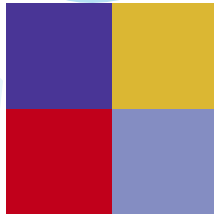


Children, Adolescents & Epilepsy



Other booklets and information available from



- What is Epilepsy?
- Living Well with Epilepsy
- Women and Epilepsy
- Elderly and Epilepsy
- Epilepsy Diary & Information Booklet
- Baby Sitter Information
- Consultation Checklist
- My Epilepsy Information Card

You can live well with Epilepsy...

Epilepsy is the most common disorder of the nervous system in the world and affects about 50 million people. However, in spite of the large numbers of people who have epilepsy, many people with the condition still face prejudice from others, often through lack of knowledge about what having epilepsy really means. Yet more people with epilepsy are realising they can live, work, have leisure occupations, enjoy normal relations and be active members of society if their seizures are well controlled.

It may be difficult to come to terms with the fact that you or your loved one has epilepsy, and you will probably be asking questions on how or why you have this condition. Try not to dwell too much on this, instead, start to focus on what you can do to better manage your epilepsy.

Just making some small changes to the way you manage your epilepsy, could make a significant improvement to your day-to-day quality of life. This booklet is a start. In here you will find out more about epilepsy, the type of seizure you have, why it is important for your doctor to know this and how the type of seizure can affect the treatment you receive. There is a **"Notes"** section at the back of this booklet for you to jot down any points you wish to ask your doctor at your next visit.

If you have a child between the ages of 6-10 you may wish to use an educational game designed to help children of this age better understand about epilepsy. If you are interested in receiving this, please go to the following link: www.action-zone.info

You may also find the “**Epilepsy Diary**” helpful in monitoring your seizure control and checking for any side effects. It can help to remind you to talk with your doctor about them, to explore the best treatment options available for you, and the possibility of stopping your seizures. Of course your doctor cannot give you any guarantees, because everyone’s epilepsy is different and the way you respond will also be different to another person. Most importantly, you will have started to explore your treatment options together with your physician.

What is Epilepsy?

Epilepsy is a disorder of the nervous system associated with repeated and unpredictable interruptions of normal brain function, called epileptic seizures (sometimes called fits).

There are many different causes of childhood epilepsy yet about three quarters of these, no cause can be found. Furthermore, epilepsy in young people differs from that in adults in a number of important aspects including:

- a greater mix of epilepsy and seizure types, causes and outcome,
- a condition that may change with age; one epilepsy type may evolve into another,
- a greater potential impact on their social, educational and behavioural development.

A diagnosis of epilepsy can have great emotional impact on both the child and the family, but children and adolescents need to be made aware that that epilepsy, if managed well, does not have to stop them from realising their goals in life

What is a seizure?

A **seizure** is the result of a brief disturbance to the brain's electrical activity. This results in the brain's messages becoming temporarily halted or mixed up. The number of seizures can vary from less than one a year to several per day. Seizures can happen at any time. They generally last only a matter of seconds or minutes, after which the brain cells return to normal.

A diagnosis of epilepsy is highest in infancy, slowly decreasing through childhood and then adolescence. A possible reason why younger children are more at risk of having seizures may be due to the fact that the brain continues to develop after birth and may not be able to fully control these seizures.

Our brains are responsible for most of our bodily functions, so what someone experiences during a seizure will depend on the part of the brain affected and how widely and rapidly it spreads. For this reason, there are many different types of seizure, and everyone will experience epilepsy in a way that is unique to them.

Seizures are classified into two types:

- Partial seizures involve a limited part of the brain, and can be either **Simple** or **Complex** - some of them can evolve to generalised seizures, involving most or all of the brain.
- Primary generalised seizures involve most or all of the brain from the start.



Simple partial seizures

These seizures do not result in the person losing contact with their surroundings (consciousness is not affected). As the brain controls most of the body's function, if a seizure occurs it usually affects the organ controlled by that part of the brain. So, for example, seizures affecting part of the brain controlling:

- The **muscles** can cause rhythmic shaking of a part of the body.
- The **sensory** organs such as:
 - Nerves: can cause tingling sensation or pins and needles in the part of the body which may or may not spread to other parts.
 - Eyes: may cause the person to see lights, objects, animals or other people.
 - Ears: may result in the person hearing sounds, voices or melodies.
 - Nose: often difficult to describe but generally disagreeable smells.
 - Tongue: disagreeable tastes.
- The **digestive system**: may cause feelings of nausea.
- The **memory or emotions**: can cause the sensation of déjà vu (the feeling you have done or been in a situation before), strange thoughts, feelings of fear, wellbeing or anxiety.
- The **heart, lungs, glands** or temperature may cause rapid heart-beat, altered breathing rates, sweating, fever or chills.

Some people may have a warning, called an **aura** (a simple partial seizure) just before losing consciousness or becoming less aware of their surroundings (complex partial seizure). An aura usually lasts just a few seconds but can be longer.



Complex partial seizures

People affected by this type of seizure lose contact with their surroundings (lose consciousness). They can be left immobile, with a fixed stare and unable to respond. They often chew or swallow, or move their hands. Sometimes, they may move as if they were conscious (in contact with their surroundings) but will act strangely, not reacting when spoken to or reacting inappropriately.

Complex partial seizures can also evolve into a generalised seizure called a tonic-clonic seizure (see below).

Generalised seizures

- **Tonic-Clonic** seizures: can produce an abrupt loss of consciousness, with the whole body going rigid at the start (the tonic phase) and, then, jerking of the arms and legs (the clonic phase). The person may bite their tongue, urinate or hurt themselves in the fall or with the jerking movements. Once the seizure is over, they will gradually recover.
- **Absence** seizures: are very short (lasting only a few seconds) but can happen many times during the day. When a person has this type of seizure they may become still and unresponsive with a fixed stare. They recover immediately. and, on many occasions, these types of seizure may go unnoticed, due to their being so short-lived. This type of seizure often begins in childhood or adolescence, and the main inconvenience is the fact that they occur very frequently which can lead to loss of attention and learning problems for the child or adolescent.

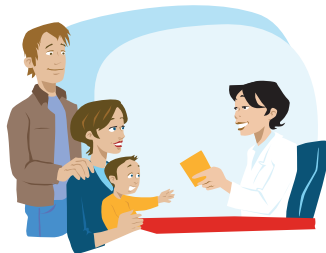


- **Myoclonic** seizures: cause a sudden jerk of the body or limbs (arms or legs), which may cause the person to drop the things they have in the hands.
- **Atonic** seizures: cause a sudden loss of muscle strength and consciousness resulting in the person falling to the floor. They recover immediately, however the seriousness comes from the risk of injury from hitting their head or falling to the floor.

Fever seizures in children are a special kind of seizure triggered by high body temperatures. In the majority of cases, children who have had a fever seizure never have one again. One way of preventing these types of seizures is to try to lower the temperature in these children, either using physical measures (removing clothes, sponging down with tepid water etc) or with medicines to bring down the temperature (such as paracetamol or child aspirin). Fever seizures are only treated with an antiepileptic drug in very rare situations.

Although the vast majority of seizures do not cause accidents, their existence causes uncertainty and insecurity in people with epilepsy, their family and friends. A series of relatively simple recommendations are sufficient to reduce the risk of injury. It is important to follow this advice especially if you have seizures that are more frequent or severe.

How is Epilepsy treated?



The goal of epilepsy management in children and adolescents is seizure freedom without unwanted symptoms (called side effects) and no long-term effects, in order to restore the best possible quality of life.

Most people with epilepsy are prescribed **Antiepileptic drugs** to re-establish the electrical balance of the brain. There are several antiepileptic drugs available today. They are used to control or, for some people, even stop seizures by reducing the sensitivity of the neurons that cause them.

The choice of treatment with an antiepileptic drug is not a random decision. According to both clinical professionals involved in the treatment of childhood epilepsies and patient support organizations, appropriate treatment for a child with epilepsy must be individualized and ought to be based on the

- specific type(s) of seizure,
- the child's age, and
- the likelihood of significant side effects.

Treating epilepsy isn't easy. Despite existing treatment options, the goal of seizure-freedom is not achieved in many of children with epilepsy. However, with the choice of drugs available it is possible that around five out of 10 children with epilepsy could become seizure-free, once the most appropriate drug and the correct dose for them have been identified, even if this could take some time to achieve.

A neurologist can best establish the type of treatment and the correct dose. It is important that the medication is taken as instructed to give your child the best chance of controlling the seizures and being able to live their life.

About Your Treatment

Antiepileptic medicines can not cure epilepsy, but they do help control the seizures. The medicines act by reducing the irritability of the neurons that causes the seizures and, thus, reducing the risk of their taking place. To be effective, the medicine has to remain at a constant level in the body and should be taken regularly.

The doctor may advise that the treatment starts slowly, with steady increases in the dosage of the medication. This is to allow the body to get used to the medicine and lessen the side effects from the medicine. If side effects appear the doctor may decide to reduce the dose for a short time before increasing the dose more slowly.

Anti-epileptic medicine may be taken once, twice or three times a day, depending on the medication and are generally taken at meal-times (before, during or after). Your doctor will advise you about how often your child will need to take the medicine he/she prescribes. The medicine should always be taken at the same time every day regardless of any changes there might be in your child's timetable. The medicine may come in different forms such as tablets, syrups, suppositories or capsules so the one most suitable for your child can be used.

If the seizures continue or the side effects become difficult to bear, the doctor may decide to change your child's medication to one that is more suitable. For many people with epilepsy, their first antiepileptic drug will sufficiently control their seizures. However, other people unable to tolerate a drug or whose seizures have not been controlled may need to change their anti-epileptic drug, or to have a second drug added to the first. Your doctor will advise if this is necessary for your child.

- **If a dose of the antiepileptic medicine has been forgotten, try to take it as soon as possible.**
- **If your child has lunch at school and needs their medicine, then the teachers and staff should be informed, in order to ensure that they do not forget.**
- **Antiepileptic medicines are not known to be addictive, but need to be taken for as long as the neurologist instructs you to do so. Never stop the antiepileptic medicine as this may cause your child to have seizures that are more serious.**
- **Some antiepileptic medicines can interfere with other medicines. Inform the neurologist if your child has other medicines to take, as there may be a need for either treatment to be modified.**

Generally speaking, epilepsies that appear during childhood or adolescence have a very good prognosis, and the probability of being able to come off the treatment at some point is very high.

Medication side effects

Any type of medication, not just anti-epileptic medicines, can have unwanted side effects. These can range from mild to severe. It is easy for a child to become used to the epilepsy treatment without realising how it is affecting them. In order to help your doctor identify the treatment that may be best for your child, it is important to be aware of the number of seizures they have (if any), and also how the medicines make them feel. Many people accept having treatment side effects as being part of having epilepsy. But this needn't be the case.

EXAMPLES OF SHORT-TERM EFFECTS

Some side effects happen at the start of taking anti-epileptic drugs, while the body is adjusting to them. Once this has happened, some of them may lessen or disappear completely.

- Sleepiness / fatigue
- Feeling unsteady, 'woozy' or dizzy
- Irritability
- Allergic reaction / skin rash (these may not disappear)

Some common side effects of anti-epileptic drugs in children include:

- skin reactions,
- sleepiness,
- difficulty concentrating, negative effects on schoolwork,
- digestive problems and nausea.

These effects are not serious and are usually related to the dose of the medicine. Some children may have an upset stomach from the medicine (either vomiting or diarrhoea).

If the child has vomited within 30 minutes of taking their medicine, you may need to give an extra dose.

If the child vomits again upon ingestion of a second dose, this may be due to a hypersensitivity to the medicine and you should consult the child's doctor immediately

EXAMPLES OF LONG-TERM EFFECTS

More troublesome side effects can happen when certain drugs are taken for a long time. They may include the following.

- Poor memory and concentration
- Slow speech, word-finding difficulties
- Swollen gums
- Acne
- Weight gain / loss
- Hair loss or thinning / excessive hair growth in unusual places

You should always inform your doctor if the child suffers from these or any other side-effects. Never stop or change the dose of the medicine yourself.

On some occasions, side effects can occur that are called idiosyncratic. These side effects do not depend on the dosage or the typical properties of a medicine, but on an individual allergic reaction to the medicine in each child. They can be dangerous and usually do not stop if the medicine is continued. Idiosyncratic side-effects often appear in the form of rashes, itches and, on some occasions, fevers and /or unspecific malaise. If you notice any of these symptoms, it is advisable to consult a doctor as soon as possible or go the Accident and Emergency department.

Over recent years, several newer antiepileptic medicines have appeared with different formulations. Some of these are thought to have fewer side effects than the older antiepileptic drugs. Your neurologist may decide to either change the dosage of the medicine or change your child's medication for one that is better tolerated.



Epilepsy in young women

There are two important sexual hormones in adolescent girls and women, oestrogen and progesterone. These hormones can affect the excitability of the neurons (the cells in the brain), and the uncontrollable discharge which lead to epileptic seizures. Generally speaking, oestrogen increases the likelihood of seizures and progesterone can reduce the seizures. Therefore, it should come as no surprise that some young women with epilepsy may suffer changes in the control of the seizures due to hormonal changes that take place during the menstrual cycle. This phenomenon is known as “catamenial epilepsy”.

You may find the **Epilepsy Diary** is particularly useful in keeping track of when your seizures occur in general and in relation to menstruation. This may help your neurologist to adjust your treatment.

Although there is no specific therapeutic recommendation to alleviate this problem some women with seizures relating to menstruation may be prescribed extra antiepileptic drugs in the days when they are more likely to suffer seizures. This can only be recommended by your neurologist.

Some young women may experience gynaecological changes such as menstrual dips, irregular cycles, etc. Although the anti-drug medicines remain just as effective in controlling the seizures, the side effects of the medication may be made more obvious during puberty resulting in weight gain, increased body hair, or hair loss (alopecia). If you notice any similar changes in your appearance discuss this with both your neurologist and gynaecologist. They will be able to find the most appropriate treatment for you.



Contraception for young women with epilepsy

Young women with epilepsy can use any type of contraceptive method (oral and non-oral hormonal contraceptives, barrier methods, those based on the calculation of the menstrual cycle, etc.). The hormonal contraceptives are believed to be the most effective for most women.



The decision regarding which method of contraception to use will depend on the choice of antiepileptic drug that best controls your seizures, with least side effects. Other relevant considerations will include:

- your individual situation,
- your age,
- the frequency of sexual relations,
- existence or not of other illnesses.

As a young woman with epilepsy, you should be aware that some antiepileptic treatments can reduce the effectiveness of contraceptives. Enzyme inducers can cause the contraceptive to be removed more quickly from the body which could lessen the protection against pregnancy. This means that women using anti-epileptic drugs known to be enzyme inducers should be taking contraceptive pills with higher levels of oestrogen.

A benefit of non-oral contraceptives (such as implants, patches or intramuscular) is that due to their high levels of progesterone, they can help reduce seizures in some women. However, these non-oral contraceptives will also be affected if your anti-epileptic drug is an enzyme inducer. Your doctor may adjust the dose of these contraceptives to increase protection against pregnancy.

- **If you notice “break-through bleeding” between your periods it may be a sign of the reduced effectiveness of your oral contraceptive pill. In this case, speak to your doctor about adjusting the dosage of oestrogen in the contraceptive.**
- **During this period of adjustment in your contraception you should use a barrier method or kits to detect possible ovulations and continue with the pill until there is no risk of pregnancy.**

Contraceptive pills may also lessen the concentrations of certain antiepileptic medicines in the blood, increasing the chances of seizures.

- **If you notice “break-through seizures” during the first three weeks of your period, it may be a sign of the reduced effectiveness of your antiepileptic medicine. In this case, speak to your doctor about adjusting the dosage of the antiepileptic medicine or a change of the contraceptive method.**

All young women with epilepsy should be given detailed information on the pregnancy and contraception so that you are aware of the possible complications and risks. Try to make an appointment with your neurologist and a gynaecologist to discuss these issues and your options.

Information for Family and Friends

A diagnosis of epilepsy has a great emotional impact on the child, their siblings and their family. All children should be happy and epilepsy should not represent any kind of problem for them. One of the biggest issues to address is the taboos surrounding epilepsy. The family can help by answering their questions about the illness and to seek the advice of your neurologist whenever possible.

Children and adolescents with epilepsy need to be made aware that they can do what most people of their age do with just a few simple checks to ensure they are safe. They, like everyone else want to learn how to look after themselves, to understand the importance of taking their anti-epileptic medicine and to be allowed to take part in activities. Here are a few suggestions that may be useful:

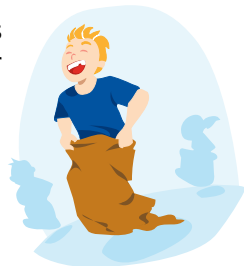
Tips around the Home

- When cooking, use back burners on the hob and keep the handles of the pots facing to the back of the cooker.
- Always put knives away inside drawers.
- Always open the cold tap before opening the hot tap.
- Try not to buy clothes/materials that require ironing at very high temperatures.
- Encourage older children to use the shower (it's also faster than taking a bath).
- Use the hand rail when climbing up or down stairs.

Staying Healthy

Just like everyone, it is important that children and adolescents with epilepsy maintain a well-balanced lifestyle to keep their bodies healthy. Some simple tips to do so:

- Eat good healthy well-balanced diet.
- Sleep well and try to limit workload and stress.
- Avoid stimulants such as coffee, alcohol and noise.



Keeping fit

Children and adolescents can take part in all kinds of sports. They should only avoid those that represent a special risk: climbing, scuba diving and parachuting.

The majority of well-run leisure activities and sports are possible and highly recommended. If their seizures are well controlled and they are able to tolerate the treatment there should not be any affect on your sporting performance.

Some simple safety checks:

- If swimming or playing water sports make sure they are with someone who knows about their epilepsy and what to do in case of a seizure.
- Follow all safety recommendations: use a helmet when cycling, skiing or horse-riding, wear appropriate clothing, etc.
- If on a sports course, inform the teacher, supervisor or trainer about your child's epilepsy, what to look for as a sign a seizure and what to do if they have a seizure.

If in doubt about a particular sport, ask your doctor.



At school

Epilepsy does not have to affect your child's progress and success at school. Above all, what is required is understanding and support from the family and school, in order to avoid both discrimination and overprotection.

If the epilepsy is well managed there is no reason why children and adolescents should not be able to receive the same schooling as other children. It is advisable that teachers are informed about the child's epilepsy and what to do in event of a seizure at school etc. You may decide to give an “**information card**” to the teacher at start of the school year. Thus, if they know the child has seizures, the teachers can help them in the best possible by knowing:

- what to look for,
- how to avoid injuries during a seizure,
- how to explain to the other children what has happened and teach them not to be afraid of seizure happening again,
- who to call in an emergency.

Watching television and playing computer games

Watching television or using computers or videogame consoles are not harmful. Only people who suffer from photosensitive epilepsies (those whose seizures can be provoked by flashing lights at a certain frequency, such as disco lights, TVs, videogames or computers) may have to take some additional precautions. Children with epilepsy can work with computers if the conditions are well managed:

- Modern computer screens are better at avoiding glare and reflections that may trigger a seizure.
- Look at the possibility of fitting a filter on their computer screen to further reduce irritating reflections.

Travelling well

Children with epilepsy can travel by plane or any other form of transport. The type of transport (plane, train or car) will not aggravate epilepsy but may cause stress and or lack of sleep that could trigger a seizure.

Some ideas to make your child's journey easier:

- Antiepileptic medication should be taken at the right time.
- Take extra medication with (enough for a longer period than the planned trip in case of unexpected events like a late departure).
- It may be useful for the child or adolescent to carry an **Epilepsy Card** explaining their condition and treatment (translated into English or into the language of the country you are visiting).
- Choose the destination well! Opt for a relaxing holiday “without too many adventures” in a country where the climate is not too hot.
- Adolescents should be made aware that alcohol or drugs (marihuana or others) may trigger seizures.
- If adolescents go out to parties, they should get extra sleep during the day (a siesta).
- Children can be vaccinated like anyone else.



First Aid for Seizures :

Many people seeing someone having a seizure can be distressing because they do not know what to do. You may decide to explain to close friends or family members how they can help if your child should have a seizure. This section can be used to explain simple first aid for seizures.

There are many different types of seizure. Most epileptic seizures last somewhere between a few seconds and a few minutes. These may be single and isolated or may occur in a series of seizures. In some seizures the person may lose consciousness and not be aware of what is happening.

After a seizure the person may be confused. Their confusion may last longer than the seizure itself and may be dangerous. Make sure the person when recovered, knows the day, where they are and where they are going next.

Most seizures are not medical emergencies. They usually end after a minute or two and do not require a trip to the Emergency Room. But sometimes there are good reasons to call for emergency help; a seizure in someone who does not have epilepsy could be a sign of a serious condition. Other reasons to call an ambulance include:

- A seizure that lasts longer than 5 minutes.
- Slow recovery, a second seizure, or difficulty breathing afterwards.
- If the person remains confused or not fully aware of their surroundings.
- If the person is pregnant or has a medical condition.
- If the person has any signs of injury or sickness.

Importance of Regular Reviews with a Specialist

Inform the doctor if your child has problems with the medication, or if you notice:

- side effects that are having an impact on their day to day life,
- an increase in seizures,
- a new type of seizure,
- their seizures last a longer time.

Your doctor may decide an appointment with an epilepsy specialist is appropriate. This will be an opportunity for you to find out about any treatment options that could offer improved seizure control and fewer side effects.

Even if you and your specialist decide not to change your medication, there may be ways of reducing the side effects you are experiencing, or the control you have over your seizures. Your specialist should be able to discuss those options with you.



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