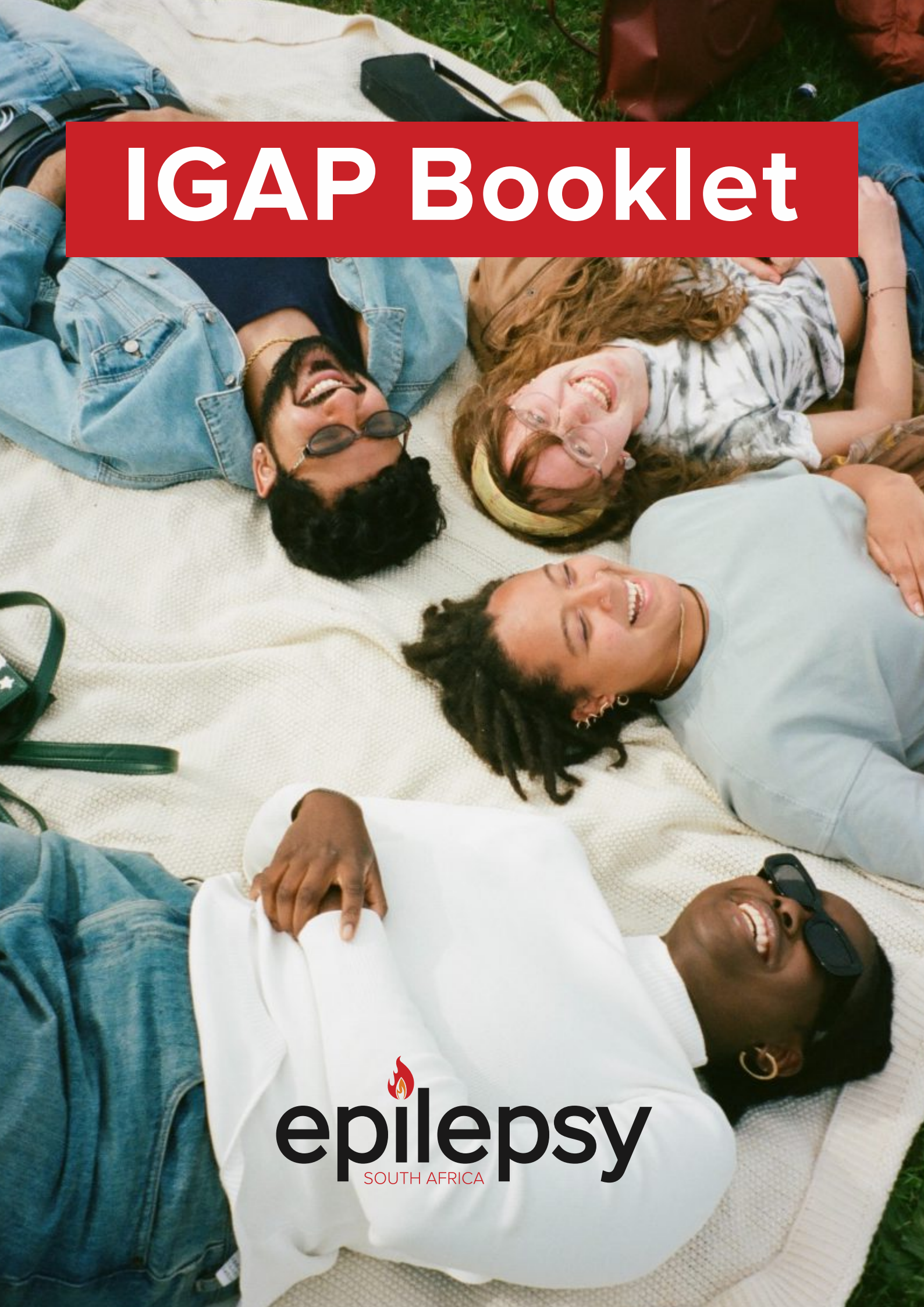


IGAP Booklet




SOUTH AFRICA



The Intersectoral Global Action Plan (IGAP) 10 Year Goal

“To reduce the stigma, impact and burden of neurological disorders, including their associated mortality, morbidity and disability, and to improve the quality of life of people with neurological disorders, their carers and families.”



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Editorial



It is an honour to present this publication. The Intersectoral Global Action Plan (IGAP) booklet is an important document that will inform and support people with Epilepsy and their loved ones across South Africa.

It is compiled by a superb team and as a person with Epilepsy I am grateful to be a part of this team.

This booklet offers a platform for people to understand the global Epilepsy communities focus and dedication to making the world an **inclusive society** for all people with Epilepsy and other Neurological Conditions.

Epilepsy is a neurological condition that affects people in many different ways. Epilepsy can and

does have adverse effects on social and psychological wellbeing. So engaging and demystifying this neurological condition is critical.

The IGAP speaks directly to the **lived experiences**, challenges, and dreams of all people with epilepsy in the world. It is an amazing tool that will support, guide, and promote how we move forward.

In this publication, we include important information about the IGAP and guidelines to manage Epilepsy. We trust you will all find this publication inspiring, and we encourage you to share it far and wide.

To the IGAP Team, Marina Clarke in Cape Town (Project Advisor) and Megan Couchman (Marketing), A Special Thanks to you for your contributions and ideas in putting this publication together and special thanks to the IBE and BAND Foundation for contributing towards making this this publication possible.

Please feel free to contact us via Epilepsy South Africa National Office on 0860 EPILEPSY or email info@epilepsy.org.za for any further information.

Thank you,

Sharlene Cassel,
National Director, Epilepsy South Africa



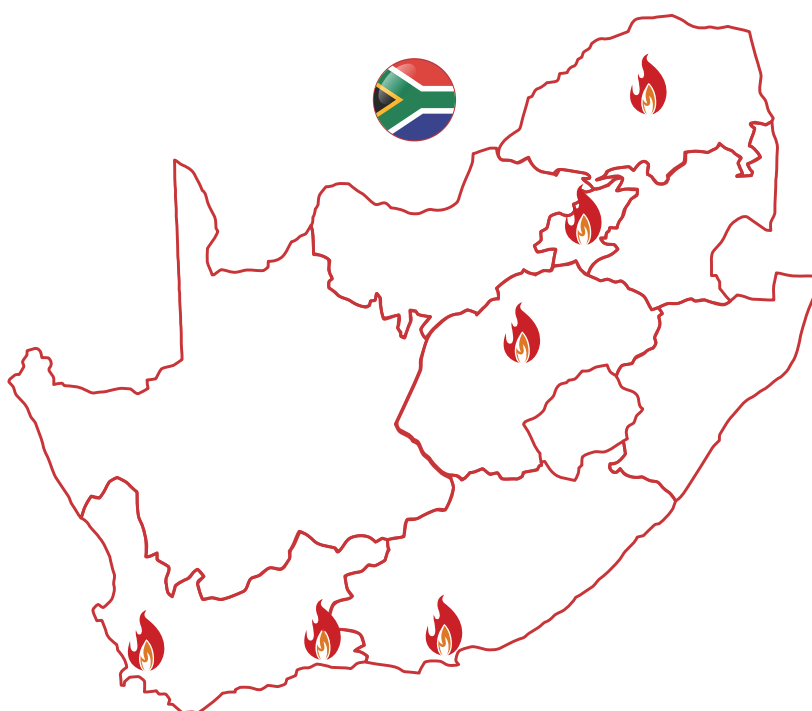
Epilepsy South Africa

Epilepsy South Africa was established in 1967 as the South African National Epilepsy League (SANEL). We are the only national organisation in South Africa offering specialised and comprehensive services to persons with and affected by epilepsy. **The vision** of Epilepsy South Africa is to see a world where people with epilepsy are included and accepted without discrimination. **Our mission** is to promote the human rights of persons living with Epilepsy.

The IBE's vision of the world is where everywhere ignorance and fear about epilepsy are replaced by understanding and care. The IBE is the recognised international umbrella body representing national epilepsy organisations that have a specific interest in improving the social condition and quality of life of people with epilepsy and their carers.

Epilepsy South Africa is proud to be the South African chapter of the International Bureau of Epilepsy (IBE). The IBE improves the social condition and quality of life of people with epilepsy and those who care for them.

Epilepsy South Africa aims to “Ignite the flame of potential” in all people with Epilepsy.



The IGAP

What is the IGAP?

The Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders as we know it, is referred to as the IGAP. It has been more than 20 years in the making.

The IGAP is a 10-year roadmap (2022 – 2031) launched by the World Health Organisation (WHO), to effectively address neurological conditions and improve the lives of people with epilepsy and other neurological conditions worldwide.

Why is the IGAP so important?

The IGAP is the **FIRST EVER** global action plan on epilepsy and other neurological disorders.

The history of this incredible document

In May 2015 the World Health Organisation (WHO) recognised the worldwide burden of epilepsy which resulted in the development of the Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Disorders 2022 – 2031. The IGAP was adopted in May 2022 by all member states, South Africa being one of these.

The IGAP aspires for a world in which:

- Brain health is valued, promoted, and protected throughout life;
- Neurological disorders are prevented, diagnosed, and treated to avoid premature death; and
- People affected by neurological disorders and their carers have the best possible health, with equal rights, opportunities, respect, and autonomy.

We need to create a world where people with epilepsy and other neurological conditions are accepted and included without discrimination.



World Health Organization



What is Epilepsy?

One in twenty people will experience some sort of seizure at some stage of their life.

A seizure (also called a convulsion) is a sudden, uncontrolled burst of electrical activity in the brain which can cause changes in behaviour, movements, feelings, and levels of consciousness. A single seizure does not mean that you have epilepsy. **A doctor will diagnose whether you have epilepsy or not.**

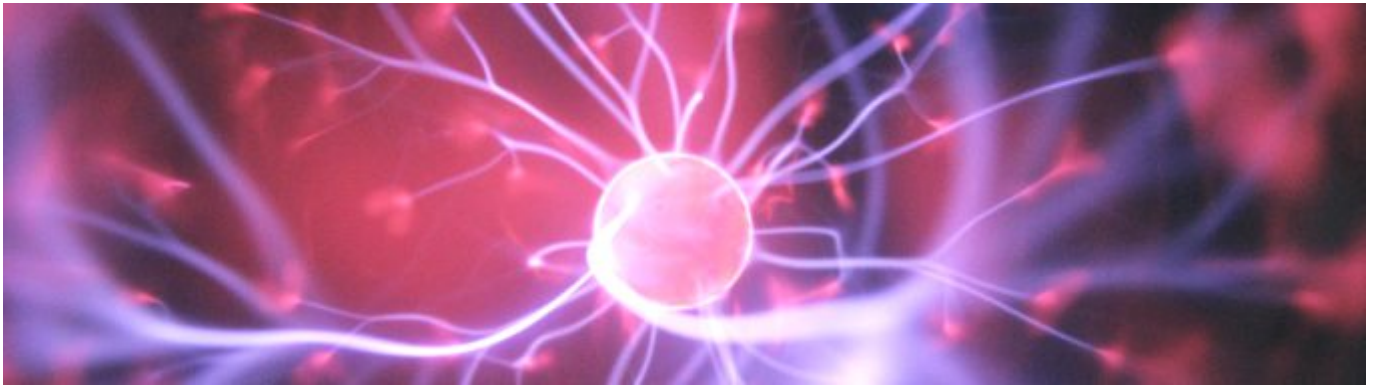
Epilepsy is a tendency to have repeated seizures. It is a spectrum disorder which means that there are many different types of seizures. In some people the cause can be identified, but in most cases the cause is not known.

Different people will have different symptoms depending on the type of seizure. Due to the fact that epilepsy is caused by activity in the brain, seizures can affect any brain process. Symptoms may include temporary confusion, staring into space, stiff muscles, uncontrollable jerking movements of the arms and legs, losing consciousness, and psychological symptoms such as fear, anxiety, or déjà vu (a feeling that you have lived through an experience before).

While many things will change when you are diagnosed with epilepsy, the most immediate and important is to tell people the true facts about your condition:

- Epilepsy can **affect any person at any age**, gender, and race regardless of economic status (income levels).
- Epilepsy is **life-threatening** if left undiagnosed, untreated, or unmanaged.
- Epilepsy can be **treated and effectively managed**.
- 25% of epilepsy cases **can be prevented**.
- Everyone can **learn how to help** someone having a seizure.
- **One in 20 people** will have a seizure at some time in their lives which does not mean that they have epilepsy.
- Children with epilepsy **should go to school** because they are able to learn like other children.
- People with epilepsy **can learn and work** because they have the same abilities as anyone else.





What are the **other neurological conditions** mentioned in the IGAP?

Neurological conditions affect the brain and spinal cord. The IGAP includes a number of conditions:

- A **headache** is a pain in your head or face. These can differ a lot in terms of the type and intensity of pain, where it is located and how often you get these. While headaches are very common and generally not dangerous, some can be a sign of a more serious condition. There are more than 150 types of headaches.
- Diseases that affect the functioning of muscles due to problems with the nerves and muscles in your body. These are known as **neurodegenerative disorders** (a slow and progressive loss of brain cells) or neuromuscular disorders. The most common are Parkinson's disease, Alzheimer's disease, dementia, muscular dystrophy, Huntington's disease, Amyotrophic Lateral Sclerosis (ALS) which is also known as Lou Gehrig's disease, and motor neuron disease.
- Diseases that affect the flow of blood to your brain (**cerebrovascular diseases**). These include stroke and brain aneurysm (caused by a weak or thin spot on an artery in the brain that balloons out and fills with blood). These conditions are medical emergencies and need immediate treatment.
- Some diseases that affect the brain are caused by a viral or bacterial infection and are known as **neuroinfectious or neuroimmunological disorders**. These include meningitis (a swelling of the protective membranes covering the brain and spinal cord), HIV, neurocysticercosis (a preventable parasitic infection generally caused by pork tapeworms), cerebral malaria, and multiple sclerosis (MS).
- Some conditions affect how the brain works (**neurodevelopmental disorders**). Examples include attention-deficit/hyperactivity disorder (ADHD), autism, some learning disabilities, and cerebral palsy.
- The **brain or spinal cord can be injured by a traumatic event** like a car accident or sport injury. It affects the normal function of the brain due to a bump, blow or jolt to the head or something penetrating the brain or spinal cord. While everyone is at risk, children and older adults are especially vulnerable.
- Some **cancers** can also affect the nervous system.

What are the Goals of the IGAP?

The IGAP has 4 goals it sets out to achieve and these inform the implementation of the IGAP in South Africa. The goals are:



GOAL 1

Reduce the **stigma, impact, and burden** of neurological conditions through creating awareness, educating people, and increasing understanding.



GOAL 2

Improve the **quality of life** of people with neurological conditions, their carers, and families.



GOAL 3

Strengthen prevention, treatment and care.

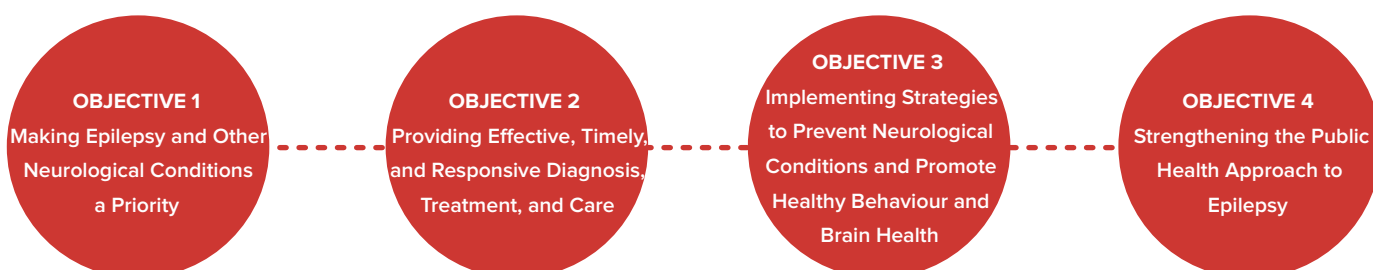


GOAL 4

Ensure a **holistic approach**, where the medical team, the individual, and all social and environmental influences work together.

How can we use the IGAP as a Roadmap in South Africa?

When you read the IGAP, you will see that it has **five strategic objectives**. Epilepsy South Africa conducted a national survey in June/July 2022 asking people with and affected by epilepsy and other neurological conditions for their opinion about the most important objectives. Through this process **four objectives were identified to be implemented in South Africa**.



Objective 1:

Making Epilepsy and Other Neurological Conditions a Priority

Did you know that in South Africa one in a hundred people have epilepsy and many more have a neurological condition?

In July 2023 South Africa's population was estimated to be 61,5 million which means that at least 615,000 South Africans have epilepsy. If we assume that every person with epilepsy has four immediate family members, nearly 2,5 million South Africans are affected by the condition.

For this very reason we need to empower ALL people in South Africa with knowledge. We can achieve this if we all support a change in policy in South Africa. We are proud to say our international community has come together and created a roadmap for this. Yes, it is the very paper we are discussing - THE IGAP.

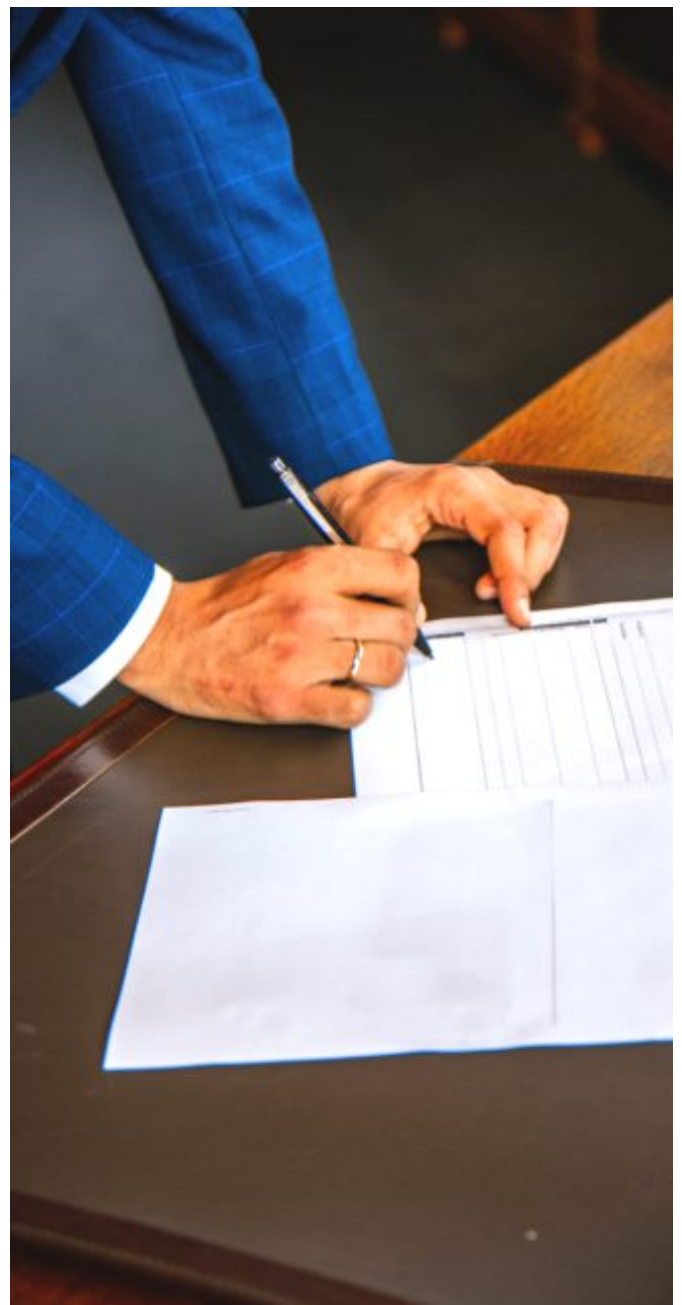
All member states adopted the IGAP at the World Health Assembly in May 2022. Now all of the stakeholders in South Africa need to come together to make this a reality.

CHANGE IN POLICY IS CRITICAL!

South Africa faces a number of important health issues like HIV/AIDS, TB, diabetes, and heart disease. This means that resources like money and staff must be made available to deal with each of these. Traditionally, neurological conditions like epilepsy have not received the resources required to make a real difference in the quality of people's lives. A dedicated policy will make it possible to allocate more resources which makes it the starting point for change.

What are we doing?

In June 2023 Epilepsy South Africa submitted the Draft National Plan on Epilepsy and Other Neurological Conditions to the Department of Women, Youth and Persons with Disabilities (DWYPD) in the Presidency. This Plan describes the current situation in South Africa and describes how things can be changed. We hope that Cabinet will approve this Plan soon.



Here are some questions you may want to ask your doctor:

Am I having seizures and what are these?

- There are different types of seizures and your doctor can help you to understand what is happening to you.

What tests are needed?

- A consultation with your doctor.
- An MRI (Magnetic Resonance Imaging) checks for structural abnormalities of the brain. It is painless and does not require hospitalisation.
- An EEG (electroencephalogram) records the electrical activities of the brain which can help the doctor find out what caused your seizures.

How do I know I have epilepsy?

- Having a single seizure also does not mean that you have epilepsy, having multiple seizures can be an indicator.

Do I need to see a specialist?

- Your doctor will decide if it is necessary for you to see a specialist like a neurologist. You may also find some counselling helpful to adjust to your diagnosis so ask your doctor for a referral.

What treatment is available?

- Medication is usually the first step in managing your seizures. There are several types of medications and your doctor will help you to find those that work best for you.
- If medication does not help, your doctor will look at other options.

Do seizures have warning signs?

- There are not always warning signs, but some people experience an aura (warning sign). This is likely to be different for every person but may include a smell, taste or feeling.



Treatment Options

The standard treatment for epilepsy is the regular use of one or more anti-epileptic or anti-convulsant medicines.

Ideally people with neurological conditions should take as little medication as possible while maintaining seizure control and other symptoms of their condition. It is important to take medication exactly as prescribed for the best results.

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

The interaction between oral contraceptives and anti-epileptic medication may reduce the effectiveness of the contraception resulting in unplanned pregnancy. Women with epilepsy should thus discuss this with their doctor to ensure effective contraception.

Avoid using alcohol and recreational drugs when taking anti-epileptic medication.

You should follow a balanced diet to ensure that the medication can work effectively.

Objective 2:

Providing Effective, Timely, and Responsive Diagnosis, Treatment, and Care

We need to look at two specific areas which are closely linked together:

- Medical care should include accurate diagnosis and effective treatment options supported by caring and well-informed health workers to reduce the treatment gap.
- Psychosocial care refers to aspects of an individual's mental health and emotional well-being. This includes care pathways, support for carers, and teamwork.

The Treatment Gap

The “treatment gap” is the difference between the number of people with epilepsy who are getting the right treatment and those who do not.

About 75 in every 100 people with epilepsy in Africa are not receiving treatment or have access to healthcare and medication (which is generally cheap). While the situation is much better in South African cities, the same cannot be said about rural areas. It is also concerning that many people have very little information about their condition and often do not understand their treatment or their responsibilities.

This treatment gap is generally caused by:

- Insufficient supplies and the high costs of anti-epileptic medications.
- The lack of primary health workers trained to diagnose and treat epilepsy.
- Limited access to health facilities particularly in rural areas.
- Social stigma, misinformation, and traditional beliefs.
- Limited opportunities for specialty training in neurology.

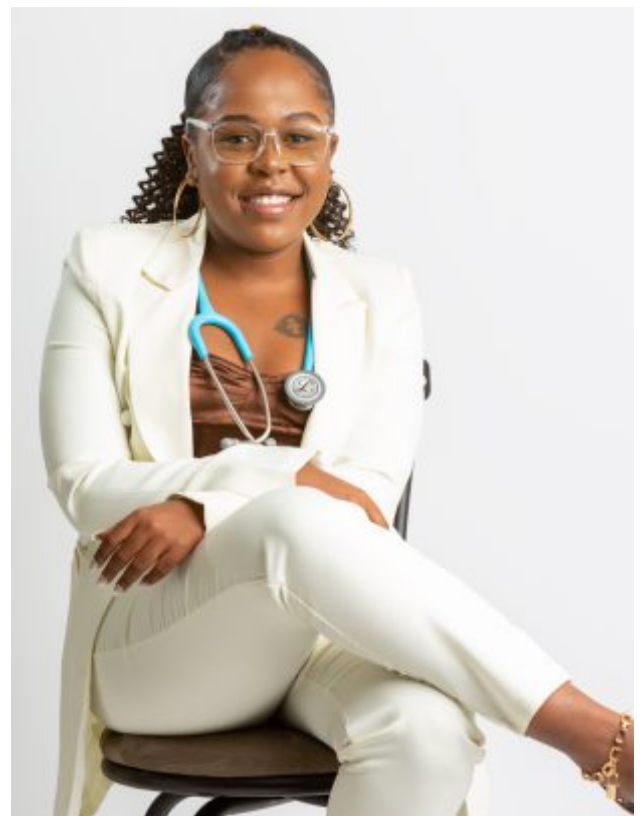
Diagnosis

Epilepsy must be diagnosed by a qualified doctor.

While there are a number of tests available to help the doctor many diagnoses are effectively made based on a discussion between the doctor and the individual (including family members/carers) based on their experiences and the symptoms. This is known as a clinical history.

Your doctor will ask different questions such as:

- When did your seizure(s) start?
- How many seizures have you had?
- Do you notice any changes before you have a seizure?
- How long did the seizure(s) last?
- Have you been able to identify any triggers leading to a seizure?
- Are you taking any medication?



How to Care for a Person with Epilepsy

A care pathway is a plan for the person with epilepsy. It should include all aspects of the person's health and life from pregnancy to old age.

Good care pathways respond to the needs of persons with neurological conditions and their families/carers. Living in an urban or rural area may determine what care options are available. Similarly, different approaches are needed at different times in a person's life.

It is important that persons with neurological conditions not only get medical care, but also social care to improve their wellbeing and quality of life. This type of support must also be available to families and carers as there are many stresses caused by a person with a condition like epilepsy.

Teamwork

It is very important for the individual, his/her family/ carer and the doctor to work together for the best results.

The doctor will be able to prescribe medication more precisely if the individual or a family member can accurately describe symptoms and the effect of medication.

The pharmacist can also provide information and advice about medication.

Neurological conditions such as epilepsy have a big impact on individuals, their families, and communities. There is a lot of support available.

Caring for a person with epilepsy is often the responsibility of family members or close friends. Caring for a person with a neurological condition can affect the carer's own health, wellbeing, social relationships, and ability to earn an income. It is thus important that families and carers have the necessary support.

What are we doing?

Epilepsy South Africa is a national organisation supporting persons with epilepsy and their families/ carers.

Epilepsy South Africa can help you to understand your condition and adjust to it. Contact the nearest Branch of Epilepsy South Africa for more information and help to adjust to your diagnosis.

There are also a number of organisations working with persons with different neurological conditions. For more information about these organisations visit the website of the South African Disability Alliance (SADA).



Objective 3:

Implementing Strategies to Prevent Neurological Conditions and Promote Healthy Behaviour and Brain Health



Preventing neurological conditions

Many neurological conditions can be prevented (including 25% of epilepsy cases). This needs a broad response from public health, especially care of expecting/new mothers and their newborns, better control of contagious diseases, preventing injuries and improved care for diseases affecting the heart and blood vessels (cardiovascular health).

If we want to **prevent neurological conditions** it is important to **identify causes** of these conditions that can be changed. This includes removing risks and improving protection, especially for children and teenagers when brains are still developing.

Some risks are medical such as birth complications and infections and will need action by the health departments at national, provincial, and local levels.

Women and girls should be **educated** about their reproductive rights and encouraged to get medical care once they suspect they may be pregnant. It is important to follow medical advice during a pregnancy and take advice on safely delivering your baby. Unfortunately, women are still experiencing complications during pregnancy and childbirth with some even dying. As such, **government** must improve the care available to pregnant women and their newborn children if we are to prevent neurological conditions caused by birth complications.



It is the responsibility of parents to make sure that their children receive all **required vaccinations** to prevent diseases that could result in neurological conditions. All South Africans should support vaccination campaigns on the understanding that good health is a **shared responsibility**.

Lifestyle choices can lead to accidental injuries. It is a fact that many road accidents are caused by choices such as drinking and driving or using a cellphone while driving. There are already **laws** in South Africa to **protect people** on the roads such as wearing seatbelts, transporting babies and children in safety seats, and complying with rules aimed at keeping us safe. However, not all road users adhere to these.

Sporting injuries can also result in brain injuries. You can protect yourself and your children against these by using proper safety equipment such as cycling helmets and gum guards.

Preventing neurological conditions rests upon promoting and developing optimal brain health throughout life.

Promoting healthy behaviour and brain health

Good brain health is when every person can learn and realise their full potential. This includes effectively using the ability to think for yourself, make your own decisions, understand the world around you and live life to the fullest, **even in a changing world**.

Promoting brain development is important throughout life and starts from pregnancy. It is particularly important during childhood and adolescence when the brain is still developing. However, it also applies to healthy ageing.

There is a **strong relationship** between many neurological conditions (such as dementia and stroke) with health risks such as high blood pressure, diabetes, and obesity (being overweight). These risks are made worse by lifestyle choices such as physical inactivity (lack of exercise), poor eating habits, smoking, and alcohol and drug abuse.

For example, smoking has been linked to neurological conditions like stroke, dementia, and multiple sclerosis.

Alcohol and drug abuse can affect the nervous system and result in neurological conditions, but also contribute to road traffic accidents, violence, and falls which may result in brain and spinal cord injuries.

It is important for the health and wellbeing of both children and adults to have **good sleeping habits**. Irregular and insufficient sleep can be a risk factor.

While we all enjoy unhealthy snacks and food from time to time, it is important to **maintain a healthy diet**. This means eating balanced meals with enough vegetables and fruits, and reducing harmful foods like refined sugar, saturated fats, and a lot of caffeine.

Objective 4: Strengthening the Public Health Approach to Epilepsy

Access to healthcare

There are only 278 neurologists registered in South Africa. However, some of these have retired or emigrated but still remain on the register. Many are in private practice with only a few in public healthcare. This means that there is approximately one neurologist per 218,547 people.

It was reported in 2021 that only 16% of South Africans were members of medical aid schemes which means that most South Africans rely on public healthcare services. This is further complicated by the lack of services in rural areas.

The heavy burden on public healthcare (especially at primary health clinics) adds to the challenges people with epilepsy and other neurological conditions face in accessing healthcare.

Self-representation and advocacy

People with epilepsy and other neurological conditions have the right to represent themselves and voice their own opinions and views without fear. You are able to advocate on your own behalf which means that you can stand up for your rights.

It is important to identify the issue you want to address and understanding the realistic solution to the problem. You will need relevant facts and information to support your position, find others who agree with you and know your opposition. Using the media (especially community media in your area) will help you to let others know about this issue.

For example, if you are worried about the stigma faced by persons with epilepsy and want to change it, you may want to start by getting rid of some of the things people believe about epilepsy. You can do that by providing facts about the condition. This could be as simple as speaking to your friends and neighbours, but may also include an interview on a radio station or getting the local newspaper to publish an article about this.

What are we doing?

Epilepsy South Africa actively develops self-advocates through training programmes and other services. Contact your local Branch if you need information, advice, or help.





What Can You Do Now?

Contribute daily to breaking the **STIGMA** of Epilepsy that abounds in South Africa

In South Africa many people believe that epilepsy is caused by magical powers or that it is a curse on the person and their family because they did something wrong. Many people with epilepsy spend a lot of time and money looking for remedies from traditional healers rather than seeing what is often thought of as “Western” doctors. This means that they are not properly diagnosed or treated.

Many of the **things people believe about epilepsy is simply not true**, but because people believe it, they try to avoid people with epilepsy and their families and will even discriminate directly. This is because we try to stay away from things that we fear, and we fear epilepsy because we know very little about it. We need to **provide accurate facts** and information about neurological conditions like epilepsy to **change the root cause of discrimination and stigma**.

Join an organisation like **Epilepsy South Africa** and participate in activities and events that raise awareness and educate others about neurological conditions.

Stigma and discrimination

Even though South Africa’s has a proud human rights tradition, persons with epilepsy and other neurological conditions **still** face negative behaviour and attitudes resulting in poor self-image. However, this can be addressed through awareness, education, and advocacy initiatives as well as social protection measures (disability grants).

How does stigma affect people with epilepsy and other neurological conditions?

Stigma can discourage people from seeking treatment and thus has consequences for their quality of life and social inclusion in all aspects of life and the community.

You can **reduce stigma by telling others** about your condition and explaining how stigma has affected you. When you talk about your condition and the impact of stigma on you, others will begin to understand that these conditions affect people in all communities and that when treated, people can live productive lives.

Learn how to deal with a seizure

Seeing someone having a seizure can be very frightening, but everyone can **learn what to do to help**. Remember that you can’t stop a seizure and that it will stop on its own.

Dealing with a Seizure

Do Not

- Try to hold the person in any way stop their movements, or move them (unless they are in direct danger)— you will only hurt them as you can't stop the seizure.
- Put anything in the person's mouth as this may break teeth or even their jaw. A person can't swallow their tongue (although many people believe this to be true).
- Burn anything in front of the person's mouth or nose as this will make it difficult for them to breathe.
- Give the person anything to eat or drink or any medication.

Do

- Time how long the seizure lasts.
- Cushion the persons head and protect their body from further injury.
- Loosen any tight clothing and remove their glasses.
- Turn the person onto their left side into the recovery position.
- Stay with them and reassure them until they have fully recovered.
- Call an ambulance if the seizure continues for longer than 5 minutes.



“A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles”.

Actor Christopher Reeve best known for playing superman
and being an activist for quadriplegia



References:

Epilepsy South Africa www.epilepsy.org.za

South African Disability Alliance (SADA) at www.sada.org.za

Independent Bureau of Epilepsy (IBE) at www.ibe-epilepsy.org

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Twitter: @EpilepsyZA

Contact Us



Website:

www.epilepsy.org.za



Email:

info@epilepsy.org.za



Physical Address:

C/O Cotte and Govan Mbeki Roads, Wetton, Cape Town, South Africa



Postal Address:

PO Box 586, Fourways North, 2085, South Africa



Contact Number:

0860 374 537 (South Africa)