

Understanding **Epilepsy**

A guide to living and thriving



epilepsy.org.za



A Message from the National Director

Dear Reader,

Welcome to Understanding Epilepsy: A Guide to Living and Thriving.

If you're holding this booklet, you've already taken a significant step toward knowledge, empowerment, and hope. Whether you're living with epilepsy, supporting a loved one, or seeking to better understand this condition, we've created this resource with you in mind.

Epilepsy affects over 50 million people worldwide, and yet, for many, it remains a misunderstood condition. Stigma, misinformation, and limited access to care create barriers that affect not just individuals, but families and communities.

It's why the World Health Organization's Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Disorders, adopted in 2022, is such a pivotal milestone. This 10-year plan is a global commitment to reduce the stigma, improve access to care, and enhance the quality of life for people living with epilepsy and their loved ones.

This booklet is a reflection of that vision. It's more than just a collection of information—it's a tool designed to empower you with knowledge, equip you with practical strategies, and offer you a sense of community and understanding. Inside, you'll find everything from the basics of epilepsy to how it affects specific groups, such as women and the elderly.

You'll learn about managing day-to-day life with epilepsy, responding to seizures, exploring treatment options, and even how diet can play a role in living well with this condition.

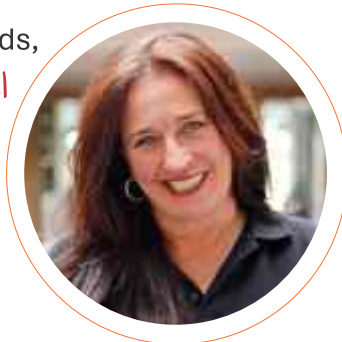
Our hope is that this guide not only provides clarity but also inspires confidence.

Epilepsy does not define a person – it's possible to live fully, thrive, and dream beyond its challenges. You are not alone on this journey.

Together, we can work toward a world where epilepsy is understood, where stigma is a thing of the past, and where everyone affected has access to the care and support they need.

Thank you for being part of this journey toward understanding, inclusion, and hope.

Warm regards,
Sharlene Cassel
National Director
Epilepsy South Africa





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Epilepsy Facts

Epilepsy does not affect men less than women



Epilepsy can affect employment opportunities



Effective seizure control is key when in the working environment



A physically active lifestyle can help reduce occurrence of seizures



Do not continue exercising if you feel faint, nauseous or dehydrated



Alcohol can increase the occurrence of seizures



Some anti-epileptic medication should not be taken when consuming alcohol



Epilepsy, all you need to know

Living with epilepsy

- People with epilepsy is still able to do physical and intellectual work.
- People with epilepsy should not be treated differently.
- People with epilepsy are not bewitched/cursed.

Facts

- 1** Epilepsy is a neurological condition characterised by unusual electrical activity in the brain.
- 2** A single seizure does not mean that you have epilepsy.
- 3** Epilepsy is not contagious.
- 4** Epilepsy affects 1 out of 100 people in SA.
- 5** 75% of people with epilepsy have their first seizures before the age of 20.
- 6** 1 in 20 people have seizures at some point in their lives.

A person living with Epilepsy can achieve everything you can, so why treat them differently?

They are after all, just like you.

Causes

- In approximately 66% of cases the underlying causes of the epilepsy is unknown (idiopathic epilepsy)
- A head injury occurring at any age could be an underlying cause of symptomatic epilepsy.
- A birth injury could be an underlying cause of symptomatic epilepsy.
- Alcohol and drug abuse could be an underlying cause of symptomatic epilepsy.

How to help



Protect the person from injury



Cushion the head



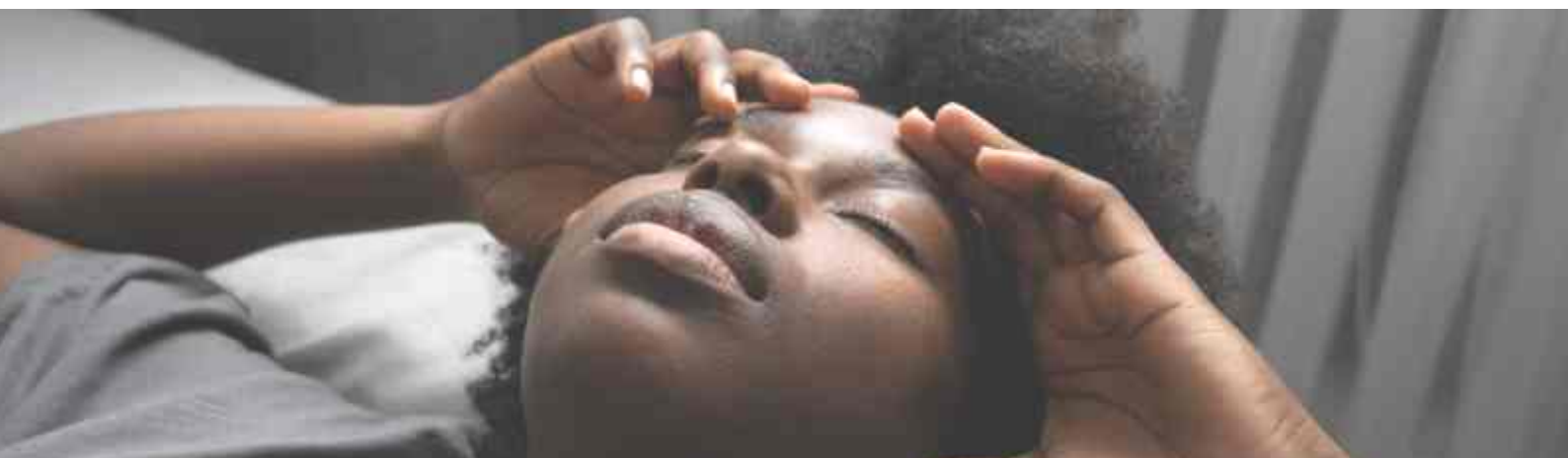
Do not restrict movement or put anything in their mouth



Help breathing by laying the person on the side



Stay with him or her until fully recovered.



Epilepsy Myths & Facts

Myth

Fact

<i>Epilepsy is caused by a curse, bewitchment, or demon-possession. It means that the person or their family members are to blame.</i>	Epilepsy is a non-communicable, neurological condition characterized by seizures. It is not caused by witchcraft, magic, or evil spirits.
<i>People with epilepsy can predict the future.</i>	People with epilepsy do not have any special or magical powers such as predicting the future.
<i>People with epilepsy are insane.</i>	Epilepsy is a neurological condition rather than a mental health issue.
<i>Epilepsy is contagious.</i>	While epilepsy have many different causes, it is not contagious. Thus, it is impossible to “catch” epilepsy from another person through contact.
<i>You should put something like a spoon in a person’s mouth during a seizure to prevent them swallowing their tongue.</i>	It is not possible to swallow your tongue as it is attached to the floor of the mouth. Never put anything in a person’s mouth during a seizure as this will hurt the person (e.g., breaking their teeth or even their jaw).
<i>Epilepsy is a death sentence.</i>	While epilepsy cannot be cured, it can be treated. More than 70% of people with epilepsy can live seizure-free lives with appropriate treatment.
<i>People with epilepsy will always fall down, foam at the mouth and even wet themselves.</i>	Epilepsy is a spectrum disorder which means that there are many different types of seizures.
<i>You should restrain a person having a seizure.</i>	Never restrain a person during a seizure as it is impossible to stop the seizure which will run its course. Restraining the person may cause injury.
<i>Only children get epilepsy.</i>	Anybody can develop epilepsy at any stage during their life.
<i>People with epilepsy cannot work.</i>	People with epilepsy have the same range of abilities and intelligence as any other people. While the severity or frequency of seizures may prevent some people from working and other are successful and productive in a wide range of jobs.
<i>People with epilepsy should not be appointed in jobs with responsibilities and stress.</i>	People with epilepsy can successfully hold down a variety of jobs at all levels in business, professions, and government. Many persons with epilepsy do not disclose their condition as they fear negative reactions and even discrimination and victimization.

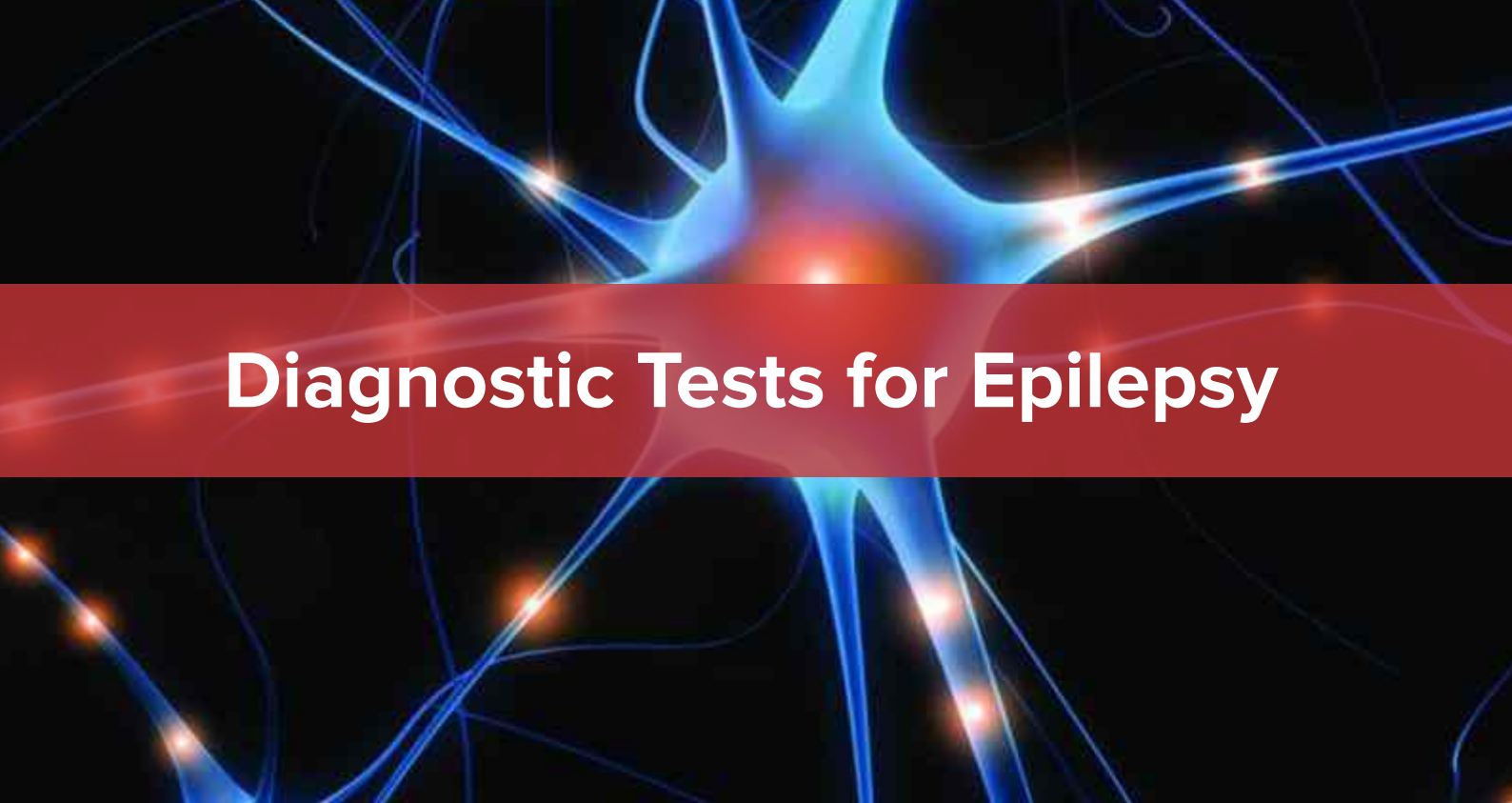


Epilepsy Myths & Facts

Myth

Fact

<i>With today's medication, epilepsy is largely a solved problem.</i>	Epilepsy is a chronic condition which can be treated and managed, but not cured. Unfortunately, treatment does not always work for all people, often requiring more than one option before a suitable one being found. There is a critical need for more research.
<i>Epilepsy is rare.</i>	The World Health Organisation (WHO) estimates that one in a hundred people in developing countries (like South Africa) will have epilepsy, with one in two hundred people in developed countries. Approximately 50 million people in the world have epilepsy.
<i>You can't die of epilepsy.</i>	Epilepsy is still a very serious condition and can unfortunately result in death. This may be due to status epilepticus (non-stop seizures), SUDEP (Sudden Unexpected Death in Epilepsy), drowning and other accidents. The best way to be safe is to obtain a proper diagnosis and comply with prescribed treatment.
<i>People with epilepsy are physically limited in what they can do.</i>	Generally, epilepsy is not a barrier to physical achievement although some people may be more severely affected than others. People with epilepsy participate safely and successfully in a wide variety of sports. The most famous South African sports personality with epilepsy is cricketer legend Jonty Rhodes.
<i>If someone has a seizure, they must go to hospital</i>	Not all seizures require medical help or hospitalization. In most cases, the person will simply need to rest and recover after a seizure. Generally, medical attention is only required if the person is injured during the seizure or if the seizure continues for more than five minutes without recovering.
<i>If you have a seizure, you have epilepsy.</i>	Epilepsy is characterized by repeated seizures and requires medical testing for a diagnosis. Seizures may be caused by several medical conditions (e.g., a recent concussion, a high fever or low blood sugar).
<i>All seizures involve convulsions.</i>	Seizure can present in different ways. Some cause a person to lose consciousness and have convulsions (when the body stiffens and jerks uncontrollably). Other seizures can cause brief spells of blinking rapidly and staring off, or simply cause the person to experience strange sensations.
<i>Video games or strobe lights will trigger seizures.</i>	Very few people are affected by visual triggers (photosensitive epilepsy).
<i>Epilepsy treatments don't work.</i>	Some 70% of persons with epilepsy will be able to control their seizures with the right treatment. Although medication is usually the first option selected, other treatment options may include surgery, nerve stimulation with an implanted electrical device or the ketogenic diet.
<i>Epilepsy is hereditary.</i>	Epilepsy is not a hereditary condition. Anyone can be diagnosed with epilepsy at some point in their life. While a few people are born with this disease, others may be diagnosed with no clear cause. Regardless of age, sex, ethnicity, or financial background, epilepsy can happen unexpectedly.
<i>Epilepsy affects intelligence.</i>	People with epilepsy have the same intellectual range as other people. However, the learning ability of people may be affected if the frequency and severity of seizures increase or remain untreated.
<i>People with epilepsy can't get married or have children.</i>	People with epilepsy form relationships, get married and have families. However, women with epilepsy are advised to seek medical advice before starting a pregnancy to ensure not only their own health, but also that of their unborn child. Most women with epilepsy can conceive, have healthy pregnancies and give birth to healthy children.



Diagnostic Tests for Epilepsy

There are a number of procedures available to assist the doctor in making an accurate diagnosis of the type of epilepsy a person has. The names can be confusing and what follows is a brief summary of the various tests which might be recommended.

The EEG

An **electroencephalogram** or **EEG** is a written record of the brain's electrical rhythms. To record these rhythms, a number of small metal discs (electrodes) are placed against the scalp at various points. These are held in place by a glue-like substance which can easily be washed off later. With the electrodes in place, the person will either sit or lie down in a restful state with his/her eyes closed.

The test takes about 30 minutes. During this time the person will be asked to perform certain simple tasks, such as blinking, breathing deeply or some form of mental activity. The test usually includes a series of flashing lights at various frequencies since some forms of epilepsy may be stimulated in this way.

When testing young children who may become restless, it may be necessary to give them a mild sedative. Sometimes it is necessary to obtain a recording over a period of several hours/days. A portable EEG machine can be attached to the person to perform the test while carrying out normal daily activities/routines, including sleep. This is called EEG telemetry.

In certain circumstances it is necessary to admit the person to hospital and monitor brain activity through EEG telemetry and continual video recording at the same time. This enables the doctor to match brain rhythms with behaviour and seizure activity.

The CT Scan

Computerised Tomography (CT) provides cross sectional images (slices) of the brain. The person lies on an X-ray table which is moved slowly into the CT unit containing the scanner. Only the upper part of the head moves into the scanner. An X-ray device rotates around the person's head in an arc formation, recording a number of images of the brain. To make the images clearer, a dye is injected into a vein in the person's arm. The entire procedure takes about 45 minutes and is painless. It is used to diagnose a probable cause for seizures.

The MRI Scan

Magnetic Resonance Imaging (MRI) is a method of scanning the brain without using X-rays. During the MRI scan the person's head is surrounded by a magnetic field. Radio frequency waves are produced to stimulate the brain.

Resulting energy changes are used to produce computer images which look like two-dimensional slices of the brain.

The magnetic field and the radio frequency waves are completely painless and cause no known physical harm. At worst the person may feel some discomfort from having to lie still in the "tunnel" while the machine is scanning their head. To minimise discomfort, a fan circulates air and a mirror at the end of the tunnel allows the person to see the room and scanner operator.

An intercom call button is beside the person's hand to maintain verbal communication throughout the procedure. Some people choose to wear earplugs to block out the metallic thumping noise of the machine. The MRI scan takes about an hour and a half.

The PET Scan

Positron Emission Tomography (PET) scanning is a non-invasive imaging technique that creates a three-dimensional image of the brain.

Short-acting radio-isotopes are injected into the blood where after the person rests for about 30 minutes. During the scan a mask is placed gently over the person's face to limit movement. An EEG recording is taken at the same time.

There are microphones in the scanner to enable the person to communicate with the operator at all times. As images are produced by analysing the uptake of glucose in the brain it is necessary for the person to fast for a period prior to the PET scan.

A PET scan takes between 30 and 60 minutes. However, it is extremely costly and has been largely replaced by the SPECT scan.

Your pharmacist is also able to assist with information and advice about your medication.

The SPECT scan

Single Photon Emission Computed Tomography (SPECT) is similar to PET scanning, but uses different radio-isotopes able to hold the image of the blood flowing through the brain for up to 24 hours. The SPECT scan looks at blood flow through the brain during a seizure (ictal phase) and compares this with the inter-ictal (seizure-free) scan. This highlights the "hot spot" or origin of the seizure in the brain.

The scan can be performed anytime from an hour after the radio-isotopes have been injected for a period no longer than 24 hour.

A mask is not required and an EEG is not taken.

A SPECT scan usually takes about 20 to 30 minutes.



EEG Scan



CT Scan



MRI Scan



PET Scan



SPECT Scan



Epilepsy and Drug Therapy

Medication for epilepsy

The standard treatment for epilepsy is the regular use of one or more chemical substances called anti-epileptic or anti-convulsant drugs/medication.

Ideally you should take as little medication as possible while maintaining seizure control.

Drug options

In recent years new developments have made more specific drugs available through ongoing research internationally. This does not mean that older drugs have become obsolete. In fact, newer drugs may not be suitable or appropriate for you.

Each drug has two names: (1) The generic or chemical name such as carbamazepine and (2) the trade name such as Tegretol which is given by the manufacturer. It is helpful to know the generic name of your drugs, especially when travelling internationally.

Drug choices

The table below contains information about the most commonly used anti-epileptic drugs. This is only a summary and by no means a full description of the drugs.

It is essential to always discuss your medication needs and queries with your doctor. Special consideration must be given regarding drugs for children with epilepsy since the effects of medication may differ from adults.

As some drugs have proven to be harmful to your unborn child (particularly valproate) it is advisable for a woman to discuss her individual situation with her doctor prior to becoming pregnant. This will allow her to assess potential risks and options in good time.

Drug interactions

When you use more than one type of medication the drugs may influence each other and change their effect. It is essential to tell your doctor about any other drugs you are taking when discussing potential treatment options (even over-the-counter medication).

The interaction between oral contraceptives and anti-epileptic medication (particularly carbamazepine, phenobarbitone and phenytoin) may reduce the effectiveness of the contraception resulting in unplanned pregnancy. Women with epilepsy should thus obtain specific medical advice and information about effective contraception.

Alcohol and recreational drugs taken in combination with anti-epileptic medication poses a problem and is best avoided.

A balanced diet with adequate nutrients and sufficient daily water intake is advised for optimal drug absorption.

Team work

Cooperation between you and your doctor is essential to establish optimum control of your seizures (epilepsy). Your doctor will be able to prescribe medication more precisely if you or a family member can accurately describe your seizures and the effect of medication.

It is important to take your medication exactly as prescribed. Treatment compliance is a major factor in the overall results that can be achieved.

Your pharmacist is also able to assist with information and advice about your medication.

Drug	Epilepsy/seizure type	Side effects
Carbamazepine (Tegretol, Degranol)	Simple and complex partial seizures, generalised tonic-clonic seizures.	Dose related: Nausea, double vision, unsteadiness. Allergic: Rash, reduced white blood cells count, increased appetite (rarely), no obvious effect on concentration, memory or behaviour.
Clobazam (Frisium)	“Add-on” in tonic-clonic, myoclonic and partial epilepsies. Effective in catamenial epilepsy (menstrual seizures).	Dose related: Drowsiness and lethargy. Drug loses effect over time despite increasing dosage.
Clonazepam (Rivotril, Clonopil)	Second or third choice for myoclonic seizures. Effective “add-on” for tonic-clonic and absence seizures. May be used in status epilepticus.	Dose related: Drowsiness, lethargy, drooling and hyperactivity in children. Drug loses effect over time. May cause inflammation of the veins.
Diazepam (Valium)	Drug of choice in status epilepticus (rectally or intravenously). Rarely used in regularly in tablet form.	Dose related: Drowsiness, lethargy, drooling and hyperactivity in children.
Ethosuximide (Zarontin)	First or second choice for typical absence seizures. May be effective in myoclonic seizures. Not effective in generalised tonic-clonic seizures.	Dose related: Drowsiness, nausea, vomiting, headache, irritability. Allergic: Rashes.
Gabapentin (Neurontin)	“Add-on therapy in partial seizures.	Dose related: Drowsiness, lethargy, nausea.
Lamotrigine (Lamictin)	“Add-on” and (in patients over 12 years) monotherapy in generalised tonic-clonic seizures (possible second choice after sodium valproate). Effective in absences with myoclonic seizures and partial seizures.	Dose related: Sedation, unsteadiness and possibly worsening of seizures. Allergic: Rashes may occur in 10% of patients, particularly if sodium valproate is taken simultaneously. To avoid rashes the drug must be introduced very gradually.
Oxcarbazepine (Trileptal)	Primary generalised tonic-clonic seizures and partial seizures.	Similar to carbamazepine, but less severe.
Phenobarbitone (Phenobarbital, Luminal, Gardenal)	Effective in generalised tonic-clonic, myoclonic and partial seizures. Effective in status epilepticus.	Dose related: Drowsiness, lethargy, unsteadiness. Chronic use: Tolerance and impairment of concentration and memory, slowness in activities. Withdrawal seizures if discontinued too quickly.
Phenytoin (Epanutin, Dilantin)	Second or third choice in generalised tonic-clonic seizures. Effective in partial and myoclonic seizures. Drug of choice in status epilepticus.	Dose related: Nausea, vomiting, unsteadiness, slurred speech. Allergic: Rash, hepatitis (inflammation of the liver), swelling of lymph glands. Chronic use: Gum, swelling, acne, hairiness (face and body), folate deficiency, involuntary movements, rickets.
Sodium valproate (Epilem)	First choice in primary generalised tonic-clonic seizures, typical absence, atonic and myoclonic seizures and photosensitive epilepsy. Effective in partial seizures (second choice after carbamazepine).	Dose related: Tremor, sedation, restlessness, increased appetite. Allergic: Stomach irritation, inflammation of liver and pancreas. Chronic use: Hair loss (usually transient), weight gain, low platelets in blood (may cause excessive bleeding if cut). Should not be taken during pregnancy.
Topiramate (Topamax)	Prescribed for partial seizures with or without secondarily generalised seizures, inadequately controlled by conventional first-line drugs.	Dose related: Drowsiness. Loss of appetite and weight may occur.
Valproic acid (Convulex)	Similar to sodium valproate.	Similar to sodium valproate.

How can I help someone HAVING A SEIZURE

When Roxy's friend Sipho has a seizure, she knows that she must...



Time how long the seizure lasts.



Cushion his head and protect his body from further injury.



Loosen any tight clothing and remove his glasses.



Turn Sipho onto his left side into the recovery position.



Stay with him and reassure him until he has fully recovered.



Call an ambulance if Sipho's seizure lasts longer than 6 minutes.



NEVER move Sipho or pick him up unless he is in direct danger.



NEVER put anything like a spoon in his mouth or burn anything in front of his nose.



NEVER give him anything to eat or drink or give him any extra medication.



But Roxy knows that she should...



NEVER move Sipho or pick him up unless he is in direct danger.



NEVER put anything like a spoon in his mouth or burn anything in front of his nose.



NEVER give him anything to eat or drink or give him any extra medication.



DO'S AND DON'TS FOR PEOPLE WITH EPILEPSY

As a person with epilepsy you have certain responsibilities about your own lifestyle and care.
Here are some do's and don'ts to help you:

DO'S

Get enough sleep every night as a lack of sleep can trigger seizures.

Eat a healthy diet to keep your blood sugar levels stable. Fluctuations in these levels can trigger a seizure. Read the Epilepsy South Africa brochure for advice on a healthy diet.

Exercise regularly after talking to your doctor about suitable exercise/sport for you.

Be safe in your daily activities. For example, use a microwave for cooking and don't lock the bathroom door.

Look after your health as infections or trauma can lower your seizure threshold resulting in more frequent/severe seizures.

Inform people around you about your epilepsy and what to do when you have a seizure. Epilepsy South Africa can provide you with a free poster to help other understand.

Take your medication exactly as prescribed by your doctor. Make sure that you have an adequate supply of your medication (especially if you will be away from home).

Keep a seizure diary to help your doctor treat you effectively. Download your free seizure diary from our website (www.epilepsy.org.za) or contact Epilepsy South Africa on 0860EPILEPSY.

Discuss your epilepsy and treatment with your doctor regularly (e.g. side effects of medication, changes in seizure patterns and a healthy lifestyle).

Contact Epilepsy South Africa for support, advice and assistance on 0860EPILEPSY, info@epilepsy.org.za or find us on Facebook.

DON'T

Expose yourself to over-exertion which may trigger a seizure. This is especially important when exercising.

Use alcohol or other drugs.

Smoke or take in excessive amounts of caffeine (e.g. coffee, tea and fizzy drinks).

Expose yourself to heights or open fires as this makes injuries during a seizure more likely.

Have very hot showers as this could trigger a seizure.

Bath – rather shower as this is safer during a seizure. People have drowned even in shallow water.

Lock any doors (including bathrooms or toilets). If you have a seizure it will be difficult for people to reach you. Swim alone. Always practice water safety.

Expose yourself to flashing or flickering lights if you have photosensitive epilepsy (e.g. watching TV in a dark room). Be aware of flashing lights in clubs, at parties or in movies.

Cycle without a protective helmet and avoid busy roads if possible.

Participate in high-risk activities.

Stop taking your medication or change your dose without discussing this with your doctor first.

Take over-the-counter medicine without discussing this with your doctor or pharmacist first as drugs can interact with each other.

Share your medication with anyone and never take someone else's medication.

Miss your follow-up appointment with your medical team (even if you have not had a seizure for a while).

Allow your epilepsy to define who you are.



Epilepsy and Women

Our bodies experience many physical changes throughout our lifetime and there is no evidence suggesting that epilepsy interferes with this process. However, epilepsy has specific implications for women in respect of their gynaecological and reproductive health.

Female biological changes

Menstruation

There is no evidence to suggest that women with epilepsy experience any major differences in their menstrual patterns.

Some women may find a change in seizure pattern with an increase in seizures either during their period or at the time of ovulation.

Menopause

Menopause usually occurs between your mid-40s to mid-50s and may have unpleasant symptoms such as hot flushes and night sweats.

Hormone Replacement Therapy (HRT) may be prescribed to relieve these symptoms.

There is no medical proof to indicate an association between epilepsy and menopausal changes or that HRT influences seizure control or the absorption of anti-epileptic drugs. However, you may very well experience problems if you have both osteoporosis and seizures.

You and your partner

Relationships

It is understandable that women with epilepsy may be anxious about establishing intimate relationships, but many women form satisfying and stable relationships.

A successful relationship is built on honesty and trust. This means that both of you need to be open with each other

and discuss your epilepsy and its implications for your life together.

Sex drive

Anti-epileptic medication may slightly lower your sex drive. However, this is only likely in a small number of persons with epilepsy.

For most people this is not a problem and they are able to enjoy healthy sexual relations.

Fertility

Research has shown that a limited number of women may have a lower fertility rate due to epilepsy. However, there is no reason to believe that anti-epileptic medication will reduce your fertility.

Contraception

Women with epilepsy can choose from all the contraceptive methods available. Your doctor will be able to advise which is the most suitable for you.

It is important to note that the effectiveness of some forms of oral contraception may be reduced by anti-epileptic medication and higher doses or alternative methods may be necessary to provide adequate contraception.

Heredity

The likelihood of passing epilepsy on to your children will depend on a variety of factors, particularly the specifics of your diagnosis.

If you have had epilepsy since birth your child has a 6% likelihood to also have epilepsy.

Pregnancy and birth

Family planning

If you are thinking about having a baby it is best to discuss this with your doctor as early as possible, but definitely before becoming pregnant. This will allow you to gather sufficient information to make informed choices about family planning. Your partner should join you in counselling and be encouraged to share concerns. This will ensure that both of you are informed about possible risks to you and your baby.

Anti-epileptic medication and pregnancy

Discuss your medication with your doctor before becoming pregnant as changes may be required to minimise the risks to your baby. As some drugs can affect the growing fetus it is essential to check this with your doctor as soon as possible. For example, research has shown the risks of sodium valproate exposure in the womb resulting in physical and development disabilities.

Up to 40% of children in a British study were found to have developmental problems (delayed walking, speech, memory and language skills) while others were diagnosed with autism.

Despite these risks, it is generally preferable to remain on medication and your doctor will advise you how to balance potential risks to your baby and your own health. Sudden withdrawal of anti-epileptic medication is risky as you are likely to lose control of your seizures.

Seizure patterns

Some women experience changes in their seizure patterns during pregnancy. There may be a slight increase or decrease in frequency.

Diet

Some anti-epileptic medication may reduce vitamin K in the blood which can affect the clotting mechanism. In such cases your doctor may recommend that you take vitamin K orally before delivery and by your baby for a short period after birth.

While all pregnant women are advised to take a folic acid supplement during pregnancy it is particularly important for women with epilepsy.

Medical check-ups

It is essential to see your doctor regularly during your pregnancy. You should report any seizures or incidents which occurred such as falls, vomiting, illness or injury.

Delivery and caring for your baby

Labour

Your labour and the delivery of your baby are not likely to be different from that of other mothers.

By taking your medication correctly and getting as much rest as possible, you will reduce the risk of a seizure during labour. Remember that you should not be alone during this time and immediately after the birth.

Breastfeeding

The likelihood of your baby being affected by anti-epileptic medication in your breast milk will depend on the specific medication you take. In most cases very little of the drug is passed on to the baby and should thus not pose a problem. In fact, this may be a way of weaning your baby off the medication absorbed during pregnancy. If you tend to have seizures without warning it is advisable to take precautions while feeding your baby. Try sitting on the floor with your back to the wall surrounded by cushions as this will protect you and your baby in the event of a seizure.

Bathing and changing your baby

As a raised bath stand could be risky it is best to put the baby bath on the floor. If you feel this is still too risky and there is nobody to assist you, it may be best to sponge your baby down on a waterproof sheet.

Changing your baby in the cot or on a blanket on the floor is a good idea. By kneeling to the side you will fall away from your baby should a seizure occur.

Sleep

Having a new baby in the home is physically and emotionally draining. Make sure to get plenty of rest and accept offers of assistance from family and friends.

Parenthood

Like all new parents you and your partner will find parenthood exciting and challenging. The pleasure you get from your baby should not be affected in any way by the fact that you have epilepsy.





Epilepsy and the Elderly

Only 2% of the total population diagnosed with epilepsy for the first time are elderly people. The physical changes related with aging are most likely the cause of epilepsy.

Causes of seizures

- Epilepsy in an elderly person could be the return of a seizure disorder that was in remission for many years.
- Strokes can cause seizures because of the hemorrhage and damage to the brain itself.
- Heart attacks and diseases such as Alzheimer's can cause changes in the brain which may lead to seizures.
- Disease of the kidneys, liver and even diabetes may cause epilepsy in later life.
- Excessive use of alcohol can trigger seizures or latent epilepsy.
- Brain tumours of any kind may cause seizures.
- Post-traumatic and post-operative traumas can cause epilepsy.
- Surgery to the brain can leave a scar that may cause a seizure.
- A positive family history of epilepsy may be a cause.
- Seizures are associated with physical changes in an older person's brain caused by a stroke, heart disease, Alzheimer's disease, or brain tumours.
- Multiple sclerosis may lead to epilepsy.
- Physical changes may cause epilepsy by bodies becoming less resilient with age (e.g. bones are more fragile and make elderly people prone to falls which may result in head trauma and thus epilepsy).
- Neglected and acute meningitis (encephalitis) may cause epilepsy.
- As we get older the blood vessels that supply blood to the brain may become narrower and harder which can affect the flow of blood (and thus oxygen) to the brain.

The most common causes of seizures starting in later life are cerebrovascular (i.e. changes or damage to the blood vessels around the brain).

Epilepsy and the process of ageing

Decrease in mental alertness, mood changes and memory loss can be caused by several health problems associated with aging. Older people may be more sensitive to drug side effects which can include tiredness, unsteadiness, tremor, visual disturbances, changes in mood or behaviour, depression or stomach upsets. It may be possible to completely eliminate these by adjusting or changing medication. Should these occur you should report any side effects to your doctor or specialist.

The social impact of epilepsy on the elderly

The first seizure is a very traumatic experience with far reaching social consequences. An elderly person may feel useless and of little value to society. For any person with epilepsy loneliness, physical changes, their inability to live independently or drive a vehicle can cause depression. This is even worse for an elderly person with epilepsy.

Elderly persons with epilepsy have a higher risk of sustaining head injuries or fractures due to frequent falls.

They may feel as if they have lost control over their own lives and uncertain about their future which may be worsened by social isolation.

If the person does not experience an aura (a warning sensation that occurs prior to a seizure) he/she will need to adjust accordingly.

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Medication

Memory problems often affect people with epilepsy. However, epilepsy medication works best when blood levels remain steady which requires the correct dosage taken at specific times (as prescribed) to achieve optimum therapeutic results.

It can be especially difficult for older persons to keep track of when to take what medication. Therefore we recommend:

- Using a pill box/dispenser divided into segments according to the time and day which may be purchased from most chemists and even some retail stores.
- Always asking your doctor/pharmacist when to take your tablets (e.g. before or after meals).
- Packing medication in sachets (plastic bags) marked with the specific hour of the day and day of the week these should be taken. A friend or family member can pack these if the person has difficulty in packing his/her own medication.
- Always monitoring the expiry date of all medication. If your dosage is changed and you have a surplus of medication take note of the expiry date thereafter medication should be carefully destroyed and not taken.
- A wristwatch with an alarm to remind you when to take your medication.
- Asking a friend or family member to assist in keeping track of reordering dates and marking the calendar accordingly.
- Keeping your tablets in a cool and dry place. Some medication (e.g. Epilim) is very sensitive to moisture and is best kept in their blister packs until needed.
- Not giving any of your epilepsy treatment to another person who had a seizure or complain of headaches.

If you forget to take your medication do not take a double dose. Ask your pharmacist or doctor for advice.

Toxicity: The therapeutic levels of anti-convulsant medication must be monitored through regular blood tests. If the levels are too high it could cause toxicity which could, in turn, manifest as dizziness and confusion.

Drug Interaction: Elderly persons are more likely to be taking a variety of medication for different medical reasons.

These drugs can interact and produce negative side effects. It is therefore very important to discuss possible drug interaction with the doctor and/or pharmacist.

Sensitivity: A negative reaction to drugs may result in depression, agitation, confusion or loss of memory. Monitor any changes in sleeping or eating patterns, bearing in mind that people may be sensitive to a specific drug. Consult the doctor and never change or stop medication without medical advice.

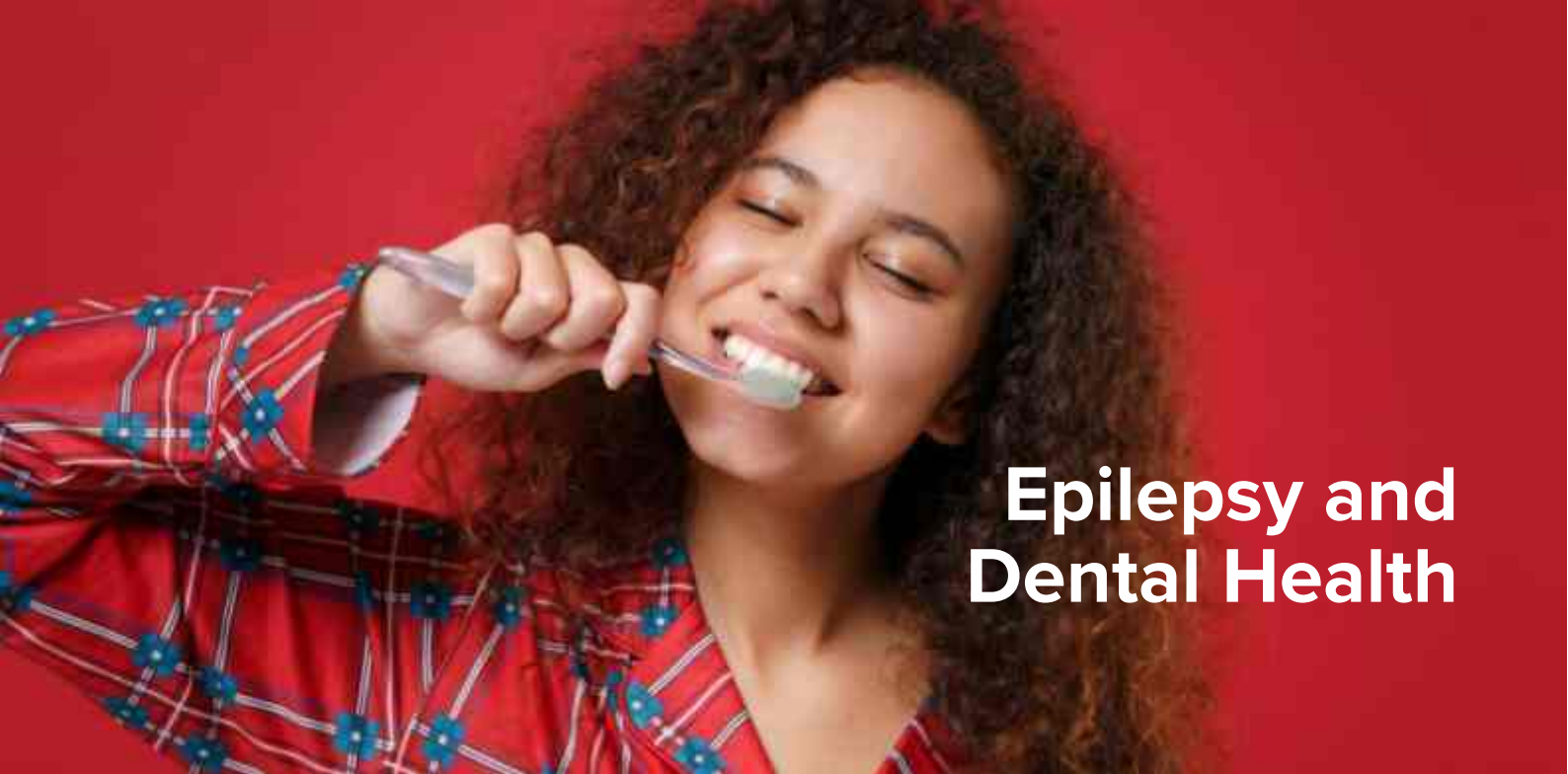
Do's and don'ts

- Remember that fire, heat and water can be dangerous to any person with epilepsy and especially older persons.
- Do not smoke or abuse alcohol if you have epilepsy.
- Avoid carrying hot dishes or boiling water in a kettle.
- Set the water temperature on your geyser lower to prevent the water from burning you.
- Do not bath or shower in excessively hot water as it may trigger seizures.
- Avoid ironing if at all possible.
- You can drown in very small amount of water. If possible, shower rather than taking a bath and do not lock the bathroom door.
- Wear rubber gloves when handling or washing glassware.
- Place a screen in front of open fires and do not carry hot ashes.
- If possible, avoid living in a house or flat with stairs as you may fall down the stairs while having a seizure.
- Carpeted floors and padded furniture provide more protection.
- Protective padding can be used on sharp corners of tables to prevent injuries.
- Keep in touch with family or friends with beepers and/or mobile phones.
- A MedicAlert bracelet can be useful to identify a person having a seizure enabling a member of the public to assist him/her. You can purchase a MedicAlert bracelet at www.medicalert.co.za or by calling 0860 111 2979.

It is important to remember:

- DO emphasise what an elderly person with epilepsy can do rather than what he/she cannot do (while at the same time taking sensible precautions).
- DO treat the elderly person like everyone else in the family.
- DO help your elderly relative/friend to integrate into as many social activities as possible (with the necessary precautions) to enable a healthy social life.
- DO allow the elderly person to make his/her own decisions where possible.
- DON'T overprotect elderly people with epilepsy, but allow him/her to identify his/her own strengths and weaknesses.

Should you have any further concerns about caring for an elderly person with epilepsy you can contact an Epilepsy South Africa Branch close to you for assistance and advice, including contact details of other organisations able to offer support and advice on various issues concerning elderly persons.



Epilepsy and Dental Health

Healthy teeth and gums and good oral hygiene are very important to ensure good health and general wellbeing. This is particularly true for persons with epilepsy and can be achieved by following a few simple steps.

INFORMING YOUR DENTIST

Whether your epilepsy diagnosis is new or long-standing it is vitally important to inform your dentist of your epilepsy and any medication you are taking. Take your drugs with you if you cannot remember the name of the various drugs. Also take your seizure diary describing your seizure pattern, duration and any likely seizure triggers.

Discuss with your dentist what actions should be taken if you have a seizure in the surgery to ensure your safety and appropriate care, e.g. the name and contact details of the appropriate person to notify and when it is necessary to call an ambulance. If you are particularly anxious about the visit, it would be helpful to have someone accompany you.

REGULAR DENTAL CHECK-UPS

Your dentist will advise you how often you should have dental check-ups. Do not wait until problems become difficult and painful to treat.

INFANTS AND CHILDREN

Expectant mothers should consider breastfeeding which is good for your baby's dental and general health. It is never too early to introduce a child to dental care. Brushing with a smear of fluoridated toothpaste should start when your baby's first tooth appears. Baby teeth are very important, not only for chewing, but for keeping the space needed for permanent teeth.

Some of these first teeth have to last until the child reaches the age of 11 years. Following a few simple rules will help your child have healthy teeth. Parents play an important role in caring for your child's teeth and training them to look after their teeth as they grow older. It is equally important to ensure that a child does not develop a fear of the dentist. If anxiety is causing your child to have seizures before a visit, discuss this problem with the dentist as it may be possible to prescribe a mild sedative before treatment.

PLAQUE AND CLEANING TEETH

Good oral hygiene is very important for everyone to ensure healthy teeth and gums. Plaque is a sticky film formed from food residues (such as sweets and sugary drinks) which coats your teeth, encouraging bacteria growth and causing tooth decay. Some types of bacteria in plaque cause the formation of acids which attack your teeth while other types produce substances that can harm your gums.

A build-up of plaque can lead to both gum swelling and gum inflammation which, in turn, can cause bleeding gums and lead to gum disease. Gum swelling and inflammation can be painful and affect anyone, but groups at greater risk are young children in the early stage of physical development, adolescents and pregnant and menopausal women undergoing hormonal changes.

Pain in your gums during and following brushing may prompt you to stop cleaning your teeth which, in turn, will make the situation worse unless the plaque is removed. The removal of plaque is of prime importance for dental health.

Regular, thorough brushing and flossing after each meal is advised to prevent problems. Dental experts recommend brushing with fluoride toothpaste for three minutes twice daily (preferably after breakfast and before bedtime) rather than brushing less thoroughly more often.

Choose an ordinary or electric soft or medium soft toothbrush in good condition – never a hard one - and be sure to brush your gums as well. Bleeding gums after brushing indicates a problem. However, continue brushing and seek dental advice.

Cleaning children's teeth should begin as soon as the primary teeth appear (anytime from five months onwards). Use a soft baby toothbrush and a small (pea-sized) quantity of fluoride (1,000 parts fluoride per million) toothpaste. Twice daily supervised cleaning of children's teeth should be routine.

Most dental surgeries employ a dental hygienist who can offer invaluable help and advice on the day-to-day care of teeth and gums.

DIET AND DENTAL HEALTH

A diet containing a lot of sugar is a major contributor to tooth decay. Bacteria in your mouth feed on the sugar in your diet which creates acid. This acid attacks the enamel of your teeth resulting in dental decay. The best is a healthy and varied diet with as little sugar as possible. Check the labels on containers of processed food as much of the sugar is "hidden" under different names such as fructose, sucrose, molasses, dextrose, glucose, glucose syrup, maltose, corn syrup, honey or caramel.

If "sugar" is one of the first ingredients listed it indicates a higher sugar content. Avoid sugary drinks (including fruit juice) between meals and never put these in your baby's feeding bottle, rather giving water or milk. Never dip pacifiers (dummies) in sugary liquids. Adults and (particularly) children should be encouraged to develop a taste for a wide range of unsweetened foods, drinks and snacks such as unsweetened cereals, rice, bread, yoghurt, fish, meat and eggs. Eat fruit in preference to sweets and chocolate.

ANTI-EPILEPTIC DRUG (AED) TREATMENT

The majority of people with epilepsy control their seizures with prescribed anti-epileptic drugs (AEDs). As some AEDs may have potential adverse side effects on your dental health it is best to ask your doctor/neurologist about:

- The most effective AEDs to control your seizures with minimal side effects. Some AEDs may have side effects affecting the health of your teeth and gums. For example, phenytoin can cause overgrowth of gum tissue. Some drugs such as carbamazepine, primidone and phenobarbitone may cause dryness of the mouth due to changes in the composition or reduction in the production of saliva which is necessary for digestion of food. Other possible oral side effects of AEDs include glossitis (a smooth and painful tongue and oral ulceration) caused by carbamazepine and taste disturbances (phenytoin).

- If you are affected by any of the AED side effects consult your doctor/dentist.
- The most effective format of AEDs. Children with epilepsy prescribed AEDs in syrup form may have problems with their teeth due to the sugar content in the medication, particularly if the dose is taken at night. It may be possible to prescribe sugar-free liquid preparations.
- Reducing the risk of dental problems during pregnancy (to both mother and baby). Women who are planning a pregnancy should consult their doctor about treatment options. Some older AEDs like phenytoin (Epanutin), primidone (Mysoline), carbamazepine (Tegretol) and sodium valproate (Epilim) are associated with a slightly higher risk of birth defects such as a cleft lip and/or palate which can affect your child's speech, eating and confidence.
- Risk assessment of seizures likely to result in facial/dental injury.

DENTAL ACCIDENTS DURING SEIZURES

Some types of seizures such as tonic-clonic (major convulsive) and myoclonic (muscle jerks) may cause fall and injuries to your mouth and gums. In the event of a fall tooth fragments, crowns, fillings or even loose dentures may become dislodged or swallowed. If teeth are damaged arrange an emergency appointment with your dentist as soon as possible.

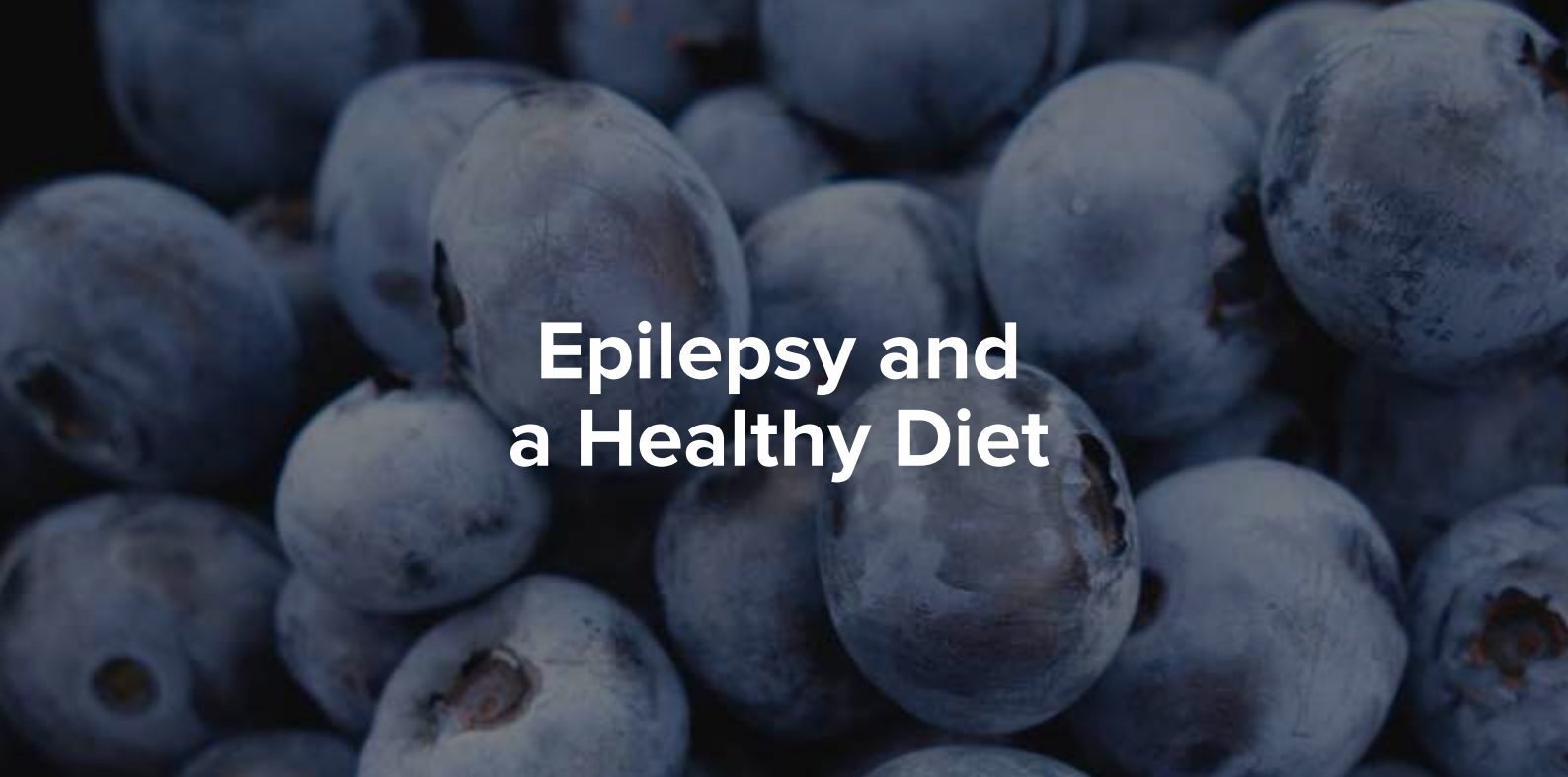
You might bite the inside of your mouth during a seizure making brushing painful. Dental advisers suggest using Corsodyl mouthwash (available over the counter from pharmacists) rather than brushing until the pain or ulcers subside. You can reduce any swelling by holding a cold compress to your cheek or sucking an ice cube. Hot salt water mouthwash (half a teaspoon of salt to one tumbler of water) can help soothe during a seizure pain and heal your mouth.

ORTHODONTIC TREATMENT

Some children (regardless whether they have epilepsy or not) may require orthodontic treatment. This is not usually undertaken until the child's upper canines (eye teeth) appear at about the age of 11 or 12 years.

Cosmetic dentistry injuries sustained as a result of seizures and the side effects of some medications may cause dental problems that can affect your appearance, speech and self-confidence. Some types of treatment may improve the appearance of your teeth. Seek advice from your dentist.





Epilepsy and a Healthy Diet

Facts about eating patterns

Eating irregular meals can cause changes to your blood sugar levels which may affect how you feel and how your body functions. Eating well balanced meals regularly can help increase your energy levels and boost your immune system, which may help you to feel more positive and reduce the risk of seizures.

What foods make up a 'healthy diet'?

Your diet needs to include a wide variety of foods from all three of the food groups: fats, carbohydrates and proteins.

Adults should aim to eat no more than 70g of fats per day – with most of these coming from mono-unsaturated fats such as using olive oil in cooking and olive oil spreads. We should reduce our use of vegetable oils and increase our intake of omega 3 fats. We can consume small amounts of saturated fats but should avoid trans fats as much as possible.

Most of our diet should be made up of 'complex carbohydrates'. These include high fibre foods such as wholegrain bread, cereal, pasta and rice, along with a variety of fruit and vegetables. Try to avoid refined sugars and syrups like those found in fizzy drinks, sweets, cakes, biscuits and adding sugar to hot drinks.

Protein can be found in meat and fish, but also in tofu (soya bean curd), dairy products, nuts, seeds, pulses and legumes (lentils and beans). It is good to choose lean cuts of meat and remove any skin as this is where saturated fat can be found. Oily fish such as mackerel, salmon and sardine are good sources of protein and also contain healthy omega 3 fats.

An important way to maintain a healthy body weight is to balance calorie intake with physical exercise. Calories are units of energy contained in foods. If a food source contains a high number of calories but you do not use all the energy (in your day-to-day activities through exercise) you are likely to gain weight.

Eating '5 a day'

We should eat a range of different coloured fruit and vegetables each day as each colour relates to a different set of vitamins and minerals called phytonutrients. Eating a variety (as recommended) gives our bodies all the vitamins and minerals it needs to function well. Fruit and vegetables also contain valuable antioxidants which can help to protect the body from damage.

What is a 'balanced diet'?

A balanced diet is one made up of a mixture of carbohydrates, proteins and fats. It is important to eat a variety of foods from all three food groups.

- Carbohydrates release energy into the body and feed the brain.
- Proteins build and support your muscles, hormones, enzymes, red blood cells and your immune system.
- Fats help your body to absorb certain nutrients, warm the body, promote healthy cell function and can be used for energy.

You may have heard of diets such as low fat diets, low carbohydrate diets or GI diets. Some foods are better for you than others, but getting the right balance of the different types of carbohydrates, proteins and fats is also important.

Fats

Some people eat too much of the wrong types of fat and become overweight.

However, some fatty acids are essential nutrients, meaning that they can't be produced in the body from other nutrients and so need to be eaten as part of our diet to enable our bodies to function well.

All other fats required by the body can be produced in the human body without being eaten.

Which fats are best for our bodies?

You should know about four types of fats:

- **Monounsaturated fats (omega-9 fats) such as olive oil, avocados, almonds and macadamia nuts.** Research suggests that eating omega-9 fats can lower cholesterol, reduce the hardening of arteries, improve immune function and provide protection against certain types of cancer.
- **Polyunsaturated fats include two main types:** omega-3 and omega-6. Some foods contain both omega-3 and omega-6 fats. Oily fish such as mackerel, salmon, sardines, herring, anchovies and fish oil supplements (e.g. cod liver oil) contain high levels of omega-3 which can be extremely good for you. Omega-3 fats can help you maintain a healthy heart, skin and bones, as well as boost your energy levels and your ability to deal with stress. Foods that contain omega-6 fats include sunflower, pumpkin and sesame seeds, pine nuts, pistachio nuts, chicken, and grapeseed, vegetable and sunflower oils.
- **Saturated fats are mainly found in animal products such as butter, cream and animal fats.** Saturated fats are associated with increased 'bad' cholesterol and are thought to increase the risk of coronary heart disease - which can lead to angina, heart attacks and strokes. Aim to eat foods that contain less than 5g of saturated fats per 100g.
- **Trans fats are mostly found in processed foods such as cakes, biscuits and margarine as these give foods a longer shelf life.** However, these trans fats are extremely difficult for your body to break down. As a result these can cause a number of health problems. Trans fats can raise 'bad' cholesterol levels and decrease 'good' cholesterol levels.

Some research also suggests that diets high in trans fats can increase your risk of a number of cancers. Aim to eat as little trans fats as you can by avoiding processed foods and by being aware of the words 'trans' or 'hydrogenated' in the list of ingredients of any food product.

Are some carbohydrates better than others?

If your seizures are triggered by changes in blood sugar levels eating low to medium GI foods may help to reduce your seizures.

Low GI

Wholewheat pasta and bread, brown rice, new potatoes, sweet potatoes, noodles, wheat tortilla.

Kidney beans, lentils, chickpeas and any other pulses or beans. Milk, soya milk, yoghurt. All vegetables, salad items, fruit, nuts.



Medium GI

Porridge oats, white pitta bread, croissant, digestives, crispbread. Honey, mango, sultanas, bananas, raisins. Ice cream. Baked beans.



High GI

Brown and white bread, honey, crackers, noodles, tiger oats, rice crispies. Jasmine rice. Sports drinks such as Energade and Powerade.





The Ketogenic Diet

Epilepsy and the Ketogenic Diet

Up to 70% of people with epilepsy will be able to control their seizures with anti-epileptic drugs. The Ketogenic Diet (together with anti-epileptic medication) may help some children and adults with drug-resistant epilepsy to reduce the number or severity of their seizures or even stop these seizures completely.

What is the Ketogenic Diet?

The Ketogenic Diet is a high fat, adequate protein diet in use since the 1920s to treat epilepsy. The word “ketogenic” refers to chemicals called ketones made in the body. Thus “keto” refers to these ketones and “genic” to producing/manufacturing.

How does the Ketogenic Diet work?

Your body typically uses glucose from carbohydrates as its energy source. Glucose is a type of sugar while carbohydrates are found in foods like sugar, fruits and vegetables. The Ketogenic Diet changes your body's energy source from using ketones that come from fats rather than glucose originating from carbohydrates. The adequate production of ketones is called “ketosis”. It is very important to carefully measure the level of ketones your body is producing to determine if it is getting energy from the fats you are eating.

Is the Ketogenic Diet suitable for everybody?

The Ketogenic Diet is easier to implement with children, although similar diets are available for adolescents and adults. The efficacy of the diet differs from child to child and it is not possible to predict to what extent the Diet will help. The Diet is usually considered as a treatment option when three or more medications have been ineffective in controlling seizures.

The Diet must be followed with the support of an experienced neurologist and dietitian (nutrition specialist). It can be adapted to all ethnic diets and is suitable for children who are allergic to dairy and other products.

Is the Ketogenic Diet suitable for all ages?

Although the Diet is suitable for children between the ages of one and 10 years old, it has been very successful in babies younger than 12 months. However, in these cases monitoring is very important. An adapted version of the Diet is used with adolescents and adults.

Does the Ketogenic Diet work?

The Diet has been shown to reduce the number of seizures between 50 and 100% in some children/adults with intractable epilepsy (i.e. difficult to control seizures). However, some people may have other benefits such as improved day-to-day wellbeing. Some children benefit from the Ketogenic Diet within a week while others show a slower response. Usually the Diet is tested for three months to determine how well it works.

Making the decision

Most experts say the Diet is worth trying when three or more medications have failed to control seizures or when medications cause side effects harmful to a child's life. The Diet seems to work for more than one type of seizure and for children/adults with higher and lower seizure frequency. Doctors say it shouldn't be used instead of medication if drugs are working and the child is not having bad side effects. However, parents have the right to decide if they want to try the Diet since it is more natural, have less side effects and has a very high chance of reducing seizures.

Parents must be educated and need to know everything about the Diet since it might seem like a barrier regarding their social life (e.g. eating out and taking holidays). Even though the Diet has side effects all of these are treatable. As with any kind of treatment you will need to consider many factors before deciding to try the Diet.

The best way to make this decision is to discuss all the possibilities and factors with your doctor and obtaining as much information as you can. It may also be helpful to talk with other parents whose children have been on the Diet.

Frequently asked Questions

Will I/my child gain weight from eating so much fat?

The amount of food is carefully calculated and weighed so that you/your child will eat only the required calories for good health. The fat content of the food doesn't affect weight since it forms part of the total calories calculated.

How long should I sit with my child before I give up trying to get him to finish all his food?

Some parents report that mealtimes can wrap up in twenty minutes while others say they have to sit with their children for two hours before all the food is finished.

A child must finish all the food because the meal is put together in amounts that will give him the right balance between fat, protein and carbohydrates. If some food is not eaten, the balance is lost and breakthrough seizures will occur.

Since this is important parents often try tricks like playing a video during meals or playing games to distract the child while they're encouraging him to eat. Parents who've been successful advise others to use the diet creatively and try offering something new and special for each meal to keep the child interested. Older children may be more cooperative as they know the diet is helping to control their seizures.

Will taking prescription or other medicines affect the Diet?

All medicines and pharmaceuticals such as toothpaste, cough syrup, vitamins and prescription medicine must, whenever possible, be free of sugar and other

carbohydrates. Remind your doctor to prescribe all medication in sugar-free and carbohydrate-free forms. Read labels carefully and check with your pharmacist.

Does the Diet cause a problem with high cholesterol?

When children are switched from a high fat diet both cholesterol and triglyceride levels can go up. However, the Ketogenic Diet is not a lifetime diet as children stay on it for about two years. When weaned off the Diet cholesterol levels return to normal.

Important: Don't try it alone

The Ketogenic Diet has special appeal to families since a "diet" seems a more "natural" way of preventing seizures than taking pills. However, the Diet is anything but natural.

It is a highly unusual choice of foods and reverses the body's natural way of using glucose as a source of energy. In fact, the Ketogenic Diet, like taking medications or having surgery, is considered medical treatment.

It is not a "do-it-yourself" diet as every step of the process must be managed by an experienced medical practitioner and dietitian.





Website: www.epilepsy.org.za



Email: info@epilepsy.org.za



Physical Address: 85 East Geduld Road,
Geduld, Springs, 1559



Postal Address: 85 East Geduld Road,
Geduld, Springs, 1559



Contact Number: +27 (0)79 119 3607

Facebook: www.facebook.com/epilepsy.southafrica

YouTube: www.youtube.com/SAEpilepsy

Instagram: www.instagram.com/epilepsy.southafrica

TikTok: <https://www.tiktok.com/@epilepsy.south.africa>

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