



**WHO Information
Kit on Epilepsy**
What you can do



**World Health
Organization**

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Abbreviations

AEDs – Antiepileptic drugs

IBE – International Bureau for Epilepsy

ILAE – International League Against Epilepsy

LAMICs – Low- and middle-income countries

mhGAP – Mental Health Gap Action Programme

mhGAP-IG – Mental Health Gap Action Programme Intervention Guide

NGOs – Nongovernmental organizations

WHA – World Health Assembly

WHO – World Health Organization

Introduction

The treatment of epilepsy has long been neglected in public health programmes despite its high disease burden, the major impact on the people it affects, and the existence of inexpensive and cost-effective treatment. Access to treatment for those in need is crucial: up to 70% of people with epilepsy could be seizure free if they received treatment with oral antiepileptic medicines.

Not only is it essential to ensure that those in need be able to access this treatment, access to information about epilepsy is equally important. People with epilepsy and their families often suffer from stigma and discrimination because of the lack of knowledge and understanding about the condition.

In 2015, the World Health Assembly (WHA) adopted a resolution on epilepsy, WHA68.20, which urges coordination action at the country level to address its health, social and public knowledge implications. The resolution highlights the need for the WHO to help strengthen countries' capacities to address epilepsy and facilitate resource mobilization. This resolution is a powerful tool to assist countries implement effective actions to improve medical and social services for people living with epilepsy, promote public awareness about epilepsy and allocate resources towards epilepsy research.

The Global Information Kit on Epilepsy has been developed as part of the WHO Programme on Reducing the Epilepsy Treatment Gap to support implementation of WHA68.20 recommendations. It provides general information about epilepsy, an overview of current pilot projects as examples of what can be achieved, and actions that can be taken by specific stakeholder groups with reference to WHA68.20. The intended audiences for the Global Information Kit on Epilepsy are policymakers, specialist and non-specialist health care providers, people living with epilepsy and their families, nongovernmental organizations (NGOs) and the general public.

The epilepsy “treatment gap” is the percentage of people with epilepsy whose seizures are not being appropriately treated at a given point in time.

Epilepsy. Treat it. Defeat it.

Epilepsy is a chronic disorder of the brain characterized by recurrent seizures. It affects people of all ages and often has no identifiable cause. More than 50 million people worldwide have epilepsy, and nearly 80% live in low- and middle-income countries (LAMICs). Every year, an estimated 2.4 million people are newly diagnosed with epilepsy.

Epilepsy can be treated

Epilepsy treatment is inexpensive and is effective for controlling seizures in 70% of all cases. Despite this, about three fourths of people living with epilepsy in LAMICs do not receive the treatment they need.

Why is this the case? In most LAMICs, antiepileptic medicines are frequently unavailable. In these countries, there are also very few health care providers who have the appropriate training to recognize, diagnose and treat epilepsy. Furthermore, lack of knowledge or misperceptions about epilepsy may affect health-seeking behaviour. People with epilepsy may not access treatment from health care facilities and instead might seek help from other sources that may be ineffective. They also may not seek regular follow-up care or adhere to medications as prescribed.

Epilepsy can be defeated

To support countries to defeat epilepsy, the WHO Programme on Reducing the Epilepsy Treatment Gap focuses on expanding the skills of non-specialist health care providers to diagnose, treat and follow up with people with epilepsy. The Programme engages in health systems strengthening, helping to increase sustainable access to antiepileptic medicines and reinforcing referral systems. It also raises awareness about epilepsy among policymakers, health care providers, people living with epilepsy and their families, NGOs and the general public. Pilot projects for the Programme have been initiated in four countries: Ghana, Mozambique, Myanmar and Viet Nam.

Challenges and gaps in epilepsy care:

1. Still considered a low priority in many countries.
2. Limited capacities of health care systems and inequitable distribution of resources.
3. Lack or severe shortage of appropriately trained staff.
4. Inadequate access to affordable medicines.
5. Societal ignorance and misconceptions.
6. Poverty.

Together we can succeed

The World Health Organization has long recognized that epilepsy is a major public health concern. It has been working with many partners and stakeholders including WHO Collaborating Centres, nongovernmental organizations such as International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), and many others to support countries to reduce the epilepsy treatment gap.

The World Health Assembly's adoption of the epilepsy resolution (WHA68.20 – 'Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications') presents a historical opportunity to improve epilepsy care worldwide. WHA68.20 highlights the need for governments to formulate, strengthen and implement national policies and legislation to promote and protect the rights of people with epilepsy. It also emphasizes the importance of training of non-specialist health-care providers as key to reducing the epilepsy treatment gap. The resolution, with coordinating support from WHO, calls all countries to action on the following:

- Strengthen effective leadership and governance;
- Improve provision of epilepsy care;
- Integrate epilepsy management into primary health care;
- Increase access to medicines;
- Support strategies for prevention of epilepsy;
- Increase public awareness and education;
- Strengthen health information and surveillance systems;
- Improve investment in research & increase research capacity.



WHO's Work on Epilepsy

The Global Campaign Against Epilepsy: Out of the Shadows was established in 1997 as a partnership between WHO, the International League Against Epilepsy, and the International Bureau for Epilepsy. ILAE member organizations consist of professionals concerned with medical and scientific aspects of epilepsy, while those of IBE are concerned with social aspects and the quality of life of people with epilepsy.

This campaign raises general awareness and understanding about epilepsy and supports governments in identifying needs and promoting education, training, treatment, services, research and prevention in their countries.

As part of the *Global Campaign Against Epilepsy: Out of the Shadows*, projects were carried out in the following countries: Argentina, Brazil, People's Republic of China, Georgia, Pakistan, Senegal, Timor Leste and Zimbabwe. Some of these projects resulted in the integration of epilepsy care into countries' primary health care systems.

The WHO Programme on reducing the Epilepsy Treatment Gap builds upon these previous collaborative projects.

Out of the Shadows: China Demonstration Project

From 2000 to 2004, the Global Campaign Against Epilepsy: Out of the Shadows conducted a demonstration project in The People's Republic of China (China), where epilepsy prevalence is approximately 4.6/1000.

The project was carried out in six provinces to test the feasibility of diagnosing and treating epilepsy at the primary health care level, using the first-line medication phenobarbital. During the project's implementation phase in 2002 to 2004, 2,455 patients with convulsive epilepsy were treated out of the 66 000 people who were screened. Educational activities on epilepsy for the general public, patients, and their families were conducted via media channels (TV and newspapers) and aimed to show the general community that epilepsy is treatable. The results were conclusive:

- 34% of the patients were seizure-free within one year and another 34% had their seizures decreased by over 50%;
- After 2 years of intervention, which included antiepileptic medication and education, the treatment gap in the project area of the participating provinces decreased by 12.8% from 62.6% to 49.8%, a statistically significant reduction;
- It is possible for trained primary health care physicians to diagnose and treat people with epilepsy, and this care model can be successful in significantly reducing the epilepsy treatment gap.

Thanks to this demonstration project, the government has supported the scale-up of the project to cover 75 million people in 18 provinces, who now have better access to epilepsy diagnosis and treatment. As of 2012, over 24 000 public health workers have been trained in epilepsy management and nearly 200 000 people have been screened for epilepsy.

Epilepsy: A Public Health Issue

Quick facts

- 1** Epilepsy is a chronic disorder of the brain that affects people of all ages.
- 2** More than 50 million people worldwide have epilepsy.
- 3** Nearly 80% of people with epilepsy live in low- and middle-income countries.
- 4** With daily, inexpensive antiepileptic medicines, 70% of people with epilepsy can be seizure free.
- 5** About three fourths of people living with epilepsy in low- and middle-income countries do not get the treatment they need.
- 6** People with epilepsy and their families often suffer from stigma and discrimination.



Epilepsy is a medical disorder

- Epilepsy is a neurological disorder that affects people in every country of the world. It is one of the world's oldest recognized medical conditions.
- Epilepsy is defined by two or more unprovoked (spontaneously occurring) seizures occurring at least 24 hours apart.
- A seizure is a temporary disturbance in the brain's electrical activity.
- Having one seizure does not mean a person has epilepsy: 1 out of every 10 people will have one seizure during their lifetime but do not have epilepsy.
- Characteristics of seizures vary and may include convulsions of the body and limbs, loss of awareness or consciousness, and irregular sensations (including vision, hearing and taste).
- People with epilepsy are at higher risk for physical problems like fractures or burns, as well as higher rates of other conditions like anxiety and depression.



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- The risk of premature death in people with epilepsy is up to 3 times higher than it is for the general population.

Epilepsy is prevalent all over the world, but more so in low- and middle-income countries

- Nearly 80% of people living with epilepsy live in LAMICs.
- Two-thirds of newly diagnosed cases of epilepsy are in LAMICs, where there is a higher risk of conditions that can lead to permanent brain damage.

Left: Boy in Myanmar being treated at participating clinic
Above: family in Mozambique at participating health-care facility;
Right: Reading an epilepsy project brochure in Myanmar;
Far-right: Patients with epilepsy in Myanmar wait to be seen at participating clinic
Copyright: DOH/San Oo

Epilepsy can be treated, but many lack access to treatment

- With regular treatment, 70% of people with epilepsy will be seizure free. Most of them can stop taking antiepileptic medicines after two years without seizures, however some may require treatment for longer.
- In many LAMICs, antiepileptic medicines are often not available, so even if people seek treatment they cannot receive it.
- In some countries in Africa it is estimated that up to 90% of people living with epilepsy go untreated.

Epilepsy can be prevented in some cases

- Many of the causes of epilepsy are preventable, and the health and social sectors of countries should be supported to reduce new cases of epilepsy. For example:
 - Preventing head injury, which is the most effective way to prevent post-traumatic epilepsy.

- Accessing antenatal and perinatal care, which can reduce new cases of epilepsy caused by complications at birth like lack of oxygen or trauma.
- Elimination of parasites that cause central nervous system infections (for example neurocysticercosis).
- Educating people about how to avoid infections in tropical areas.
- Preventing stroke.

Human rights of people with epilepsy are not always respected

- In some countries, community perceptions and certain legislation reflects centuries of misunderstandings about epilepsy. As a result, people with epilepsy and their families often experience social exclusion and discrimination.
- National legislation based on internationally accepted standards on human rights can help prevent discrimination and rights violations against people with epilepsy. It can also improve access to health care services and raise the quality of life for people living with epilepsy and their families.



Epilepsy Myths Debunked

Myth 1: Epilepsy is contagious.

Fact: Epilepsy is not contagious. You cannot get epilepsy from another person in any way.

Myth 2: Epilepsy is caused by spiritual possession or punishment.

Fact: Epilepsy does not have any spiritual or supernatural cause. It is a medical condition, a chronic neurological disorder that can happen to anyone.

Myth 3: People with epilepsy cannot work.

Fact: People with epilepsy can and should be supported to work. However, jobs that have a higher risk for injury should be avoided, including those involving heights, heavy machinery or fire.

Myth 4: People with epilepsy cannot get married or have children, and if they do then their children will also have epilepsy.

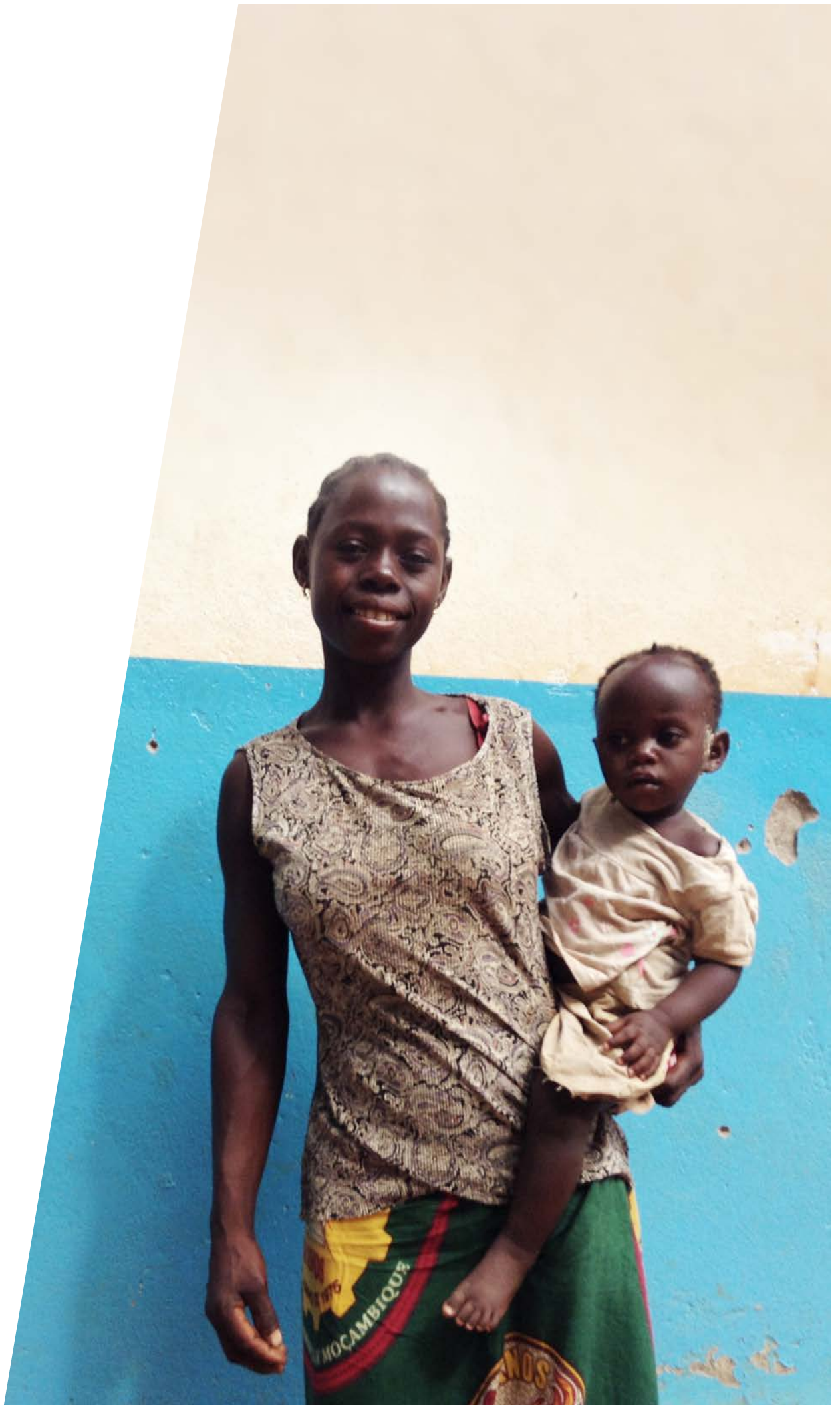
Fact: People with epilepsy can get married and maintain stable, supportive relationships. Epilepsy is not transmitted from parents to their children. Women with epilepsy can have healthy pregnancies, however they should consult a trained health care provider if they are pregnant or planning to become pregnant.

Myth 5: Children with epilepsy cannot go to school.

Fact: Children with epilepsy should not be prevented from going to school. They are not a danger to other children. Teachers should be educated about epilepsy and what to do in the event of a seizure.

Myth 6: People with epilepsy cannot participate in recreational activities.


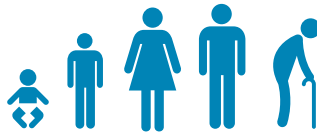
Fact: People with epilepsy can safely participate in recreational or sporting activities if their seizures are under control. Activities involving heights or water require specific safety considerations.



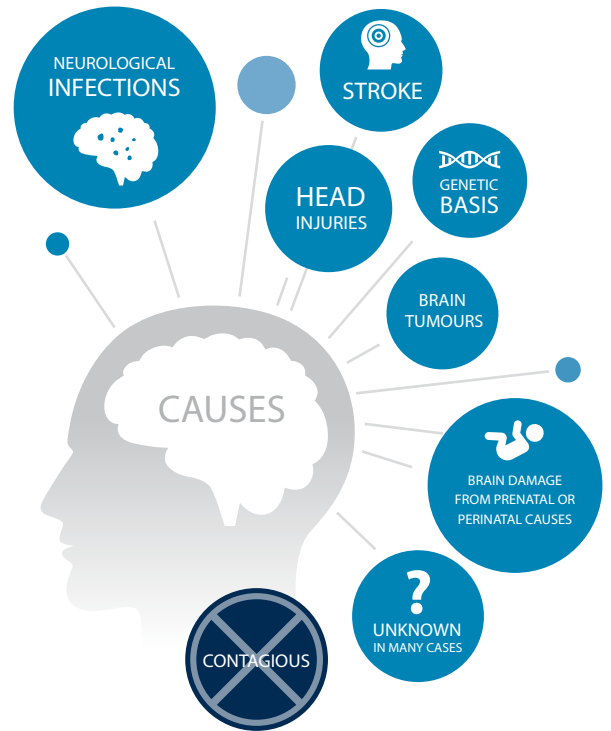
WHAT IS epilepsy?

A NEUROLOGICAL CONDITION characterized by *recurrent seizures*

Seizures are due to *brief disturbances* in the *electrical functions* of the brain

Epilepsy affects people of all ages


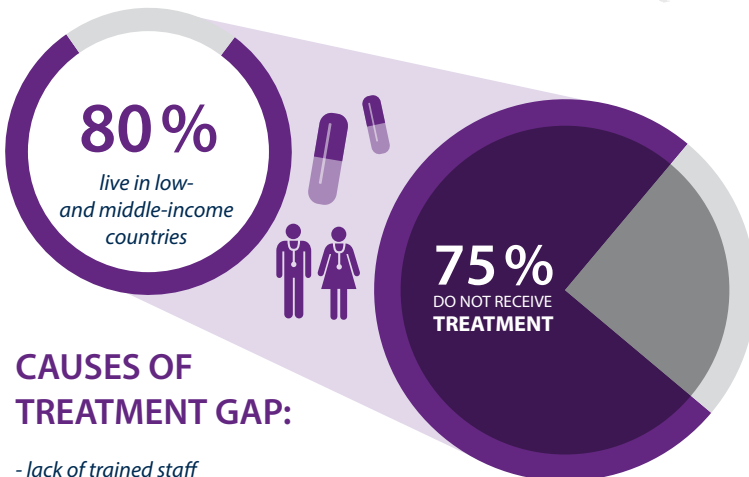


What is the **IMPACT** of epilepsy?

50 000 000

More than 50 million people are living with epilepsy globally

3-6 ^{TIMES}
GREATER
RISK
OF PREMATURE
DEATH

CAUSES OF TREATMENT GAP:

- lack of trained staff
- poor access to anti-epileptic medicines
- societal misconceptions
- poverty
- low prioritization for the treatment of epilepsy



STIGMA & DISCRIMINATION



FAMILY

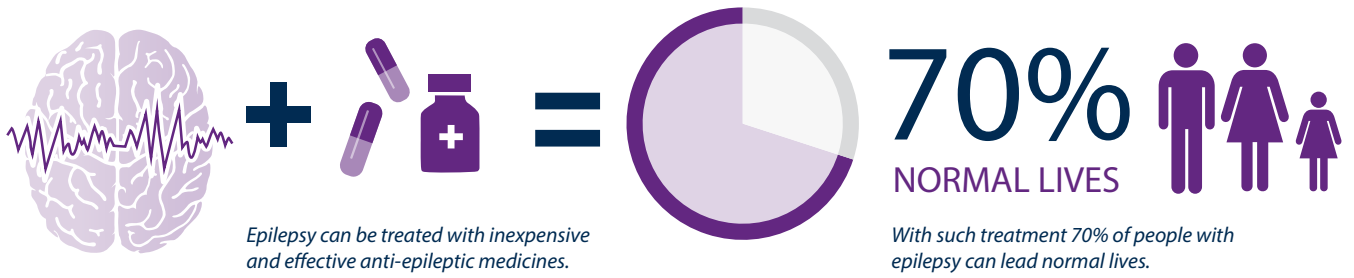


WORK

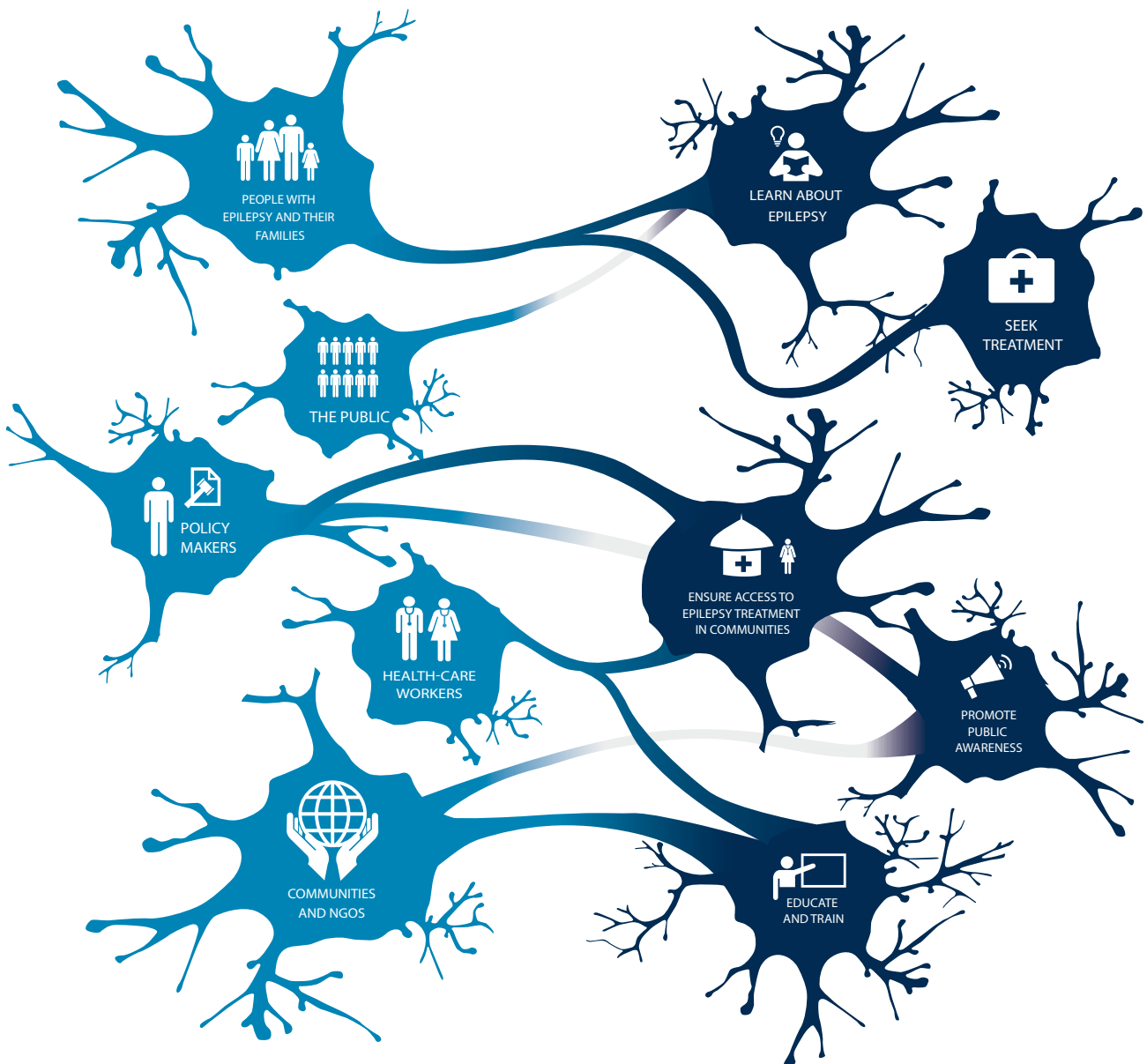


SOCIAL
STANDING

What is the SOLUTION?



WHO can do WHAT?



The WHO Programme on Reducing the Epilepsy Treatment Gap: An Overview

The WHO Programme on Reducing the Epilepsy Treatment Gap is piloting an improved model of epilepsy care in four countries: Ghana, Mozambique, Myanmar and Viet Nam.

Building on previous WHO collaborative projects to reduce stigma and improve access to treatment, this model combines several innovative strategies and demonstrates how WHA68.20 recommendations can be systematically and effectively implemented at a country level. It expands the skills of primary care, non-specialist health care providers to diagnose, treat and follow up people with epilepsy; it mobilizes NGOs, community groups and volunteers to raise awareness about epilepsy and support people with epilepsy and their families; and it assists with health systems strengthening to ensure sustainable access to antiepileptic medicines, reinforce referral systems, and enable better monitoring of epilepsy within health information systems.



Community durbar in Ghana to create community awareness about epilepsy; Photo: Ghana team
Copyright: MOH/GHS/Dr. A. Osei

"Epilepsy. Treat it. Defeat it."

Epilepsy is treatable with inexpensive and effective medication, and in most cases, people receiving treatment can lead a normal life. The slogan of the WHO Programme on Reducing the Epilepsy Treatment Gap reflects that treating epilepsy means not only defeating the disorder, but also defeating the stigma and inaccurate beliefs associated with it. Everyone has a role to play in treating and defeating epilepsy.

Overarching goals of the Programme

- Persons living with epilepsy have better access to essential treatment and the epilepsy treatment gap is reduced.
- There is increased awareness about epilepsy and less stigma associated with the condition.
- Persons living with epilepsy and their families have an improved quality of life.
- Policies for sustainability of the epilepsy programme are developed and implemented.

Specific objectives of the Programme

1. To strengthen policy and governance for delivery of epilepsy care and services.
2. To promote training of all professional health-care providers, making them competent in diagnosing and treating epilepsy.
3. To develop epilepsy information, education and communication campaigns to improve awareness among the public and community groups.
4. To integrate provision of care and services for epilepsy within the primary healthcare system.
5. To enhance the capacity to monitor and evaluate epilepsy care and treatment.



Ghana



In Ghana, it is estimated that 250,000 people live with epilepsy and the disorder is considered one of the top five burdensome medical problems in the country. Despite the fact that epilepsy is easily and affordably treatable, more than 85% of people with epilepsy in Ghana do not receive the treatment they need because of a lack of appropriately trained health service providers, difficulties accessing medicines and because epilepsy is highly stigmatized.

In 2012, and in collaboration with the Ghana Ministry of Health, the WHO Programme on Reducing the Epilepsy Treatment Gap in Ghana, entitled Ghana's Fight Against Epilepsy Initiative, commenced. Successful pilot projects were implemented in two districts, one in the Northern Region and the other in Ashiedu-Keteke sub-metro, located in the Greater Accra Region. Since then, Ghana has continued to scale up the project to include another nine more districts from three additional regions. As of 2014, the project covers more than 1.15 million people.

After adapting mhGAP resources to local needs, healthcare providers, including physicians, nurses and midwives, have been trained in epilepsy management. Additionally, regular meetings with community leaders have been held in participating districts to increase public awareness about epilepsy and its medical treatment. Awareness raising materials, such as posters, pamphlets and flyers have also been developed.

In Ghana, stigma and discrimination are major obstacles for the early identification, treatment and social integration of people with epilepsy: a large majority of the population believes epilepsy is caused by evil spirits. Because of this the Ghana project team have also included traditional and faith healers in their model of care, since they are often the first port of call for epilepsy care. The project team have invested time into increasing the understanding of epilepsy and its medical nature within communities with great success.

Since availability of antiepileptic medicines remains an issue in community health facilities, the Ghana team have been working to create a consistent, sustainable supply of essential antiepileptic medicines throughout its districts. This includes the development of national epilepsy guidelines and integrating epilepsy care within the national mental health care framework. Monitoring and evaluation of the project began in 2014.

Ghana: A Calling to Treat Epilepsy

Thirteen years ago, Stephen Kontoh got a call. But this was no ordinary call: it was a call from God to become a spiritual leader. So he stopped farming cocoa and selling timber and became a faith healer who treats people with physical, mental and spiritual ailments.

Today, Stephen oversees all faith healers in three districts of Ghana's Central Region. He runs a prayer camp in Kotokye, Central Ghana, where he sees people with various illnesses. He claims to heal people who have had strokes, have problems with alcohol consumption, diabetes, infertility, and other health issues. It is said he even cures blindness.

Stephen's prayer camp is only 20 metres away from a community health clinic where the Programme on Reducing the Epilepsy Treatment Gap is being implemented by Ghana Health Services and WHO. As part of the project, several community volunteers who work at the health clinic have been trained to raise awareness about epilepsy and support people living with it.

Kotokye's top faith healer has become involved in the initiative, learning that epilepsy is a non-contagious, chronic brain disorder that requires treatment with antiepileptic medications. Stephen now refers people with epilepsy from his prayer camp to the nearby community health clinic, and is an example of how educating traditional and faith healers can help reduce stigma and discrimination against people with epilepsy.



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Mozambique



In Mozambique, it is estimated that 260,000 people live with epilepsy and that approximately 85% of people living with epilepsy do not receive the treatment they need. The WHO Programme on Reducing the Epilepsy Treatment Gap in Mozambique, entitled Mozambique's Epilepsy Programme was initiated in 2013. It is coordinated by WHO and managed by the Mozambique Ministry of Health. As of 2014, the project covers approximately 3.4 million population in five provinces: Gaza, Nampula, Niassa, Sofala and Zambezia.

The Mozambique team have translated & adapted mhGAP training manuals for the training of doctors, nurses, midwives and psychologists. This has better equipped district clinics identify, diagnose and treat people living with epilepsy. mhGAP resources have also been adapted for use at community leader and volunteer training sessions, which have been carried out at each province. Traditional and faith healers, as well as religious leaders from the Christian, Hindu and Muslim faiths, have been involved in many of the trainings and educational sessions, and can now identify and refer people they believe may be living with epilepsy to medical services for treatment.

Stigma and discrimination not only prevent people with epilepsy from seeking treatment but can also prevent them from leading meaningful lives. A number of community awareness activities and products have been developed by the Mozambique team, including an epilepsy education booklet, brochures, fact sheets, and flyers. These have been disseminated to people living with epilepsy, medical clinics, the general public, traditional and faith healers, NGOs and schools.

Mozambique have strengthened policies and systems related to the supply of medications across the country; this has included many antiepileptic medications. Similarly, the Mozambique team have advocated for many antiepileptic medications to remain on the country's essential medicines list. This has led to improvements in medication availability and distribution, so people living with epilepsy can now access antiepileptic medicines at community clinics and rural areas. Drafting of a national epilepsy care model is under-way, which will integrate epilepsy care within mental health services at the primary health care level. Monitoring and evaluation of the project began in 2015.

Mozambique: The Journey to Epilepsy Care and Treatment

In a country where more than one quarter of a million people live with epilepsy, seeking and receiving care and treatment for the condition can be a long and complex journey. Maria Augusta Alves Vilas Boas, a nurse at the Ituculo Health Centre, in Monapo district of Nampula province in Mozambique, has witnessed this journey for over 6 years.

Epilepsy care was part of Maria Augusta's study curriculum to become a nurse in Portugal and she completed an internship in a psychiatric hospital. She feels confident to diagnose and treat the condition. The last time the district's health care facilities had antiepileptic medicines available, she was able to provide care for people with epilepsy even without the support of a psychiatric technician.

Most of the time, however, antiepileptic medicines are not readily available in public health centres in Mozambique. The absence of basic medication in the public sector prevents health care providers like Maria Augusta from prescribing conventional medicine, or in some cases even drives them to discredit the effectiveness of the same. Maria Augusta also knows that when medication is available, many patients often do not take it regularly as prescribed.

A lack of antiepileptic medicines is not the only challenge Maria Augusta faces in Mozambique's official healthcare system. Too often, she has seen parents of children with epilepsy turn to medical care only when traditional healers either failed to improve their child's condition or worsened it. Why? In Mozambique, many people think epilepsy is the result of witchcraft.

The Mozambique Epilepsy Programme team, part of the WHO Programme on Reducing the Epilepsy Treatment Gap, has therefore involved traditional and faith healers and religious leaders from the Christian, Hindu and Muslim faiths in the initiative. The project team is also training healthcare workers and advocating for an improved scheme that will ensure the regular availability of basic antiepileptic medicines. This means that nurses like Maria Augusta, and other health care providers, will be able to offer safe and effective epilepsy treatment in the future, improving the journey to health of people with epilepsy in Mozambique.



Copyright: MOH/L. Gouveia

Myanmar



Epilepsy is one of the most common neurological disorders in Myanmar and ranks third among the neurological diseases seen in tertiary health centers. The Myanmar Hope for Epilepsy Initiative is a collaboration between the WHO Programme on Reducing the Epilepsy Treatment Gap and the Myanmar Ministry of Health.

After initiating the project in two pilot townships, Hlegu and Hmawbi, in 2013, the project has expanded to an additional three townships: Lewe township in the Nay Pyi Taw region, and Thanlyin and Kawhmu townships in the Yangon region. The Myanmar Ministry of Health has approved plans for further project expansion in 2015, with the township of Nyaungdon in the Ayeyarwady region, and the townships of Thaton and Kayikhto in the Mon region having been chosen. A particular aim of the 2015 scale up will be to link and integrate the project with non-communicable disease programs already established in these areas. This expansion will take the project beyond the original pilot regions of Nay Pyi Taw and Yangon, and cover a total population of approximately 1.4 million.

The Myanmar project team have developed two manuals for the clinical management of epilepsy in Myanmar. These manuals have been integrated into medical officer, nurse and community volunteer trainings which have been conducted at each participating township to diagnose, treat and follow-up people living with epilepsy. Voluntary health workers have been trained to recognize epilepsy and play an active advocacy role in the community, including regularly meeting with people living with epilepsy, their families, and the general public. Communications materials, including posters, brochures and videos have been developed with the purpose of raising awareness about epilepsy within communities and reducing stigma surrounding epilepsy. A national epilepsy day has also been created to promote awareness across the country each year.

Myanmar's approach has involved liaison and advocacy to amend policies and increase the availability and accessibility of antiepileptic medications. This has included provisions for the local production of phenobarbital within Myanmar. The Myanmar project team remains committed to working with government and other partners towards scaling up the project nationally, to ensure access and sustainability of care for all persons living with epilepsy within Myanmar. Monitoring and evaluation of the project began in 2015.

Myanmar: Ma Nwe Nwe: Wishing They Had Known Earlier...

Ma Nwe Nwe Yee works in a Buddhist nunnery near the little village of Bo Daw Na Gone in Hlegu Township, Myanmar. She helps the nuns with their chores so she can pay for her daily antiepileptic medication.

The 18-year-old orphan has been suffering from epilepsy since childhood. She was forced to leave primary school because of her frequent seizures, memory loss and learning difficulties, and she has stayed at home with her grandmother ever since. Ma Nwe Nwe's grandmother tried many of the traditional healing methods but none of them helped her granddaughter. The seizures continued, and so did the isolation.

Last year, Ma Nwe Nwe's life changed radically. On a field visit to Hlegu Township to raise awareness about epilepsy, medical students met the orphan. They referred her to a nearby health facility, where she was enrolled in the Myanmar Epilepsy Initiative, part of the WHO Programme on Reducing the Epilepsy Treatment Gap, and prescribed daily antiepileptic medication.

Ma Nwe Nwe's seizures have decreased considerably since she started her daily medication. Had she and her grandmother known about epilepsy and had the seizures been medically treated earlier, Ma Nwe Nwe could have continued her schooling and created a better life with her grandmother.

Although Ma Nwe Nwe's health has improved, she still struggles: Myanmar does not have a health insurance scheme and her work at the nunnery barely covers the cost of her daily medication.



Viet Nam



In Viet Nam, it is estimated that 350,000 people live with epilepsy. Despite the fact that epilepsy is easily and affordably treatable, more than 75% of people living with epilepsy in Viet Nam do not receive the treatment they need because of a lack of trained health staff, difficulties accessing medications, and because epilepsy is highly stigmatized.

Having commenced in 2012, the Viet Nam's "Fight Against Epilepsy Initiative" is a collaboration between WHO and the Viet Nam Ministry of Health. Pilot project provinces have included Ban Ninh, Hung Yen and Phu Tho and a total population coverage of 2.9 million. Further scale up is planned for 2015 to include the Ha Nam province.

The process used to implement the project has required regular advocacy meetings between WHO, the Ministry of Health and provincial psychiatrists to explain the project model in depth and demonstrate how non-specialist health care providers can help reduce the workload of specialist health care providers.

In Viet Nam, stigma and discrimination are major obstacles for the early identification, treatment and social integration of people with epilepsy. Therefore, project activities have included communications and education sessions about epilepsy. Health care workers have been trained to educate patients and communicate with them effectively and compassionately, and conduct community meetings in an effort to raise awareness about epilepsy among the general public.

Viet Nam's approach includes extensive work on the development of guidelines and frameworks, including the integration of the project with established non-communicable disease programmes. Similar to other country approaches, there is a major focus on training health care workers in epilepsy management. This capacity-building of human resources helps to ensure the sustainability of the project. Monitoring and evaluation of the project began in 2014.

Viet Nam: Improving Epilepsy Awareness and Care

Epilepsy can be caused by a number of health problems, such as genetic factors, brain damage caused by infection, complications at birth, brain injury, parasites, alcohol or other substances. More often than not, however, epilepsy does not have a visible or identifiable cause. In many places in Viet Nam, the existence of such a spontaneous and invisible condition is explained by beliefs of ghostly influences, or madness. These superstitious beliefs and other myths, for example that epilepsy is contagious and hereditary, are important causes of stigma, which has serious social repercussions.

Dr Tran Quy Tuong is Deputy Director of the Medical Service Administration at the Viet Nam Ministry of Health, and a staunch advocate for mental and neurological health. “The Ministry of Health has long been motivated to help combat the superstitions surrounding epilepsy and address the country’s epilepsy treatment gap”, states Dr Tuong. “Fifteen years ago, epilepsy was identified as one of the top two priorities in a nation-wide programme to address mental health and neurological disorders. Today, most people with epilepsy in Viet Nam are able to access treatment if they live in large urban areas, which are served by central or provincial level healthcare facilities”.

However, a challenge remains in rural areas, where people with epilepsy are still frequently not diagnosed or treated at the commune health stations, district health centres or district hospitals, because of a lack of qualified health professionals. It is often in these areas where myths about epilepsy and discrimination towards people with epilepsy are most persistent.

The Viet Nam Ministry of Health are committed to bringing greater understanding about epilepsy and increasing epilepsy management capacity at the district and commune levels. Collaborating with WHO as part of the WHO Programme on Reducing the Epilepsy Treatment Gap, a new approach for epilepsy is being carried out and will provide evidence for the Ministry of Health to change strategies for epilepsy management.

To dissipate the belief that people with epilepsy are possessed by ghosts, healthcare providers have been trained not only on the management of epilepsy, but also on how to communicate about epilepsy in their communities. They are engaged in distributing information and communication materials to communities at district and commune levels.

“Local government also plays a big role in engaging the community, raising awareness and providing social support to families and patients with epilepsy”, says Dr Tuong. By raising awareness about epilepsy at the community level, discrimination against people with epilepsy may become a thing of the past.

Reducing the Epilepsy Treatment Gap: What You Can Do

The objective of the Global Information Kit on Epilepsy is to provide easy-to-understand information about epilepsy to key stakeholder groups. While information is important to increase knowledge, *actionable* information is critical to effect sustainable change. This “What you can do” section offers concrete, practical actions for policymakers, specialist and non-specialist health care providers, people with epilepsy and their families, NGOs and the general public.

Some of the suggested actions are simple and can be taken at the individual level, whereas others require collective involvement. When undertaken, all the actions reflect a commitment to defeating epilepsy and reducing the unacceptable and preventable treatment gap. WHO invites international, regional, national and local partners from within the health sector and beyond to engage in, and support, the implementation of WHA68.20 actions and will continue to lead and coordinate support for countries in addressing the global burden of epilepsy.

What You Can Do

Information for Policymakers

Epilepsy is a serious public health issue that imposes an enormous physical, psychological, social and economic burden on individuals, communities and countries. This burden is in part due to stigma and discrimination directed at people with epilepsy and their families, preventing them from being educated, working and impeding their overall quality of life and productivity. Available and accessible, treatment for epilepsy is cost-effective and can be provided within the existing healthcare system of any country.

Strong policies and orchestrated support can set the foundations that effectively and sustainably help reduce the epilepsy treatment gap.

As a policymaker, this is what you can do:

- Consider undertaking a situation analysis to find out more about the burden of epilepsy and the health service needs for epilepsy care in your country.¹
- Integrate epilepsy management into primary health care in your country. In order to help reduce the epilepsy treatment gap, non-specialist health care providers should be trained and supported so that epilepsy can be diagnosed and treated in primary health care settings.
- Formulate, strengthen and implement effective and inclusive national health policies and legislation that protect the human rights of people with epilepsy. Ensure that local and national stakeholders, including people with epilepsy and their families, become involved in these policymaking plans.
- Carry out strategies to make antiepileptic medicines more available, accessible and affordable.
- Strengthen health information and surveillance systems to better capture data on epilepsy in your country.
- Implement the WHO Programme on Reducing the Epilepsy Treatment Gap in your country by first piloting it in a particular area and then scaling up nationally. Contact WHO to talk about how you can implement the Programme in your country.

What will you do today?

1) Tools for conducting training in epilepsy management, situation analysis, awareness-raising about epilepsy, and monitoring and evaluation are available from WHO upon request.

What You Can Do

Information for Specialist and Non-Specialist Health Care Providers

With appropriate training and supervision it is possible for non-specialist health care providers to manage epilepsy in primary care settings. This helps to shift the burden of epilepsy away from specialists and hospitals, and back into the community where health facilities are more accessible. It is important to recognize that all health service providers have an essential role to play in bringing treatment to the millions of people with epilepsy.

As a non-specialist health care provider, this is what you can do:

- Learn more about epilepsy and the associated burden in your community.
- Identify and collaborate with other health care providers or community groups who can help advocate for and support people with epilepsy.
- Request and participate in training on epilepsy management if you do not feel confident assessing and treating epilepsy.
- Advocate to administrators and policymakers for the integration of epilepsy treatment and care into the primary healthcare system of your region or country.

As a specialist health care provider, this is what you can do:

- Help increase awareness and reduce stigma about epilepsy by participating in events that increase community awareness, for example school visits or community gatherings.
- Train and supervise non-specialist health care providers to diagnose, treat and follow-up people with epilepsy, including when to refer if necessary.
- Advocate to high-level policymakers for increased access to treatment for people with epilepsy, including making essential antiepileptic medicines available through the national health insurance system.

What will you do today?

What You Can Do

Information for People with Epilepsy and Their Families

Epilepsy is a medical condition that can be treated in most cases. Having epilepsy is not shameful; people with epilepsy have the same range of abilities as anyone else and can lead meaningful lives.

Unfortunately, many people don't yet understand that epilepsy is a non-contagious medical condition that can affect anyone, and which is not caused by evil spirits or curses. People with epilepsy can be productive members of the community, and can work, get married and have happy, healthy families.

As a person with epilepsy or a family member of a person with epilepsy, this is what you can do:

- If you have epilepsy, seek treatment. In most cases, epilepsy is easily and affordably treated with daily oral antiepileptic medicines.
- Learn more about epilepsy and talk to your health care provider about available treatments and support groups.
- Find out if there are community support groups or NGOs near you who can help you learn more about epilepsy and provide support. You can also ask a health-care provider to give you information about these groups.
- Ensure that your family can help and support you. Talk to them about what you've learned about epilepsy and ask them to talk to healthcare providers or community groups for support.
- Find out if there are other people with epilepsy who live near you, and how you can support each other. Consider starting your own support group and become a champion for epilepsy awareness! You can also reach out to NGOs and ask them to help you raise awareness and reduce stigma about epilepsy in your community.

What will you do today?

What You Can Do

Information for Nongovernmental Organizations (NGOs)

The lack of understanding around epilepsy causes unnecessary suffering for people living with epilepsy and their families. NGOs and other community groups can help relieve this suffering by providing information and support to people with epilepsy and their families, and by raising awareness about the disorder in their communities.

As an NGO, this is what you can do:

- Get informed. Learn more about epilepsy and the associated burden in the communities you work in. Learn more about the WHO Programme on Reducing the Epilepsy Treatment Gap and how it might help.
- Help reduce stigma by organizing education and awareness-raising activities for the community and health service providers.
- Implement support programmes to help people with epilepsy and their families to be fully integrated into the community, including in professional and social capacities.
- Activate your networks and lobby administrators, policymakers and other stakeholders to learn more about epilepsy and establish appropriate national policies.

What will you do today?

What You Can Do

Information for the General Public

Epilepsy is the most common serious brain disorder worldwide and can affect anyone. Epilepsy is not contagious.

People with epilepsy are normal people whose brain, for a variety of medical reasons, has unusual electrical activity that causes physical symptoms and seizures. People with epilepsy and their families should be included in the community and recognized as contributing members of society. By learning more about epilepsy, you can help reduce the misunderstandings about the condition and the discrimination that is directed towards people with epilepsy and their families.

As a member of the general public, this is what you can do:

- Learn more about epilepsy. You can go to page 9, the WHO website² or talk to a trained health care provider at your community medical facility.
- Lobby administrators, policymakers and other community members to learn more about epilepsy and the WHO Programme on Reducing the Epilepsy Treatment Gap.
- Help reduce stigma by talking openly about the facts of epilepsy with your family, friends and community, and by supporting people with epilepsy to attain the highest possible quality of life.
- Get involved with epilepsy-focused community groups or NGOs to support their advocacy efforts.

What will you do today?

2) <http://www.who.int/topics/epilepsy/en/>

The WHO Programme on Reducing the Epilepsy Treatment Gap: Implementation Approach

Building on previous WHO collaborative projects and the evidence-based methods of the WHO Mental Health Gap Action Programme (mhGAP), the WHO Programme on Reducing the Epilepsy Treatment Gap is showing great promise in increasing access to treatment for hundreds of thousands of people living with epilepsy.

If you want to reduce the epilepsy treatment gap in your country and help improve the quality of life of people living with epilepsy, you can also implement the WHO Programme on Reducing the Epilepsy Treatment Gap.

Method

The overarching goal of the WHO Programme on Reducing the Epilepsy Treatment Gap is to improve the quality of life of patients living with epilepsy and their families and assist in reducing the epilepsy treatment gap. The foundations for project implementation and its activities are built on the following components:

Get started

Identify the burden of epilepsy in your country context, as well as the key stakeholders who will need to be contacted and engaged. Critically consider the overarching objectives for the project:

1. To strengthen policy and governance for delivery of epilepsy care and services;
2. To promote training of health care providers, making them competent in diagnosing and treating epilepsy;
3. To develop epilepsy information, education and communication campaigns to improve awareness among the public and community groups;
4. To integrate provision of care and services for epilepsy within the primary health care system; and
5. To enhance the capacity to monitor and evaluate epilepsy care and treatment.

A) Gather information and conduct a situation analysis

A situation analysis provides a thorough understanding of the needs and resources available related to epilepsy in the country, and the coverage and quality of essential treatment. It helps identify any strengths and weaknesses of the current system and any barriers to expanding services. Human, financial and material resources will also be identified. Normative situation analysis templates are available from WHO for national, regional, district and facility level analyses. It is encouraged that these templates be adapted to the local context in which they are being used.

B) Form a national coordination committee

A national coordination committee takes on various responsibilities related to the implementation of the project. Examples of committee members include: Ministry of Health representatives, neurology or mental health specialists, WHO Country Office representatives, and Chief Pharmacists or Medical Officers. The committee uses consensus building and participatory processes to make decisions.

C) Develop an action plan

An action plan should be developed at the beginning of the project to outline the overarching activities and timelines, including which areas of the country will pilot the project. Updated and detailed action plans should also be developed periodically, for example annually, to guide the yearly activities and progress. The action plan should reflect the overall objectives of the project, should be reviewed regularly, and adapted if necessary.

D) Adapt and prepare to use normative protocols and tools for implementation of activities

A number of normative tools and protocols have been developed by WHO to facilitate various country-specific activities and are available for free. These include training materials for epilepsy management; a communications strategy to enhance visibility of the project and awareness-raising; and a monitoring and evaluation toolkit for assessing epilepsy care and treatment. These can be adapted to the local context or used as examples in the development of new tools and protocols.

E) Build national capacity through training

Training in the WHO Programme on Reducing the Epilepsy Treatment Gap is carried out in three tiers.

- Training is conducted with neurologists and mental health specialists to become “trainers” and “supervisors” for non-specialist health care providers, for example general physicians or nurses.
- Training of the non-specialists in epilepsy management is carried out, to improve the delivery of epilepsy services and care in primary health care facilities.
- Training of community-based health workers, community groups and volunteers is conducted to provide them with skills to recognize, refer and support people with epilepsy and their families.

Training and reference materials have been developed by WHO for all three tiers of training and are freely available upon request. The technical aspects of each training are based on the WHO mhGAP Intervention Guide for Mental, Neurological and Substance Use Disorders (mhGAP-IG).

F) Raise awareness

A main barrier to reducing the epilepsy treatment gap in low- and middle-income countries has been the stigma that surrounds the condition. Therefore, raising awareness and educating the public about epilepsy remains a key priority. This includes learning more about people's current attitudes and knowledge about epilepsy, developing key messages which address any knowledge gaps, and creating communication materials that are pointed, relevant, and practical for use by their intended audiences. Engagement with stakeholders at international, national, and local levels is also critical to ensuring the sustainability of the Programme.

G) Strengthen the health system

Several actions should be taken to help strengthen the health system to improve provision of epilepsy care. National policies and legislation should be reviewed to include consideration of care for people living with epilepsy, and should be formulated, strengthened and implemented to promote and protect the rights of people with epilepsy. Activities to support the availability of a strong and functional referral system should be carried out. Strategies should be formulated and implemented to make antiepileptic medicines more available, accessible and affordable. Health information and surveillance systems should be strengthened to ensure the collection, routine reporting, and analysis of epilepsy data.

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Contact information

Department of Mental Health and Substance Abuse
World Health Organization
Avenue Appia 20
CH-1211 Geneva 27
Switzerland

Email:
mhgap-info@who.int

Website:
www.who.int/mental_health/neurology/epilepsy/en/

