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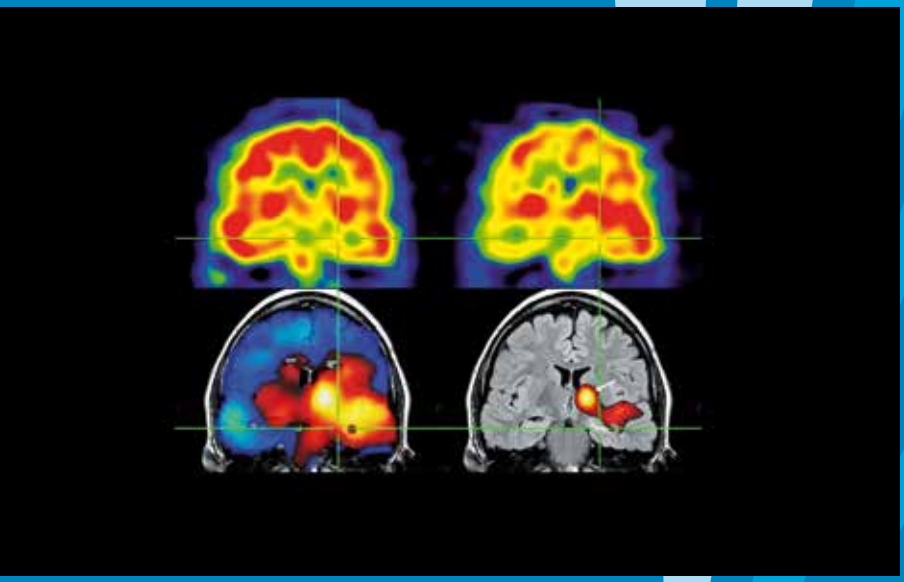

Epilepsy

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Introduction

Epilepsy occurs more often than you think: approximately one in 200 people suffer from active epilepsy. The disorder is also associated with a lot of uncertainty and misunderstanding.

You will have been provided with this brochure because you are confronted with epilepsy as a patient, or as a family member or acquaintance of a patient.
Diagnosis and treatment of epilepsy raise quite a few questions. This brochure aims to provide initial answers. Epilepsy can also have an impact on various aspects of your day to day activities. For example, safety at home, your driving licence, travel, study, pregnancy etc. We also provide initial guidelines concerning these aspects.

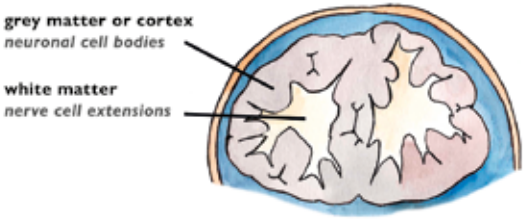
Obviously, you can also contact the doctor in charge of your treatment for more information. Please do not hesitate to submit your particular questions to them.

The medical team and staff of the pediatric and adult neurology department

WHAT IS EPILEPSY?

EPILEPSY: A 'SHORT CIRCUIT'

In order to understand epilepsy we need to gain an insight into the functioning of the brain, as everything we do and think is controlled by the billions of cells in our brain.



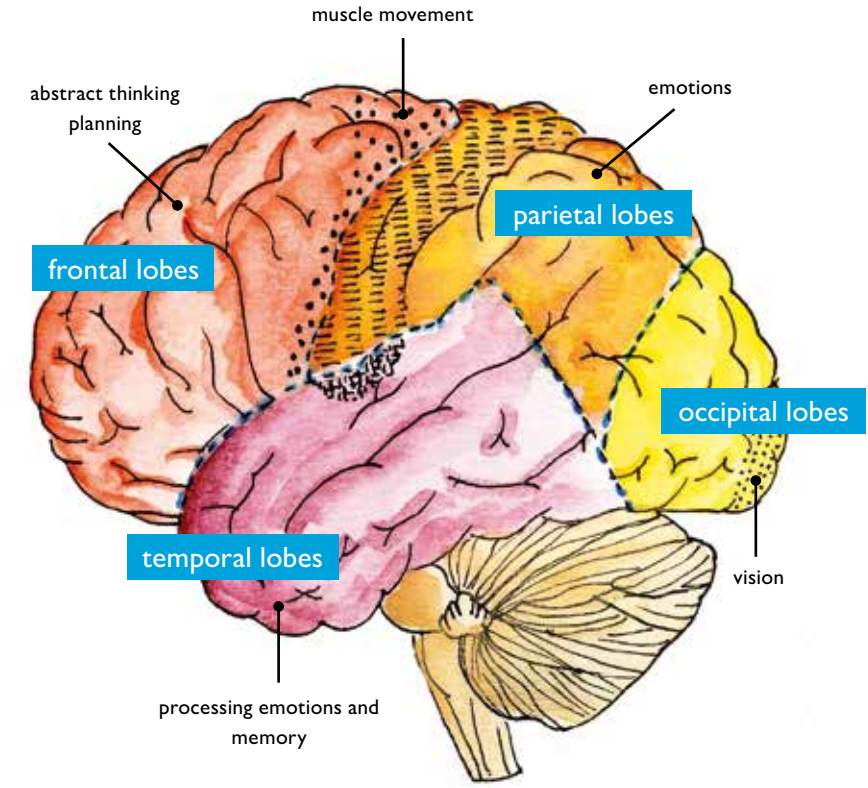
Our brain consists of grey matter (the cortex) and white matter. Grey matter contains neuronal cell bodies and white matter nerve cell extensions. These neurons are in fact **electrical cells**: to transfer messages to other cells and organs electrical discharges occur and chemical substances are released. These impulses are then transmitted via the nerve cell extensions. For example, if you want to move your leg the impulse is transmitted to the relevant muscles in your leg.
An epileptic seizure is in fact a kind of **short circuit**: a sudden abnormal discharge in a group of nerve cells in the brain that has a specific impact on the patient. We only diagnose epilepsy when someone suffers repeated epileptic seizures with the cause originating in the brain. In the absence of a seizure the brain usually functions completely normally again and the person suffering from epilepsy will show no symptoms.

Epileptic seizures manifest themselves in different ways. There are several types of seizures: the sufferer may become rigid, perceive unusual smells, make uncontrolled movements, suffer a brief

absence seizure etc. The exact effect of the short circuit depends upon which nerve cells are involved. In fact there is no single type of epileptic seizure. There are **different types of epileptic seizures** which your doctor will discuss with you.
Why do epileptic seizures manifest themselves in so many different ways? This is related to the division of tasks within our brain.

OUR BRAIN: AREAS AND TASKS

The large brain consists of four lobes, which are each responsible for their own specific tasks.



An epileptic discharge in an area of the frontal lobe (at the front) will, for example, have an effect on muscle movement and often coincides with intense motor function. A short circuit in the occipital lobe (at the back) will have an impact on vision. To put it in a nutshell: the area in the brain where the short circuit occurs will determine the type of symptoms and indicators.

IS EPILEPSY QUITE COMMON?

Epilepsy occurs more frequently than people think, as demonstrated by the following statistics.

- ✔ One in 20 people has suffered an epileptic seizure at some point in their lives.
- ✔ One in 200 people suffers from active epilepsy.
- ✔ Every year one in 2,000 people develops epilepsy.

In Flanders (approximately 7 million inhabitants) this implies that approximately 35,000 patients suffer from active epilepsy and that 3,500 new patients develop epilepsy every year.

TYPES OF EPILEPTIC SEIZURES

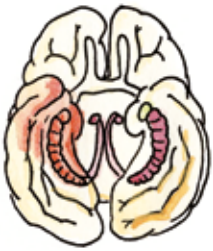
There are two main types of epileptic seizures:

- ✗ **focal seizures:** which start in one part of the brain;
- ✗ **generalised seizures:** which start across both brain hemispheres (left and right).

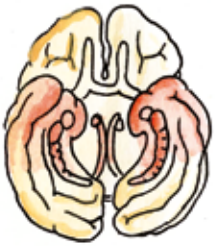
It is vital to recognise and differentiate between the types of seizures, as this will determine the choice of anti-epileptic drug.

FOCAL SEIZURES

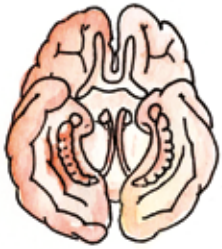
There are three types of focal seizures:



focal aware seizures



focal impaired awareness seizures



focal bilateral tonic-clonic seizures

Focal aware seizures or auras

These seizures are limited to part of the brain. A person who suffers a focal aware seizure remains **aware and alert**. The patient is consequently well aware that they are suffering a seizure and can describe what they feel.

These seizures can manifest themselves in different ways depending on the part of the brain that is affected.

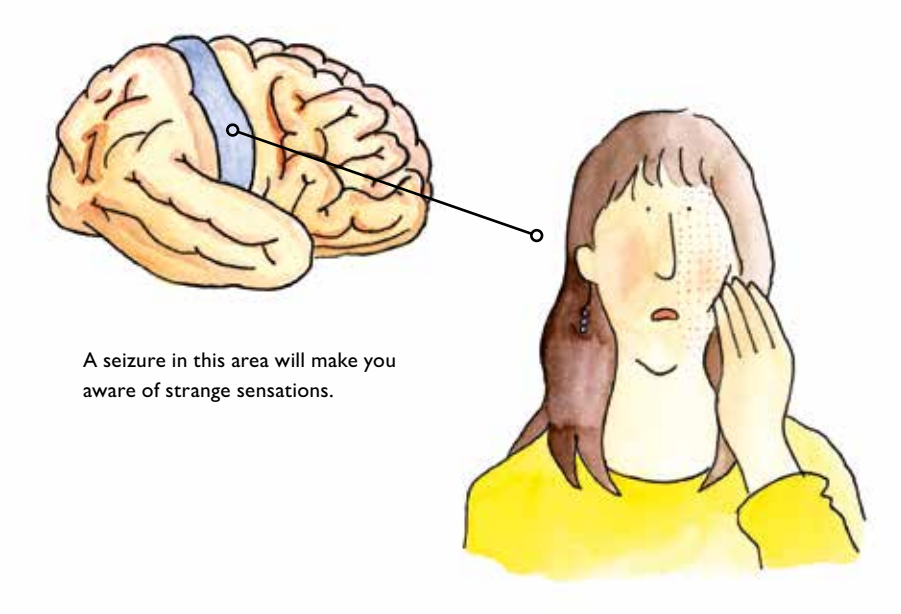
Symptoms

✗ **Motor seizures:** the seizure causes sudden spasms or shocks, e.g. in the arm and face.

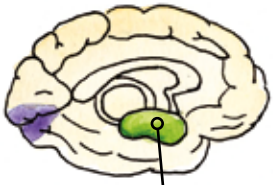
A seizure in the 'motor strip' of the brain (pink area in the illustration) has an effect, for example, on the hand, leg, arm or face.

✗ **Sensory seizures:** the seizure causes a sudden sensation. The patients feels (e.g. tingling), sees (e.g. flashing lights, colours), hears (e.g. smells, whooshing or buzzing sounds, words or music), smells or tastes (usually an unpleasant smell or taste) something unusual.

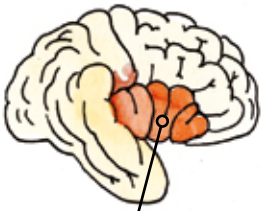
The following drawings illustrate the various types of sensory seizures. With each sensation (feeling, smelling, tasting Something, etc.) the part of the brain responsible for it is also coloured in.



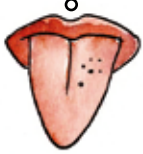
A seizure in this area will make you aware of strange sensations.



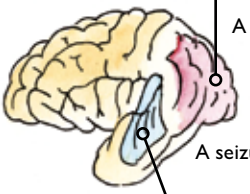
A seizure in this area will make you notice strange smells.



A seizure in this area will make you notice strange tastes.



A seizure in this area will make you see strange things.



A seizure in this area will make you hear certain things.

✗ **Autonomic seizures:** becoming pale, perspiring, developing goosebumps or heart palpitations, hyperventilating, feeling nauseous.

Feeling nauseous

A hot flush

✗ **Emotional seizures:** developing indescribably strange sensations, anxiety, confused sense of time, a feeling that something has happened before (déja vu), feeling as if you are dreaming, difficulty finding words.

Focal impaired awareness seizures

Focal impaired awareness seizures are limited to part of the brain, but always associated with **impaired or loss of consciousness or awareness**. This may occur from the outset. A focal aware seizure can progress to a focal impaired awareness seizure.

Symptoms

Focal impaired awareness seizures can also manifest themselves in different ways depending on which area of the brain is involved:

- ✗ no response when the patient is spoken to;
- ✗ no reaction to pain impulses;
- ✗ the patient does not recognise people;
- ✗ subconsciously performing automatic activities (e.g. rubbing hands, wriggling, walking around, etc.);
- ✗ staring;
- ✗ unusual facial movements (grimace, smacking, swallowing, etc.);
- ✗ repeating the same thing time and again;
- ✗ shouting;
- ✗ cycling movements with both legs;
- ✗ an arm stiffening

etc.

Automatic movements with complex focal activities

What can you do to assist?

Patients may sometimes put themselves at risk during impaired awareness seizures, e.g. by touching something that is hot or by walking into a busy street. Even after the seizure the patient may be confused and disorientated for a few minutes ('postictal confusion').

Physically restraining a patient may make them aggressive (this is a subconscious reaction that they will not remember). It is not advisable, therefore, to take hold of the patient. Better to assist them in a different way, e.g. by removing hazardous objects, by talking to them, by taking protective measures inside the home, etc.

You should not take hold of the patient if they are confused and disorientated after a seizure.

Focal bilateral tonic-clonic seizures

These seizures start as a focal aware seizure or impaired awareness seizure. However, the localised short circuit in the brain then spreads to the entire brain.

Symptoms

During a **focal bilateral tonic-clonic seizure** the patient is unconscious and makes jerking movements. This is also referred to as **a 'grand mal' seizure** and is the type of seizure that people often associate with epilepsy.

Will sometimes be preceded by an aura

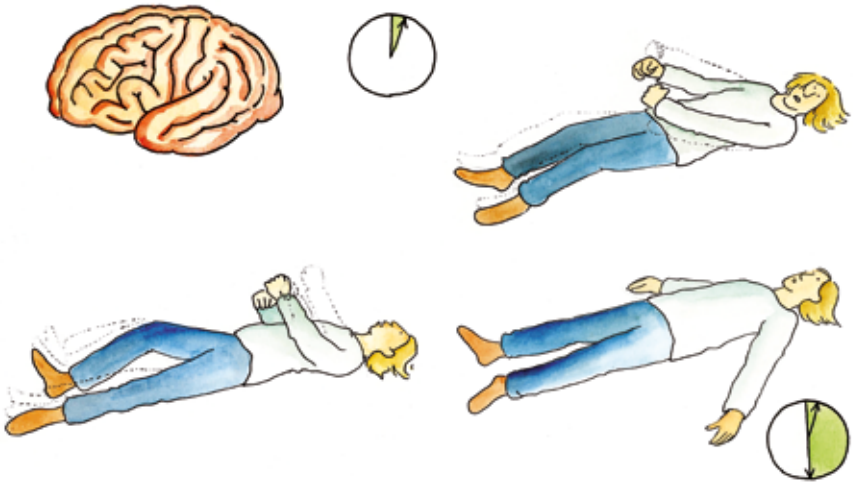
Sometimes this will be preceded by an aura (see: focal aware seizures). How the aura is perceived may differ substantially, depending on the area of the brain where the discharge started. Patients may briefly see flashing lights, notice strange smells, perceive strange emotions or feel nauseous. If you perceive and recognise an aura it is advisable to lie down or retire to a safe place.

Next: the tonic-clonic seizure

The tonic phase will happen first: the muscles stiffen and the patient becomes rigid as a result of the discharge in the brain. This is followed by the clonic phase: the brain defends itself and the muscles relax. Another short circuit will then occur followed by another defensive response by the brain, etc. This sequence of cramping and relaxation results in jerking and spasms of the body. On average this phase lasts **one minute**.

The strong contractions also affect the breathing muscles: forcing air out of the lungs resulting in a specific cry or moan at the start of the seizure. The patient's face may become bluish and saliva will accumulate because the patient cannot swallow. The cheek muscles also stiffen so the tongue can inadvertently be bitten resulting in slight loss of blood from the mouth.

The jerking movements will gradually slow down and the body will relax again. Sometimes this may lead to loss of urine or vomiting.



The sequence of tonic (cramping) and clonic (relaxation) phases results in jerking of the body. Eventually the body will relax again and the patient will briefly remain unconscious (postictal phase).

Followed by: brief period of unconsciousness

In the end the brain will suppress the tonic-clonic seizure. During this 'postictal' phase the patient will briefly remain unconscious and comatose as a result of exhaustion of the brain.

This should end after **maximum 30 minutes** and the patient should be conscious again. During the postictal phase breathing will return to normal with jerky and loud snoring sounds: saliva is mixed with air resulting in foaming at the mouth. If this contains specks of blood (as a result of biting the tongue), the foam will be pinkish in colour.

What can you do to assist during a tonic-clonic seizure?

There is in fact little you can do: the seizure itself lasts on average one minute and will usually end spontaneously. There are, however, a few important guidelines.

What you **can do**:

- ✗ ensure that the patient doesn't injure themselves (e.g. remove hazardous objects in the vicinity);
- ✗ free the airways (e.g. loosen a tie or open the upper part of a shirt);
- ✗ place the patient on their side (to allow saliva and where necessary vomit to escape).

What you **must not do**:

Placing something between the patient's teeth is based on misunderstanding.

Don't do this. It does not help and may lead to injury to the patient or yourself.

When should you call a doctor or ambulance?

- ✗ in the event of a tonic-clonic seizure (stiffness + jerking) that lasts more than five minutes, or if the seizures recur in rapid succession;
- ✗ if it is the first time the person has an epileptic seizure;
- ✗ if confusion persists for more than thirty minutes after the seizure; it should be possible to converse with the patient again after fifteen to thirty minutes;
- ✗ if the patient injures themselves or swallows something during the seizure.

Memorise the emergency number, 112, to call the emergency services. This number can be used throughout Europe.

GENERALISED SEIZURES

With a generalised seizure the abnormal discharge occurs suddenly **across the entire brain**. It always coincides with **a loss of or impaired awareness**: the patient will not remember what happened during the epileptic seizure.

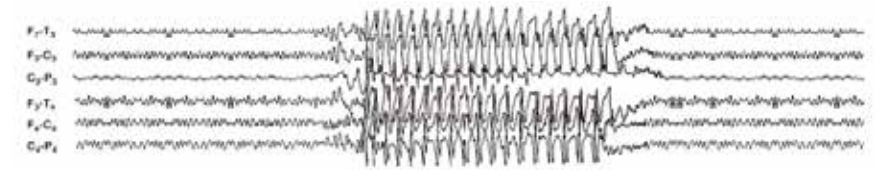
There are different types of generalised seizures.

Absence

Absence literally refers to being 'absent'. With absence the patient is 'briefly absent': there is a brief period of impaired awareness that starts and ends suddenly. These kinds of seizures last five to ten seconds during which the patient suddenly stops an activity and then equally suddenly takes it up again as if nothing happened. That is why the people around them sometimes don't even notice.

During the seizure, the patient will stare blankly ahead and will not respond to their environment, which may coincide with rolling eyes or fluttering eyelids. Sometimes slight trembling of the hands or around the mouth and eyes may occur, not unlike daydreaming.

Absence seizures typically occur during **childhood**. They generally respond well to treatment and usually disappear during puberty.



During an absence seizure the patient is ‘briefly absent’ for five to ten seconds. This also shows up during an EEG (the lines above the drawing): during an absence seizure the EEG will suddenly record intense spikes that point to epileptic discharges in the brain.

Myoclonic seizure

During a myoclonic seizure, the muscles will suddenly contract resulting in a small shock. Sometimes it can be a series of shocks. The attack is very brief, which is why the impaired awareness is hardly noticeable.

Tonic-clonic seizure

This is the type of seizure that most people associate with epilepsy: the patient loses consciousness, becomes rigid ('tonic' phase), makes jerky movements ('clonic' phase), air is forced out of the lungs, cheek muscles become tense, saliva is mixed with air resulting in foaming at the mouth (pinkish in colour if stained with blood as a result of the patient biting their tongue).

The symptoms are consequently the same as with a focal bilateral tonic-clonic seizure. The difference lies in how the seizure starts: with one type it starts in part of the brain and only becomes generalised during a second phase. With the other the seizure is initiated across the entire brain and the patient consequently enters the tonic phase immediately.

The guidelines for **assistance** are the same as for a focal bilateral tonic-clonic seizure (see pages 15 and 16).

Clonic seizure

This type of seizure only results in muscle contractions, usually in the arms or legs.

Tonic seizure

With a tonic seizure the patient loses consciousness and the muscles stiffen, resulting in a cramped, distorted posture. Standing up may cause the patient to fall flat on the floor. Obviously, they are at risk of injuring themselves and appropriate preventive measures (e.g. wearing a helmet) may be necessary. On the whole recovery from the seizure is quick.

Atonic seizure

During an atonic seizure, the patient loses consciousness and the muscles suddenly lose strength. This means that someone can suddenly collapse without warning and fall to the ground. These patients often wear a helmet to prevent injuries. The period of unconsciousness is often brief and the patient will immediately stand up again.

EPILEPSY SYNDROMES

In addition to the types of seizures, we can also classify syndromes or types of epilepsy. A specific epilepsy syndrome is characterised by a series of symptoms that are typical of that specific disorder.

An epilepsy syndrome is characterised by:

- the types of epileptic seizures: focal, generalised, or a combination of both;
- the image, whether or not abnormal, on the EEG (electroencephalogram);
- the cause: e.g. hereditary, a brain trauma etc.;
- other epilepsy related disorders: e.g. psychological disorders, learning difficulties etc.;
- the prognosis: how does this specific type of epilepsy progress?
- the treatment: what is the most effective treatment for this type of epilepsy?

By noting the characteristics of a patient's epilepsy, the doctor tries to arrive at a diagnosis of a specific syndrome for each patient. This makes it easier to choose a suitable therapy and predict how the disorder will progress. Unfortunately, it is not always possible to classify an individual patient's epilepsy as a specific syndrome or type.

TYPES OF EPILEPSY SYNDROMES

There are focal, generalised and combined epilepsy syndromes.

Causes of epilepsy syndromes:

- ✗ **Genetic:** these types are hereditary.
- ✗ **Structural:** there is an abnormality in the structure of the brain, e.g. a brain tumour or brain contusion following an accident.
- ✗ **Metabolic:** a metabolic abnormality causes epilepsy.

- ✗ **Infectious:** epilepsy is caused by an infection, e.g. malaria, tuberculosis, HIV.
- ✗ **Immunological:** epilepsy can be caused by antibodies that bind to brain tissue, e.g. anti-NMDA antibodies.
- ✗ **Unknown**

Comorbidity disorders

Some epilepsy syndromes coincide with other disorders such as autism or an intellectual disability.

Special syndromes

These are epileptic seizures that only occur in specific circumstances. Strictly speaking they are not really epilepsy.

- ✗ **febrile seizures:** febrile seizures are associated with tonic-clonic seizures or complex focal seizures. Approximately 5% of children will suffer one or more febrile seizures if their temperature rises too quickly. This usually doesn't require any treatment. If the seizure continues for more than five to ten minutes it is advisable to call the 112 emergency number. The risk of children suffering from febrile seizures subsequently developing epilepsy is very small.

- ✗ **Acute symptomatic epileptic seizures:** these are the kind of seizures that anyone could actually suffer from in the right circumstances. These seizures are usually caused or triggered by an acute medical or neurological disorder. For example, a brain trauma, CVA (a stroke), meningo-encephalitis (inflammation

of the brain and meninges) or diabetes can cause an epileptic seizure. Moreover, drug use and withdrawal from alcohol, for example, can also cause this type of seizure. When the cause of the acute symptomatic seizures is removed (e.g. the diabetes is treated) the seizures will stop. There is clearly a causal link, these types of seizures do not recur and anti-epileptic treatment is not required in the long term.

Frequently occurring syndrome: juvenile myoclonic epilepsy

'Juvenile' implies that this type occurs in young people. 'Myoclonic' refers to the type of seizure: muscle jerks.

This type of epilepsy is **characterised as follows:**

- It is one of the most common epilepsy syndromes (5 to 10% of all epilepsy cases).
- It usually starts between the ages of 12 and18, around puberty.
- It typically manifests itself in the morning when the person gets up as a myoclonic seizure, i.e. a brief series of muscle spasms, often in the arms.
- Occasionally tonic-clonic seizures will occur.
- Absences also occur in about one third of patients.
- These seizures are caused by lack of sleep and excessive alcohol consumption. Typically this will occur when, for example, a teenager, having finished their exams (lack of sleep), attends a party (alcohol).
- In 30 to 40% of cases the seizures are triggered by 'photo sensitivity': flashing or flickering lights causing a seizure (e.g. television screen, computer, stroboscopic light, sunlight 'flickering' through the trees whilst travelling in a car).
- An MRI scan will record a normal image. An EEG will show a normal background image with generalised epileptic abnormalities.
- Predisposition or hereditary factors will play a key role in determining the cause.
- Treatment is highly effective: with medication (Depakine® or Keppra®) 80 to 90% of patients will not suffer any seizures. Medication will have to be taken for life though.

TRIGGER

Some circumstances, e.g. lack of sleep, stress, alcohol use or flashing lights, are more likely to trigger an epileptic seizure. This should not be confused with the cause of the epilepsy. Epilepsy is present due to an underlying brain disorder but an actual seizure is more likely to be triggered by certain factors.

TRIGGER: PHOTO SENSITIVITY

In the case of photo sensitivity epileptic seizures can be triggered by flashing lights. Sometimes this phenomenon will be highlighted in the media, usually when children spend too much time gaming or watching TV. A minority of patients with epilepsy (less than 5%) are sensitive to flashing lights. Photo sensitivity mainly tends to be a trigger factor in children and adolescents. This type of epilepsy is also referred to as **photo sensitive epilepsy**.

The most common 'triggers' with photo sensitive epilepsy:

- ✔ television
- ✔ computer screens
- ✔ driving when sunlight flickers through a row of trees
- ✔ sunlight flickering on water
- ✔ stroboscopic light

Preventive measures to be taken if you are photo sensitive.

- Avoid tiredness: it increases the risk of photo sensitive epileptic seizures.
- Avoid sitting too close to the screen.
- Use the remote control to 'zap' channels on the TV, not the unit itself.
- Do not watch a badly adjusted TV set.
- Preferably watch on a 'high frequency' TV set (100 Hz or above) as this projects a more restful image.
- Reduce the on screen clarity.
- Ensure that you have appropriate background lighting.
- Avoid environments with stroboscopic lights.

WHAT IS THE PROGNOSIS OF EPILEPSY?

The prognosis differentiates between four types of epilepsy.

Mild epilepsy: no treatment is required, the epilepsy will disappear spontaneously after a brief period.	30% of cases
This type of epilepsy can successfully be controlled with anti-epileptic drugs. It will be followed by remission: seizures reduce in number or disappear altogether.	30% of cases
Chronic epilepsy that only partially responds to medication.	20% of cases
Chronic epilepsy that is difficult to control with medication.	20% of cases

NOT TO BE CONFUSED WITH EPILEPTIC SEIZURES

Some non-epileptic seizures or disorders can mistakenly be confused with epilepsy. When arriving at a diagnosis it is important to exclude these disorders ('differential diagnosis') because the treatment will be different.

Confusion associated with epilepsy can occur with:

- ✗ syncope or fainting (often coinciding with several jerking movements)
- ✗ metabolic disorders
- ✗ migraine
- ✗ CVA: a stroke
- ✗ motor disorders
- ✗ hyperventilation and panic attacks
- ✗ psychological or emotion related non-epileptic seizures

PSYCHIATRY AND EPILEPSY

Half of all patients with non-controlled epilepsy also suffer from psychological problems, frequently depression and anxiety. They could be caused by epilepsy, but also by anti-epileptic drugs, a brain disorder or social circumstances.

Approximately10% of patients who suffer from seizures that are difficult to treat have psychogenic non-epileptic seizures, which should preferably be the subject of psychiatric treatment rather than using anti-epileptic drugs.

LEARNING DIFFICULTIES AND EPILEPSY

- Learning difficulties are prevalent in approximately 20% of the population.
- Approximately 20 to 30% of patients with learning difficulties also suffer from epilepsy.
- 50% of patients with severe learning difficulties are affected by epilepsy.
- Both epilepsy and learning difficulties could be a symptom of an underlying brain disorder.

HOW IS EPILEPSY DIAGNOSED?

CONSULTATION

Before making a diagnosis the doctor will initially listen intently to what you have got to say. They will make a diagnosis primarily on the basis of a **detailed description of a seizur**e, or where applicable referring to a video clip (mobile phone, video camera, etc.) that you can provide.

The doctor will discuss the different types and frequency of these seizures. They will also ask you to keep a **seizure diary** recording the frequency of these different types of seizures.

You need to enter how often the seizures occur and use an agreed symbol for each type of seizure. An example of a seizure diary is included as an appendix to this brochure.

If you are attending an epilepsy consultation for the first time please complete the **questionnaire**, which is also included as an appendix to this brochure and bring it with you to the consultation. People are increasingly providing digital video clips of their seizures.

Epilepsy consultations

- ✗ Are always by appointment only.
- ✗ Take place on Tuesday, Wednesday or Friday.
- ✗ Tel. +32 (0)16 34 48 00 or +32 (0)16 34 48 01
- ✗ Where do they take place? Address: Gasthuisberg Campus, Herestraat 49, Leuven. Follow the arrows in the reception area to the outpatient centre: orange arrow, ground floor level 0, gate 2. Consultations in the outpatient centre are held in the basement level -1.

TYPES OF EXAMINATIONS

When the doctor arrives at a clinical diagnosis of epilepsy, we will perform a number of tests in the hospital to confirm this diagnosis and identify the cause.

The following **three examinations** will be performed **for every patient**.

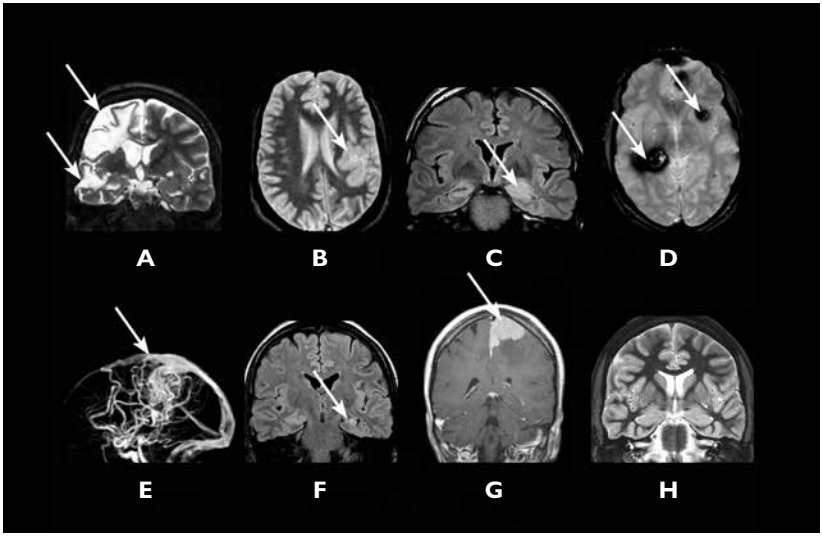
1. Blood test

Before starting treatment with anti-epileptic drugs a general blood test will be performed focusing on salt, sugar, protein, liver and kidney function. The blood test will enable us to check whether the seizures might be caused by inflammation, an infection or toxic substances. The doctor will also check the composition of the blood. Irregularities in blood composition can also cause seizures, e.g. low levels of calcium or sugar in the blood. Genetic or immunological tests can also be performed via a blood test.

2. Magnetic Resonance Imaging (MRI) scan

An MRI scan provides the doctor with a detailed picture of the structure of the brain, to enable them to try and identify the underlying disorder and make a prognosis.

An MRI scan lasts approximately 30 minutes. Some people may suffer from claustrophobia because the scan involves being moved into a narrow tunnel like tube. However, the tunnel is well lit and airy and you will be able to communicate with the medical team at all times. You won't feel anything during the examination but you will hear regular knocking sounds.

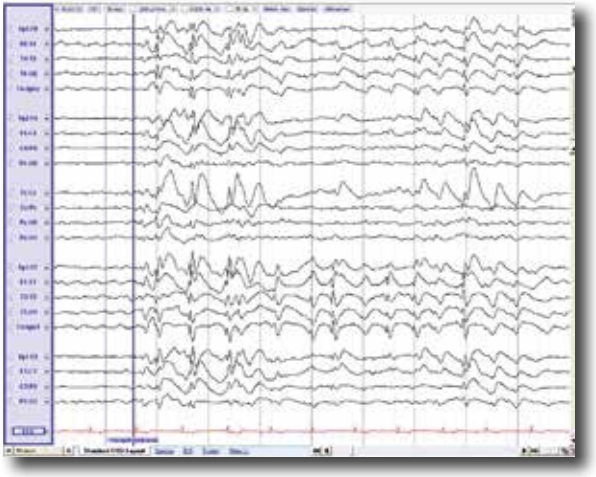


The most common epileptic lesions that cause focal seizures that are difficult to treat are clearly visible on an MRI scan of the brain. All lesions on images A to G are indicated with a white arrow. Image H shows a normal scan.

3. Electroencephalogram (EEG)

With an EEG, electrodes will be attached to your head. An EEG depicts electrical brain activity as a series of waving lines, which correspond with separate regions of the brain.

During epileptic seizures discharges occur in the brain which are usually visible on an EEG as **spikes or spike waves**.



An EEG enables us to differentiate between epileptic and non-epileptic seizures and establish whether it involves focal or generalised seizures. Photo sensitivity is also measured, i.e. during an EEG we project stroboscopic light and check whether this has an effect on the EEG. An EEG is also a crucial tool to investigate whether a patient qualifies for epilepsy surgery.

Epileptic abnormalities already show up on the first EEG in approximately half of all epilepsy patients. After four EEGs the abnormality is visible on the EEG in 80 to 90% of epilepsy patients. Approximately1 to 2% of people who don't suffer from epilepsy still produce an epilepsy disrupted EEG.

With a **24 hour video EEG** you have to come to the hospital to be wired up with electrodes for 24 hours. This usually starts at 08.00 or 09.30 hrs and continues until the following morning. The

main advantage of a 24 hour EEG is that we can study brain activity for a longer period of time, and when the patient is asleep, which is not possible during a routine EEG. With certain types of epilepsy the epileptic changes only occur during sleep.

Other examinations may also be carried out depending on the individual situation.

Video EEG

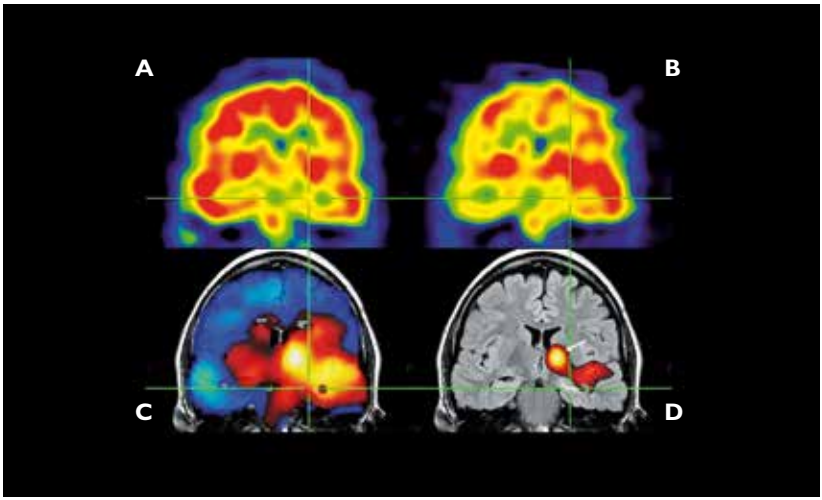
A video EEG makes it possible to study the clinical characteristics of a seizure. For this type of examination you will be admitted to hospital for 24 hours or for a week. An EEG will be taken during a seizure and a contrast medium will be injected in order to be able to conduct a SPECT scan. You will also be filmed with a video camera during this examination. These recordings are used to make it possible to relate certain behaviours to changes in the EEG.

SPECT scan (Single Photon Emission Computerized Tomography)

A SPECT scan creates an image of the relative blood circulation in the brain. This technique allows us to establish where in the brain the epileptic focus is situated. A SPECT scan is particularly important to evaluate whether a patient qualifies for epilepsy surgery and can often avoid invasive EEG studies.

If, during a SPECT scan, the injection is administered at the time of an epileptic seizure (i.e. during the seizure or 'ictus') we refer to it as an **ictal SPECT scan**. This scan clearly shows the location of increased blood supply and is consequently an excellent technique to identify the origin of the epileptic seizure. We will then conduct a second SPECT scan during which the injection is administered when you are not suffering a seizure.

This is referred to as an **interictal SPECT**. This second SPECT scan is then compared to the ictal SPECT using a computer. The remaining image (the difference image) will clearly show where there were signs of epileptic activity during the injection.

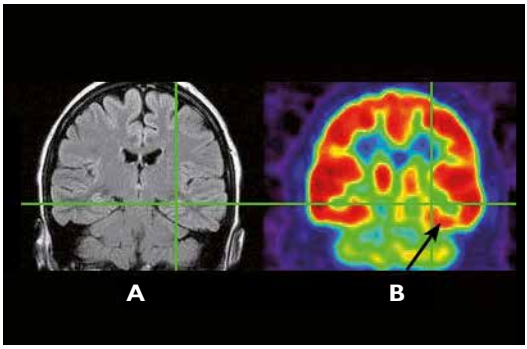


A. Interictal SPECT
B. Ictal SPECT
C. Difference image between ictal SPECT and interictal SPECT. The orange red zones highlight the areas in the brain with increased circulation during the epileptic seizure. The blue zones are the regions with reduced circulation during the seizure.
D. Difference image between ictal SPECT and interictal SPECT, but only showing the areas with the highest increased circulation. With this patient the area coincided with the location of an epileptic lesion highlighted by the MRI scan. This SPECT test showed that the lesion visible on the MRI scan was responsible for the patient's epileptic seizures.

FDG PET scan

PET is an abbreviation of 'positron emission tomography'. This scan is performed using a substance called fluorodeoxyglucose (FDG). Glucose or sugar is a key fuel for the brain. This examination tells us how the brain consumes sugar. Sugar consumption is often reduced in the parts of the brain that experience epileptic activity.

This is highlighted on a PET scan.



A. The MRI scan shows a lesion (hippocampal sclerosis) at the location of the green cross.
B. The PET scan shows reduced sugar consumption (black arrow).

Functional MRI (fMRI)

This is a special MRI technique used to measure brain activity. It enables us to verify which areas of the brain are involved in tasks such as movement and speech. This is an important test if surgery is being considered and the epileptic focus is located near brain areas that are responsible for language and motor skills.

Genetic testing

Several forms of epilepsy are hereditary. Febrile seizures can also be hereditary.

The likelihood of parents not suffering from epilepsy having a child with epilepsy is small, i.e. approximately 1%. Several types of epilepsy are partially hereditary. In that case there is a 5% risk of the descendants also suffering from epilepsy. Certain types of epilepsy are 'autosomal dominant hereditary', i.e. there is a 50% chance of descendants suffering from epilepsy.

If epilepsy or febrile seizures, or both, occur in your family it is possible to verify whether a hereditary factor is involved. However, first and foremost this requires your family members to be prepared to participate in this kind of study. It is not just important for scientific research. It can also be beneficial, for example, to advise family members who are thinking of starting a family.

Practical progress of a family study.

- ✗ All names and contact data are collated.
- ✗ All family members have to complete a questionnaire.
- ✗ All family members get together, relevant questions are asked and a blood sample is taken.
- ✗ You may subsequently have to visit UZ Leuven's Gasthuisberg Campus for an EEG and MRI scan of the brain.

Studies of this nature are conducted in the strictest confidence.

New techniques such as molecular karyotype testing make it possible to identify minute abnormalities in the DNA that might be responsible for epilepsy. These minor abnormalities could occur 'de novo', i.e. in a child whose parents are not carriers of the abnormalities and do not suffer from epilepsy.

Immunological testing

Certain antibodies in the blood can lead to inflammation in the brain which then causes epilepsy. Several of these antibodies can now be detected via a blood sample. These disorders can be treated with anti-inflammatories such as corticosteroids.

HOW ARE EPILEPTIC SEIZURES TREATED?

ANTI-EPILEPTIC DRUGS

If epilepsy requires treatment, it usually involves administering anti-epileptic drugs. Anti-epileptic drugs are meant to control all epileptic seizures without any side effects for the patient.

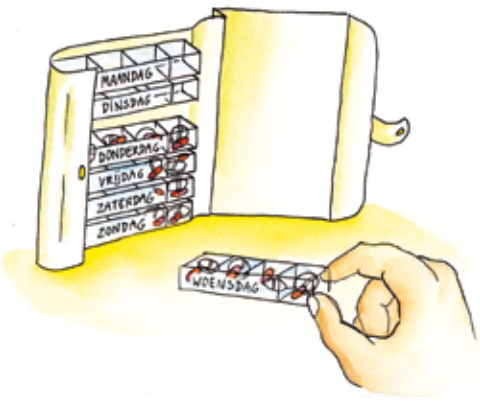
Different types of anti-epileptic drugs are available. Your doctor will choose a medication on the basis of the type of seizures and the type of epilepsy. In principle it will be the drug with the highest likelihood of success and fewest side effects for a specific type of epilepsy. Your doctor will provide you with a medication schedule tailored to your requirements.

Anti-epileptic medication does not cure epilepsy. It only increases the threshold for an epileptic seizure and prevents short circuits in the brain.

Therapy compliance

In order for it to be effective you need to take the medication regularly at the set time. If you don't take it regularly the blood level (anti-epileptic drug concentration in the blood) will drop and increase the risk of seizures.

A **pill organiser** (with separate compartments for each day of the week) will be a useful tool. Always get the organiser ready in advance for each week. This will make it easy to check whether or not you have forgotten a dose.



What should you do if you have forgotten to take your medication?

If you realise that you have forgotten to take a dose of your medication, we recommend that you still take the skipped dose, preferably before the next planned dose.
However, if it is also time to take the next dose, you can exceptionally take the forgotten dose together with the next one.

EXCEPTION: Rivotril® and Frisium®
These medications must NOT be taken simultaneously with the next dose. Have you forgotten a single dose? If so, skip this dose and take your medication again when the next planned dose is due.

Interactions with other medication and substances

Some anti-epileptic drugs are **liver enzyme inducing**: over time the liver will **speed up the conversion of** both the anti-epileptic drug and other medication. This means that patients who also take,

for example, the contraceptive pill, anticoagulants or other anti-epileptic drugs, must be careful as these medications will also be converted more rapidly, making them less effective so that a higher dose may be required. Traditional anti-epileptic drugs with a liver enzyme inducing effect include Carbamazepine (Tegretol CR®), Phenytoin (Diphantoïne®, Epanutin®), Phenobarbital (Gardenal®), and Primidone (Mysoline®).

Certain other drugs **lower the threshold** for the occurrence of an epileptic seizure. Antimalarial drugs, for example, can trigger epileptic seizures more easily. In such cases the dose of the anti-epileptic drug needs to be increased temporarily.

Alcohol can also lower the threshold for epileptic seizures. Moderate alcohol consumption is OK, i.e. no more than two units a day.

1 unit equals:

- ✔ 1 glass of beer
- ✔ 1 glass of wine
- ✔ 1 measure of spirits
- ✔ 1 small glass of sherry

Procedure following a first epileptic seizure.

We will not automatically start administering anti-epileptic medication following a first seizure. If all tests remain negative following a first seizure we may wait and see what happens next. We may consider treatment with medication if there are indications of an increased risk of relapse. Such indications could include: an

epileptic abnormality in the EEG, a structural epileptic lesion on the MRI scan, or indications of 'status epilepticus' (a prolonged seizure or series of prolonged seizures) right from the first seizure. If driving is important to you, we recommend that you start taking an anti-epileptic drug after the first seizure. This will lower the risk of a second seizure and you will be declared fit to drive more quickly.

Side effects

Treatment with anti-epileptic medication is meant to eliminate seizures without side effects. Nevertheless, you may suffer certain side effects depending on which medication you take (e.g. dizziness, drowsiness, increase in weight, etc.). Your doctor will explain the potential side effects of your medication.

If you think you are suffering side effects from the anti-epileptic medication, immediately talk to your doctor about it.

In order to eliminate seizures without side effects it is important that you take the medication **regularly and at the set time** and that you faithfully keep a seizure diary (see appendix). This will enable the doctor to adapt the medication if necessary.

When can you stop taking anti-epileptic drugs?

When a patient **has not suffered any seizures for two years** and continues to take their anti-epileptic medication without any changes, has about a 20% chance of having another attack. If

after two years free from seizures the medication is gradually reduced, the risk of relapse is approximately 40%. This means that approximately 60% of patients have no further seizures when they are no longer taking anti-epileptic medication.

The decision to stop the medication after two years depends upon the type of epilepsy. Juvenile myoclonic epilepsy, for example, can be treated very successfully with the anti-epileptic drug Depakine Chrono®: in 80 to 90% of cases the patient will no longer suffer any seizures. However, most patients will relapse when the medication is gradually phased out. With this type of epilepsy it is advisable for the patient to take the medication for life.

When making a decision to try and phase out the anti-epileptic medication completely, it is advisable to also take into account relevant legislation concerning driving and epilepsy.

EPILEPSY SURGERY

UZ Leuven is one of the four RIZIV recognised reference centres in Belgium where pre-operative and epilepsy surgery can be performed.

If you don't or only partially respond to treatment with medication or suffer unacceptable side effects, we can investigate whether surgery would be an option. However, an operation is **not an option for everyone** or for any type of epilepsy, which is why an **in-depth pre-operative assessment** is always performed first.

Pre-operative assessment at UZ Leuven

- ✗ An initial selection of suitable candidates is made during the epilepsy consultation.
- ✗ We will discuss the potential risks and benefits with you if surgery is being considered.
- ✗ If you would like to be considered for epilepsy surgery you will be admitted to hospital for a week for further examinations and tests. You will stay in a single room, with a 'rooming-in' option for a family member or partner. Because this admission is covered by the RIZIV convention for patients with refractory epilepsy (i.e. epilepsy that cannot be successfully treated with medication) no supplementary costs are involved and any costs you may incur will consequently be minimal.
- ✗ The results are discussed by a multidisciplinary team. If the team is of the opinion that epilepsy surgery would offer a good chance of freedom from seizures, with a limited risk of permanent neurological damage, this option will be discussed with you during the epilepsy consultation. If you decide to go ahead with an operation, a consultation will be arranged with the neurosurgeon, who will explain all the practical aspects of an operation.

Which patients qualify?

✔ Patients with focal seizures only (at least one to two focal impaired awareness seizures per month).

✔ Each focal seizure should arise in the same location. All test data must consequently point to a single 'epileptogenic zone' in the brain.

✔ Active epilepsy has persisted for more than two to three years, despite treatment with at least two anti-epileptic drugs.

✔ Normal neurological functions must be restored following the operation. If there is a risk of paralysis, loss of speech, memory loss or loss of other important brain functions the operation will not be performed.

✔ You must be in good health.

✔ You must be familiar with, and accept, the risk/benefit ratio. What is the **risk/benefit ratio**?

✗ You have a 60 to 80% chance of being free from seizures following the operation.

✗ In approximately 30% of cases the operation results in a postoperative neurological deficit, i.e. paralysis, impact on memory, vision or speech.

✗ Not having the operation also involves risks:

- One in 200 patients with epilepsy that is difficult to treat die every year as a result of an epileptic seizure.

- The underlying cause (e.g. a brain tumour) can be fatal.
- Epilepsy and the use of medication can have an adverse effect at a social and neurological level.

The results of neuropsychological and psychiatric tests also have to be favourable. Neuropsychological testing includes memory tests, language tests and tests that investigate which brain halves are involved in the language process. Psychiatric tests focus on personality, depression and anxiety, psychosis and the social network. If seizures are of a psychiatric rather than an epileptic nature, you may qualify for surgery following treatment of the non-epileptic seizures.

The operation and what happens afterwards

- You will be admitted to hospital on the day before the day of the operation when preoperative tests will be performed (e.g. blood samples).
- The operation itself lasts approximately four hours.
- You may suffer from headaches during the first few days after the operation. We provide painkillers to manage this.
- You will have to stay in hospital for approximately one week.
- You can return to work after one to two months.
- You will have to continue taking medication for a period of two years. The dose may be reduced until any side effects have disappeared.

Results of the epilepsy surgery programme at UZ Leuven

- 65% of patients no longer suffer from seizures following the operation.
- 20% of patients suffer almost no seizures after the operation.
- 9% of patients experience a significant improvement following the operation (seizures reduced by more than 75%)
- 6% of patients do not experience any improvement following the operation.

OTHER TREATMENTS

Vagus nerve stimulation

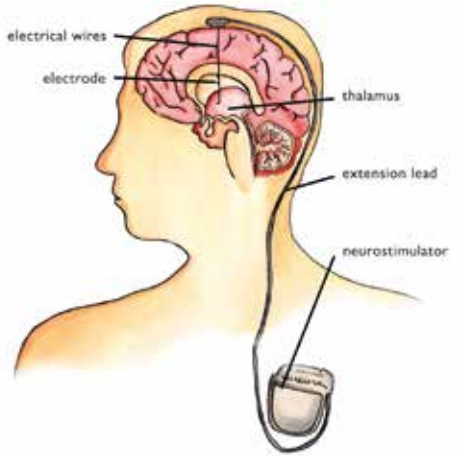
The vagus nerve is the main nerve that links the brain with many organs. During vagus nerve stimulation the nerve is stimulated in order to reduce epileptic seizures.

Stimulation is provided by a vagus nerve stimulator, similar to a pacemaker, which is implanted below the left collarbone. The stimulator sends intermediate impulses to the nerve in the neck area: 30 seconds on, 5 minutes off.

Vagus nerve stimulation is indicated when the epilepsy is difficult to control with medication and does not qualify for epilepsy surgery. Vagus nerve stimulation will only be refunded by RIZIV providing you underwent a pre-operative assessment at one of the four approved epilepsy surgery centres.

Potential side effects include hoarseness and throat discomfort when the stimulator is switched on.

Deep brain stimulation



Deep brain stimulation of the thalamus is a new technique used for the treatment of difficult to treat focal epilepsy. This treatment has been refunded by RIZIV since January 2015. An electrode is implanted on both sides of the thalamus during a surgical procedure. The patient will not be aware of the electrical impulses that can be controlled via a neurostimulator, a device implanted below the left collarbone. Approximately 20% of patients will be free from seizures, a majority will experience a reduction in epileptic seizures of more than 50%. The seizures will generally become less severe and the patient's quality of life will improve.

Ketogenic diet

In some cases a ketogenic diet is used to try and reduce epileptic seizures. This diet focuses mainly on **fats**, with very little sugar or protein. The energy for the brain primarily has to be derived from fats. The diet aims to produce ketones, which are created as a result of breaking down fats and play a role in reducing epileptic seizures.

A keto diet is **difficult** to maintain and is associated with certain **side effects**. It is consequently only prescribed in specific cases. It is most effective in children with severe types of epilepsy who cannot easily be treated with medication and don't qualify for surgery. It is the best available treatment for a rare form of epilepsy which is the result of a hereditary disorder whereby the transfer of sugar from the blood to the brain is impaired. In such cases a keto diet makes it possible for the brain to function by burning fats rather than sugar.

LIVING WITH EPILEPSY

With treatment many patients can live their lives without having seizures. Epilepsy doesn't necessarily have to rule your life, but it does have an impact on your lifestyle and requires you to make certain choices.

BEING AWARE OF TRIGGER FACTORS

In a number of patients epileptic seizures are triggered more easily in certain circumstances (also refer to the chapter on 'trigger factors'). If you are sensitive to these kind of trigger factors it is advisable to take preventive measures in order to avoid them whenever possible.

Trigger factors

- ✔ Lack of sleep and tiredness
- ✔ Stress
- ✔ Emotions
- ✔ Hormonal changes: e.g. someone suffering epileptic seizures around the time of menstruation can anticipate this by taking Frisium®.
- ✔ Excessive alcohol consumption: alcohol is OK, but maximum two units per day (one unit = one glass of wine or one glass of beer).

SAFETY AT HOME

Everyday activities or situations may suddenly become hazardous if you suffer and epileptic seizure.

By taking a number of simple preventive measures, you will avoid or limit the risks.

Bathing and washing

- Have a shower instead of a bath to avoid the risk of drowning during a seizure.
- If you do decide to have a bath don't overfill the bathtub.
- Make sure that there is always someone in the vicinity when you are having a bath.
- Use cold water before switching to warm water (risk of burns).
- Always turn off the tap before stepping into the bath.
- Avoid using electric hair styling tools.
- Do not lock the bathroom or toilet door.
- Use a hot water tap with a thermostatic valve and adjust it to a sufficiently cool setting to avoid burning yourself.

Cooking and eating

- Preferably use a microwave when cooking. There is a real risk of burning yourself when cooking with gas or electricity.
- If you are using a normal hob always point pan handles to the rear and use the rings nearest the back wall.
- Do not carry dishes with hot food, use a trolley.
- Use plastic where possible rather than glass (bottles, glasses, dishes).

DIY jobs

- Don't climb ladders or work at height.
- Use an iron that will switch off automatically.

Other

- Don't smoke. Smoking doesn't raise the risk of a seizure but loss of consciousness is a fire hazard for a smoker.
- Use carpet flooring to limit falling injuries.
- Avoid stairs whenever possible.

WORK

Most people suffering from epilepsy have the same opportunities to work as other people. A lot depends upon **the nature of the epilepsy**. The type, seizure frequency and epilepsy syndrome must be taken into account. Impaired awareness seizures, for example, will more often result in hazardous situations than focal aware seizures.

The **nature of the patient's job** also plays a part. In Belgium there are certain limitations regarding jobs in the transport sector. For example, epilepsy patients are not allowed to work as a pilot, bus or train driver.

There are no specific legal requirements when it comes to completing an **application form**. You can choose a specific option depending on your individual situation. You may decide to mention the situation on the application form or leave it and discuss it during a subsequent interview, or you can wait and discuss it with the company physician.

ABILITY TO DRIVE

An epileptic seizure whilst driving can have serious consequences. It is understandable, therefore, that this is strictly regulated. The rules are set by law (Act dated 10 September 2010).

Relevant legal rules are indicated below. The doctor in charge of your treatment or social worker can discuss this with you in more detail.

A candidate with epilepsy or a candidate who has suffered an epileptic seizure is **not considered fit to drive**. The law defines epilepsy as two or more non-triggered epileptic seizures. After being free from seizures for a period of five years, a subsequent seizure can be considered a first seizure. A doctor who specialises in neurology or neuropsychiatry will define the specific epilepsy syndrome and types of seizures. This information is needed to assess the risk of potential future seizures.

Standards for candidates in group 1: driving licence A3, A, B, B+E (moped, motorbike, car, etc.)

- ✗ A candidate who has suffered a single epileptic seizure may be declared fit to drive following a period free of seizures of at least six months.
- ✗ A candidate who has suffered a single epileptic seizure may be declared fit to drive following a period free of seizures of at least three months, providing the EEG does not show any epileptic discharges and neurological imaging does not indicate an epileptic lesion.
- ✗ A candidate who has suffered a single epileptic seizure triggered by a demonstrable and avoidable cause, may be declared fit to drive following a period free of seizures of at least three months.

- ✗ A candidate suffering from epilepsy can be declared fit to drive following a period free of seizures of at least one year.
- ✗ A candidate with a previously stable situation who suffered an epileptic seizure as a result of anti- epileptic medication being phased out, a change in dosage or type of anti-epileptic drug, can still be declared fit to drive three months after the last seizure if the previous treatment is reinstated. If a different type of treatment is initiated the candidate can be declared fit to drive six months after the last seizure. The doctor will explain the potential risks associated with phasing out or changing the medication to the candidate.
- ✗ If the candidate solely suffers from epileptic seizures that do not affect consciousness and do not cause any other impairments that might impede safe driving practices, they can be declared fit to drive if this condition has existed for at least one year.
- ✗ A candidate who for a period of two years only suffered epileptic seizures whilst being asleep, can be declared fit to drive.
- ✗ A candidate suffering from epilepsy who underwent surgery for this condition can be declared fit to drive following a seizure free period of at least one year.
- ✗ If the patient suffers from simple focal seizures that do not affect their driving ability and they have been free from seizures for three months. The ability to drive applies for a period of one year and can be extended.
- ✗ The assignment of a driving ability certificate or extension of the validity period is subject to the following conditions:
  - The candidate must be under regular medical supervision.
  - The candidate must have a sufficiently clear understanding of the disorder.
  - The candidate must demonstrate strict therapy compliance and closely observe the prescribed anti-epileptic medication schedule.
  - An extensive neurological test will assess whether the condition is stable. A favourable neurological report is always mandatory.

✗ When first issued the validity period of the driving ability certificate is limited to one year. If the candidate remains free from seizures during this period the validity period can be extended to maximum five years after the last seizure. After a period of five consecutive years free from seizures a driving ability certificate can be issued without a limited validity period.

Standards for candidates in group 2: driving licence C, C+E, D, D+E (lorry, lorry with trailer, bus, etc.)

✗ A candidate who suffered a single, non-triggered epileptic seizure and has had no seizures of any kind over the past five years can be declared fit to drive.

✗ A candidate who has suffered a single epileptic seizure triggered by a demonstrable and avoidable cause, can be declared fit to drive after a period free from seizures of at least one year. If the prognosis is based on exceptionally favourable factors the candidate can be declared fit to drive following a period free from seizures of at least six months.

✗ A candidate suffering from epilepsy, irrespective of which type, can be declared fit to drive following an uninterrupted period of at least ten years free of seizures of any kind. If the prognosis is based on exceptionally favourable factors, a candidate suffering from epilepsy can be declared fit to drive a vehicle in category C1 (for lorries with a maximum acceptable mass of 7,500 kg), following an uninterrupted period of at least two years free from seizures of any kind.

✗ The assignment or extension of the validity period of the driving ability certificate is subject to the following conditions:

- The candidate has been free from seizures for the stipulated period without anti-epileptic medication.

- The candidate is under regular medical supervision.
- The candidate must have a sufficiently clear understanding of the disorder.
- The EEG does not show any epileptic abnormalities.
- Neurological imaging does not indicate an epileptogenic cerebral pathology.
- A favourable neurological report is always required. This report should indicate that there are no signs that the risk of another seizure, loss of or impaired consciousness when driving, exceeds 2% per annum.

If you have reduced functional skills that are required to drive a motor vehicle – for example as a result of epilepsy – the law stipulates that an assessment by CARA is mandatory. CARA is a department of the Belgian Institute for Road Safety.
CARA, Haachtsesteenweg 1405, 1130 Brussels
Tel. +32 (0)2 244 15 52, www.bivv.be

Advice on driving ability for **group 1** is provided by a **neurologist**. The latter will provide you with a certificate stating that you are not fit to drive, which you will have to submit to the local council together with your driving licence. If you remain seizure free for long enough, you will be issued with a driving ability certificate that you can use to collect a provisional driving licence.

Advice on driving ability for **group 2** is provided by a **'medical examiner'**, e.g. the company doctor. Advice from the neurologist in charge of the treatment is mandatory.

TRAVEL

There are no specific indications as to why a patient suffering from epilepsy should not travel by plane. However, you should be aware that anxiety or tiredness as a result of jet lag might trigger a

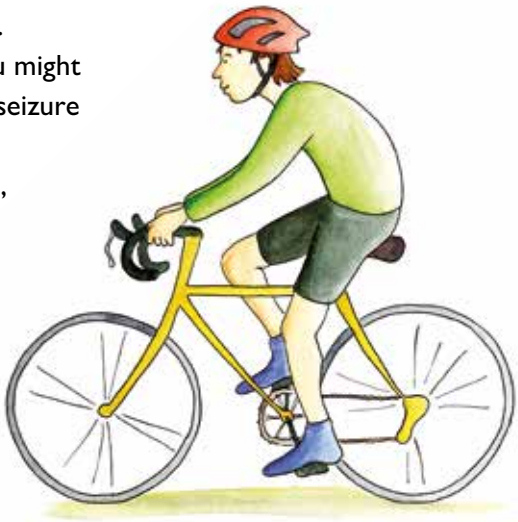
seizure. Hence the following advice:

- ✔ Discuss your situation with personnel on board the plane.
- ✔ Ensure that you have your medication at hand in your hand luggage.
- ✔ Keep a letter with you from your doctor with details of your situation and medication.
- ✔ If you are travelling to exotic destinations bear in mind that antimalarial drugs can lower the threshold for an epileptic seizure. Discuss this in advance with your doctor.

SPORT

Sport is beneficial for your health and that includes patients suffering from epilepsy. Epilepsy patients can practice a large number of sports. Sometimes you will have to take preventive measures and take into account the risks associated with certain sports.

- ✔ Swimming is only allowed with appropriate supervision.
- ✔ Sports during which you might injure yourself during a seizure are not advisable, e.g. horse riding, gymnastics, mountain climbing, etc
- ✔ It is advisable to alway wear a helmet when cycling.



You will often have to weigh up the risk of injury against (over)protection.

STUDY

Epilepsy is a symptom of an underlying brain disorder. As mentioned earlier (see the chapter on 'Learning difficulties and epilepsy') there is a potential link between epilepsy and learning difficulties. However, epilepsy should not be equated with learning difficulties. Many epilepsy patients can study normally.

Students suffering from epilepsy must be aware though that stress and lack of sleep can lower the threshold for epileptic seizures.

It is, therefore, feasible to spread out exams as much as possible for medical reasons in order to avoid this. However, this statute has to be applied for in advance with the relevant educational institution, backed up by a medical certificate provided by your doctor.

CONTRACEPTIVE PILL

The contraceptive pill does not have an impact on epileptic activity, i.e. it does not increase or reduce the risk of seizures.

However, some anti-epileptic drugs do have an adverse effect on the effectiveness of the contraceptive pill. This type of medication stimulates the liver function so that certain substances are broken down more quickly. This also applies to the active ingredient of the contraceptive pill, which means that some anti-epileptic drugs lower the effectiveness of the pill which could lead to undesirable pregnancies. If you are taking the contraceptive pill in combination with Carbamazepine (Tegretol CR®), Phenytoin (Diphantoïne®, Epanutin®), Phenobarbital (Gardenal®), Primidone (Mysoline®), Oxcarbazepine (Trileptal®) or Topiramate (Topamax®) and suffer

spotting or mid cycle bleeding, you should consider it a non-protected cycle. In such cases it is advisable to use additional contraception and to contact the doctor in charge of your treatment.

This issue can be solved in conjunction with your doctor by switching to an appropriate type of contraceptive pill. Moreover, some anti-epileptic drugs do not stimulate the liver function and consequently do not change the effectiveness of the pill: Valproate (Depakine®), Gabapentin (Neurontin®), Levetiracetam (Keppra®), Vigabatrin (Sabril®), Pregabalin (Lyrica®). Overall, the contraceptive pill is a sound choice of contraceptive for women suffering from epilepsy who are taking anti-epileptic drugs.

The contraceptive pill will reduce the blood concentration of the anti-epileptic drug Lamotrigine (Lamictal®) by half, but your doctor will resolve this together with you.

PREGNANCY

Women suffering from epilepsy can have children. The **large majority** of pregnancies in women taking anti-epileptic drugs proceed **normally**. If you suffer from epilepsy and would like to have children it is important to discuss this with the doctor in charge of your treatment **well in advance** (before you stop using a contraceptive). This way the epilepsy treatment can be adapted to prevent congenital abnormalities in the baby. Depakine® is not recommended during pregnancy.

UZ Leuven also provides a **brochure entitled 'Epilepsy and pregnancy'**, which provides more detailed information on appropriate treatment before and during pregnancy, on breastfeeding and how to handle the baby. The brochure is available online at www.uzleuven.be/brochure/700251.

FURTHER INFORMATION

CONTACT INFORMATION

Neurology department
UZ Leuven Gasthuisberg Campus, Herestraat 49, 3000 Leuven
Call +32 (0)16 34 48 00 to make an appointment.

ADDITIONAL INFORMATION

Patients, family members or acquaintances and other interested parties who would like to know more about epilepsy can participate free of charge in **epilepsy information evenings**, which are organised at regular intervals at UZ Leuven. They are presented by Prof. Dr. Wim Van Paesschen. For further information on this topic call +32 (0)16 34 42 80 or visit the website www.uzleuven.be/epilepsie.

Patients, family members or acquaintances and professionals can also contact the **Vlaamse Liga tegen Epilepsie** (Flemish Epilepsy League), which offers individual assistance and support, specific services and information.

For further information concerning the Vlaamse Liga tegen Epilepsie visit www.epilepsieliga.be.

The Vlaams Brabant section can be contacted via:

Gwen Maris
CGG Vlaams-Brabant Oost vzw

Kapucijnenvoer 16
3000 Leuven
016 85 79 79
vlaamsbrabant@epilepsieliga.be

APPENDIX:
EPILEPSY SEIZURE DIARY

SEIZURE DIARY 20 . .

	Jan		Feb		Mar		Apr		May		Ju
1											
2											
3											
4											
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31											

Record the number and time of seizures in the seizure diary.

Seizure descriptions: use the agreed symbols.

ne	Jul		Aug		Sept		Oct		Nov		Dec		
													1
													2
													3
													4
													5
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during the day

whilst asleep

APPENDIX: QUESTIONNAIRE INITIAL EPILEPSY CONSULTATION

It would be useful to complete and bring this questionnaire to your initial epilepsy consultation.

Are you right or left handed?

. . . . . .

How old are you?

. . . . . .

Did you have febrile seizures when you were a child?

. . . . . .

If so, did they last a long time, occur on one side, or were you paralysed on one side following the febrile seizures?

. . . . . .

. . . . . .

Did you ever suffer a head trauma that resulted in loss of consciousness?

. . . . . .

Did you ever suffer a brain infection (meningitis, abscess etc.)?

. . . . . .

Was the early development as a child normal?

. . . . . .

. . . . . .

At what age did you sit up, walk, talk?

Did you have difficulty keeping up at school?

Does anyone in the family suffer from epilepsy, febrile seizures or migraine? If so, can you provide details?

Which diseases have you suffered from so far?

When did the epilepsy start?

How many different types of seizures do you suffer from (e.g. grand mal or petit mal seizures, absences, fits etc.)?

What does it feel like, are you getting a warning?

How often do each of these seizures occur?

Can you describe each type of seizure? What do people around you tell you about what they have noticed when you are having a seizure?

Have you ever suffered a series of consecutive seizures which r equired the presence of a doctor or admission to hospital?

Do you suffer from memory problems?

What medication are you currently taking (name and dose)?

Are you suffering side effects from this medication (e.g. drowsiness, trembling, weight increase, etc.)?

Which medication, and which doses, have you taken previously?

Why was this medication stopped?

In your opinion which is the best medication you have ever taken?

Which tests have already been performed?

Have you been told by doctors what causes your seizures?

What kind of education and training have you attended?

What is your marital status and your profession?

Do you consume alcohol?

What has epilepsy prevented you from doing in life?

Have you ever suffered psychiatric problems?

What do you expect from this consultation?

Would you like to be considered for epilepsy surgery if it would help alleviate your condition?

NOTES

Design and implementation
This text was written by the Neurology Unit in cooperation with the communications department.

You can also find this brochure at www.uzleuven.be/en/brochure/700234.

Please send comments or suggestions relating to this brochure to communicatie@uzleuven.be.

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