

Helping those with epilepsy by giving them a better understanding of the condition and its treatment





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Mrs Gordon had just celebrated her 68th birthday when it happened. Her daughter suddenly noticed that she was staring blankly, straight ahead. Her mouth was moving and she was tapping her hand on the table.

"Mother! What's wrong?" her daughter cried. But Mrs Gordon just looked straight ahead. It lasted about two minutes. Then she sighed, rubbed her forehead, and looked at her daughter. "I feel strange," she said. "I don't know what happened just now. What was I saying?"

SENIORS AND SEIZURES

When people in their sixties experience unusual feelings—lost time, suspended awareness, confusion, seizures—they may think their symptoms are caused by some of the physical or mental problems that sometimes accompany aging.

But there may be another explanation for what is happening: they may have become one of the growing number of Canadian senior citizens with epilepsy.

For a long time epilepsy has been seen as a condition that affects young people, often starting in early childhood; sometimes lasting throughout life.

But now we know it can affect anyone at any age. In fact, a careful look at the statistics shows us that it's as likely to begin in one's sixties, seventies and eighties as it is during the first ten years of life.

Having epilepsy at any time of life takes some getting used to. People want to find out about the disorder, how it's treated, and what kinds of changes it may make in their lives.

That's why we've written this pamphlet. It's for senior citizens who have epilepsy, their families, and all the other people who care about their well-being.

ABOUT EPILEPSY

Epilepsy is a functional disorder of the brain, a kind of occasional glitch in the amazing electrical system which controls everything we feel and do.

These brief malfunctions (which are called seizures) may temporarily block awareness. They can also cause uncontrollable shaking, convulsions, confusion, or affect the senses.

Anyone at any age can have a seizure if the brain is stressed sufficiently by injury or disease.

A single seizure isn't epilepsy, although the symptoms are the same.

Epilepsy is the name given to seizures that occur more than once because of an underlying condition in the brain.

You may sometimes hear people call epilepsy a *seizure disorder* and we'll use both terms in this pamphlet.

Françoise Dubé was very, very frightened. She had had a mild stroke and afterwards began to see things that she knew weren't there. Sometimes her living room seemed to grow longer, like a corridor, right in front of her eyes. She was afraid to tell anyone because she thought she was losing her mind. Finally she told the doctor and was relieved to discover that it was not at all the case.

TYPES OF SEIZURES

The kind of seizure a person has depends on where the electrical disturbance takes place and how much of the brain is affected. It's possible to have just one type of seizure, or more than one type.

Generalized Seizures

Generalized seizures happen when waves of electrical activity affect the whole brain at once. These may produce convulsions (tonic clonic or grand mal seizures); sudden falls (atonic seizures); massive muscle jerks (myoclonic seizures); or momentary blackouts (absence seizures).

Tonic Clonic Seizures

Tonic clonic seizures, which many people call convulsions, are the ones most people think of when they hear the word "epilepsy". They often start with a cry, caused by air being suddenly forced out of the lungs. The person slumps in his seat or falls to the ground, unconscious. The body stiffens briefly and then begins to jerk.

The tongue may be bitten. A frothy saliva may appear around the mouth. Breathing may be very shallow and even stop for a few moments.

Sometimes the skin turns a bluish colour because breathing may be briefly interrupted and the blood doesn't get as much oxygen as usual.

After a minute or two the jerking movements slow down and the seizure ends naturally. Bladder or bowel control may be lost as the body relaxes after the seizure. Consciousness will then slowly return.

Partial Seizures

Partial seizures happen when a smaller area of the brain is affected. They may produce uncontrolled shaking, alter emotions, or change the way things look, smell, feel, taste or sound to the person having the seizure. When people have these experiences, yet stay fully conscious, the episodes are called **simple partial seizures**.

But there's nothing simple about them to the person going through this experience. When familiar surroundings suddenly look different, when people hear voices and nobody's there, when they see images—perhaps of a loved one who's passed on, or an object that suddenly appears where it's not supposed to be—it can be terrifying.

Episodes of this kind are caused by electrical disturbances in the part of the brain that controls senses such as sight (causing visual disturbances), or hearing (producing the illusion of voices or sounds) or even memory (creating perhaps an image of the past or blocking recognition of familiar places).

People may not talk about these episodes, even to their doctors, because they're afraid they're losing their minds. They're not, of course. These are seizures, not symptoms of mental illness.

And the doctor should be told about them because these seizures may require a medicine that's different from what he or she might otherwise prescribe.

Complex partial seizures are experienced in a different way. They affect consciousness while they're happening and people can't remember them afterwards.

Complex partial seizures typically produce a kind of dreamlike state. The person may stare, make chewing movements with the mouth, pick at clothing, mumble, do the same actions over and over again.

He or she can't talk to other people while the seizure is going on, but may respond to simple requests made in a calm, friendly voice.

Complex partial seizures are particularly common in older people with epilepsy, but they occur at any age.

Sometimes people wander during these episodes. In rare cases they may become very agitated, make flailing movements with their arms, try to undress, try to run, scream, or cower in fear. Joe Devilla, 72, had been keeping a secret. For several months he'd been "missing" sections of time. He'd go into the garden to do yard work and suddenly it was much later in the day and he couldn't figure out where the time had gone or even what he'd been doing. Sometimes he'd find himself in another room and couldn't remember how he got there. He was afraid to tell anyone because he thought he might be developing Alzheimer's disease. But that wasn't what it turned out to be.

Although, it's always possible for seizures to change, people usually develop a pattern of things they do and these are likely to occur in the same order each time.

Sometimes partial seizures spread to involve the whole brain, causing a convulsion or a fall. When this happens as a regular part of a person's seizure pattern, the special feeling produced by the partial seizure acts as a warning. Sometimes it gives people enough time to get to a safe place before they lose consciousness. The warning feeling is often called an aura.

THINGS TO REMEMBER

Seizures look different, but they have certain things in common:

- They don't last long. Most last only a minute or two, although people may be confused and need a lot more time afterwards to recover fully.
- They end naturally. Except in rare cases, the brain has its own way of bringing the seizure activity safely to an end.
- You can't stop them. In an emergency, doctors may use drugs to bring a lengthy, non-stop seizure to an end. However, the average person can't do anything except wait for a seizure to run its course.
- **People don't feel pain during the seizure**, although their muscles may be sore afterwards.
- Seizures are usually not life-threatening. although in senior citizens the extra strain on the heart, the possibility of injury and the reduced intake of oxygen may increase the risk.
- Seizures are not dangerous to others. Even in rare cases where people become angry or afraid during the seizure, their movements are almost always too vague, too unorganized and too confused to threaten the safety of anyone else.

RESPONDING TO SEIZURES

Handling any type of seizure involves one simple principle: to protect the person from harm until full awareness returns.

Handling Convulsions

- Ease the person having the seizure into a reclining position on the floor or flat surface.
- Put something soft and flat under the head.
- Turn him or her gently on to one side to prevent choking and keep the airway clear.
- If the person having the seizure is seated, turn their head gently to one side so any fluids drain away from the mouth.
- Don't try to force anything into the mouth. Seizures do not cause people to swallow their tongues.
- Don't try to give fluids or medicine until the seizure is completely over and the person is fully alert again.
- Don't try to restrain the jerking movements. Muscles contract with force during seizures. Applying restraint could cause tears in the muscle or even break a bone, especially in elderly people whose bones may be fragile.

Responding To Confusion

Confusion may occur during a complex partial seizure or during the recovery period after other types of seizures. In either case, the same basic rules apply:

- Remove anything from the area that may cause injury or could be a hazard to someone who is temporarily unaware of where he is or what he's doing.
- Don't try to restrain someone who is wandering and confused during a complex partial seizure. If danger threatens, guide gently away. People may be quite agitated during these episodes. Trying to restrain them, or grabbing hold, is likely to make the agitation worse and may trigger an aggressive response.
- Be reassuring, comforting and calm as awareness returns.

Mary Page's elderly mother had had two or three seizures following a heart attack. She was taking seizure medicine, heart medicine, and drugs for other conditions. She became increasingly depressed, confused, and forgetful. The family was afraid she was losing her mental abilities. But when the doctor checked, he came up with a better answer.

Warning Signals

Most seizures, even in elderly people with other health problems, end naturally without any special treatment. Although emergency medical assistance should be obtained when someone has a first seizure, subsequent seizures usually do not require special treatment.

However, it is always possible for more serious problems to develop. Here's a few ways to spot them:

- Watch the time. If the convulsive shaking and jerking of a tonic clonic seizure lasts longer than five minutes, or starts up again shortly afterwards, call an ambulance. Non-stop seizures, which doctors call *status epilepticus*, are quite dangerous for elderly people and prompt medical care is needed.
- Check for secondary injuries. Seniors who have seizures may break bones, so special care should be taken to find out if there's any unusual pain following a seizure. Headaches are quite common, but a severe headache after a seizure in someone who doesn't usually have them should be checked out.
- Call for help if breathing is laboured following the seizure, if there is chest pain, or unusual pain of any kind, or if consciousness does not return after a few minutes.
- Be aware that periods of confusion lasting more than one hour associated with seizures may signal that something is seriously wrong. If an older person with a seizure disorder who does not have a mental impairment seems to slip in and out of a confused or agitated state with few intervals of normal awareness, you may be seeing another kind of continuous seizure activity. This, too, should be evaluated at a hospital.

Special Circumstances

If you are living with an older person with seizures who has other medical problems, check with the doctor about how he or she wants you to respond when a seizure happens.

Find out whether the doctor wants to be notified every time or just in certain circumstances.

Ask whether or when you should call an ambulance; and if there are any special warning signals that you should be on the lookout for.

Harry Schwartz had been nervous about his brain surgery for cancer. But it went well. "We're very pleased," the doctors told him. "We're sure we got it all and you're going to be fine." And he was. Until about four months later when he had an attack of some kind that made him fall unconscious, stiffen, and writhe on the floor. It really scared his wife. They were both afraid the tumor had come back. But after tests they found out that wasn't what the problem was at all.

CAUSES OF EPILEPSY

Half the time there's no obvious reason why someone begins to have seizures.

Causes that can be identified include severe injury to the brain from accidents or other trauma; the aftereffects of serious brain infections, like encephalitis or meningitis; certain genetic conditions; or changes in metabolism which prevent important nutrients from getting to the brain.

Things that cause seizures in older people, however, are sometimes related directly to physical changes associated with aging.

- **Stroke** is the most frequent cause of seizures that begin in later life. As people age, arteries may become narrowed or clogged, depriving parts of the brain of blood and oxygen. The result may be damage that produces seizures. Bleeding in the brain, which is another form of stroke, may also leave a person with seizures afterwards.
- **Heart attacks** may temporarily cut off oxygen to the brain, with a similar result.
- **Diseases** such as Alzheimer's, or other brain diseases that change the internal structure of the brain, may cause seizures. Complications of kidney disease, liver disease, alcoholism and even diabetes may make people more likely to have seizures in later life.
- **Brain tumours** of any kind may cause seizures. If an operation is done to remove the tumor, the seizures may stop.
- **Brain surgery** occasionally leaves a scar that causes seizures later on.

It is also possible that epilepsy in a senior citizen marks the return of a seizure disorder that was in remission, or it may be the continuation of a life-long problem.

Even if someone has had epilepsy for a long time, it's still a good idea to have the treatment reviewed by the doctor once that person becomes sixty-five or seventy.

PREVENTING SEIZURES

If the underlying cause of seizures is known, there may be ways to treat it directly—with surgery or medication.

However, if direct treatment isn't possible, then the doctor will usually prescribe one or more medications to control the seizures.

Antiepileptic drugs (also called anticonvulsants) will usually prevent seizures or reduce their frequency once a certain level has built up in the blood.

To keep the level steady and the seizures under control, the medicine has to be taken every day, on time. Missing doses will lower the blood level and make it more likely that seizures will occur. Taking an extra pill if you feel a seizure coming on is not going to help either, because the medicine can't be absorbed fast enough to make a difference.

It's only a steady, day by day use of the medication that keeps the blood level where it's supposed to be. People should be especially careful not to stop the medicine suddenly. Doing so may cause serious rebound seizures that could even be life-threatening.

A number of drugs are used to treat epilepsy. However, people do not all respond the same way. Some are more sensitive to side effects than others. And sometimes seizures continue even though the medication is being taken regularly.

MENTAL ALERTNESS, MOOD, MEMORY

There are a number of health problems associated with aging that affect a person's mental alertness, mood, or memory.

But when an older person who is being treated for epilepsy becomes unusually depressed, confused, and unable to remember things, there may be some other explanations. For example:

Toxicity

If the level of medication in the blood gets too high, it can produce these kinds of changes.

It often takes longer for older people to process medicines and to eliminate them from the body. The level in the blood then slowly rises to levels which cause problems even though there's been no increase in the dose.

On the other hand, some older persons may have toxic symptoms at levels that don't cause problems in younger people.

When Doris Jackson was diagnosed with epilepsy, her family became very concerned for her safety. Even though the medication controlled her seizures, they didn't want her to live alone anymore, or to drive, or even to go out alone. "They mean well, but I don't want to be dependent on them," she told her doctor. "I'm going to go right on doing things for myself."

Drug Interactions

People over the age of 65 may be taking a lot of other medicines besides anti-seizure drugs.

They may be on blood pressure medicine, blood thinners, drugs to reduce cholesterol, drugs to prevent stomach irritation, insulin for diabetes, as well as medicines for kidney disease, bronchitis, indigestion or the flu.

Some of these medicines may interact with epilepsy drugs, or be affected by them. Interaction means one drug changes the effect of another drug.

It may lead to negative side effects or reduce the usefulness of the medicine. Epilepsy drugs of different types may also interact.

It's important for the doctor treating your epilepsy and the pharmacist who fills the prescription to be told about all the other medicines (including over the counter products) that you are taking so the chances of interaction are reduced.

Also, whenever you change other medicines, either to start or stop, make sure to ask your doctor about the effects on your seizure medicine.

Sensitivity

Older people may be more sensitive to the depressive aspects of a drug, or combinations of drugs, and these may lead to altered mood and changed behaviour.

The important thing to remember about all this is that when an older person being treated for epilepsy suddenly becomes depressed, forgetful, agitated, confused, loses appetite, gets a rash, wants to sleep all the time, or in any way seems different from his or her usual self, the doctor should be told so the medication can be checked and, if necessary, adjusted.

People often assume that these feelings are just things that have to be accepted as part of the treatment—but that's not necessarily true. It's always worth speaking up and telling the doctor when you don't feel right. Roland Boisvert refused to believe what his doctor was telling him. "Doctor, I'm almost seventy. How could I possibly have epilepsy at my age? It must be something else. Why, epilepsy is something you're born with. I don't want to have this at my time of life. What will my family say? What can I tell my friends?"

The one thing you should not do, however, is to stop epilepsy medication on your own. Always check with the doctor first. And always alert the doctor treating your epilepsy whenever you're about to start or stop other medications.

REMEMBERING THE MEDICATION

As already noted, epilepsy medicine works best when the blood level remains steady. To achieve this, some of the drugs have to be taken twice a day, some once a day, and some as many as four times a day.

It can be hard to keep track, especially when someone's trying to remember to take several other medicines as well. It's a good idea to ask your pharmacist about ways to help you remember to take the drug correctly. One of the things he or she may suggest is using a daily chart showing which medicines have to be taken, and when.

Making a daily routine of counting out medicines into a pill box divided by segments according to time of day is also a useful memory aid.

People who live alone may want to try wearing a wristwatch with an alarm that sounds when medicine has to be taken, or posting reminder notes in places where they're sure to be seen during the day.

Marking dates on calendars to re-order medication, and doing so before the prescription runs out, is important because of the risk of rebound seizures if the medicine is suddenly unavailable.

LIVING WITH EPILEPSY

Although there are always exceptions, senior citizens with epilepsy who are otherwise in good health and whose mental abilities are unaffected can usually continue to live independently.

Families may find this idea difficult to accept. With the best of intentions, they often become over-protective, making an older relative more dependent than is necessary.

Of course, there are risks associated with seizures when people live alone. However, making certain changes in the home can reduce them.

For example, living in a house or apartment which does not have stairs reduces the risk of injury from falls; carpeted floors provide a softer surface; and so does using padded furniture and putting protective padding around the corners of tables.

Technology is also available to help older people with disabilities to keep in touch with family members.

If seizures are fairly frequent, portable phones or beepers provide a way to call for help from any part of the house. Some seniors living alone prefer to work out a simple code, like a flower pot in the window, or a shade that is lowered and raised according to a schedule, to reassure friends and neighbours that all is well or to alert them if there are problems.

Fire, heat, and water are hazards for people of any age who have seizures. That's because people do not feel pain during seizures and are unable to protect themselves.

Although you can't protect against them completely, some simple precautions can reduce these risks as well. For example:

- Don't smoke. Having a seizure while smoking could cause a fire.
- Use a microwave oven for cooking.
- Serve food from where it's cooked directly onto plates so you don't have to carry saucepans or casseroles of hot food.
- Use an automatic coffee pot or heat water by the cup in the microwave instead of boiling a kettle.
- Use a regular knife for carving, not an electric one.
- Set the temperature on the water heater low enough to prevent scalding.
- Keep electrical appliances far away from the sink or source of water.
- Avoid the need to iron by buying permanent press clothes and linens, or sending things that have to be ironed to the cleaners.
- Keep bathtub levels low, or use a hand held shower with no plug.

- Wear rubber gloves when washing glassware and china or loading it in the dishwasher.
- Don't use space heaters that have hot surfaces, open heating elements, or can be tipped over.
- Keep a screen in front of an open fire; don't carry hot ashes out to the trash can.

DRIVING

People who are having active seizures with loss of consciousness should not drive, no matter what their age.

However, senior citizens with epilepsy whose seizures are fully controlled with medication (and who meet other licensing requirements) can qualify to drive in all parts of Canada.

In most cases they will have to show that they have met their province's seizure-free requirement (usually of one year). They will also have to provide any statements from their doctor required by their provincial department of motor vehicles.

If driving is not an option, then using public transportation, signing up with local services for the elderly or disabled, or even moving to an apartment complex or community that has its own transportation may be among the alternatives.

THEN AND NOW

If you are a senior citizen reading this pamphlet, you can probably remember a time when there were no reliable treatments for epilepsy. People did not understand why seizures happened and they were afraid of them.

You may remember, as a child, that families often sent people with seizures off to institutions, or kept them at home, isolated from others.

And you may have heard it whispered (incorrectly) that epilepsy is a form of mental illness.

Perhaps when you were growing up, people with epilepsy were not allowed to marry. Or you remember someone at school who had a seizure—and wasn't allowed to return.

Not surprisingly, people with those kinds of memories may need reassurance that things have changed and we hope this pamphlet has provided that.

We hope it has made clear that epilepsy is now a well understood neurological disorder, no more mysterious than other physical illnesses.

Today we know that epilepsy is not contagious, not a mental illness, not a symptom of intellectual decline, and certainly not a reason for shame or family embarrassment.

As we have seen, the good news today is that epilepsy can often be treated quite successfully.

And even if seizures continue to happen sometimes, that need not by itself prevent an otherwise healthy, active senior citizen from living an independent and satisfying life. For more information on health, employment and social services, contact the nearest epilepsy association.



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