Disclosing your epilepsy – to get the job done!

Disclosing your epilepsy diagnosis in the workplace
Every person with epilepsy must choose whether to disclose their diagnosis to their employer and co-workers. Some of the most influencing factors will be whether you need workplace adjustments at your job and whether your co-workers will need to provide support to you, should you have a seizure in the workplace. This disclosure guide aims to help you decide what will work best for you.

First, identify a **NEED** for disclosure. Consider your answers and decide whether you have a reason to disclose. Remember, if you choose to disclose your epilepsy there are discrimination laws that protect you.

If you decide that disclosure will help you in your job, consider **WHEN** to disclose. Then decide **HOW** to disclose.

Effective disclosure can establish a positive working relationship with your employer and co-workers.

1. Determine the **NEED** for disclosure
2. Decide **WHEN** to disclose
3. Choose **HOW** to disclose
Determine the NEED for disclosure: gather all the facts

Answer the following questions. A ‘yes’ answer in any of the yellow boxes may indicate a need to or benefit from disclosure. ‘No’ may indicate a need for more preparation.

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Questions</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Job</td>
<td>Has the company participated in any disability related recruitment programs?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Job role</td>
<td>Have I requested a detailed job description for the position?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td></td>
<td>Do I know what the essential functions and expectations of the job are?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td></td>
<td>Does the job role indicate any risks where I or others could be injured?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td></td>
<td>Will I need workplace adjustments (eg. lighting, later start in the mornings)?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td></td>
<td>Does my epilepsy potentially impact on the health and safety of workmates or the public?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>My boss</td>
<td>Does your boss use a flexible and personal management style?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td></td>
<td>Can I provide my boss with additional information about epilepsy at work?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Myself</td>
<td>Am I familiar with my rights related to discrimination laws?*</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td></td>
<td>Am I comfortable about my epilepsy—have I educated myself about my condition?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td></td>
<td>Am I aware of my strengths and functional limitations?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td></td>
<td>Will I need potential first aid assistance in the workplace?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td></td>
<td>Have I explored strategies to self manage my epilepsy?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td></td>
<td>Have I practised disclosure with a family member, close friend or career professional?</td>
<td>☐ Yes ☐ No</td>
</tr>
</tbody>
</table>

*How can your local legal aid commission support you?

- Provides free phone legal information
- Access to legal information online
- Representation at legal mediation (in some cases)
## Decide WHEN to disclose: consider the pros and cons

<table>
<thead>
<tr>
<th>When</th>
<th>Potential gains</th>
<th>Potential setbacks</th>
</tr>
</thead>
<tbody>
<tr>
<td>In a resume or on a job application</td>
<td>Establishes “up front” relationship and communication</td>
<td>Employer may have stereotypes about epilepsy and may not offer you an interview—you may simply not get a call back</td>
</tr>
<tr>
<td>Before the interview</td>
<td>Shows respect to employer, gives employer time to research, to ask appropriate questions or refresh their knowledge on discrimination acts</td>
<td>Employer had advance time to yield to his or her stereotypes about epilepsy—will they see you first, or your epilepsy diagnosis first?</td>
</tr>
<tr>
<td>During the interview</td>
<td>Opportunity to read employer body language, to time the disclosure and to disclose in a brief, positive manner</td>
<td>Employer may feel uneasy and ill prepared to respond with appropriate and legal questions</td>
</tr>
<tr>
<td>After the job offer</td>
<td>There is time for the employer to make reasonable workplace adjustments before the job starts</td>
<td>Employer may feel that you have been dishonest in the application process, which may erode trust</td>
</tr>
<tr>
<td>After the job begins</td>
<td>Gives opportunity to establish credibility before disclosure. Gives freedom to talk with co-workers about epilepsy related issues</td>
<td>May take time to arrange requested workplace adjustments. Employer may believe you have not been honest which may affect your relationship</td>
</tr>
<tr>
<td>When performance issues arise</td>
<td>Employer may be more understanding of work difficulties</td>
<td>Employer may have difficulty changing his or her perceptions of your work performance, feel betrayed, or wonder why you waited so long</td>
</tr>
<tr>
<td>Never</td>
<td>Your epilepsy information is kept private</td>
<td>You don’t give your workplace an opportunity to understand or support you. In order for reasonable workplace adjustments to be made, you need to discuss the issues</td>
</tr>
</tbody>
</table>

Your local Epilepsy Australia member organisation can support you:
- In working through this resource
- Referral to relevant organisations where you may be better assisted by another service
- Provide workplace epilepsy training to manager and workers
- Support in better understanding your epilepsy and managing your employment
Choose HOW to disclose: some ideas

<table>
<thead>
<tr>
<th>Considerations</th>
<th>Example</th>
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</table>
| Disclosing to your supervisor is one thing (you expect this to remain confidential) — disclosing to your workmates is another and you should be the one who controls how and when your epilepsy (if ever) comes into the conversation. It is often a good idea to allow workplace relationships to get started before you reveal that you have epilepsy. Wearing epilepsy on your sleeve and just blurting it out on the first day on the job for many may not be the best way. Refer to the resource, Epilepsy: who & how to tell by Robert Mittan in ‘The Epilepsy Report, May 2010). | “Since we will be working closely together, I would like you to know I have a medical condition you might help with …”  
“There is something I would like you to know about me. There is a possibility that I might have a seizure while on the job. Hopefully it won’t happen, but if it does I could use your help …”  
“I have a common medical condition I would like you to know about …”                                                                                       |
| Face employer concerns by talking about your compensatory strategies.          | “I use an ipad to keep a list of tasks that I need to do so I don’t forget tasks at work—it’s really effective and works really well for me” (example for person who’s memory has been effected due to their epilepsy)                                                                                                                   |
| Use general, functional terms to briefly explain the impact of your epilepsy on the job; avoid technical, medical diagnoses—always offer a strategy that will enable you to do the job. | “I notice a lot of the team meetings start at 8.30am. Due to my epilepsy, especially if I’ve had a seizure during the night, I can be very tired. In my previous role I was able to start a little later at 9.30am. Could we move the meeting times to 9.30am so that I don’t miss out—I really value being part of a team and feel uncomfortable coming into the meeting at the end, when other people then suspect I’ve had a seizure—I really do want to contribute” |
| In a private setting, remind your employer about your right to privacy         | After disclosing your epilepsy in your employer’s office:  
“Thank you in advance for keeping this information confidential”                                                                                                                                                                                                                                                                         |
| Frame any difficulties around how you work best                                | “I have noticed that I am having difficulty in completing my work tasks. I have a medical condition that requires frequent breaks in order to do my work. Would you allow me to work later to enable me to take more breaks? I always get the job done”                                                                                     |
Summarise your situation to help you make your disclosure decision:

YES
I will disclose

1. List the reasons why you **NEED** to disclose

   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

2. **WHEN** will you disclose your epilepsy?
   List the reasons for choosing this time
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

3. **HOW** will you disclose your epilepsy?
   Write a few phrases telling your employer about your epilepsy
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

Practise your disclosure with another person

NO
I will not disclose

List the reasons why you choose **not** to disclose

   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

For each new job, review the information in this brochure to determine whether or not to disclose
Notes

Links

Australian Human Rights Commission
1300 369 711
www.humanrights.gov.au

Job Access
1800 464 800
www.jobaccess.gov.au

Legal Aid Information
Special thanks to Virginia Commonwealth University Rehabilitation Research and Training Centre, USA for granting permission to adapt their resource in the development of this booklet.

www.worksupport.com

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