

Made Available to Epilepsy Durham Region By:

Victoria Epilepsy & Parkinson's Centre
SOLUTIONS TOGETHER

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...LOOKS LIKE I HAVE EPILEPSY... CAN I STILL HAVE A LIFE???

INFO FOR TEENS

Am I still normal?

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Just what is epilepsy?

JUST WHAT IS EPILEPSY?

Having epilepsy means you've had more than one seizure, and that the seizures tend to recur. Seizures happen when your brain's electrical activity doesn't work like it usually does. There are several different types of seizures, depending on which brain cells are affected, and some people have more than one type of seizure. For example, maybe people have told you that you've been staring off into space, and you don't remember doing it, or maybe you've spaced out and people have told you that your arms, legs and head jerked repeatedly. Maybe you've been aware that part of your body was jerking and you couldn't control it. Sometimes people make sounds or wander around without realizing what they're doing.

AM I STILL NORMAL?

It can be pretty scary not being able to control what's happening to you. Almost everybody who finds out they have epilepsy worries about whether they're normal, and whether they'll be able to live an O.K. life. It's normal to have lots of questions and fears about whether having epilepsy will change your life. Sometimes it can feel that your life will never be normal again, like if your doctor or family tells you that you can't get your driver's licence because you have epilepsy, or that you're not supposed to party with your friends any more. Sometimes teens feel really angry about restrictions to their lifestyle, because they didn't "do" anything bad to get epilepsy in the first place. It can be very hard to adjust when you're newly diagnosed with epilepsy, but most teens find that they feel better once they've had some time to figure things out.

Being a teen means learning how to make choices in your life. While you didn't choose to have epilepsy, how you live your life with epilepsy is about making choices. Lots of teens who have epilepsy say they've discovered that they don't have to totally stop doing things, they just have to make sure they're safe doing them. And yes, to be honest, depending on the type and frequency of seizures you have, there may be some things that won't be totally safe for you to do.

Hopefully some of the things in this brochure that have worked for other teens will help you too.

CAN I DRIVE?

In most provinces, you have to be seizure free for 6 months (and take any epilepsy medications your doctor has prescribed, on a regular basis) before you can drive. Lots of teens look forward to being able to drive, and it's totally frustrating to be told you can't. The scary part about driving is that you're legally responsible for any injuries or deaths you cause. It could be your best friend that dies if you have a seizure and crash your car while driving, and that's a lot harder to live with than having to ask a friend for a ride, or taking the bus or walking. If you don't already have your licence, you may be able to get a headstart by doing the theory part of some driver training programs.

Remember that, in most provinces, a parent or guardian has to give formal permission for you to learn to drive if you're under 19. Lots of adults are concerned about their kids learning to drive whether their kids have epilepsy or not! If your doctor says you can go ahead and learn to drive, both you and your parent(s) or guardian(s) might really appreciate a chance to have an open discussion about any extra concerns that having epilepsy may add to the mix.

WHAT ABOUT DRINKING?

Deciding whether or not to drink or do drugs can be a tough decision for teens, even if you don't have epilepsy. It's even harder for teens with epilepsy because using some drugs (like crack cocaine, crystal meth or ecstasy) or drinking too much alcohol can cause seizures. Some antiepilepsy medications can interact with alcohol and cause you problems, too. If you do decide to drink, and you're having trouble deciding how much to drink, imagine whether you'll be more unhappy if a) your friends bug you about having only one drink all evening, or b) you drink too much and have a seizure in front of everybody. Some people try to figure out how much they can drink before they have a seizure, by trial and error. It's not that easy to predict, though, because things like stress, not enough sleep, dieting, and having your period if you're female, can make seizures more likely to happen.

CAN I WORK?

Lots of people with epilepsy have jobs. Before you start looking for a job, it can really help to figure out a few things. If you find that stress can trigger seizures for you, can you handle the stress of a job on top of school work or your other activities? Is your epilepsy well enough controlled at the moment, so that you won't be stressing out all day every day at work worrying that you're going to have a seizure? It can really help if you find a job you like that doesn't stress you out, and if the job works well with the type and frequency of seizures you have (you probably don't want to work in a commercial kitchen with knives and hot foods if you are having frequent generalized tonic-clonic seizures). Often, it's

better not to work long hours or switch shifts (like going from working nights to working days).

Lots of teens wonder if they have to write on their application or resumé that they have epilepsy, and whether they have to tell an employer or co-workers. Well, different provinces have different requirements. To help you find out about the laws in Ontario, contact the Ministry of Labour (<http://www.labour.gov.on.ca/>), you could call your nearest employment centre. If you call your nearest epilepsy association (you can reach them by calling (905) 666-9926), you can ask them to send you their latest information about 'epilepsy and employment' including an information sheet to help you decide when, or whether, to disclose to an employer that you have epilepsy.

Some teens with epilepsy decide to leave any questions about health issues on application forms blank in case the potential employer might discard their application because of fear or ignorance about epilepsy. That way, they figure they may have a better chance of getting to meet the employer in person and convincing them how valuable an employee they would be.

If you get to the interview stage, you really need to know the laws in your province about the employer's right to ask medical questions and your obligations to answer them. For example, some provinces allow potential employers to ask medical questions when you're looking for a job, and others don't. While no employer can fire you from a job you already have if you have epilepsy and it doesn't interfere with your ability to carry out the duties of the job, things can be a little trickier at the interview stage. If you did tell the potential employer that you had epilepsy and then didn't get offered the job, it could be really hard to prove whether that was the reason you did not get hired.

Some teens feel better having things "out in the open" and decide they want to tell during the interview, even if it's not required in their province. They may simply want to be up-front, or they figure that if the employer freaks out, then they wouldn't want to work there anyway. One strategy that some teens use is to go through most of the interview, highlighting skills and special gifts, then talk about epilepsy toward the end of the interview, saying something like *"I know I could be a real asset to your business, because I really enjoy... and I'm really good at... it's important to let you know that I have epilepsy, and it's controlled."* You could then let the employer take the lead in asking you questions, or you could explain what seizure types you have, what seizures look like for you, how the employer could help you if needed, and help dispel some myths! It might help to rehearse a job interview with someone you trust, so you can try out how to present yourself, and the fact that you have epilepsy, in a positive and realistic way to the employer.

Some people would rather wait until they know their new co-workers better before telling anyone at their workplace that they have epilepsy. Sometimes people may choose to give information about epilepsy to their co-workers, so that

if they have a seizure at work it won't be a surprise, and their coworkers will know what to do to help (and what not to do!).

Remember, once you have been hired, no employer is allowed to fire you from a job because you have epilepsy unless it will affect your ability to do the job. You do have legal rights! For more information, contact the epilepsy association nearest you by calling (905) 666-9926.

WHAT IF MY FRIENDS FIND OUT I HAVE EPILEPSY?

Sometimes it's really hard for teens to figure out whether to tell their friends that they have epilepsy. Some people are afraid that if they tell others, maybe they'll lose their friends and they won't be treated the same any more. Maybe you want to tell one friend and not another, but you're afraid once you tell one person then everyone will know. There aren't any easy answers to this one, but maybe a few things can help you decide. If you keep epilepsy a secret and have a seizure in public, will you wish you had told people earlier and not worried about what people thought, or do you feel more comfortable not telling people and dealing with your friends' reactions if you do have a seizure? Maybe your seizures are barely noticeable and you feel it's really no one else's business, or you aren't having seizures very often at all.

Lots of teens find that, while they're really afraid before they tell their friends, they're actually relieved afterward. Many teens decide it's better to tell their friends and teachers, so that if they have a seizure they'll be safe and get help if they need it. One teen's guideline is "if you're concerned about who to tell—what friends, what teachers—think if you were with that person and you were falling, would you trust them to catch you or would they step away and laugh?" Sometimes, it may feel safest to start off by telling just one person first, and then gradually building some support for yourself by telling others later. Remember that, if you do feel O.K. about telling people, you are the very best person to correct misconceptions if you are the one sharing the information!

WHAT ABOUT DATING AND SEXUALITY?

Some teens with epilepsy feel really uncertain about whether to tell the people they are dating about their condition, for some of the same reasons they are afraid to tell their other friends. Some people say it's important to be really up front from the start, so there won't be any surprises if you have a seizure, and the person you're dating will know how to help and support you. Other teens want to wait until they know someone better because they are afraid they may scare the other person away if they tell them right away. It's really an individual decision. Some teens find it easier to ask someone else to help them explain things, like a school counsellor or school nurse, parent, or doctor.

Teens who have chosen to be in an intimate relationship sometimes don't feel very confident about things, and some teens with epilepsy may find it a bit more difficult. It may be that they're not feeling very sure of themselves, or they're

afraid they will have a seizure during sex, or even that sexual activity may bring on a seizure. It's also known that some epilepsy medications may affect sexual performance. It can feel really awkward to talk about this stuff, but a trusted school counsellor, doctor, friend or family member may be able to help, and your doctor may even be able to adjust or change your medications if you mention your concerns. If you are relying on birth control pills to prevent pregnancy, you need to know that some epilepsy medications can make the birth control pills less effective, increasing the chances of pregnancy. Talking about this with your doctor is really important, and it is possible that you may need to consider alternative (or additional) forms of birth control.

CAN I STILL PLAY SPORTS?

Yes, if your seizures are under control, and depending on the types of seizures you have, it's probably safe to participate in most sports and other physical activities. Some studies suggest that some people may have fewer seizures when they are active. Some epilepsy medications can make you gain weight and feel sluggish, and exercise may be a very helpful strategy for keeping healthy. If you are having other side effects from medications (like dizziness), or if you are having seizures quite often, you need to be very careful about exercising (and the type of exercising you choose to do). Playing sports usually involves some risks, and depending on the types of seizures you have, there may be extra risks for you to participate in certain sports. Sports like rugby and boxing, that involve physical contact and can cause head injuries, are dangerous for you, just as they are dangerous for anyone.

Water sports can be dangerous for people with epilepsy, especially with certain types of seizures. You should never swim alone, and ideally should swim with someone you trust, and make sure they know you have epilepsy, what a seizure might look like for you, and how to help. Some teens with epilepsy also choose to quietly tell the lifeguard at the pool that they have epilepsy and ask the lifeguard to watch out for them too; still others always wear a life jacket any time they're in the water (the kind that will flip you onto your back). Prior to joining any sporting activity, consult your family doctor for the OK!

Lots of teens with epilepsy say that playing sports and being physically active is all about choices. They say they have to decide what's more important to them—playing the sport or activity (and putting themselves at risk but being prepared to accept the consequences), or not playing the sport and reducing the risks.

While some teens have found that they have been discriminated against by coaches if they tell them that they have epilepsy, other teens have found it helpful, in case they have a seizure while playing. There isn't an easy answer for this one, and talking with your family or with a counsellor at school may help you decide what to do.

DO I HAVE TO TAKE MY MEDICATION?

It is dangerous to skip a dose of your epilepsy medications, or stop taking your medication suddenly. Even though remembering to take your medication can be a pain, if you skip a dose, you might start having continuous seizures (known as status epilepticus) which is a medical emergency and could even kill you.

Some teens think that if they take more medication it may help them not to have seizures. Unfortunately, taking too much medication can make you feel dizzy or nauseated, mess up your sense of balance, or cause you to overdose. If you want to make any changes to your medications, or if you haven't had a seizure for a long time and want to try to stop taking your medication, you need to talk to your family and your doctor first.

Everybody talks about the importance of taking in lots of calcium when you're a teenager. It's really important for you to know that some epilepsy medications can take calcium away from your bones, making them less strong over time. You may need to take in extra calcium and vitamin d, so it's important to ask your doctor about whether this applies to your particular medication.

Some teens find it hard to remember to take their medications, especially if life is already busy, or they're having some problems remembering things because of epilepsy. In most cases, it is really important to take your medications at the times you've been told to, and the same time every day. Teens say that tying their meds in to something predictable they do every day really helps, like brushing teeth or eating a meal. There may be some other things in addition to your medications that may help with your seizures, like meditating, and relaxing. Remember, never change any aspect of your medications without discussing it with your doctor.

Another thing people with epilepsy suggest is to wear something like a medical-alert bracelet or pendant that will help you get you the care you need wherever you are when a seizure happens. You can get more information about this from your neighbourhood pharmacy or from an epilepsy association.

MANAGING AT SCHOOL

Some teens feel overwhelmed when they find out they have epilepsy. It can be even harder if the seizures aren't controlled very well yet. Depending on your individual experience with seizures, you may feel really tired after a seizure, or have problems remembering things or concentrating. Sometimes you might also get side effects from medications like feeling groggy or sluggish. All of these things can really affect how you do in school. Finding out you have epilepsy can shake your confidence, and one of the most important things you can do is to believe in yourself and your abilities.

You may find you need to give yourself time to get your school work under control. Some people keep going with a full load of classes because it feels good to challenge themselves, and they do just fine. Others say it's a struggle, but

they choose to continue with a full course load anyway. Some teens who don't tell anyone they are having problems at school, and struggle on, find the stress seems to bring on more seizures. That makes things even harder! If that seems to be happening for you and you don't feel comfortable talking directly to some of your teachers, maybe your family, the school nurse or a school counsellor could help out. Sometimes asking for more time to finish your assignments is helpful. If your teachers know what's happening to you, they may even keep your work waiting for you if you're absent, but the truth is that different teachers will respond differently to your situation. Teens with epilepsy sometimes say it can be really helpful to find a trusted buddy at school who will help by bringing home assignments from missed classes. You could also check in with your buddy if you have a seizure at school and need some support.

Some teens say they realize later that it would have been better to take fewer classes and finish school some months later, rather than finish school on time with lower marks than they knew they were capable of getting. Whatever decision you make, remember not to compare yourself with other people, because everyone's experience with epilepsy (and with life!) is different.

WHAT NEXT?

There are some things that can trigger seizures, so you need to know them. They include too much stress, alcohol and drugs, lack of sleep, playing video games, fluorescent lights (common at school), caffeine products (like Coke, coffee and chocolate), and aspartame (a sweetener found in lots of diet-type foods). Some teenage girls find that they may have more seizures just before or at the beginning of their periods. Remember that these are only some of the more common triggers, and they may or may not be a problem for you. Everyone's experience is different, and you may find that there are other things that seem to trigger your seizures, or there aren't any triggers you can identify at all.

Have confidence in your ability to manage with epilepsy. You will encounter lots of situations and choices in your life that are not even touched on in this brochure. The bottom line for making decisions is to make sure you are as safe as possible, without stopping yourself from having a life.

In figuring out what works best for you, there are lots of things you can do to feel good about life. Do as much reading as you can to educate yourself about epilepsy, and ask lots of questions. Access as much support as you feel comfortable with, from family, friends, health professionals, school counsellors and teachers, spiritual connections and any other meaningful connections in your life. As much as you can, continue to do the things you love to do, and try new things! Just remember to be safe! Some days will be better than others, so, above all, be kind to yourself.

HOW CAN I GET MORE INFO ABOUT SEIZURES AND EPILEPSY?

This brochure addresses issues of special concern to teens with epilepsy. It is not intended as a comprehensive source of information about epilepsy. There is

lots of great information about epilepsy available on the web, but as you know not all information on the web is accurate, so remember to cross-check your sources! If you search the web using keywords like 'seizure' or 'epilepsy' and whatever area interests you, like 'employment', 'medications', 'youth' or 'teens' you'll get lots of results. If accessing a computer is not possible where you are living, you can try using the computers at your public library or at your school.

You can also call Epilepsy Durham Region at (905) 666-9926.

**REMEMBER YOU ARE NOT EPILEPSY—YOU ARE A PERSON WITH
EPILEPSY!**