

Epilepsy Disclosure in the Workplace

DISCLOSURE

The action of making new or secret information known.

Source: Vocabulary.com

Q. I have epilepsy. Am I required to disclose this in the workplace? When is the best time? What should I say and not say? To whom? What about my right to privacy?

A. The decision to disclose must be YOURS. By law, disclosure is not mandatory but there are many good reasons for doing so. If you are let go because of sub-standard job performance, that is not the correct time to tell the employer they didn't accommodate your medication-related memory concerns. If you are likely to have a seizure at work, and there are potential safety concerns, disclosing your epilepsy to your employer will let them know the kind of first aid you require, and enable them to accommodate you so you can perform at your optimal level.

Personnel at your local epilepsy organization can help you with the formulation of a disclosure statement as well as help you determine the best time and way to disclose your disability.

■ Epilepsy Disclosure Statement

A disclosure statement can be a very valuable tool. Some people choose to memorize its contents and vocalize the content to their employer or co-workers at an appropriate time. Others may provide the employer with a hard copy for their employment file. Disclosure, at the appropriate time, often results in everyone feeling much more at ease in the workplace.

A Disclosure Statement addresses the following points:

Identify the kind of seizure you experience with a technical or descriptive name.

Explain the effect it has on you at work.

Outline the basic accommodations you require to do the job.

State your willingness to discuss the Statement contents with relevant others in the workplace.

EXAMPLE

Sometimes I experience complex partial seizures, where I am still standing but lose consciousness. They last a few minutes during which time I stare, pick at my clothes and cannot respond. Within about 15 minutes, I can return to normal activity and work.

To reduce the risk of these seizures, working a regular shift is very important. When a seizure occurs, it helps if one of my co-workers guides me toward a safe spot and stays with me until it passes. Apart from these occasional interruptions, I can do all the elements of this job.

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■ Types of Disclosure

Under the Ontario Human Rights Code, you are only required to disclose your accommodation needs, not the disability itself. There are different types of disclosure:

FULL DISCLOSURE

Disclosing the disability to its full extent, including the disability type and your accommodation needs. If you have seizures at work, it's likely that you will fully disclose that you have epilepsy.

PARTIAL DISCLOSURE

Stating only partially what the disability is. I.e. Just the parts of the disability related to the position that you will have a hard time doing. For example, you may disclose that you are unable to drive and will need accommodated by having a coworker drive to off-site meetings. However, you may not disclose the reason that you aren't able to drive.

THIRD-PARTY DISCLOSURE

Having someone else disclose on your behalf. E.g. A representative from your local epilepsy organization, a mentor, advocate, union member, etc.

■ Disclosure Do's and Don'ts

If you choose to disclose your epilepsy, here are some helpful tips:

- Know your rights as a person with a disability (See Rights and Responsibilities *Spark* Sheet).
- Be honest, straightforward and factual.
- Be brief - don't dwell on your disability. Start with talking about your competencies.
- Be knowledgeable - be aware of how you do things, what you need, and how your employer can provide help if necessary.
- Be prepared to educate your employer about your disability and necessary accommodations. Your local epilepsy organization can provide you with literature, videos and perhaps services at the workplace.
- Speak with confidence.
- Relate your disclosure comments to the job and your performance. Be realistic about how your disability might affect your work.
- If possible, describe how your disability did NOT affect your previous job performance (i.e. few sick days, drove a forklift, was punctual).
- At the end of the disclosure, ask if there is anything else they need to know about you.

■ What to Avoid:

If you choose to disclose, here are some common mistakes to avoid:

- Assuming that the employer will respond negatively to disclosure of your disability.
- Dwelling on your disability and spending too much time trying to convince the employer that your disability will have no effect on your performance.
- Dwelling on what you cannot do rather than being assertive and positive about what you can.
- Being ashamed, apologetic and embarrassed about your disability.
- Lacking knowledge about your disability and anti-seizure medications and any possible job restrictions.

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- Disclosing your disability unnecessarily or too early in the process.
- Disclosing your disability without also discussing safety and accommodations.
- Failing to disclose your disability when it will affect job performance.

With disclosure, many individuals will then choose to create a separate, more detailed, First Aid Plan and an Accommodation Plan.

(See samples at www.epilepsyatwork.com)

You may never need it, but some people, at the time that an offer of employment is made to them, get for their own files a letter from their doctor that essentially says they are ‘deemed fit to work in this position’.

Your personal information is protected by various provincial and federal laws so remember, just because you disclosed to management and the union, doesn’t mean your co-workers have the same information. Consider gaining the assistance of your local epilepsy organization in educating your co-workers. (1-866-EPILEPSY)

(See also the “Epilepsy Disclosure Chart” *Spark* sheet)

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