

EPILEPSY

A public health imperative

SUMMARY



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EPILEPSY

A public health imperative



Foreword

Epilepsy is one of the most common neurological diseases worldwide, affecting around 50 million people of all ages around the world. The risk of premature death in people with epilepsy is up to three times that of the general population. The lives of people with epilepsy are often impacted by stigma, discrimination and human rights violations.

We know that while 80% of people with epilepsy live in low- and middle-income countries, most of them do not have access to treatment. This is despite the availability of effective antiseizure medicines, which can cost as little as US\$ 5 per year. A lack of action to address the epilepsy treatment gap has dire consequences for people's lives and well-being, and impacts social and economic development.

This report presents encouraging evidence that almost a quarter of epilepsy cases are preventable and 70% of people with epilepsy can live seizure free with low-cost and effective medicines. As evidence from multiple countries shows, it is feasible to integrate epilepsy into primary health care and thereby ensure that all people with epilepsy have access to quality and affordable treatment and services.

If we are to achieve the health-related Sustainable Development Goals (SDGs), it is imperative that we substantially scale up global efforts to address epilepsy. The SDGs include the targets of reducing premature deaths from noncommunicable diseases and promoting mental health and well-being; as well as achieving universal health coverage with access to quality services and effective, affordable essential medicines. The importance of addressing epilepsy was also underlined in a World Health Assembly (WHA) resolution on the global burden of epilepsy in 2015. The resolution requests that WHO provide technical support to countries for epilepsy management, especially those with the lowest access to services and resources, where the burden of epilepsy is greatest.

This is the first global report on epilepsy produced by WHO and key partners. It highlights the available evidence on the burden of epilepsy and the public health response required at global, regional and national levels. The report is also an important milestone in re-energizing and translating the WHA resolution into action as it provides guidance to governments, policy-makers and stakeholders as they seek to reduce the disease burden as part of the universal health coverage agenda.

I encourage all WHO Member States and partners to build on the findings and recommendations of this report and to share it widely.



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Preface

Epilepsy is a brain disease characterized by abnormal electrical activity causing seizures or unusual behaviour, sensations and sometimes loss of awareness. It carries neurological, cognitive, psychological and social consequences and accounts for a significant proportion of the world's burden of disease. Despite availability of effective and low-cost antiseizure medicines, more than 75% of people with epilepsy in low-income countries do not have access to treatment.

This report is the product of a long-standing collaboration between WHO and leading nongovernmental organizations working in the area of epilepsy, the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). Together we have made substantial progress in encouraging countries to prioritize epilepsy in public health agendas.

Epilepsy: a public health imperative presents a comprehensive picture of the impact that the condition has on people with epilepsy, their families, communities and societies. Epilepsy has a high risk of disability, psychiatric comorbidity, social isolation and premature death. Across the world, people with epilepsy and their families suffer from stigma and discrimination. Many children with epilepsy do not go to school; adults are denied work, the right to drive or marriage. The human rights violations faced by people with epilepsy around the world are unacceptable.

It is time to highlight epilepsy as a public health imperative, to strongly encourage investment in reducing its burden, and to advocate for actions to address gaps in epilepsy knowledge, care and research.

Raising epilepsy on the global public health agenda cannot be done alone. The adoption of the World Health Assembly resolution on epilepsy by Member States drew attention to the need for coordinated action at country level. The resolution provides a powerful tool to engage governments and civil society in taking concrete action to promote access to care and to protect the rights of people with epilepsy.

Epilepsy: a public health imperative is a call for sustained and coordinated action to ensure that every person with epilepsy has access to the care and treatment they need, and the opportunity to live free from stigma and discrimination in all parts of the world.



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Overarching messages



BURDEN

The burden of epilepsy is high and often neglected in public health agendas. Epilepsy is one of the most common neurological diseases, affecting nearly 50 million people of all ages around the world. The risk of premature death in people with epilepsy is up to three times that of the general population. Roughly half of adults with epilepsy have at least one other health condition. Psychiatric conditions, such as depression and anxiety, make seizures worse and reduce quality of life. Epilepsy has significant economic implications in terms of health care needs and lost productivity at work.



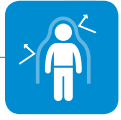
STIGMA AND DISCRIMINATION

In all parts of the world, people with epilepsy are the target of discrimination and human rights violations. The stigma of epilepsy can discourage people from seeking treatment and has consequences for quality of life and social inclusion. Improving knowledge and raising awareness of epilepsy in schools, work places, and communities is needed to reduce stigma. Legislation based on internationally accepted human rights standards can prevent discrimination and rights violations, improve access to health care services, and raise the quality of life for people with epilepsy.



TREATMENT GAP

Three-quarters of people living with epilepsy in low-income countries do not get the treatment they need. Yet, up to 70% of people with epilepsy could become seizure free with appropriate use of cost-effective antiseizure medicines. A significant proportion of the burden of epilepsy could be avoided by scaling up routine availability of antiseizure medicines, possible at an annual cost as low as US\$ 5 per person. It is feasible to integrate epilepsy treatment into primary health care – training nonspecialist providers, investing in continuous supplies of antiseizure medicines and strengthening health systems can substantially reduce the epilepsy treatment gap.



PREVENTION

An estimated 25% of epilepsy cases are preventable. The major modifiable risk factors for epilepsy are: perinatal insults, central nervous system infections, traumatic brain injury and stroke. Preventing epilepsy is an urgent unmet need. Effective interventions for prevention are available and delivered as part of broader public health responses in maternal and newborn health care, communicable disease control, injury prevention and cardiovascular health.



THE TIME TO ACT IS NOW

Sustained and coordinated action to prioritize epilepsy in public health agendas is required at global, regional and national levels. World Health Assembly resolution WHA68.20 on the global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications sets the framework for increasing investment in epilepsy. There is a pressing need for increased investment in research and to address the burden of epilepsy through integration in primary health care, ensuring that all people with epilepsy have access to quality and affordable care.

Executive summary

Introduction

Epilepsy is a brain disease characterized by abnormal brain activity causing seizures or unusual behaviour, sensations and sometimes loss of awareness. It carries neurological, cognitive, psychological and social consequences and **accounts for a significant proportion of the world's burden of disease, affecting around 50 million people worldwide**. The number of people with epilepsy is expected to increase further due to rising life expectancy worldwide and an increasing proportion of people surviving insults which often lead to epilepsy, such as birth trauma, traumatic brain injury (TBI), infections of the brain, and stroke. The physical, psychological and social consequences of epilepsy impose significant burdens on people living with the condition and their families. Around the world, people with epilepsy and their families suffer from stigma and discrimination, often facing serious difficulties in education, employment, marriage and reproduction. Nearly 80% of people with epilepsy live in low- and middle-income countries (LMIC), where treatment gaps exceed 75% in most low-income countries and 50% in most middle-income countries. This is despite the effectiveness and low cost of antiseizure medicines.

The Sustainable Development Goals (SDGs), which seek to achieve global economic, social and environmental sustainable development by 2030, will not be realized without investment in physical and mental health for all people, including those living with epilepsy. This report calls for accelerated action to highlight epilepsy as a public health priority and support investment in reducing the burden it places.

At the Sixty-eighth World Health Assembly (WHA) in 2015, 194 Member States unanimously adopted resolution WHA68.20 on epilepsy which called for the need for coordinated action at the country level to address its health, social, and public knowledge implications. The third High-level Meeting on the prevention and control of noncommunicable diseases (NCDs) in 2018 highlighted the importance of

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