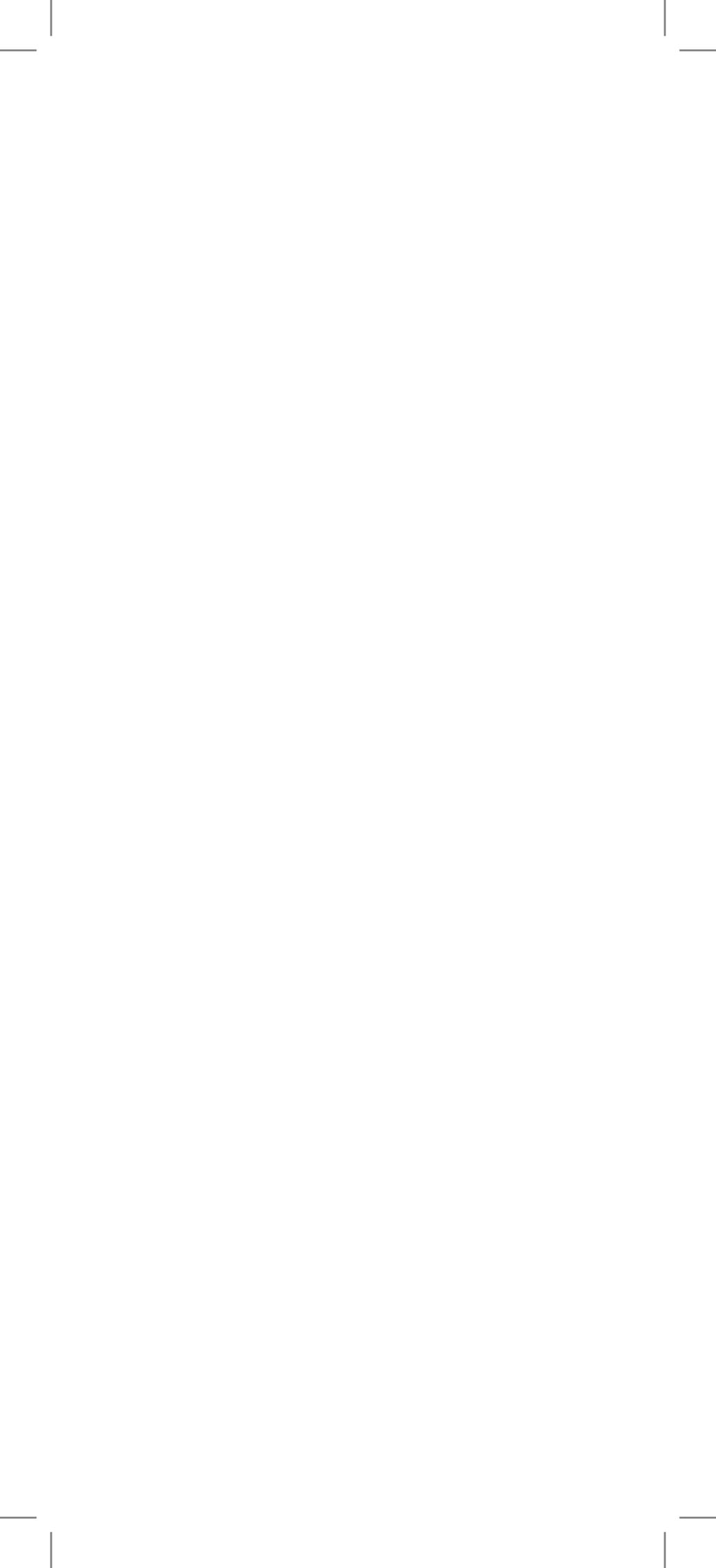


CHILDREN AND EPILEPSY

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





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This brochure is designed to provide basic information about children with epilepsy to the general public. It does not constitute medical advice. For purposes of this information, a child is considered to be anyone from a newborn to a 16-year-old. Readers should not make changes in treatment or activities based on this information without first consulting a physician.

When the doctor told us that our child had epilepsy, our first reactions were shock and dismay. We asked, “How could this happen?” and “Why did this happen to our child?”

Our child’s life has changed. Our lives are changing. We want what’s best for our child.

We want to create a loving, supportive home where our child can grow, self-confident and safe, in an understanding, accepting environment.

But how?

Where do we begin?

CHILDREN AND EPILEPSY

A Closer Look

Like all children, a child with epilepsy learns self-confidence and pride at home. What your child learns at home about living with epilepsy has a great deal to do with the kind of adult that he or she will become.

A child who learns to fear or be anxious about epilepsy, a child who is sheltered from life by well-meaning parents, a child whose life is completely dominated by epilepsy may grow into an immature, dependent adult.

A child who is encouraged to view seizures as a temporary inconvenience, a child who joins other children of the same age in everyday activities, a child who learns to participate in family and community life has a better chance of becoming a confident, independent adult.

Coping with Change

Your child has been diagnosed with epilepsy, but does that mean that your child has changed? Your son is still the same boy who loves to play hockey. Your daughter is still the same girl who wanted to join Brownies last week—and still wants to join.

This guide will help you to find the answers that you need to basic questions about raising a child with epilepsy. It deals with the common challenges of everyday life. Based on parents' experiences and what psychologists have learned from family studies, this guide may help you to cope with the kind of pressures that you're feeling right now—and help to strengthen your family.

How You Feel

What about my child's future?

What adjustments should we make at home?

How will this affect my child's education?

Are you always worried about your child? Do you hesitate to discipline your child in the same way as your other children? Do you prevent your child from rough-housing with brothers or sisters?

Do you find it hard to say that word, “epilepsy”? Try “seizures” or “seizure disorder”. Do you find it hard to explain why the idea that your child has epilepsy is so upsetting? Has it caused family tensions between you, your spouse and other family members?

Is it difficult to talk to your child's doctor about epilepsy? When you work up the courage, do you find your mind wandering onto any other subject? Is it hard to follow or understand what the doctor's saying? Are you feeling angry, sad, helpless—even guilty? Do you feel that you've failed as a parent?

These feelings are normal. Not everyone feels this way, but many parents do. These feelings are a normal reaction to a new situation. These feelings are temporary. After a while, they pass, and families pull themselves together to do what they really want to do—concentrate on helping their child.

A Family Concern

My wife takes my child to the doctor, talks to teachers, goes to meetings with other parents in the same situation. She's learned a lot about "it".

I can't get over her change in attitude. She seems so unconcerned about "it". We argue about what's right for our child. I want to see another doctor, but she disagrees. I want my child to quit the soccer team, but she disagrees. We fight all the time.

Often, one parent adapts more quickly to this new situation. By asking questions and finding some answers, that parent learns what to expect and becomes more at ease with the idea that the child has epilepsy.

Meanwhile, the other parent may still have many worries and feelings that they both started out with. This parent may still reject the idea that the child has epilepsy.

These different ways of thinking often lead to growing tensions and arguments between parents—a fact that any child senses easily and learns to manipulate.

Children with epilepsy are no different. Given the opportunity, they may divide and conquer—quickly turning any differences in the way that parents feel about epilepsy to their advantage.

If both parents are involved in the child's medical and social progress, everyone in the family moves in the same direction, at the same pace. This family harmony will support and strengthen your child's character.

WHAT IS EPILEPSY?

The brain controls how we think, how we move, what we see, hear, feel and automatic bodily functions, such as breathing, digesting and heartbeats. It's the storehouse of memory.

Epilepsy is a neurological disorder caused by sudden, brief changes in how the brain works. When brain cells don't function properly, your child's movements, actions or consciousness change for short periods. These changes are called seizures. For that reason, epilepsy is often called a seizure disorder.

Within this complex organ, brain cells communicate by means of tiny bursts of energy - electrical signals. A seizure occurs when a group of brain cells has a sudden, erratic electrical discharge. What type of seizure your child has depends on where, in the brain, the discharge begins.

Why my child?

Epilepsy can affect anyone at any age. Some children have less intense and frequent seizures as they grow older. In about 50% of childhood epilepsy, seizures disappear completely.

Many factors can lead to epilepsy, but 75% of the time, the exact cause is unknown or "idiopathic." Common causes are:

- Head injury—severe head blows from falls, car or bicycle accidents.
- Brain tumour or infectious diseases—viral encephalitis, meningitis or even measles can scar brain cells, leaving supersensitive patches of easily irritated cells that discharge erratically.

- Injury, infection or illness in pregnant women may affect the developing fetal brain. Brain injury may occur during childbirth.
- Poisoning due to substance abuse (drug or alcohol use).

With rare exceptions, seizures do not cause brain injury. Epilepsy rarely leads to developmental disability. Most children with epilepsy are not intellectually handicapped. They have the same range of mental abilities as other children—some are very intelligent, others are average, some are below average. Severe epilepsy in early childhood is associated with some degree of developmental disability. It includes:

- infantile spasms
- Lennox-Gastaut syndrome

Children with inherited disorders or birth defects—including cerebral palsy and brain damage—may have epilepsy among their symptoms.

Mental illness and epilepsy are separate, unrelated conditions. Some children with epilepsy develop behaviour problems, but they are more closely related to your child's experiences at home, school and society at large than to the physical causes of epilepsy.

Is Epilepsy Inherited?

In most cases, epilepsy is not inherited. Parents do not directly transmit epilepsy to their children, except in some specific syndromes.

Everyone inherits a “seizure threshold” when brain cells are irritated beyond this point, we will have a seizure. People with a low seizure threshold tend to develop seizures more easily than others. This tendency may be inherited.

ABOUT SEIZURES

Some children have just one type of seizure, but it's not unusual for more than one type of seizure to occur in the same child. Watch your child's reactions during seizures, and ask other family members to do the same. A detailed description can help your doctor to recommend the best treatment for your child's epilepsy.

There are two main types of seizures. If the electrical discharge disturbs the whole brain, the seizure is called generalized. If the seizure disturbs only part of the brain, it is called partial.

Partial Seizures

Simple partial seizures (formerly, focal seizures) cause strange and unusual sensations, distorting the way things look, sound, taste or smell. Consciousness is unaffected—your child stays awake but cannot control sudden, jerky movements of one part of the body. Your child will remember what happened. Other signs are stomach discomfort or a sudden sense of fear or sadness.

Children react differently to simple partial seizures, but your child is not hysterical, acting out or mentally ill. In some children, simple partial seizures develop into complex partial or tonic-clonic seizures.

Complex partial seizures (formerly, psychomotor or temporal lobe seizures) alter your child's awareness—the child is unaware of what is going on during the seizure. Dazed and confused, the child seems to be in a dream or trance. He or she is unable to respond to directions. The child may repeat simple actions over and over—head turning, mumbling, pulling at clothing, smacking lips. He or she may make random arm or leg movements or walk randomly. The seizure lasts only a minute or two, but the child may feel confused or upset for some time and may feel tired or want to sleep after the seizure. Your child will have no memory of what has happened. Two thirds of all seizures are

complex partial seizures.

When your child has a complex partial seizure, he or she is not day dreaming, behaving badly, abusing drugs or drunk. Don't expect to be heard or understood during the seizure. Speak softly and gently.

Generalized Seizures

Absence seizures (formerly, petit mal seizures) are brief periods of complete loss of awareness. The child may stare into space—completely unaware of surroundings and unable to respond. These seizures start and end abruptly, without warning. They last only a few seconds. Your child may stop suddenly in mid-sentence, stare blankly, then continue talking without realizing that anything has happened. Rapid blinking, mouth or arm movements may occur.

During seizures, your child is not day dreaming, forgetting to pay attention or deliberately ignoring your instructions. These seizures may happen many times a day, interrupting attention and concentration. About 20% of children with absence seizures develop generalized tonic-clonic seizures later in life. Absence seizures often disappear before adolescence.

Tonic-clonic seizures (formerly, grand mal seizures) are general convulsions with two parts. First, in the tonic phase, you may hear a loud cry or groan. Your child loses consciousness and falls, as the body grows rigid. Second, in the clonic phase, your child's muscles jerk and twitch. Sometimes, the whole body is involved; at other times, just the face or arms. Shallow breathing, bluish skin or lips, heavy drooling and loss of bladder or bowel control may occur.

These seizures usually last one to three minutes. Afterwards, consciousness returns slowly, and your child may feel groggy and want to sleep. Your child will not remember the seizure.

During tonic-clonic seizures, your child is not having a heart attack, stroke, fainting or holding his or her breath on purpose.

Infantile spasms are rare. They occur in clusters in babies, usually before six months of age. The baby may look startled or in pain, suddenly drawing up the knees and raising both arms - as if reaching for support. If sitting, the infant's head may suddenly slump forward, the arms flex forward and the body flexes at the waist.

Spasms last only a few seconds but often repeat in a series of 5 to 50 or more, many times a day. They often occur when the baby is drowsy, on awakening or going to sleep.

Status epilepticus is a state of repeated or prolonged seizure - your child's seizures continue without time for recovery. Your child continues to convulse, and consciousness does not return between seizures.

Status epilepticus is a medical emergency. It can lead to severe brain damage and even loss of life. If any tonic-clonic seizure lasts longer than 5 minutes, your child needs immediate medical care to prevent the onset of status epilepticus.

Will My Child Have a Warning?

Some children have a strange sensation before a seizure. This "aura" acts as a warning that a seizure is about to occur. Sometimes, it helps your child to prepare for the seizure by lying down to prevent injury from a fall.

The aura varies from one child to another. Children may have a change in body temperature or feeling of anxiety. Some experience a strange taste, striking odor or musical sound.

An aura may occur before partial or tonic-clonic seizures. An aura is not always followed by a seizure—in fact, the aura is a simple partial seizure.

An exact description of the aura may help your child's doctor to identify where the seizure starts—in what region of the brain. This information will help your doctor to recommend the best treatment for your child's epilepsy.

FIRST AID

As a parent, it's difficult to stand by feeling helpless when your child has a seizure. Here are some precautions to take—and some things to avoid—to lessen the impact of a seizure on your child.

Most people don't know how to help someone who has a seizure. This lack of awareness may prove harmful. You may find it worthwhile to review these first aid procedures with relatives, teachers and other parents who are part of your child's everyday life.

Tonic-clonic

- Remain calm. Reassure your child and onlookers.
- Move sharp or dangerous objects out of the way. Remove your child's eyeglasses. Loosen tight collars and clothing. Wipe away saliva around the mouth.
- Let the seizure run its course. Nothing can shorten a seizure, so it's pointless to try to stop it. Slapping, shaking or splashing cold water on your child is harmful and unnecessary.
- Turn your child gently on the side to keep air passages clear. Support the head with something soft—a rolled-up jacket or towel.
- Do not hold or restrain your child. Only move your child if he or she is in a dangerous position.
- Do not panic if your child seems to stop breathing, grows pale or shows temporary blueness. This is a natural part of the seizure.
- Do not push objects between your child's teeth. Your child may bite the object, inhale broken pieces then choke. It is physically impossible for children

to swallow their tongue. Forcing your child's mouth open may injure teeth and gums. Never put your finger in the child's mouth. During seizures, children have no control of their powerful jaw muscles. You will be severely bitten. If blood appears around your child's mouth, do not be alarmed. Your child may have bitten his or her tongue.

- Do not try to give medicine or any other substance to your child during a seizure.
- Get emergency aid if the seizure lasts more than five minutes, a second seizure follows immediately or if your child injures his or her head.
- As consciousness returns, speak gently to your child in a soothing, reassuring way. Let your child rest for a few minutes and help him or her to get reoriented.
- After your child recovers, he or she is often confronted by a crowd of worried onlookers.
- By knowing what to do and understanding how your child feels, you can make recovery more pleasant for your child.

Complex partial

- Do not hold or restrain your child unless he or she is headed for danger. When restrained, children may unconsciously lash out—injuring themselves or you. Move sharp or hot objects away.
- If wandering occurs, stay with your child and talk quietly.

Absence

No first aid is needed.

Simple-Partial

No first aid is needed.

Status Epilepticus

Status epilepticus—a state of nonstop seizure—is a medical emergency. Your child needs immediate treatment. If a convulsive seizure lasts more than five minutes or your child has two seizures in a row without regaining consciousness, call an ambulance or take your child to the nearest emergency room immediately.

MANAGING SEIZURES

When my daughter had a seizure, I felt useless—until our doctor asked for my help. By giving him information about her seizures, I feel like I'm an important part of the team that's helping to control her epilepsy

Your doctor will probably never see your child having a seizure. Yet, to recommend the best treatment, your doctor needs to know exactly what happens during seizures. These steps will help you to describe your child's seizures:

- Check your watch quickly when the seizure begins and ends. Note the length of time that your child was unconscious or unaware of surroundings.

- Note the time of day and what your child was doing before the seizure began.
- Observe exactly how your child behaves and what happens to your child before and during the seizure—write it down, if possible.
- Keep track of seizures—record them on a chart, so you will know how often they happen.
- Report all seizures to your child’s doctor not just the big, dramatic ones. It’s important for the doctor to know about short blackouts and memory lapses, auras and other seizure symptoms.

TELLING YOUR CHILD

Your child should know that he or she has epilepsy. Depending on the child’s age, parents should explain, “This condition sometimes gives you seizures, but the doctor has given you some medicine that may help to prevent them.”

Parents are often surprised by this advice. Some prefer not to tell their child. They also believe that the fewer people who know, the better.

Try to view the situation through your child’s eyes. He knows that something has happened to him that upsets the whole family. She’s asking herself, “Why did I need to see the doctor?”, “What did they find out from all those tests?”, “Why do I have to take these pills? I know they aren’t really vitamins.”

Sometimes, during seizures, children hear sounds or see things that aren’t there. They may “come to” in a different room. Unless these events are explained, children often fear they’re going “crazy”—or worse. When kept in the dark, confused and anxious children often create a far more damaging explanation for their condition than epilepsy—“Am I dying?”

Be straightforward about epilepsy. Offer a simple, matter-of-fact explanation that, by your example, lets your child know that epilepsy is nothing to be ashamed of.

HOW YOUR CHILD FEELS

If epilepsy was a shock to you, it was more shocking for your child. Having seizures, getting used to medication and constantly visiting doctors, clinics or hospitals for special tests may temporarily set back your child's development.

Your child will worry about having seizures and about what people—especially other children—will think.

During a seizure, your child has no control of his or her behaviour. Still, he or she may feel guilty for having a seizure or afraid of being punished for something that happened during the seizure.

Reassure your child by explaining that what's happened is just part of the seizure.

If alert, encourage your child to get busy with something he or she likes to do.

Older children get upset when they wet or soil themselves. Always keep a change of clothes handy. Waterproof pants may save school-aged children from embarrassment.

Often, children are afraid that they have disappointed you by having a seizure. If medication fails to control seizures, they may feel that it's their fault. Reassure your child that's not the case.

Your child needs comfort and reassurance—but not your anxiety. It's natural to feel concerned but try not to keep asking if he or she feels alright. Avoid communicating your anxiety about the seizures to your child—he or she will begin to feel anxious too, and lose self-confidence.

YOUR CHILD'S DOCTOR

All I heard was the word “epilepsy”. It echoed through my mind. After that, I don’t remember what the doctor said.

Good medical care is based on a partnership between the doctor, your child and you.

Choosing a Doctor

Epilepsy is often treated by family doctors, pediatricians or internists, but your child may be referred to a neurologist—a doctor with special training in brain disorders, including epilepsy.

- Whether a family doctor or neurologist, find out if the physician has a special interest and experience in treating epilepsy.
- When choosing a neurologist, ask a doctor that you respect for a referral.
- When referred to a new doctor or epilepsy clinic, ask your original doctor to send copies of your child’s records to the doctor reviewing your child’s case.

Epilepsy Clinics

When seizures resist control by medication, children may be referred to a clinic that specializes in epilepsy for further tests.

- Different clinics offer different services and staff. Ask what services or tests are necessary and available on site.

- Clinic staff should include these specialists: neurologist, neurosurgeon, neuropsychologist, clinical nurse and others who specialize in epilepsy.
- Diagnostic services should include electroencephalography (EEG) and magnetic resonance imaging (MRI) to identify and exclude brain disorders or disease.
- How does the clinic help patients and families with epilepsy-related problems? Does it have patient education? Vocational support? Outpatient services?

HOW CAN I HELP?

Well-informed parents are a doctor's best allies in managing a child's epilepsy. To play a more active role in your child's care, follow these suggestions:

Gather Information

- Asking questions will help you to dispel myths and get rid of unfounded worries. Write down your questions the night before your child's appointment.
- If you have too many questions for one session, schedule a separate, longer appointment to go over them in detail.
- Ask your doctor what to expect during diagnostic tests. Be sure that the doctor explains instructions clearly, so your child has no difficulty understanding them.

Prepare

- Bring your child's medications, dose schedule and any notes, calendars or charts with information about your child's seizures. It's especially important to report any changes in your child's status or new problems, even if they seem trivial.
- Bring your pharmacist's telephone number.
- Confirm your appointment earlier in the day to avoid long waits.

Educate

- No one knows your child as well as you do. Your doctor may never witness your child's seizures or realize when drug therapy is influencing your child's behaviour. As a parent, it's your job to inform your doctor about your child's health, state of mind, reactions during seizures and other important facts.
- Don't be afraid of giving too much detail about your child's seizures or response to treatment. This information can help your doctor to better manage your child's medication.

Understand

- At times, doctors seem to speak a foreign language. If you hear words that you don't know, ask your child's doctor to explain what they mean.
- Be assertive. If you don't understand, continue to ask questions until you're satisfied.

Be realistic

- At this time, a cure for epilepsy is beyond our knowledge and medical ability. Doctors can only help to control epilepsy. They cannot perform miracles.

Trust

- Does your child feel comfortable with the doctor? Does the doctor explain things in ways that your child understands? What about the doctor's "bed-side manner" during diagnostic tests and routine examinations? Your child's relationship with the doctor often influences his or her attitude to treatment.
- The bond of trust with your child's doctor is very important. But if you don't feel comfortable or lack confidence in the doctor, get a second opinion. Your doctor cannot refuse—it's your right.

TREATMENTS FOR EPILEPSY

Parents can play an active part in treating their child's epilepsy. For better seizure control, help your child to:

- get plenty of sleep at night
- eat three regular meals
- take anticonvulsant drugs faithfully as prescribed
- avoid alcohol or drug abuse (when older)

Your Child's Medication

Doctors usually treat epilepsy with drugs called anti-epileptics or anticonvulsants. These drugs are designed to stop seizures. Some control just one or two types of

seizure. Others have a broader range.

In some children, these drugs work so well that no seizures occur - as long as drug levels, which are measured in blood tests, remain stable. When this happens, your child's seizures are "controlled".

If drugs are stopped or given irregularly, drug levels become unstable. They may drop too low to control seizures effectively, and your child's seizures will return.

Your child should keep taking the medication as prescribed—even if he or she hasn't had a seizure in a long time. Stop medication only on your doctor's advice.

ANTICONVULSANT DRUGS

These drugs are used to treat epilepsy. Research on new epilepsy drugs is underway. The drug's generic or common name appears first (no capitals). Its brand or commercial name appears afterwards (with capitals). This brochure covers children up to age 16, even so the most recent drugs are included:

- phenobarbital
- phenytoin (Dilantin)
- primidone (Mysoline)
- clonazepam (Rivotril)
- divalproex sodium (Epival)
- valproic acid (Depakene)
- carbamazepine (Tegretol)
- ethosuximide (Zarontin)
- clobazam (Frisium)
- lamotrigine (Lamictal)
- gabapentin (Neurontin)
- vigabatrin (Sabril)
- topiramate (Topamax)

Facts About Drugs

Antiepileptic drugs come in different forms—chewable or time-release tablets, sprinkles or syrups—and different strengths. Discuss with your doctor or pharmacist which is best for your child.

Brand name and generic drugs do not always release the same amount of medication into your child's system. When your child responds to a particular drug formulation—whether brand name or generic—stick with it. Ask your pharmacist not to substitute one for the other.

Store antiepileptic drugs out of children's reach. Keep them in a dry place where humidity cannot damage them. Liquids or syrups may need refrigeration.

Order drug renewals when your child still has a few weeks' supply of medication. Don't run out. Set up an automatic reordering schedule with your doctor and pharmacist.

When travelling internationally, you'll need a note from your child's doctor that describes your child's epilepsy and prescribed medications. Take enough medication to last the whole trip.

Finding the Right Treatment

Every child responds differently to drug therapy. Your child may need to try different drugs or drug combinations over a lengthy period to find the right balance between side effects and seizure control.

All doctors will prescribe this type of “drug trial” to find the right drug and dosage for the best seizure control and least side effects.

Many children achieve complete seizure control with drug therapy; in others, seizures may lessen in number but not disappear. There is no way to predict how your child's seizures will react to drug therapy.

Unfortunately sometimes seizures cannot be controlled by drugs, or the side effects of the drugs and/or surgery are considered unacceptable. The ketogenic diet may be recommended for treatment of difficult-

to-control epilepsy in children. The diet is a rigid, strictly calculated, complex medical treatment requiring close supervision by a physician.

If your child's seizures are well-controlled for two years or more, your doctor may try to slowly reduce the dosage of drug—until your child is drug-free.

Drug withdrawal is a tricky process that should always be supervised by your child's doctor. Never try it alone. Stopping a drug suddenly can cause potentially damaging seizures or status epilepticus.

Side Effects

All anticonvulsant drugs cause unwanted side effects—to varying degrees. In most children, side effects are mild, but there's no way to predict how your child will respond. Your child may react badly to one drug but have no problems with another. Some side effects occur only at the beginning; they may lessen or disappear over time.

Ask your doctor what side effects to expect from your child's medication and what to do about them.

Find out what over-the-counter drugs—for example, pain relief, upset stomach or cough and cold medications—interact with your child's anticonvulsant drugs. These interactions can reduce the effectiveness of antiepileptic drugs, resulting in loss of seizure control.

Your child may need periodic tests or “blood work” to monitor drug levels in his or her system. This information helps your doctor to adjust the dosage for better results.

Your child's teacher and other caregivers need to know what side effects to expect or watch for when your child is at school.

Watch for side effects. Always report them to your doctor. Be alert for signs of:

- nausea
- irritability

- behaviour problems
- hair loss
- unusual clumsiness
- drowsiness
- changes in appearance or behaviour
- dulling of response
- weight gain

Call your doctor at once and bring your child in for examination if your child develops:

- fever
- skin rash
- mouth ulcers
- extreme listlessness or weakness for no reason
- pinpoint bleeding under the skin
- easy bruising
- a change in well-being

Never assume that a skin rash is due to a virus. Children can have very sensitive skin reactions to antiepileptic drugs.

A common side effect of phenytoin (Dilantin) is swelling or overgrowth of gum tissue. Good dental hygiene—regular tooth brushing and flossing and visits to the dentist—can prevent dental problems.

Long-Term Effects

Older antiepileptic drugs in use for years have shown no evidence of long-term ill effects, but doctors cannot say for certain whether lengthy treatment—over many years—is completely risk-free.

At present, the benefits of drug therapy seem to outweigh the risks.

There's no question that antiepileptic drugs have a “slowing” effect on some children. Physical coordination may be affected, too. If memory, behaviour, mood or level of activity are limited or changed in your child, discuss a change of medication with your doctor.

Some parents fear that long-term drug therapy may encourage drug abuse or dependency in their children. Most doctors believe that there is very little abuse of antiepileptic drugs. In fact, most misuse takes the form of missed doses or taking less medication than prescribed.

Giving Medication

Some drugs work better under certain conditions. Ask your doctor or pharmacist when and how your child should take the medication:

- before, after or during meals?
- in the morning?
- at bedtime?
- with or without food?
- with or without other drugs?

Regardless of seizures, never give your child more than the prescribed amount of anticonvulsant. These drugs need time to “build up” to effective levels within your child’s system—they don’t work rapidly enough to stop a seizure in progress.

Work out a schedule to ensure that your child takes the medication at the same times, every day. Use special pill dispensers, available at pharmacies, to count out a day’s supply or if you need to give the medication in sequence. Watch alarms can help you remember when it’s time to give your child’s medication.

Some drugs come in forms that children find easy to take. Others don’t. Large tablets can be crushed and mixed with a favourite food, juice or milk.

As soon as it’s practical, teach older children how to take their medication. Some parents find it easier to store a day’s supply in a special container—it’s easier to check if your child forgot to take it.

One missed dose is unlikely to trigger a seizure because it takes time for antiepileptic drug levels to drop low enough for seizures to occur. Ask your doctor

what to do if your child accidentally misses one or more doses. Usually, if one dose is missed, follow the daily schedule. If more than one dose is missed, follow the daily schedule and give your child the missed doses at bedtime. If an entire day is missed, consult your doctor. “Doubling-up”—taking two pills at once—can be dangerous. Check with your doctor first.

School rules may prohibit your child from taking any medication at school, but the school nurse is usually allowed to give prescribed drugs.

Refusing to take anticonvulsants is a common form of rebellion among teenagers.

The most important thing to remember is consistency. If antiepileptic drugs are taken regularly, seizure control will improve dramatically.

SURGERY

About 40% of Canadians have seizures not well-controlled by medication. For them, brain surgery is an alternative—one that’s chosen more and more often. Your child will need a complete neurological assessment, including detailed information about seizures and previous drug treatments. Before your doctor refers your child for surgery, he or she will want to know:

- if every effort has been made to control seizures;
- whether the seizure disorder is unlikely to disappear as the child grows;
- if repeated, uncontrollable seizures are severely compromising your child’s quality of life.

Many children with severe epilepsy have successful brain surgery. But, not all children can benefit from surgery. Sometimes, surgery can only improve the

number and severity of seizures.

Surgery for epilepsy is not the kind of operation that any brain surgeon can do. Consider a specialized centre and an experienced team of doctors who do a lot of these operations.

Your child will have extensive tests, such as 24-hour EEG monitoring and MRI scans, to help doctors discover where the seizures begin—the “epileptic focus”—and whether that area can be safely removed without affecting how the brain works. To find the focus, doctors may withdraw drug therapy and observe your child in a seizure monitoring unit.

Before surgery, find out as much as you can from the neurosurgeon:

- What are the risks?
- Why is surgery an option for my child?
- Will surgery affect my child’s memory or speech?
- What results can we expect from surgery?

Three types of operations can relieve the symptoms of childhood epilepsy:

For simple partial and complex partial seizures:

Focal brain resection removes all or part of the brain lobe where seizures begin. A focal temporal resection—the most common type of brain surgery—removes seizure generating tissue from the temporal lobe.

In rare cases:

Hemispherectomy is a rare operation that removes one side of the brain, which no longer functions due to severe brain disease. It is only done in children young enough to enable the other half of the brain or “hemisphere” to develop some functions of the missing half. This operation may improve seizure control.

For generalized seizures, unilateral multifocal seizures associated with infantile hemiplegia, violent falls with injury or Lennox-Gastaut syndrome:

Corpus callosotomy breaks the connection between the brain's two halves, so seizures can no longer spread from one side to another. This operation does not cure epilepsy but helps to reduce the number and severity of seizures.

AT HOME WITH YOUR CHILD

Parenting

What if my baby has a seizure when she tries to crawl or walk? What if my son has a seizure when I start to feed him solid food?

I get nervous when my three-year-old daughter plays with other children. Should we stay away from play groups?

Should I tell my 9-year-old more about epilepsy, so he can explain it to his friends?

My teenager wants to get involved with high-school activities? Will she be safe? What if she's not telling me everything?

Parents often worry that their child will have a seizure when learning new skills or in new situations. Like any parent, you need to encourage your child to reach

these milestones—without trying to do too much for your child.

“If your child wants to climb a tree, let him climb it. Which is worse—a broken leg or a broken heart?”

All parents of children with epilepsy struggle to find the balance between nurturing and overprotecting their children. Promote your child’s independence—his or her confidence that “I can do it myself”.

“Growing up means taking risks.”

Like all children, your child needs to try new things and learn from mistakes to grow into an independent, responsible adult. Allow your child to join in safe activities with other teenagers or children of their age. And, if your child’s friends accept your child’s epilepsy and know how to cope with seizures, safety issues will be less worrisome.

“Be reasonable when taking precautions or setting limits.”

Most parents find it difficult to set limits and rules for their children, but parents of children with epilepsy often find it especially hard. Setting too many limits—“you can’t do that”—undermines self-confidence and fosters timidity in your child. If parents set too few rules—because “my child is sick” or “my child has special needs”—their child will not learn how to manage their feelings or behaviour.

“Let your child be a child—who just happens to have seizures.”

Encourage your child:

- to learn, explore and try new situations.
- to have realistic, not pessimistic, expectations.
- to express feelings openly.
- to tell you about thoughts and ideas.
- to find ways to explain epilepsy to others.
- to accept seizures as a normal part of his or her life.
- to focus on personal triumphs and other concerns, besides epilepsy.

Your child needs parents who:

- listen
- encourage
- support
- praise
- set reasonable limits

Home Safety

A word about water—baths can be hazardous for children with epilepsy.

- Constantly supervise young children in the bathtub.
- Keep bath water levels low.
- Bathroom doors should never be locked when an older child takes a bath or shower.
- Children should never bathe or shower when at home alone.

Hand-held shower heads are preferable. If possible, water now should automatically cut off when the shower head is released to prevent the tub from filling if the drain is blocked during a seizure. When there is a conventional wall-mounted model, the child should sit in the tub during showers.

Brothers and Sisters

Like any chronic condition, epilepsy can disrupt family routines. Doctors appointments, medication schedules, special meetings with teachers and other caregivers can rob other family members of your time. Seizures, by nature, are unpredictable. They can disrupt family outings or other planned events.

When one child needs more attention, particularly over long periods of time, other children may feel loneliness and loss.

Brothers and sisters may feel ignored, left out, or neglected. They may fear that you love them less or feel jealous that you love the child with epilepsy more.

They may be afraid of catching epilepsy or having a difficult time coping with the ridicule, teasing or ignorance of their friends.

Here's what you can do:

- As much as possible, let the child with epilepsy share in the same household chores and privileges as other children.
- It may be harder for children with difficult seizures to adopt an “everything as usual” approach—especially if they must wear protective head gear. But even children with severe problems can carry out simple tasks, enjoy their success and feel like they're part of family life.
- Talk to your other children about epilepsy. Clear up any misconceptions. Help them to find ways to explain epilepsy to their friends and discuss ways to deal with teasing or ridicule at school.
- Set aside special time to spend with each child. Brothers and sisters know exactly how much time you spend with the child with epilepsy.
- Brothers and sisters are not the custodians of a child with seizures. That's your responsibility.

- Avoid limiting other children's activities because the child with epilepsy can't take part. And, when your children want to play together, encourage them to do so.
- Make back-up plans for family outings.
- Let your children know what to do or how they can help when their brother or sister has a seizure. Teach them to stay calm and call a parent or adult to help.
- When a child with epilepsy has temper tantrums, never give in. Use the same disciplinary measures for all of your children.

“Brothers and sisters need to feel included and helpful—but not responsible.”

SCHOOL DAYS

“Learning is a process that happens inside and outside school walls.”

Your child's learning experience is influenced by three things: abilities, attitudes and expectations.

Abilities

Most children with epilepsy do well in school. Learning difficulties are more often associated with behavioural than physical problems.

Since each part of the brain controls different functions—speech development, the ability to process visual information or spatial relationships—some types

of seizures may affect learning.

Occasionally, medications may cause side effects that affect learning. Some may cause hyperactive behaviour; others may interfere with concentration or shorten your child's attention span. Others may affect memory or make your child feel drowsy.

Attitudes

The attitudes of teachers and behaviour of other students affect your child's attitude towards school.

As a parent, you can create a better school environment for your child:

- Meet with teachers at the beginning of each school year to discuss how epilepsy affects your child and what to do if a seizure occurs.
- To ease anxiety, help the teacher to view the seizure as a short-term, temporary interruption.
- Share first aid and safety information to help teachers develop the “know-how” to handle seizures.
- Discuss how the teacher can help to dispel myths about epilepsy among your child's classmates.
- Arrange back-up plans to help your child keep up with missed school work—due to absence or other seizures.
- Explain how your child's medication affects school performance—by slowing your child's functional level, so your child needs more time to complete work.
- Distribute pamphlets or videos to help teachers and students understand epilepsy.

- Update the teacher on any changes in your child's epilepsy or medication.
- A letter or visit from your child's doctor or a community health nurse may reassure teachers, who are often nervous that the child will get hurt during a seizure or fear that they may do something to cause a seizure.

Expectations

Parents sometimes assume their hopes—a college education or professional career—are dashed because their child has epilepsy. Others refuse to modify their expectations at all for their child. Neither approach is good for your child.

Many children with epilepsy do well in school and find rewarding careers. They may meet with prejudice and misunderstanding, but this is less of a problem if they're well-qualified or have marketable skills.

Temporary setbacks may discourage your child if your expectations are too high—leading to feelings of failure. High expectations ignore the possibility of learning problems and effects of stress on your child.

Sports

Generally, there's no reason why a child with epilepsy cannot join sporting activities. Children and parents should use common sense and discuss the particular activity with their doctor.

Parents are usually advised to match the kind of sports activity with their child's degree of seizure control.

Most doctors would rather see children with epilepsy playing tennis than football or hockey. But, if your child has his or her heart set on playing a particular sport, the psychological benefits of playing may outweigh the physical risk.

In some sports, loss of consciousness at critical mo-

ments may lead to disastrous physical injury.

Sports not advised:

- high-tower diving
- hang-gliding
- boxing
- motor vehicle sports
- scuba diving

Participation depends on seizure control:

- hockey
- football
- soccer
- water sports—swimming, water polo, boating, water skiing

Water sports are a potential hazard, but with proper attention to safety, your child can learn to swim. A child with epilepsy should never swim alone. Supervised pools, where your child can swim with someone who has life-saving skills, are a safer environment than beaches. Keep a close watch on small children and insist on life-jackets in boats or when your child plays near water.

At local camps, pools or parks, arrange a “buddy” system for your child.

Always tell supervisory personnel—lifeguards, athletic coaches, camp counsellors, Scout leaders—about your child’s epilepsy, what kind of seizures to expect and what to do about them.

COPING WITH PREJUDICE

At School

When teachers and school officials know little about epilepsy, you may be forced to stand up for your child’s rights. Your child has a legal right to be in school—

whether or not seizures are under control. If your child has no learning problems, he or she belongs in a regular classroom—not a special education class. Your child has a right to try out for or join school sporting activities, too.

In cases like this, you may be tempted not to inform the school that your child has epilepsy—especially when seizures are well-controlled. If you don't inform the school, your child will learn that epilepsy is something to hide—a source of shame. And, a seizure may cause a major uproar and lead to more misunderstandings.

Children can be cruel. Your child may face ridicule, teasing or prejudice from classmates. Because your child just wants to “fit in”, he or she may feel isolated and rejected by peers.

You can help by:

- listening to your child's fears
- talking about how to cope with prejudice
- encouraging your child to participate in school or community activities
- equipping your child to explain epilepsy in a way that other children can understand

Family Relations

Your relatives are coming. Informed, understanding family members are an important source of support. Unfortunately, older relatives often have a different attitude about epilepsy.

They may express shock at the news and firmly but wrongly believe that seizures are:

- contagious
- somebody's fault
- a sign of mental illness
- a cause of developmental disabilities
- a sign of spiritual possession

Gently explain that medical science has discovered that these old beliefs are just not true. Calm their fears and share your knowledge of epilepsy. To lessen their anxiety, reassure grandparents that your child can participate in daily and strenuous activities.

The Neighbours

“When my daughter was growing up, she faced problems with our neighbours and their children. I told her a special secret—she didn’t have a problem, the neighbours did. Afterwards, she felt more confident. It helped her to understand that some people are ignorant because they choose to be.

Over the years, as they watched her grow into a lovely, bright, well-mannered girl, the neighbour’s attitudes did change. Now, she babysits for people on our block. But it did take much work, love, patience, understanding and confidence that everything would work out.”

You’ll probably hear some wonderful old wives’ tales—and strange remedies—when people learn about your child’s epilepsy. Some of this friendly advice may anger you, but you’ll feel a lot of satisfaction by saying, “Well, yes, that’s what people used to think. Fortunately, thanks to medical science, we know a lot more about epilepsy now.”

This is probably the first time that your neighbours

have known someone with epilepsy. They may feel the same fears or have the same notions that you once had when your child was first diagnosed.

HELP

When a child has epilepsy, even the most devoted parents are sometimes overwhelmed by their child's needs. When this happens, respite care programs may help.

Local epilepsy associations often give parents of children with epilepsy a chance to meet and share their experiences. Contact your local association to learn about their services.

*For more information on health,
employment and social services, contact
the nearest epilepsy association.*



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Registration Charity No. 13117 6042 RR0001