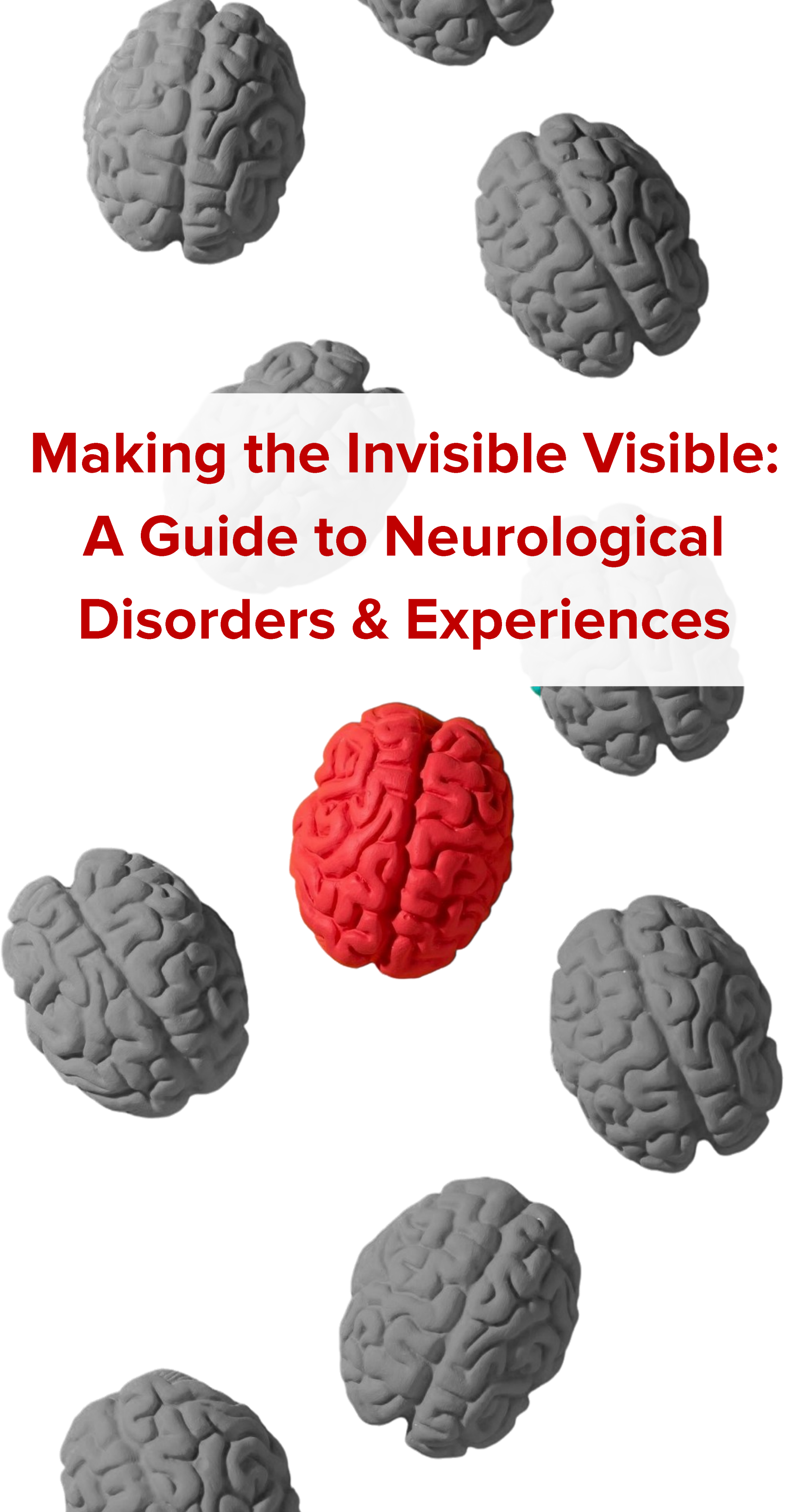
Making the Invisible Visible: A Guide to Neurological Disorders & Experiences



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Epilepsy South Africa is deeply committed to improving the lives of people with epilepsy and other neurological disorders through advocacy, education, and comprehensive support services. Our journey towards meaningful change has been significantly strengthened by the spirit of collaboration among key organisations across South Africa.

This publication marks a remarkable milestone, showcasing the alignment and unity of multiple organisations dedicated to neurological disorders. It demonstrates a pivotal collective step on our road towards Cabinet approval of the South African Intersectoral National Action Plan (SAINAP) for persons with epilepsy and other neurological disorders.

SAINAP represents a transformative national framework to enhance policy, service delivery, and awareness for neurological disorders across our nation.

I am immensely proud and grateful to have been part of bringing together this critical resource – making visible the realities and challenges faced by individuals living with neurological disorders.

My heartfelt thanks to each person and every organisation whose expertise, dedication, and collaborative spirit have made this book possible.

Together, we continue to move forward, united in purpose and determined in action.

Sharlene Cassel
National Director
Epilepsy South Africa

Understanding neurological disorders

Neurological disorders are conditions that affect your nervous system – the complex network that controls everything from moving your arm to breathing without thinking about it.

Your nervous system has two main parts:

- Central nervous system (CNS): the brain and spinal cord
- Peripheral nervous system (PNS): the nerves branching out through the rest of your body

What the Nervous System Does

- Voluntary actions: things you choose to do, like lifting a cup or walking
- Involuntary actions: automatic functions, such as breathing, your heartbeat, and digestion

Causes of neurological disorders

It isn't always possible to pin down why a neurological disorder happens, but typical causes include:

- Genetic changes: inherited DNA differences
- Congenital conditions: abnormalities present at birth
- Injury or trauma: accidents that damage the brain or spinal cord
- Infections: such as meningitis or HIV
- Tumours: abnormal growths in or near nerves
- Stroke: interrupted blood flow to the brain
- Metabolic problems: chemical imbalances in the body
- Immune reactions: when the body mistakenly attacks its own nerves

How is a neurological disorder diagnosed?

A medical doctor (neurologist, preferably) will usually:

1. **Take a detailed history:** ask about your symptoms and family health, this is one of the most important part of a diagnosis
2. **Perform a physical exam:** test strength, reflexes, coordination, and sensation
3. **Order tests** as needed:
    - Blood tests
    - **EEG** to record brain waves
    - **CT (Computed Tomography) or MRI (Magnetic Resonance Imaging)** scan to view the brain and spinal cord
    - **Angiogram** to look at blood vessels
    - **Lumbar puncture** to analyse spinal fluid
    - **Nerve conduction studies** to check how nerves send signals

Signs and symptoms of neurological disorders include

Because the nervous system controls so much, symptoms can vary widely. You might experience:

- Pain (headaches, back or neck pain)
- Movement changes (weakness, tremors, stiffness)
- Sensory changes (numbness, tingling, loss of balance)
- Sleep problems (insomnia, daytime sleepiness)
- Cognitive difficulties (memory loss, confusion)
- Speech or swallowing issues

Symptoms may come and go, be sudden, or worsen over time, depending on the disorder.

What are your treatment options?

Treatment is tailored to each person, but may include:

- **Medications** to manage symptoms or slow disease progression
- **Therapies** such as physical, occupational, or speech therapy
- **Assistive devices** like braces, walkers, or communication aids
- **Surgery** in certain cases

Your neurologist will recommend the right combination based on your diagnosis, overall health, and personal goals.

Psychosocial impact of neurological disorders

When we talk about the psychosocial impact of a neurological disorder, we mean how a person's thoughts, feelings, and social environment interact with their condition. Neurological disorders can affect not only the body, but also emotions, relationships, and daily life in many ways.

Two Ways to Look at It

Medical model
Focuses on the disorder itself – symptoms, treatments, and how to "fix" the illness.

Social & human rights model
Emphasises the barriers in society – like inaccessible buildings or negative attitudes—that keep people from fully taking part in work, school, and community life.

How neurological disorders affect individuals and families

By understanding disorders and creating awareness about the needs of persons with neurological disorders, support can be provided to individuals and families so that they can address their challenges and live fulfilling lives.

According to the World Health Organisation neurological disorders are the leading cause of ill health and disability worldwide.

Culture and religion: In Africa, cultural and religious beliefs influence how people understand neurological disorders. This determines people accept, interact and access care and services.

Relationships & Social Life: Neurological disorders can affect the way in which people interact socially and form relationships.

Loss of Independence & Impact on Self Esteem

- Needing help with everyday tasks can be frustrating and make you feel less capable.
- This shift can chip away at confidence, leading to sadness, anxiety, or even reluctance to reach out for support.

A major contributor to people not participating as equal citizens in society is Stigma and discrimination. These are common barriers! Negative attitudes and unfair treatment can be as damaging as the disorder itself.

- Stigma is a set of negative beliefs (e.g., "people with seizures are dangerous").
- Discrimination is acting on those beliefs (e.g., excluding someone from an activity).

Stigma is often due to a lack of information and understanding about the disorder which can be corrected by sharing accurate information to improve understanding.

Discrimination – raising awareness about neurological disorders can help to reduce stigma and discrimination and promote understanding, acceptance, and inclusion.

There are different types of stigma:

Health-related stigma: Blaming or shaming someone for their symptoms.
People with a specific disorder are often excluded, rejected, blamed, or seen as having less value than others.

Felt stigma: The shame or fear a person feels about being judged. It is often a very personal reaction which tends to get worse over time.

Self-stigma is when people with neurological disorders know about the negative stereotypes of others, agree with them, and turn them against themselves.

Stigma by association: Family, friends, or caregivers being targeted because of their relationship. Someone is treated badly simply because of their relationship with a person with a neurological condition.

Enacted (public) stigma is the actual discrimination based on someone's views and opinions which are not necessarily true or accurate. In some cases, this can be very clear and easy to see, but in other cases it is not as obvious.

Systemic stigma: When laws, policies, or everyday practices work against people with neurological disorders.

Why Addressing Psychosocial Needs Matters

Your mental health refers to how you feel, think and act. It is your emotional, psychological, and social well-being. Everyone has mental health, just like physical health. Your mental health ranges from good to poor.

- **A person with good mental health** generally feels good about themselves and their relationships. They can cope with stress and continue to manage their disorder.
- **A person with poor mental health** could struggle to interact with others and take care of themselves. They may feel hopeless, and disconnected from others.

Supporting psychosocial health means offering reliable information, emotional support, and practical tools all at once. By raising awareness and providing clear, accurate facts about neurological conditions, we help dispel myths and reduce fear. Access to counselling and peer support groups gives people a safe space to share experiences and learn coping strategies from others who truly understand. Inclusive communities – where workplaces, schools, and public spaces accommodate different needs – foster a sense of belonging and confidence.

At the same time, encouraging self-care habits such as pacing daily activities, practising relaxation techniques, engaging in gentle exercise, and exploring creative outlets helps individuals manage stress, boost mood, and maintain resilience.

Human rights and neurological disorders

What is disability?

Disability is a concept that keeps changing over time and is not the same thing as an impairment. Such limitations could be physical, sensory, intellectual, psychosocial and/or neurological. However, a disability is when society does not allow a person with an impairment to fully participate in all aspects of life, and when society does not uphold the rights and specific needs of persons with impairments.

People with disabilities are faced with three main types of barriers:

- **Physical** (environmental) barriers such as inaccessible buildings or services
- Barriers to **access information** because it is not available in a format that people can use such as Braille, Sign Language, or Easyread (a way of showing written information in a way that is easier to read and understand)
- **Attitudinal** (behavioural) barriers such as stigma, discrimination, isolation, and fear for personal safety

Why are disability rights important?

According to the World Health Organisation 16% of the world's population (1.3 billion people) are persons with disabilities. It is estimated that about 3.3 million people in South Africa are persons with disabilities. Despite the international and national conventions and laws, persons with disabilities still experience discrimination, stigma and isolation. To overcome this, it is important for persons with disabilities, their carers, families, and friends to know their rights and to do everything they can to ensure that they are able to enjoy these rights.

How are disability rights decided?

People with disabilities have the same rights as any other human on earth because we are first and foremost people who simply have an impairment. On 13 December 2006 the United Nations adopted the **United Nations Convention on the Rights of Persons with Disabilities** (CRPD) which came into force on 3 May 2008. South Africa was one of the first countries to ratify the Convention (and its **Optional Protocol**) in 2007. The CRPD is an international treaty (agreement) that promotes and protects the rights of persons with disabilities, including people with neurological disabilities.

The Bill of Rights (Chapter 2) of the **South African Constitution** (Act No 44 of 1995) guarantees the right to everybody to fully and equally enjoy all rights and freedoms. Government must respect, protect, promote, and fulfil these rights. The Constitution also prohibits discrimination on the basis of disability. The **White Paper on the Rights of Persons with Disabilities** (WPRPD) was adopted by the South African Cabinet on 9 December 2015 and has been the guide to realising disability rights. However, the South African Law Reform Commission is developing a new law to implement the UN CRPD in the country. This law aims to protect the rights of people with disabilities.

Other South African laws dealing with the rights of persons with disabilities include the **Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA)** (which aims to prevent and prohibit unfair discrimination, harassment, and hate speech, and promotes equality for all, including persons with disabilities), and the **Employment Equity Act (EEA)** (which aims to achieve equity in the workplace by promoting equal opportunity and fair treatment, and implementing affirmative action).

What are the rights of persons with disabilities?

Equal rights: Every person with an impairment (including neurological disorders) has the same rights as everyone else, including the right to life, freedom, and personal security. It includes the right to make decisions about your own life.

Accessibility means the right to the same physical environment, transport, information, and services as anyone else. To achieve this universal access and design must be prioritised. Universal access means that all products, environments, programs, and services must be designed in such a way that anybody can access it without needing adaptation. Universal design aims to create buildings, products, and environments that are accessible to everybody. It focuses on simplicity, flexibility, and usability for the widest range of people, rather than adding accessibility features as an afterthought.

Non-discrimination: Discrimination on the basis of impairment in any area of life is prohibited. Barriers that prevent equal participation must be removed from all areas of life.

Participation is the right to participate in all aspects of society, including education, employment, sport, recreation, and political life.

Support services make it possible to live independently, including psychosocial support, assistive technology and devices, and personal care.

Standard of living includes the right to access essential resources like housing, food, water, and services. Government must ensure financial support and social support programs.

The right to **healthcare** includes early diagnosis, treatment, rehabilitation services, and assistive devices and technology.

Equal opportunities in **work and employment** must be ensured, including access to training, career advancement, and reasonable workplace accommodations. This means adjusting or changing the job, work environment, or the way things are usually done to make it possible for employees with impairments to work effectively.

Equal and inclusive **education** is required at all levels with reasonable accommodations and support services to facilitate full participation.

How Wimpie's Challenge Changed Everything

Wimpie knew his epilepsy affected his concentration and memory and that he needed more time to complete his engineering degree.

When his university decided to academically penalise him, he decided to take his case to court. He argued that the university did not provide proper accommodations for him to succeed in his engineering program.

Wimpie launched a successful application to the Western Cape High Court who ruled that epilepsy is a disability and that the university council should reconsider his situation.

Wimpie changed the law, and this new legislation will help other people with epilepsy to succeed in school and in the workplace.

IGAP (Intersectoral Global Action Plan)

The IGAP (a World Health Organisation initiative described in this booklet) recognises the following neurological disorders:

- Epilepsy (seen as repeated seizures without an identifiable cause)
- Headache disorders
- Neurodegenerative disorders (diseases in which cells of the nervous system stop working or die)
- Cerebrovascular diseases (conditions that affect the blood vessels in the brain and spinal cord)
- Infections and inflammatory (immunological) diseases that affect the nervous system)
- Neuromuscular disorders (conditions that affect the muscles and nerves that control them)
- Neurodevelopmental disorders (conditions that impact the brain and nervous system while developing during pregnancy and early life)
- Traumatic brain and spinal cord injuries
- Cancers of the nervous system

The Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) was unanimously adopted by the World Health Assembly (WHA) on 27 May 2022.

The WHA is the decision-making body of the World Health Organisation (WHO), attended by delegations from all WHO Member States (including South Africa).

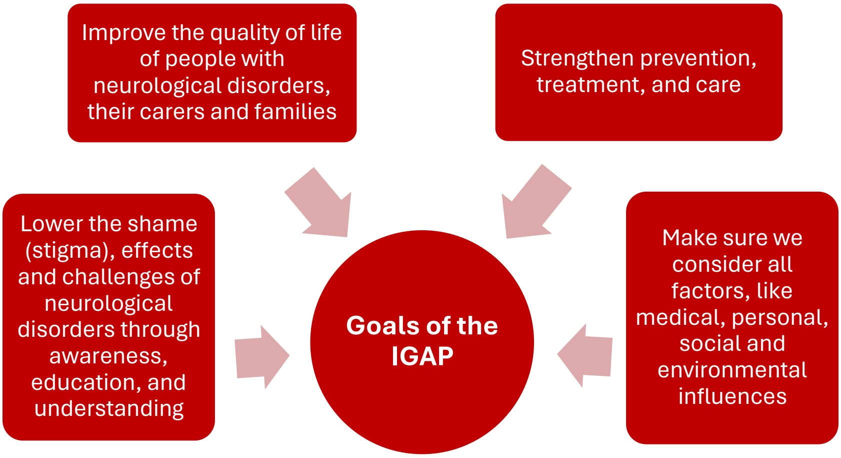
The World Health Organization is a specialised agency of the United Nations responsible for public health throughout the world.

The IGAP was made to fix the problems and gaps in care and services for people with brain and nerve issues around the world and to make sure different sectors work together smoothly.

The **vision** of the IGAP is a world in which:

- Brain health is valued, promoted, and protected throughout life;
- Neurological disorders are stopped, found (diagnosed) and treated to prevent early death and other health problems and disabilities;
- People with neurological disorders and their caregivers achieve the best possible health, with equal rights, chances, respect, and independence.

IGAP strategic objectives and global targets



Improve the quality of life of people with neurological disorders, their carers and families

Strengthen prevention, treatment, and care

Lower the shame (stigma), effects and challenges of neurological disorders through awareness, education, and understanding

Goals of the IGAP

Make sure we consider all factors, like medical, personal, social and environmental influences

Strategic objective 1: Focus on policies and plans for neurological disorders and improving leadership (governance). The IGAP aims for 75% of countries to have national plans, policies, or strategies for neurological disorders, and all countries to have functioning awareness and advocacy programmes for neurological disorders.

Strategic objective 2: Provide effective, timely and responsive diagnosis, treatment, and care. Success will be seen if 75% of countries have included neurological disorders in their Universal Health Care (UHC) benefits package, and 80% of countries provide essential medicines and technologies for neurological disorders.

Strategic objective 3: Use plans to improve brain health and prevent brain and nerve problems. To achieve this, 80% of countries should have at least one functioning prevention and brain health promotion programme, and international targets for the prevention of neurological disorders should be achieved.

Strategic objective 4: Encourage research and innovation, and strengthen information systems. This means that 80% of countries should regularly gather data on neurological disorders while global research on neurological disorders doubles.

Strategic objective 5: Strengthen the public health approach to epilepsy. This aims at a 50% increase in epilepsy service coverage with 80% of countries having replaced discriminatory legislation.

TYPES OF NEUROLOGICAL DISORDERS

Epilepsy

What is epilepsy?

Epilepsy is the most common neurological condition worldwide, affecting roughly 1 in every 100 people in developing countries like South Africa. While anyone can have a single seizure at some point (about 1 in 20 people do), epilepsy is diagnosed only when a person experiences two or more unprovoked seizures. It is neither a mental illness nor contagious – epilepsy simply reflects an imbalance in the brain's electrical activity.

Though epilepsy can appear at any age, three quarters of people with the condition have their first seizure before turning 20. Fortunately, between 70% and 80% of those diagnosed can control their seizures effectively with medication, and many children even outgrow their epilepsy as they mature. Seizures come in different forms – some people experience a brief warning or "aura," while others have sudden, unpredictable episodes. Most seizures last only a few seconds to a few minutes and can be managed safely when those around you know what to do.

Epilepsy does not discriminate. It affects men and women, people of all intelligence levels, and every racial, ethnic, and socio-economic background. History shows that epilepsy has never stood in the way of greatness – figures such as South African cricketer Jonty Rhodes, singer-songwriter Vusi Mahlasela, and author Agatha Christie have all thrived despite their diagnoses.

For many people with epilepsy, the greatest challenge is not the seizures themselves, but the misunderstanding and stigma they often face. Education and empathy from our communities are vital. When we recognize epilepsy as a medical condition – and offer support instead of fear – we help people with epilepsy lead full, productive lives.

Causes of epilepsy

In some cases it is impossible to find a cause. This is called **primary or idiopathic epilepsy** (meaning that the cause is unknown).

In others, epilepsy can be caused by anything that damages or injures the brain (**symptomatic epilepsy**). Common causes include head injuries, strokes, brain infections, and birth injuries. Rarer causes include brain tumours and some genetic conditions.

Epilepsy may also result from subtle minor abnormalities in early brain development that may not in themselves cause any constant clinical signs or symptoms.

Some people with epilepsy may identify **triggers** which bring on seizures which could include stress, hormonal changes, illness, or even something they eat or drink.

Types of epilepsy

The type of seizure is determined by where it starts in the brain:

- **Focal onset seizures** start in a specific place in the brain but may spread to other areas of the brain. These seizures are often subtle (difficult to spot) or unusual and may go unnoticed or be mistaken for the person being drunk or daydreaming.
- **Generalised onset seizures** affect both hemispheres (sides) of the brain from the start of the seizure. The person may lose consciousness at the start of the seizure as these seizures almost always affect awareness in some way.
- **Unknown onset epilepsy** means the seizure cannot be diagnosed as either focal or generalised onset.

How is epilepsy treated?

The standard treatment for epilepsy is the regular use of one or more chemical substances called anti-convulsant drugs/medication. Ideally you should take as little medication as possible while maintaining seizure control.

Other treatment options include epilepsy surgery for specific cases, special diets (like the ketogenic diet), and implantable devices like vagus nerve stimulators (which deliver electrical stimulation to the brain to control seizures).

Lifestyle modifications like managing stress and identifying triggers are also important aspects of managing epilepsy.

My Road Travelled by Sharlene

At eight years old, I had my first grand mal seizure – one moment I was playing with friends, the next I woke hours later in bed, frightened and confused. Both my parents worked in medicine, so while they knew what to do, nothing could have prepared us for the road ahead.

Epilepsy became part of my everyday life: learning was hard, after each seizure my memory was affected and the information was lost, and I spent countless afternoons relearning what others mastered in one go. Yet my parents' steadfast faith – insisting I remain in mainstream school – taught me resilience. When stress induced seizures left my prelim papers blank, I feared the worst, I was going to fail matric. But on the morning the newspaper arrived with my matric results splashed across the page, I saw my parents' tears of joy – and knew I had beaten the odds, I had passed matric and my next journey began – University.

As I went on to study and became a lifelong learner and now live a life of passion and purpose as National Director of Epilepsy South Africa, one lesson remained paramount: educating friends, teachers and loved ones about epilepsy was the key to their support and my success.

By speaking openly – never hiding seizures or making a spectacle – my parents showed me that honesty breeds understanding, not fear. They taught me to "just get on with it," to communicate clearly about my epilepsy, and to face each challenge with bravery and resilience.

As Nelson Mandela said: "Education is the most powerful weapon which you can use to change the world."

This is so true and one I hold close to my heart as it most certainly changed my life. People understand and support me today and it is so humbling. Thank you to each and every person that has made my world a little bit easier.

Headache Disorders

What are headache disorders?

These disorders cause frequent headaches and are very common brain-related issues. About 50% of adults worldwide have a headache disorder (meaning that they've experience it at least once within the last year). Headache disorders affect people of all ages, races, income levels and geographical areas.

Headaches are not only painful, but also disabling. It is a burden to those affected as it includes substantial personal suffering, impaired quality of life and financial cost. Repeated headaches and the constant fear of the next one damages family life, social life, and employment. In the long term the effort of coping with a chronic headache disorder may also make it more likely for the person to develop other illnesses. For example, anxiety and depression are a lot more common in people with migraine than in healthy people.

Causes of headache disorders

Different types of headache disorders may be caused by or go along with other conditions.

The exact cause of **migraines** isn't fully understood, but they are thought to involve changes in brain chemicals, blood flow, and nerve signalling. Triggers for migraines can include stress, certain foods, hormonal changes, and environmental factors.

Tension-type headaches can be triggered by stress, anxiety, poor posture, eye strain, or lack of sleep. They are not usually linked to an underlying medical condition.

The exact cause of **cluster headaches** is not fully understood, but triggers can include alcohol, strong smells, and certain medications.

Medication-overuse headaches are caused by overusing pain relievers like acetaminophen, ibuprofen, aspirin, and prescription medications such as triptans and opioids.

How are headache disorders treated?

Headache disorders must be accurately diagnosed by trained health professionals. Treatment is generally with cost-effective medications, simple lifestyle changes, and patient education.

Treatment options for **migraines** include over-the-counter pain relievers, prescription medications, lifestyle changes, and avoiding known triggers. It's essential for individuals who experience frequent or severe migraines to consult with a healthcare professional for proper diagnosis and management.

Tension-type headaches are treated with over-the-counter pain relievers like ibuprofen or acetaminophen (Paracetamol). Relaxation techniques, regular exercise, and maintaining good posture can also prevent or reduce the frequency of these headaches.

Acute treatments for **cluster headaches** include oxygen therapy and medications to relieve pain quickly. Preventive treatments can help reduce the frequency and severity of attacks.

The main approach to treating **medication-overuse headaches** is to stop the overused medication, which can initially worsen headaches but eventually leads to improvement. Healthcare professionals can help manage the withdrawal process and suggest alternative treatments.

Types of headache disorders

Migraine is a type of headache characterized by intense, throbbing pain, usually on one side of the head. It can be accompanied by other symptoms, such as nausea and vomiting, sensitivity to light and sound, and visual disturbances with some people seeing flashing lights, zigzag patterns, or experience temporary loss of vision, known as an 'aura.'

Migraines mostly start during puberty. The age of puberty varies, but it typically begins between the ages of 8 and 13 for girls and between the ages of 9 and 14 for boys. It mostly affects people between the ages of 35 and 45 years and is twice as common in women because of the influences of hormones. Migraine returns throughout life. Attacks can happen as seldom as once a year or as often as once a week. In children, migraine attacks tend to be shorter with more significant abdominal symptoms.

Tension-type headache (TTH) is the most common type of headache. They often feel like a constant, dull ache or pressure around the forehead or the back of the head and neck. People describe them as feeling like a tight band is squeezing around the head. Symptoms include mild to moderate pain, usually on both sides of the head. The pain is often described as a steady, non-pulsating pressure or tightness. There may also be tenderness in the scalp, neck, and shoulder muscles. These headaches can last from 30 minutes to several hours. In some cases, they can persist for days. Chronic TTH (occurring on more than 15 days per month) affects between 1% and 3% of adults and often starts during the teenage years. It affects more women than men (three women for every two men).

Cluster headaches (CH) are severe, recurrent headaches that typically happen in cycles or groups. Burning or piercing pain is usually intense around one eye or on one side of the head. The pain is often accompanied by redness and tearing of the eye, a runny or stuffy nose, and sweating on the affected side of the face. Each headache attack can last from 15 minutes to 3 hours. Attacks can occur several times a day, often at the same time each day, and can last for weeks or months, followed by periods of remission where headaches stop. Cluster headaches are considered one of the most painful types of headaches and often require medical attention for proper management.

Cluster headaches are relatively uncommon and affect less than one in a thousand adults. Men are affected more than women (6 men for every woman). Most people with CH are in their 20s or older.

Medication-overuse headache (MOH) is caused by chronic or excessive use of medication to treat headache. Instead of alleviating the pain, the overuse of these medications can lead to more frequent and severe headaches. These headaches occur on more days than not. It is overwhelming, relentless, and often worst when the person wakes up. Headaches occur daily or nearly daily. Symptoms include nausea, restlessness, and difficulty concentrating. MOH can affect up to 5% of people with more women affected than men. MOH occurs on more days than not. It is oppressive, persistent, and often worst when the person wakes up.

Yianna’s ongoing battle with migraine headaches

I suffered from migraines since I was 21 years old, on average, I experienced debilitating attacks about 8 times each month. Migraines lasted for an average of two to four days, stealing time and energy that I could never get back. This ruled my life affecting every area including my work and social engagements. I found it difficult to commit to anything as I was always afraid that I might get a migraine and then would not be able to perform. I work in a deadline-driven industry, where the pressure to perform is high. I could not afford to get migraines. I felt desperate to find solutions and experience relief. As an entrepreneur it slowed my business down.

Imbalanced hormones would guarantee the migraines every month during my menstrual cycle; stress, certain foods and exercises were often an additional trigger. The pain was very intense, unrelenting. It was like a hammer constantly pounding on my head usually on a specific side. I was ultra-sensitive to smell (very nauseous) and ultra-sensitive to sound not coping with any noise around me. The fridge sounded like a construction site in my home. My eyes felt like they were being constantly poked with a stick. My neck felt weak like a thin needle trying to hold my very heavy head up. My neck felt like I was being strangled. My chest and back were extremely tight in pain like I was being squeezed by a mammogram machine that would take days to release. I would have to hide in a dark quiet room and wait until the next morning hoping relief would arrive.

I tried many pain tablets and migraine kits - not one worked. Eventually I took nothing as nothing seemed to work. I went to a specialist clinic that deals with head pain. They designed a mouthpiece which fit in my mouth and allowed the jaw to relax whilst sleeping. This seemed to help at times however it was a temporary measure and results were not sustainable. Natural muscle relaxants which sometimes took the edge off ever so slightly. I tried a specific Omega 3 supplement and this helped me tremendously. Now I hardly experience migraines. If I do, they are light and do not last. My life has changed completely now that I no longer suffer from that terrible pain. Now, I know what it is like to be productive and feel “normal”. There are two important solutions I would like to share. Look for an omega 3 supplement as it is brain food. Please keep in mind not all omega 3’s are effective. Having a clean diet can be an additional support even if it does not reduce the migraines (cutting out sugar and ultra processed foods is a good idea). Eat good nutrition. Additionally, I recommend exploring your emotional response and your mindset by working with a specialised coach. I found I was “hitting myself over the head”. Look at your language and how you speak to yourself. Learn about being gentle and kind to yourself and others. Do not underestimate how love and kindness can help you heal. It took me over a year to learn this. The key is to love yourself and be kind to yourself.

Parkinson’s Disease

What is Parkinson’s Disease?

Parkinson's Disease is a brain disorder that affects movement. It happens when certain nerve cells in the brain stop working properly, causing a lack of dopamine (a chemical that helps control movement). This leads to symptoms like shaking, stiffness, slow movements, and balance problems. It usually gets worse over time, but treatments can help manage the symptoms.

Most people who get Parkinson’s Disease are over the age of 50, but younger people can get it too. Men are more likely to develop the disease than women.

Causes of Parkinson’s Disease

Signs and symptoms of the disease happen when nerve cells (neurons) in the area of the brain that controls movement become damaged or die. These cells usually produced a brain chemical called dopamine. The lack of this chemical causes movement problems. However, scientists still do not know what causes the neurons to die.

Some factors seem to play a role:

- **Specific genetic changes** are linked to Parkinson’s Disease, but these are rare unless many family members have it.
- Exposure to certain **toxins or other environmental** factors may increase the risk of later Parkinson’s disease.

Symptoms of Parkinson’s Disease

Parkinson’s has four main symptoms:

- Shaking in the hands, arms, legs, jaw, or head (tremors)
- Muscle stiffness (where muscles stay tight for a long time)
- Slowness of movement
- Impaired balance and coordination which sometimes leads to falls

Other symptoms may include depression and other emotional changes, difficulty swallowing, chewing, and speaking, urinary problems or constipation, and skin problems. The symptoms of Parkinson’s and how quickly it develops differ from person to person. Early symptoms are hard to notice and occur gradually.

Facts about Parkinson’s Disease

- 10 million people (and growing) in the world have Parkinson’s.
- It is the fastest growing neurological disease.
- Parkinson’s is not infectious and does not usually run in families.
- Many people with Parkinson’s lead active, fulfilling lives.

How is Parkinson’s Disease treated?

Medicines can help treat the symptoms of Parkinson’s by increasing the level of dopamine in the brain. It also has an effect on other brain chemicals (such as those which transfer information between brain cells) and helps to control non-movement symptoms. The main therapy for Parkinson’s is levodopa, but other drugs may also be prescribed.

Other therapies may help manage Parkinson’s symptoms:

- Physical, occupational, and speech therapies may help with walking and voice disorders, tremors and rigidity, and decline in mental functions.
- A healthy diet will support overall wellness.
- Exercises strengthen muscles and improve balance, flexibility, and coordination.
- Massage therapy reduces tension.
- Yoga and tai chi increase stretching and flexibility.

Rajesh’s misunderstood Parkinson’s

“You are drunk!”

That’s an accusation that Rajesh has faced many times while trying to do his shopping in Durban. However, he has Parkinson’s Disease and believes that such judgements emphasized the need for public awareness to prevent others from suffering the same ignorance.

While Parkinson’s affect mostly older people, Rajesh was 34 when he was diagnosed with the disease. With a successful career in the banking industry, a three-year-old daughter, and further studies on the cards, life was good.

Then changing gears on his manual car became difficult (and there was nothing wrong with the vehicle).

Rajesh had always been active with even a Comrades Marathon under his belt. When knotting his tie took longer than usual, he assumed he had lifted too many weights.

But when his dad died, and he struggled to keep up with the other pallbearers, his brother urged him to have a medical examination. The diagnosis changed his life.

Despite the life-altering nature of the disease, Rajesh believes very few people (including neurologists) fully understand the impact.

“If you are at the beginning or end of the medication window, you find your disability is more pronounced and then you tend to rely on your walking apparatus.

This is what confuses people who see you struggling with the waling apparatus and might see you later moving around without it.”

Now aged 54, he still manages to live alone, drive, and does all his household chores without assistance.

“Acceptance, learning as much as possible about Parkinson’s Disease and proper disease management were imperative to living a full life.

Motor Neuron Disease

What is Motor Neuron Disease?

Motor Neuron Disease (MND) is a group of rare neurological disorders that affect the nerve cells (motor neurons) responsible for controlling voluntary muscle movements.

Appearance of the disease can be different depending on the particular groups of muscle where deterioration starts. In the beginning, you may notice that muscles in your hands get thinner and weaker (sometimes one side first), your legs may feel stiff with one leg dragging, or definite weakness in your legs.

Sometimes the muscles of the tongue and swallowing are affected early with slurred speech, difficulty in swallowing and coughing.

The disease may stay about the same for some time or spread to other limbs, including breathing muscles. It usually starts with mild weakness in the muscles, which gradually gets worse. This can lead to difficulty walking, gripping objects, speaking, swallowing, and breathing. Motor Neurone Disease does not affect the intellect, does not cause bladder or bowel symptoms and does not cause sensory, visual or hearing disorders.

The majority of people with MND are older than 50 but people in their 20s and 30s can also develop the disease. About twice as many men than women have MND.

Life expectancy varies from a year up to 5 years (or occasionally longer) and is determined by how quickly the disease worsens and the particular muscle groups that are affected.

Causes of Motor Neuron Disease

The exact cause of MND is not fully understood, but it can be linked to genetic mutations in some cases. Most cases occur randomly without a known cause. However, research continues.

Types of Motor Neuron Disease

The most well-known type is **Amyotrophic Lateral Sclerosis (ALS)** which is also known as **Lou Gehrig's** disease. Other types include **Primary Lateral Sclerosis (PLS)**, **Progressive Bulbar Palsy (PBP)**, and **Progressive Muscular Atrophy (PMA)**.

How is Motor Neuron Disease treated?

There is no cure for MND, but treatments focus on managing symptoms and improving the quality of life. This can include medications to reduce stiffness or difficulty moving.

Treatment by physiotherapists, occupational therapists, and speech therapists can help to manage symptoms, while assistive devices and family support improves quality of life.

A Tribute to Joost

Joost van der Westhuizen's journey with motor neurone disease (MND) was marked by courage and determination. As his condition progressed, he became an outspoken advocate for MND research and patient support, using his platform to raise awareness of the challenges faced by those living with neurodegenerative diseases.

Through his foundation, the **J9 Foundation**, he worked tirelessly to provide assistance to individuals diagnosed with MND, ensuring they had access to essential medical resources and support networks. His advocacy helped to shine a light on the importance of early diagnosis, experimental treatments, and holistic care, inspiring hope in countless patients and families.

Before his diagnosis, Joost was widely recognized as one of South Africa's greatest rugby players. As a scrum-half for the national team, the Springboks, he earned over 80 caps and played a crucial role in South Africa's 1995 Rugby World Cup victory. His fearless playing style, quick decision-making, and exceptional leadership on the field made him a legend in the sport. Joost was known for his relentless drive and ability to perform under pressure, securing his place as one of rugby's most respected athletes. His contributions to the game continued beyond his playing days, as he remained active in supporting and promoting rugby in South Africa.

Even in the face of physical decline, Joost remained deeply committed to his mission, attending events and delivering heartfelt speeches that resonated with audiences worldwide. His efforts led to increased collaboration between South African medical institutions and international experts in neurodegenerative research.

Although Joost passed away in 2017, his vision lives on through the **Joost van der Westhuizen Centre for Neurodegeneration**, which continues to drive innovation in treatment and care for patients across the country.

His legacy is one of resilience, compassion, and an unwavering dedication to making a difference in the lives of others

Image sourced as fair use – photo by Odd Andersen AFP

Stroke

What is a stroke?

A stroke is a brain attack! It happens when the blood flow to part of your brain is reduced or blocked. Blood carries essential nutrients and oxygen to your brain and without blood, your brain cells can be damaged or die. This damage can have different effects, depending on which part of the brain is affected. No two strokes are the same.

What are the symptoms of a stroke?

To make it easier to remember the symptoms, simply remember "**BE FAST**" as each of these letters describes a symptom:

- **Balance:** There is a loss of balance or dizziness.
- **Eyes:** Vision is blurred or lost.
- **Face:** One side of the face is drooping (sagging).
- **Arm:** One arm is weak or numb.
- **Speech** is difficult.
- **Time:** Call 112 from a cell phone or 10177 from a landline for medical help.

Types of strokes

Haemorrhagic stroke (bleeding) occurs when a blood vessel in the brain tears causing bleeding in and around the affected area.

Ischaemic stroke (clot) is caused by a blood clot which blocks the flow of blood to the brain. This is also known as a cerebral thrombosis.

Transient ischaemic attack (TIA), also known as a mini-stroke shows the same symptoms as a stroke. However, these symptoms last for a short time only and will pass. Although it is temporary, it is still very serious as it is a sign of a problem that needs attention. It can warn of a future stroke if the problem is not taken care of as a matter of urgency.

How is a stroke treated?

Quick medical attention is the key to limit brain damage and improve outcomes. Treatment depends on the type of stroke and how quickly it is diagnosed.

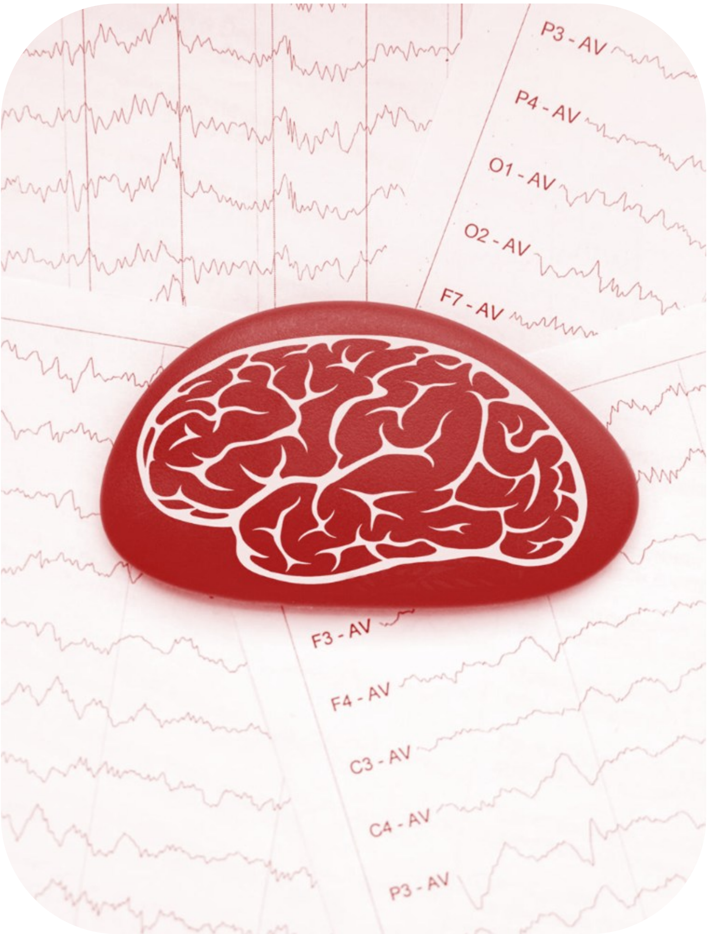
Emergency treatment: For ischemic strokes medication can be given intravenously to dissolve the blood clot and restore blood flow. However, this can only be done safely within the first few hours from onset, so speedy attention is crucial. For haemorrhagic strokes emergency surgery may be needed to control the bleeding and reduce pressure in the brain.

Medication: Blood thinning and anti-platelet drugs can help prevent future strokes by reducing the risk of blood clots. Medication to control blood pressure medication, lower cholesterol, and manage diabetes can reduce risk factors.

Surgery: In some cases, an operation may be needed urgently to remove a blood clot from the large cerebral arteries or treat a bulge in an artery. Surgery and medications may also be needed to reduce the risk of a stroke in persons with a build-up of fatty deposits in the walls of the arteries which narrow them.

Rehabilitation: This is essential for recovery and may include physical, occupational, speech, and cognitive therapy to help regain lost functions and improve quality of life.

Lifestyle changes can help prevent future strokes. This means adopting a healthy lifestyle, including a balanced diet, regular exercise, giving up smoking, and limiting alcohol.



George’s Life-changing Story with Stroke

In 2008, at the age of 37, George considered himself relatively healthy, despite carrying a few extra kilos. He had even completed a mini-triathlon two months before suffering an ischemic stroke, leaving him with lasting physical and hidden disabilities. Despite these challenges, he became a passionate advocate for stroke survivors, dedicated to improving post-hospital stroke care and support for both current and future survivors. Recognized as a Fellow of the World Stroke Organisation and an influential voice in stroke advocacy, George channels his positive mindset, resilience, and unwavering self-belief to inspire others with disabilities. His motto, Adapt, Improvise, Overcome, reflects his determination to help others navigate life after a stroke. George often says, " Surviving a stroke is the easy part. However, it is when you return home that both the survivor and his or her family are faced with the challenge of a new reality of living with the devastating impact of a stroke.”

"Feeling dizzy, I had no idea what was happening when I leaned against the wall and slid to the floor. Suddenly, my leg wouldn’t straighten, my arm wouldn’t move, and my words came out as gibberish. We were in the middle of moving house, and the thought of a stroke never crossed my mind – I believed strokes only happened to older people. There was no family history, my blood pressure and cholesterol levels were fine, and though I smoked five cigarettes a day, my weight wasn’t excessive for my 190cm frame. However, I was under a lot of work-related stress at the time." Thankfully, a friend recognized the signs, called for an ambulance, and within 45 minutes, George was in the hospital. "Lying in the ambulance, I wasn’t in pain, I wasn’t bleeding, but my arm and leg were paralyzed, and I had lost my speech. I knew something was seriously wrong, but it took days to grasp the full picture. The shock was overwhelming, but I quickly realized I had two choices: give up or fight back. I wasn’t ready to surrender. I had my whole life ahead of me, and a motorbike waiting to explore the world. That’s when the biggest challenge of my life began."

Recovery was gruelling. "With past injuries, rehab helped my body relearn how to function. With a stroke, it’s the opposite - my body worked, but my brain didn’t. Reprogramming my brain was incredibly tough. With the support of brilliant therapists, my family, and my friends, I learned to walk and talk again. It takes sheer resilience to accept baby steps - literally. Relying on others to feed you and assist with basic needs tests every ounce of your determination. It’s all about mindset and taking responsibility for your own recovery." Having a stroke in his 30s brought unique challenges. "There’s no manual for how to rebuild your life after a stroke. It tests your relationships, your identity, and your willpower. When I returned home, walking with the help of a crutch, I knew I had to keep pushing forward. And that’s exactly what I did and continue to do."

Multiple Sclerosis

What is Multiple Sclerosis?

Multiple Sclerosis (MS) is a long-term disease where the immune system wrongly attacks the protective covering of nerves in the brain and spinal cord. Because this covering is similar to the plastic that protects an electrical wire, MS causes nerve damage and disrupts communication between the brain and body.

Symptoms include difficulty walking, problems with vision, numbness, pain, dizziness and vertigo, spasticity, tremors, headaches, and many more.

Types of MS

Relapsing-Remitting MS (RRMS) is the most common type, with flare-ups (relapses) followed by periods of remission.

Secondary Progressive MS (SPMS) develops after RRMS, with symptoms worsening over time. Primary Progressive MS (PPMS) is the gradual worsening of symptoms from the start, without relapses.

Progressive-Relapsing MS (PRMS) is rare, with steady progression and occasional relapses. It is now classified under PPMS/SPMS.

What causes MS?

The exact cause is unknown, but it's thought to be a mix of **genes and environmental** factors.

Some possible but unproven triggers include:

- Genetic tendency which is the likelihood of developing a disease due to genetics – it is through genes that qualities and features are passed from one generation to the next.
- Viral infections like the Epstein-Barr virus.
- A lack of vitamin D which helps maintain healthy bones, muscles, and nerves.
- Smoking.
- Problems with the immune system (autoimmune dysfunction).

Treatment options

While there is no cure, treatments help control symptoms, reduce relapses, and slow down the disease:

- **Disease-Modifying Therapies (DMTs)** reduce inflammation and slow down the disease.
- **Symptom management** includes medications for tiredness, pain, muscle spasms, bladder/bowel issues.
- **Physical and occupational therapy** improve mobility, coordination, and daily functioning.
- **Lifestyle changes** include a healthy diet, regular exercise, stress management, and enough rest.

Facts about MS

- Many symptoms can be successfully managed and treated.
- Most people are diagnosed between the ages of 20 and 50 although cases may start earlier.
- Women are two to three times more likely to have MS than men.
- MS is not passed down directly from parent to child (hereditary), although having certain genes makes you more likely to develop the disorder.
- It is one of the most common diseases of the central nervous system (the brain and spinal cord) in young adults for which there is currently no cure.
- MS is not contagious or infectious. Having contact with a person with MS will not cause you to "catch" it.
- MS affects more than 2.8 million people in the world.
- MS is found more often in countries further from the equator.
- Between 3,000 and 5,000 people in South Africa have MS.

MS stories

"My reaction to the diagnosis was a complete shock. I only knew that it was a debilitating disease. I did not know anybody else with the disease and felt immense fear for my future and how it would affect not just me, but my family too. I found invaluable support and information through MSSA and its members."
– *Helga, Gauteng*

"My diagnosis followed years of being left in the dark as to whether I am mad, going nuts, or imagining things. Great was my relief when I found hundreds of people who totally 'get it' when I joined the patient group of MSSA. Not only am I grateful for the peer-to-peer support that I found, but also grateful for the value that I could bring to the group through my own experience."
– *Albertus, Western Cape*

"During my first encounter, I was told that I might have had a mild stroke. A series of tests all resulted in a misdiagnosis. For 2 years I lived thinking that I have a cardiac related disease. I was clueless. The neurologist diagnosed me with MS only once I went for an MRI. Many myths surfaced and I was told it's not an African disease so it must just be a 'bug in my system'. Dr Google gave me crucial information that made sense. It was scary. One of my first thoughts was not being able to play soccer or rugby with my kids or do physical work. Fortunately, I was referred to MSSA where I met up with a network of people from different places and backgrounds and that demystified everything for me, and I could set my clock back to normal again. Today I'm thankful to all the men and women under the MSSA banner for being my MS family."
– *Brian, Gauteng*

Neuromuscular Disorders

What are neuromuscular disorders?

Neuromuscular disorders are conditions that affect the muscles and the nerves that control them, causing muscle weakness, pain, and sometimes loss of function.

They can affect people of all ages and can vary widely in terms of symptoms, seriousness, and development.

Causes of neuromuscular disorders

Changes in genes (genetic mutations) inherited from parents cause some neuromuscular disorders like muscular dystrophies and spinal muscular atrophy.

Autoimmune reactions are when the body's immune system mistakenly attacks its own muscles or nerves like myasthenia gravis and certain types of neuropathy.

Certain viral or bacterial **infections** can damage nerves and muscles, such as poliomyelitis and leprosy.

Toxic exposure happens when a person comes into contact with harmful substances like chemicals, pesticides, or drugs. This can damage the nervous system.

Metabolic disorders are conditions that affect the way your body processes and uses nutrients and energy. For example, diabetes can cause peripheral neuropathy, affecting nerves in the limbs.

Physical injury (trauma) to nerves or muscles, such as from accidents or surgery, can result in neuromuscular disorders.

In some cases, the exact cause of a neuromuscular disorder is not known.

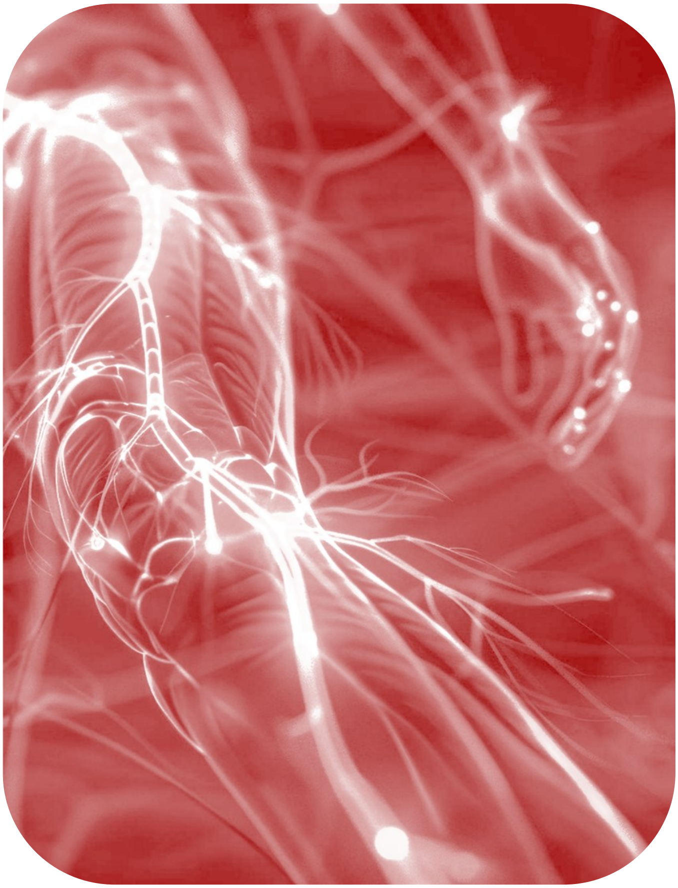
Examples of neuromuscular disorders

- **Muscular dystrophy** is a genetic disorder making muscles weaker and smaller over time.
- **Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's disease)** affects nerve cells in the brain and spinal cord leading to muscle weakness and paralysis.
- **Myasthenia Gravis** is an autoimmune disorder that causes muscle weakness and tiredness.
- **Peripheral Neuropathy** damages the nerves outside the brain and spinal cord, often resulting in weakness, numbness, and pain, usually in the hands and feet.
- **Spinal Muscular Atrophy (SMA)** is a genetic disorder that affects the motor neurons in the spinal cord, leading to muscles weakening and wasting away.

How are neuromuscular disorders treated?

Treatment depends on the specific disorder and may include:

- **Medications** including drugs to manage symptoms, reduce inflammation, or suppress the immune system in autoimmune disorders.
- **Physical therapy** helps maintain muscle strength, flexibility, and function.
- **Occupational therapy** helps with daily activities and adapting to physical limitations.
- **Surgery** may be needed to correct deformities or relieve pressure on nerves.
- **Assistive devices** like braces, wheelchairs, or communication aids can improve mobility and independence.
- **Lifestyle changes** include a healthy diet, regular exercise, and avoiding triggers that can worsen symptoms.
- **Supportive care** can include respiratory support, pain management, and psychological support.



Autism

What is autism?

Autism is a group of complex neurodevelopmental disabilities. Because it is a difference in the brain (neurodiversity) autistic people experience the world differently. This may include social differences, sensory differences, repetitive behaviour and thinking, communication differences, and motor differences.

Why do we call it a spectrum?

When we talk about autism as a spectrum, we don't mean a straight line from 'less autistic' to 'more autistic.' Instead, the spectrum represents the different ways autistic people experience the world compared to non-autistic people.

Autistic individuals have a variety of strengths and challenges, and these can differ from person to person.

Not all autistic people struggle with the same things, and their experiences can change depending on the situation. For example, someone might be very good at speaking but find it very difficult to communicate in a noisy or overwhelming environment. Another autistic person might have no difficulty being in a loud space but may find spoken communication challenging in general.

The idea of a spectrum highlights that autism is not a single, uniform experience. Autistic people, like everyone else, have unique abilities, challenges, and ways of interacting with the world.

Types of autism

The exact cause of autism is currently unknown. However, we know that no-one is to blame for a child or an adult being autistic.

A widespread myth is that vaccines lead to autism, but this is not true—there is no scientific evidence to support such a claim. Research is ongoing to better understand the possible causes of autism, and current findings suggest that genetics may play a role. Research suggests that autism can run in families. Even if a parent isn't autistic themselves, they might have certain autistic traits or characteristics.

How is autism treated?

There are various types of therapy available for autistic people, however, there is no cure or medication for autism. Instead, autistic individuals need to be loved, accepted, and supported in accessing services that help them thrive.

Therapies for autism spectrum disorder include occupational therapy, speech therapy, physical therapy, family therapy, and medication.

When seeking therapy, it is essential to find professionals who respect the individual and treat them with dignity. Therapists should provide choices and encourage autonomy, acknowledge and accommodate sensory differences, and focus on regulation and emotional well-being. Doctors might prescribe medication for co-occurring conditions such as ADHD or anxiety.

Signs of autism

Social interaction: Social rules have been developed by non-autistic people and autistic people don't get the non-autistic way of social interacting. They might find eye contact difficult, be very direct, use and understand body language differently, have flat or exaggerated facial expressions, and show differences in tone and/or voice pitch. However, some autistic people can empathise on a very deep level.

Communication: Some autistic people don't use speech to communicate, others may use a few words, and some might be able to speak fluently. It is important to remember that speaking is not the only form of communication. Speaking autistic people might struggle in certain situations and also require alternative forms of communication.

Repetitive movements: Many autistic people have self-stimulatory behaviour. These movements help with regulation, concentration and relaxation and can include hand flapping, spinning, clicking fingers, and many other movements.

Need for order and routine: Some autistic people thrive on routine as it helps to reduce anxiety and provides predictability. You might notice your child becomes upset when there is no routine or structure in place.

Sensory differences: Autistic people experience the world differently. Some may be very sensitive and others may not be sensitive at all. This can be with touch, taste, sight, sound or smell. Autistic people might cover their ears, wave and move their fingers in front of their eyes, avoid touch or seek out touch, avoid or seek out certain fabrics or textures.

Executive functioning difficulties may include focus, following directions, and regulating emotions.

What causes an autistic meltdown?

A meltdown is an intense reaction to feeling overwhelmed, distressed, or overstimulated. They can last from a few minutes to an hour or more, depending on the situation.

Meltdowns can be caused by emotional build-up, trauma, sensory overload, lack of processing time, tiredness or illness, an overload of the stress hormone (cortisol), surprises, changes in routine, or a combination of these factors. During a meltdown, an autistic person may temporarily lose control of their behaviour, which can include crying, yelling, self-harm, or shutting down completely.

Autistic people may become so overwhelmed, they "shut down". They may be unable to move or speak, feel drained and unable to function, and disconnect with people and the world around them.

Cerebral Palsy

What is cerebral palsy?

Cerebral Palsy (CP) is a disorder of voluntary movement and coordination. It can take many forms with some people so slightly affected that their disability is difficult to see, while others may have many and serious disabilities. The main feature of all types of cerebral palsy is abnormal muscle tone, leading to problems with posture and learning coordinated movements like grasping, hand-eye coordination, sitting, crawling, walking, swallowing, and speaking. Persons with cerebral palsy may also have other conditions such as epilepsy, developmental delay, visual problems, and difficulties with concentration, learning, language, and communication.

Causes of cerebral palsy

CP is caused by damage to or abnormalities inside the developing brain that disrupt the brain's ability to control movement and maintain posture and balance. The term cerebral refers to the brain, and palsy refers to the loss or impairment of motor function. In some cases, a part of the brain has not developed normally before the baby was born. In others, the damage is a result of injury to the brain either before, during, or after birth. In either case, the damage is not repairable and the disabilities that result are permanent.

Types of cerebral palsy

Spasticity results from damage to the motor cortex (a part of the brain) and is the most common affecting about 80% of people with CP. The muscle tone in the affected limbs increases stubbornly, affecting the range of movements in the joints.

Dyskinesia is associated with damage in a deeper area of the brain which affects the ability to carry out voluntary movements and results in abnormal involuntary movements (dyskinesia).

There are two types of dyskinesia: **Athetosis** can be seen in slow, squirming movements, especially in the hands, feet, and face which often causes frowning and drooling. Dystonia can be seen in sudden, continued muscle contractions resulting in twisting, repeated movements or abnormal postures.

Ataxia is much rarer and generally associated with an acquired head injury (especially vehicle accidents) that causes damage to the part of the brain known as the cerebellum. It causes difficulty with balance and coordination leading to unsteady walking and shaking when attempting fine movements.

How is cerebral palsy treated?

There is no standard treatment for CP. Each person will be evaluated by a team of health professionals to determine which treatment would work best. This could include **physiotherapy** (including special braces called orthotic devices), **occupational therapy** (to improve everyday activities), **recreation therapy** (to improve wellbeing), and **speech and language therapy** (including new ways to communicate).

Hillary's lifelong story with CP

"As a mature woman, having been diagnosed at 15 months old, with athetoid and ataxic. I was very fortunate to receive early intervention which enabled me start walking when I was five and a half years old. As soon as a child is diagnosed, it is important to receive physiotherapy, occupational therapy and speech therapy which has assisted me to lead a very full and inclusive life. One of my biggest disabilities has been my handwriting because my hands are unsteady. I soon taught myself to hold my pen in my left hand and rest it on my right hand, but it still meant that I was pressing too hard, and it was slow and tiring. At the age of seven I was given a typewriter which I used my entire school life. My teacher was determined that I could sign my name, saying that one day I would need to sign a cheque!

As a young child, I would drool a lot, and my parents were always telling me to swallow. Fortunately, I grew out of this. It is important to understand that the body of a person with CP is like driving a manual car, while the body of someone who doesn't have CP is like driving an automatic car. The resounding words from my mother was "put you heals down", and that mantra helped me enormously. I'm still known to rush, but walking is about balance. When you take a step there is a split second when you are balancing on one leg. By 'rushing' I am actually shortening the length of time when I have to balance!

I was brought up with the philosophy "it's not what happens to you, but how you handle it". I think that is what has made me what I am today. It is primarily how my parents, husband, children, and friends treat me. It is also in a way how I project myself – Hillary with her slight shakes or falling over my own feet. This has not stopped me from being a disability activist. I have been married for 45 years to an able-bodied man. We have two children (both born by caesarean section) and I am now grandmother to five. I never applied for a job, but always somehow had jobs, either as the CEO of the Western Cape Cerebral Palsy Association for seven years, or running two different second-hand clothes projects, or running a project for Stellenbosch University for 12 years. I now serve on various boards as chairperson, or vice chairperson.

My passion is sewing. It is something I have mastered and yes, I can thread a needle which many people find amazing. I make my own clothes and enjoy doing patchwork and quilting. I also completed the New York Marathon in 2011 (52km which took me 10 hours and 7 seconds)! The venture was to raise money and see the effect on my body. Tests done by Stellenbosch University before and after showed an amazing improvement in the way I walk. The aging process has taken its toll on my body and so I now walk with a walker. I chose to use the walker myself, which made a huge difference in how I feel about myself. Now I like to think people simply see an older person using a walker: "You are what you believe yourself to be"!

Intellectual Disabilities

What is an intellectual disability?

Intellectual Disability is when a child has major difficulty or delay in acquiring skills across most developmental areas including motor (movement) skills, communication and speech, social interaction, play, and learning (cognitive skills). It is a neurodevelopmental disorder that:

- Begins in childhood or at birth
- Affects intellectual functioning (mental abilities) such as reasoning, problem-solving, planning, abstract thinking, judgement, academic learning and learning from experience.
- Affects adaptive functioning that impacts independence and social responsibility.

Causes of intellectual disability

Intellectual disability occurs when normal brain development is disrupted. Some common causes include:

- Genetic factors are inherited conditions or genetic abnormalities like Down syndrome and Fragile X syndrome.
- Pregnancy and birth complications include poor foetal growth, exposure to alcohol or infections during pregnancy, lack of oxygen during birth, or extreme prematurity.
- Illness and injury such as brain infections like meningitis, whooping cough, measles, severe head injury, near drowning, or severe malnutrition.
- Environmental factors include radiation exposure, exposure to toxins like lead or mercury and maternal malnutrition.

How are intellectual disabilities treated?

There is no cure for intellectual disability. However, depending on the severity of the disability and the areas of function impaired, different techniques are available to help the child function better. The most common services that can help your child function better and adapt to everyday life include:

- **Physical therapy** to help increase mobility and find adaptive solutions to mobility problems.
- **Speech therapy** to improve communication by enhancing reception and expression skills.
- **Occupational therapy** to improve self-care, leisure (knitting, playing games), domestic activities such as cooking and cleaning, and employment skills.

The best way to approach the treatment is to consider all personal factors, including identity, biology, psychology, and societal factors.

Dignity and inclusion come first. People with disabilities must be central in decisions affecting them and fully included as a right, not a privilege. Inclusion means changing structures, and not forcing people to fit in. Accessible information, like Easy-to-Read formats, supports true inclusion. Disability must be mainstreamed in all policies while providing targeted support to empower individuals. Inclusive development requires a mind-set shift to ensure equal participation.

Types of intellectual disability

There are four levels of intellectual disability:

Mild:

- IQ between 50 and 69
- Delayed development but communicates well
- Can learn basic job skills, reading, and computer use at a 9 to 11-year-old level
- Able to work with regular support.

Moderate:

- IQ between 35 and 49
- Delayed development
- Simple communication
- Struggles with learning and logic
- May recognise and write a few words, requires varying support to live and work.

Severe:

- IQ between 20 and 34
- Significant developmental delay
- Speech difficulties and limited vocabulary
- Learns basic self-help skills with time but needs community support
- Functions at a 3–5-year-old level.

Profound:

- IQ less than 20
- Fully dependent
- Little or no speech
- Unclear emotional expression
- Often has seizures, physical disabilities, and shorter lifespan
- Functions below a 3-year-old level

Gabriel’s Journey to Acceptance

“My name is Gabriel. Growing up people would tell me that I am stupid and that I would never amount to anything. These words would hurt me deeply and caused me not to have a good self-image. I felt broken inside. I felt like everyone was talking about me and would make fun of the fact that I had an intellectual disability.

They would call me names like “dom’, “vertraag” and these words caused severe feeling of sadness. I had to tell myself that I could do things and that everyone is special.

I started at Training Workshops Unlimited in Cape Town and worked on contracts. I worked at a couple of shops in a contract position afterwards. I also participated in the Hygiene and Cleaning Learnership. I started believing in myself and with each opportunity; I was more convinced that I would be able to find a job in the open labour market.

When a position was advertised at Cape Mental Health as a parking assistant, I jumped at the opportunity and got it. I am responsible for keeping the parking area clean and assisting staff and visitors with parking.

In 2018, I applied for an opportunity to go to Germany on an exchange programme and came across the “Easy-to-Read” programme. I asked Cape Mental Health to develop this programme and became involved in the Easy-to-Read Committee which developed Cape Mental Health’s 500-word Easy-to-Read dictionary.

This will ensure that people who have difficulty in reading will be able to access information in an easy-to-read format. Today, I am the ambassador of the Easy-to-Read programme.”

Traumatic Brain and Spinal Cord Injury

What are traumatic brain and spinal cord injuries?

A **traumatic brain injury** is a disruption of the normal function of the brain that can be caused by a bump, blow, or jolt to the head or a head injury that enters the brain. While everyone is at risk, children and older adults are especially vulnerable.

Spinal cord injuries occur when the spinal cord is damaged due to vertebrae being dislocated, broken, or crushed.

These are among the most severe and life-altering injuries a person can experience. These injuries often lead to significant physical, emotional, and social challenges.

Causes of traumatic brain and spinal cord injuries

Injuries can result from both traumatic and non-traumatic events, all of which have serious impacts on the lives of those affected.

The most common causes:

- Motor vehicle accidents cause nearly half of all injuries worldwide.
- Interpersonal violence like gunshot wounds and stabbings in South Africa and globally contribute significantly to cases.
- Falls account for many injuries, particularly among older adults.
- High-impact sports such as mountain biking, rugby, and horse riding frequently lead to severe injuries.
- Diving accidents can cause injury due to impact with the bottom or hidden obstacles in swimming pools, oceans, rivers, or dams.

Types of traumatic brain and spinal cord injury

The effects of a spinal cord injury depend on where and how serious the injury is:

- **Traumatic brain injury** disrupts normal brain function, including fatigue, changes in behaviour, and cognitive impairment.
- **Quadriplegia:** Cervical (neck) injuries can result in loss of function and sensation in both arms and legs.
- **Paraplegia:** Thoracic, lumbar, and sacral injuries occur in the chest, back, and lower back. These typically affect only the legs.
- **Severe spinal cord injury** can affect breathing, heart rate, blood pressure, and bladder and bowel control.

How are traumatic brain and spinal cord injuries treated?

While there is currently no cure for these injuries, rehabilitation and ongoing exercise programs help strengthen muscles and improve mobility. With the right support, people can live fulfilling lives, including pursuing careers, starting families, engaging in sports, and becoming community leaders.

Assistive technology plays a crucial role in enhancing independence:

- Both motorized and manual wheelchairs provide mobility.
- Adapted vehicles allow people to drive with modified controls.
- Specialized computer equipment enables accessibility for work and communication.
- Resources and opportunities create a positive mindset.

QASA's story

It comes as a great shock to hear those words: "You are not going to walk again," "You have severed your spine and will be in a wheelchair for the rest of your life." These are words no one ever wants to hear. It's natural to experience shock, depression, anxiety, and wonder what the future holds.

However, with proper rehabilitation and family support, there is a small light at the end of the tunnel. While good rehabilitation is crucial, it's not always accessible in places like South Africa. That's where peer support - offered by organizations like the QuadPara Association of South Africa (QASA) - becomes invaluable, helping you take those first small steps towards your future.

At some point, you have to stop asking, "Why me?" and focus on what's next. It's important to make plans that help you move forward, whether it's developing new skills or reintegrating into your career. Ask yourself: What skills do I have? What am I going to do with them? And how will I go about it?

Once you start thinking and planning this way, it's surprising how the community will rally around you, opening doors and laying the foundation for your integration into mainstream society. The key is to find purpose. It may seem impossible at first, but the influence we, as wheelchair users, have created has helped society engage with us more equitably, providing us with new opportunities.

A wheelchair is simply a tool that allows us mobility and independence. It should not define or limit us. By using adapted assistive devices, we can be functional and self-sufficient.

Our goal is to continually influence society toward universally accessible environments, which is essential for maximizing our mobility. The experience of living with a spinal cord injury can be one of new adventures and opportunities, but it also requires constant advocacy.

Our families are our first support system, and their adaptation is crucial. We must ensure they are on this journey with us, even if it means using wheelchairs to navigate it.

Cancers of the Nervous System

What are cancers of the nervous system?

Cancers of the central nervous system happen when harmful (malignant/cancerous) cells in the brain or spinal cord grow and multiply uncontrollably to form a mass (tumour) that interferes with brain functions such as muscle control, sensation, memory, and other normal body functions. It may lead to a variety of neurological symptoms depending on their location and size.

Causes of cancer of the central nervous system (CNS)

Most of the time the cause is unknown, but certain factors may make it more likely to develop cancer of the nervous system:

- It is more common in children and older adults.
- Men are more likely than women to develop a CNS tumour.
- About 5% of CNS tumours may be linked to inherited genetic factors or conditions.
- It would appear that white people are more likely to develop gliomas (a type of tumour in the brain or spinal cord), but less likely to develop meningioma (a type of tumour that forms in the layers of tissue around the brain and spinal cord) than black people.
- Previous treatment to the brain or head with ionizing radiation (including X-rays) may increase the risk for a CNS tumour.
- Some studies seem to show that N-nitroso compounds may increase the risk of both childhood and adult CNS tumours. These compounds are formed in the body from nitrites or nitrates found in some processed meats and cigarette smoke.

How are cancers of the central nervous system treated?

CNS cancers are mainly treated with:

- **Surgery** (an operation)
- **Chemotherapy** uses drugs to destroy cancer cells, but can also affect healthy cells. It can be given through pills, an intravenous injection, or directly into a specific area of the body. It is usually given in cycles (periods of treatment followed by periods of rest). Side effects depend on the specific drug used and the individual, but common side effects include tiredness, nausea, vomiting, hair loss and an increased risk of infection.
- **Radiation therapy** uses high doses of radiation to kill cancer cells and shrink tumours. It is typically given over several weeks, with short daily sessions. Common side effects include tiredness, skin changes, hair loss in the treated area, and other site-specific effects such as difficulty swallowing for head and neck radiation.

There are two main types of radiation therapy:

- **External beam radiation therapy** delivers radiation from outside the body, aiming beams at the cancer.
- **Internal radiation therapy (brachytherapy)** places radioactive material directly inside or near the tumour.

Types of cancer of the central nervous system

There are more than 120 different types of CNS tumours, lesions and cysts. The difference is where they occur and what kind of cells they are made of.

Conn's Creative Thinking

In 2006 Conn was a leading South African creative director, big wave surfer, Fear Factor winner, husband and father of two young children when he was diagnosed with a severe and extremely rare form of adult malignant brain cancer: Medulloblastoma. It is a rare and aggressive type of brain tumour that originates in the cerebellum, the part of the brain responsible for balance, coordination, and movement. It is classified as a central nervous system (CNS) tumour and is most common in children but can very rarely occur in adults.

"Using my experience in creative thinking and storytelling, I immersed myself in my cancer to gamify it by using creativity, paint, sticks of chalk and cognitive framing techniques to bring my cancer to life in a way that I could participate in its demise - by augmenting my treatments with actions and thinking. The world literally became my physical, metaphoric cancer-beating playground. An upbeat, visually engaging canvas that helped me augment my treatments, my resilience and my immune system. That ultimately increased my chances of survival and helped me beat my cancer in 2013. And what was most surprising about my recovery, was that after all the treatments I had undergone, my immune function was found to be stronger than the average adult man. This fact galvanised my mission to begin sharing this approach with others.

My method of participating together with the many treatments enabled me to tap into the science of psychoneuroimmunology (how one's psychological state affects one's immune system over time) and develop a more resilient mindset is shown to not only increase recovery time, but also reduce the negative side effects of treatments enabling me with a more positive cancer outcome .

My approach to empowering cancer patients to engagement and participation in their own healing process together with the medicine, has garnered much support from South Africa's top professors of Oncology as it helps patients shift from helpless, to actively resilient. Urged by doctors, oncologists, neurologists and professors of science to share this way of thinking. I then created the multiple award-winning Cancer Dojo: a platform built to empower patients with the tools, content and information they need to help them become, in my own words 'Happier, Healthier and Harder to Kill.' I have since expanded this approach of empowering people to better overcome their challenges by helping business and staff to find their purpose and grow their own resiliency for our current and crazy, changing, challenging world. I and my team have successfully used this methodology to empower over 160,000 employees of Africa's largest retailer, The Shoprite Group.

Cancer can ruin your life, or it can enable you a new one, to fly!"

Rare Neurological Disorders

What are rare diseases?

Rare neurological disorders each affect fewer than one in 2,000 people (defined by the WHO), but together they touch the lives of millions – and their families – worldwide. It is estimated that about 4.2 million South Africans are affected by a rare disease with around 7,000 conditions described. More than 1,200 of these are neurological disorders that affect the brain, spinal cord, and peripheral nerves and are known as rare neurological disorders. Although each condition is uncommon, the challenges they bring can be very real: delayed diagnoses, limited treatment options, and feelings of isolation.

What causes these?

Genetics greatly influence how these conditions start, develop, and how severe they are. In many cases, the exact cause is unknown.

Specific causes include:

- Genetic mutations are changes in DNA due to inherited or spontaneous changes in genes that affect nerve function.
- Autoimmune responses where the immune system mistakenly attacks the nervous system.
- Metabolic disorders are problems with how the body processes nutrients, leading to nerve damage.
- Infections as certain bacteria or viral infections can trigger neurological damage.

Examples of rare neurological disorders

Dravet Syndrome is a severe form of epilepsy that begins in babyhood, causing lengthy seizures, developmental delays, and movement issues. It is linked to mutations in the SCN1A gene.

Lennox-Gastaut Syndrome (LGS) is a severe form of childhood epilepsy characterised by multiple seizure types, intellectual disability, and resistance to standard epilepsy treatments.

Rasmussen's Encephalitis is a progressive inflammatory disease affecting one half of the brain, often leading to seizures, loss of motor skills, and worsening mental abilities (cognitive decline). It is believed to be caused by an autoimmune reaction.

Rett Syndrome is a rare neurodevelopmental disorder that primarily impacts girls, causing severe cognitive (mental) and motor impairments.

Mitochondrial Diseases are a group of disorders that disrupt how cells make energy leading to muscle weakness, neurological symptoms, and seizures.

How are rare neurological disorders treated?

While most of these disorders have no cure, treatment focuses on managing symptoms and improving quality of life, through:

- Medications like anti-seizure drugs, muscle relaxants, or medications targeting specific symptoms.
- Specialised diets like the ketogenic diet may help reduce seizures in some cases.
- Surgical procedures like corpus callosotomy or hemispherectomy may be considered in severe cases.
- Physical and speech therapy supports movement, communication, and daily activities.
- Supportive care includes counselling, advocacy, and assistive devices to improve overall well-being.

Many of these disorders arise from changes in our genes – tiny differences in DNA that make our bodies unique. Others happen when our immune system accidentally attacks healthy nerve tissue, or when certain infections or metabolic problems interfere with the way nerves and muscles communicate. Because doctors see each rare condition so infrequently, it can take time and a few visits before the correct diagnosis is made.

During this period, it’s natural to feel frustrated or anxious, so having a caring medical team and a support network can make a world of difference.

Once a diagnosis is in hand, treatment usually focuses on easing symptoms and helping people live their fullest lives. That might mean medications to reduce seizures or muscle stiffness, specialised diets that can calm overactive nerves, physical and speech therapies to build strength and confidence, or – with some conditions – surgical options.

Assistive devices like braces, walkers, or communication aids can also help with everyday tasks. Living with a rare neurological disorder often means becoming your own best advocate.

Learning as much as you can – whether through trusted medical sources, patient groups, or fellow warriors on the same journey – brings clarity and hope.

Connecting with others who truly understand whether in person or online, reminds you that you’re not alone. With the right combination of medical care, emotional support, and practical tools, many people with rare neurological disorders go on to lead active, rewarding lives.

Sarique’s story

After years of struggling with chronic fatigue, anxiety and depression Sarique became severely ill in May 2015 at the age of 33:

“Throughout the years I could not understand my depression and anxiety. I have accepted it, but I now know it is secondary symptoms of dealing with an auto immune disease. Before my diagnosis with Myasthenia Gravis I constantly googled my symptoms as I needed answers and knew there was something severely wrong with me. My journey to diagnosis was a whirlwind of medical exploration over ten years. I visited many specialists, doctors, alternative therapies, psychologists and psychiatrists, which finally culminated in a diagnosis of MG in December 2017 by a neurologist willing to listen to me, believed me and has knowledge of MG.

My current symptoms are chronic fatigue, anxiety, depression, brain fog, unrefreshed sleep even if you sleep 10 plus hours per night, shortness of breath, blurry vision, overactive bladder and overall skeletal muscle pain and stiffness (my neck is especially weak which results in back and neck pain) with some days better than others.

I think the biggest challenge is my mental state and challenges. Life seems to be slipping away as I spend most of my time resting at home between activities. There is so much more I would like to achieve and experience in life, but my body just doesn’t allow me. Even if you do these things it takes days of inactivity to recover.”

Myasthenia Gravis (MG) is a chronic neuromuscular disease characterised by weakness and fatigue of the voluntary muscles (especially the eyes, mouth, throat and limbs). It is a breakdown of the normal communication between the muscles and nerves. There is no cure for MG but treatment may bring much improvement.

The condition is more common in younger women (under the age of 40) and men above the age of 60 but can happen at any age.

Other Neurological Disorders

Important disorders not yet fully covered in this guide – but just as relevant

While this guide shares many of the most common and visible neurological disorders, the World Health Organisation's IGAP (Intersectoral Global Action Plan) also includes other disorders that are especially relevant in countries like South Africa.

Here are some additional disorders that affect brain health, behaviour, and function that deserve attention:

Alzheimer's Disease and Dementia

These are progressive brain disorders that affect memory, behaviour, and thinking. Dementia is a general term for a decline in mental ability severe enough to interfere with daily life, while Alzheimer's is the most common cause of dementia.

It mostly affects older people but can impact families and caregivers of all ages. There is no cure, but support, structured routines, and memory care can help improve quality of life.

HIV and Neurological Disorders

HIV can affect the nervous system in different ways — leading to disorders like HIV-associated dementia, peripheral neuropathy, and neurocognitive challenges. These are especially important in South Africa due to the high number of people living with HIV.

Neuroinfectious Disorders

These are infections that affect the brain and spinal cord. Common ones in South Africa include:
- Meningitis – inflammation of the brain's protective membranes
- Neurocysticercosis – a parasitic infection caused by tapeworms, often through undercooked pork or poor hygiene
- Cerebral malaria – a severe form of malaria that affects the brain, most common in young children and pregnant women

These disorders can lead to seizures, coma, long-term disability, or death if not treated quickly.

Attention-Deficit/Hyperactivity Disorder (ADHD)

ADHD is a neurodevelopmental disorder that affects focus, self-control, and impulse regulation. While often associated with children, ADHD can continue into adulthood. People with ADHD may be misunderstood as disruptive or lazy — but with the right support, they can thrive.

Brain Aneurysms

A brain aneurysm is a weak spot in an artery that bulges and fills with blood. If it bursts, it can cause a life-threatening stroke. Often there are no symptoms until it's an emergency. Quick treatment is key.

This section shows how neurological disorders are broad and diverse. Some are well-known, others are rare or overlooked. But all deserve awareness, access to treatment, and compassion.

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Resources

You can find out more about the IGAP in a language of your choice:

IGAP BOOKLET
English

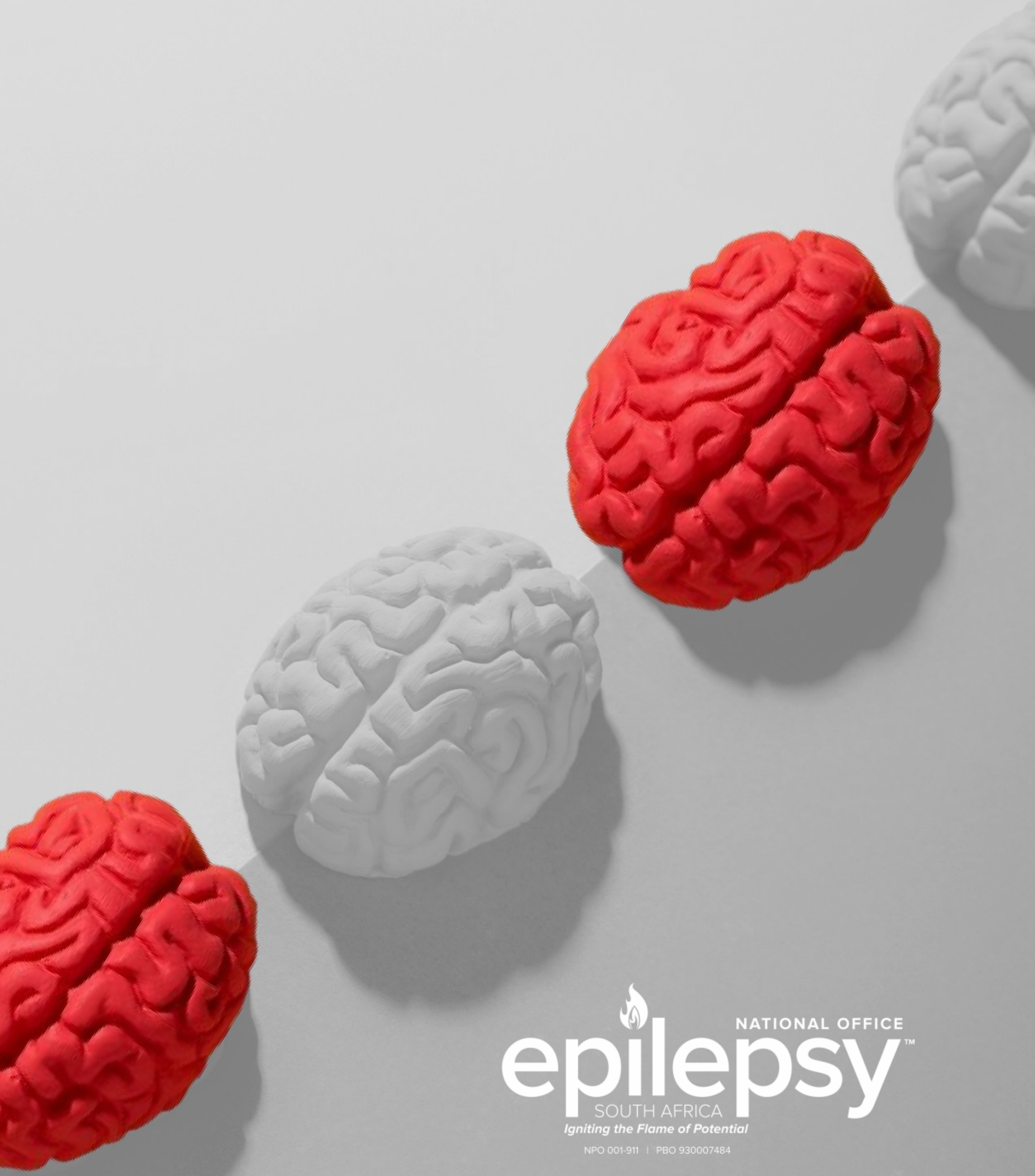
IGAP Booklet
isiZulu

IGAP Booklet
isiXhosa

IGAP Booklet
Afrikaans

IGAP Booklet
Sesotho

You can also download a copy of the IGAP at
https://www.who.int/publications/i/item/9789240076624



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