be more likely.

### Some other situations, besides the workplace, require particular care and consideration:

#### Telling someone you are dating

- Timing is important. Trust and honesty between partners is essential so hiding epilepsy for a long time is not wise. But at the same time if you are worried about disclosing, then it may help to let the relationship grow a little first. If your seizures are not well-controlled, you will want to tell your partner earlier - perhaps after the first two or three dates when it appears your partner is interested in more than just a casual relationship.
- Aim not to be apologetic as that may signal to your partner that you think your epilepsy is a bad thing. Epilepsy is just another medical condition and as such, it is a part of human experience. If your partner can't handle it then they are not someone you should build a successful relationship with.
- It is important that your partner doesn't have a fear of seizures. Information about what you do during your seizures and what you would like them to do will help.
- You can explain that nothing about epilepsy prevents you from being a full and equal partner and expectations for you can be the same as they would be for anyone else.
- If your partner acts embarrassed about your having a seizure in public, try not to be offended as this reflects our culture's beliefs and their lack of experience with dealing with seizures. It helps to reassure them that their reaction is normal and that the feeling will get less over time.
- The important thing is who you are as a person, and what you can become together. This, not epilepsy, should be the focus of your interactions.

#### Revealing epilepsy at school

##### Telling other parents

- Expect it will be difficult the first few times. Sometimes others may react in a way you don't expect, but this is probably because they don't know much about epilepsy and don't know what to say.
- Every parent wants to protect their children from possible social rejection. These deep-seated feelings make it particularly important to plan disclosure in advance.
- Negative reactions are part of our cultural programming. So give the other parent(s) time to adjust.

##### Telling other children

- You will need to tell playmates along with their parents - they're likely to be there when your child has a seizure. When describing seizures to children a demonstration helps. If this is difficult, a clear explanation, a large doll, puppet, story book or a video might be more useful. A seizure 'demonstration' may not seem ideal, but it can reassure all concerned.
- For a child, what-to-do instructions should include how to contact you or your spouse (or the right adult) when a seizure occurs.
- Your child's worries about seizures can be dispelled by seeing that other people know what to do. At the same time their playmates learn to help with seizures and feel proud of their achievement.

##### Telling the school

- **Advise the school that your child has epilepsy straight away** especially if seizures are not well-controlled.

## Fact Sheet: Disclosure

- Again your main goal is reducing fear and to ensure that your child is appropriately cared for if/when a seizure occurs. The best way to describe your child's seizures is in detail (such as what happens before, during and after). The teacher's understanding during a seizure will calm them and the whole class.
- Because your child has epilepsy, teachers may make incorrect assumptions about your child's abilities. Perhaps meeting with them in person and explaining what, if any, limitations there are for class and homework tasks and how previous teachers have managed would be helpful. Also providing the information in writing may help to remind the teachers about seizures and what to do if one is witnessed.
- Meet the teacher after any change in your child's usual seizure patterns, for e.g. a sudden new seizure type or an increase in seizure frequency. The teacher will appreciate their involvement, translating into better care and teacher attention to your child in class.
- School staff will also need to know other details such as possible seizure triggers, medications and a seizure management plan for the teachers is advisable.

Education Sessions and Seizure Management Plans are provided to schools, staff and students, by Epilepsy Action Australia explaining your child's seizures and safe response. Call 1300 37 45 37 for more details.

### To tell or not to tell?

Disclosing epilepsy is a complex process, and as with any personal revelation, a good outcome is not guaranteed. But benefits such as peace of mind, greater self-esteem, increased safety, and closer relationships, make it worth serious consideration. If or when you do decide to take this important step, being well-informed and prepared can help you minimise any potential harm – and maximise the positives.

### Final tips to stay positive:

1. Whether you chose to disclose or not, do not feel ashamed of your diagnosis. Epilepsy is a medical condition and it doesn't define you.
2. Your tone will often affect people's reactions. Keep it simple and matter of fact and then people are less likely to panic.
3. When you do talk about it, be honest and straightforward and allow the other person time to react and adjust to the news.
4. Highlight to them what you can do rather than what you cannot.
5. Consider telling people in person so that you can monitor their reactions and be ready to answer their questions.
6. Once you disclose, do not allow epilepsy to be the focus of every encounter. It does not define you and it should also not define a relationship.

Ring Epilepsy Action Australia to speak to someone about disclosure.

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This information is given to provide accurate, general information about epilepsy. Medical information and knowledge changes rapidly and you should consult your doctor for more detailed information. This is not medical advice and you should not make any medication or treatment changes without consulting your doctor.

