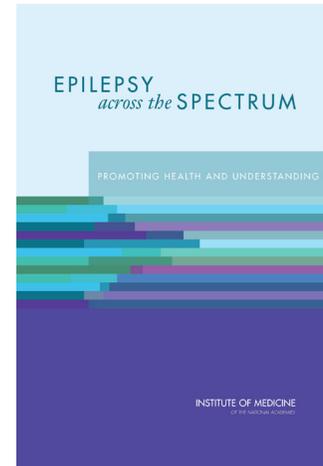


# Epilepsy Across the Spectrum

## Promoting Health and Understanding



**Epilepsy is the nation's** fourth most common neurological disorder, after migraine, stroke, and Alzheimer's disease; but public understanding of epilepsy is limited. For example, many people do not know the causes of epilepsy or what they should do if they see someone having a seizure. Epilepsy is a complex spectrum of disorders—sometimes called the epilepsies—that affects millions of people in a variety of ways and is characterized by unpredictable seizures that differ in type, cause, and severity. Yet living with epilepsy is about much more than just seizures. For people with epilepsy, the disorder is often defined in practical terms, such as challenges in school, uncertainties about social situations and employment, limitations on driving, and questions about independent living.

An estimated 2.2 million Americans have epilepsy, with approximately 150,000 new cases diagnosed in the United States each year. Approximately 1 in 26 people will develop epilepsy at some point in their lives, and the onset of epilepsy is highest in children and older adults.

The Institute of Medicine (IOM) was asked by 24 sponsoring federal agencies and nonprofit organizations to examine the public health dimensions of the epilepsies, focusing on public health surveillance and data collection; population and public health research; health policy, health care, and human services; and education for people with the disorder and their families, health care providers, and the public. The IOM committee presents recommendations to improve the lives of people with epilepsy in its report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*.

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## Close the Data Gap and Prevent Epilepsy

Data are lacking that could improve the lives of people with epilepsy, the committee concludes. Current data sources provide a patchwork of surveillance activity that, if coordinated and linked, could shed light on the full physical, psychological, social, and economic burdens of epilepsy and improve knowledge about its risk factors, associated health conditions, consequences, and health and community service needs. The committee calls for improved data collection on epilepsy to inform health policy and to identify opportunities for reducing the burden of the disorder (see Box).

Preventing epilepsy is possible for some causes of the disorder. Prevention efforts to reduce epilepsy's known risk factors, such as traumatic brain injury, stroke, and brain infections, will likely result in fewer new cases of epilepsy. Other opportunities exist to prevent the consequences of epilepsy, including interventions to improve seizure control in people who have both epilepsy and depression, to reduce internalized feelings of discrimination, and to eliminate epilepsy-related

causes of death, such as sudden unexpected death in epilepsy (SUDEP). The committee highlights the need for additional research, which will contribute to new insights and approaches to the prevention of epilepsy.

## Improve Health Care and Community Services

Progress has been made in developing new seizure medications and refining medical devices and surgical techniques to reduce or eliminate seizures for many individuals with epilepsy. However, referrals to specialized care are often delayed, and access to these treatments fall short, particularly for rural and underserved populations and for people with persistent seizures. The committee outlines steps to expand access to high-quality, patient-centered health care that include focusing on timely identification and treatment of epilepsy and its associated health conditions, implementing measures that assess quality of care, and establishing accreditation criteria and processes for specialized epilepsy cen-

### **BOX: Highlights from the Committee's Recommendations**

- Validation and implementation of standard definitions and criteria for epilepsy case ascertainment, health care and community services use and costs, and quality measurement
- Continuation and expansion of collaborative surveillance efforts
- Development and evaluation of prevention efforts for epilepsy and its consequences
- Improvement in the early identification of epilepsy and its comorbid health conditions
- Development and implementation of a national quality measurement and improvement strategy for epilepsy care
- Establishment of epilepsy center accreditation and an Epilepsy Care Network
- Improvement in health professionals' education about the epilepsies
- Improvement in the delivery and coordination of community services
- Improvement in and expansion of educational opportunities for patients and families
- Provision of information to media to improve awareness and eliminate stigma
- Coordination of public awareness efforts
- Continuation and expansion of Vision 20-20 working groups and collaborative partnerships
- Engagement of people with epilepsy and their families in education, dissemination, and advocacy for improved epilepsy care and services

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The wide variety of health professionals who care for those with epilepsy need improved knowledge and skills to provide high-quality health care. Building the health care workforce's knowledge base and skill sets in diagnosing, treating, supporting, and generally working with people with epilepsy is necessary to ensure that individuals and their families have access to high-quality, patient-centered care.

Living with epilepsy includes not only dealing with seizures and their impact on health, but also involves developing knowledge and skills to manage the psychological and social challenges and co-existing health conditions associated with the disorder, side effects of medications, and fears of discrimination and prejudice—all of which can significantly affect quality of life. In addition, people with epilepsy are at risk for premature death and SUDEP. At the same time, they are faced with health care and community services that are often fragmented, uncoordinated, and difficult to obtain.

Family members may struggle with how to best help their loved one and maintain family life. The committee recommends that community services and programs be bolstered to ensure that they meet the needs of people with epilepsy and their families, are easily accessible, and work closely with health care providers. These services should take a whole-patient perspective by providing a range of resources and services, including

support groups, vocational training, transitional care, assistance with independent living, and respite for caregivers.

### **Raise Awareness, Improve Education**

Education for people with epilepsy and their families plays an important role in adapting to life with epilepsy, developing self-confidence, and competently managing the disorder and its associated health conditions. The committee recommends that educational opportunities be expanded and improved through the evaluation and updating of epilepsy websites and educational resources, among other efforts designed to increase knowledge and skills relevant to living with epilepsy.

Public misperceptions and misinformation about epilepsy have persisted over centuries. Inaccurate or sensationalized depictions of people with epilepsy, often used for dramatic effect in the entertainment media, have reinforced negative perceptions. To raise public awareness and reduce stigma, ongoing efforts are needed, using clear messages and diverse activities targeted to specific audiences through multiple media, including social media and the Internet.

### **Strengthen Stakeholder Involvement**

Currently, a number of organizations are engaged in efforts to advance research, improve health care and human services for people with epi-



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### Vision 20-20 Sponsors

American Epilepsy Society  
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International League Against Epilepsy  
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Preventing Teen Tragedy  
Rasmussen's Encephalitis Children's Project  
Tuberous Sclerosis Alliance

lepsy and their families, and increase knowledge about the disorder. Vision 20-20, a collaborative effort of more than 20 nonprofit organizations and 3 federal agencies, focuses its actions on moving the epilepsy field forward. The committee urges further partnerships and expanded efforts by working groups within Vision 20-20.

Among the most persuasive advocates and educators are people with epilepsy and their family members. Individuals who are willing to speak out can provide a more complete picture of the disorder and its impact. While many people may be willing to play such a role, training and support will help them do so more effectively. People with epilepsy and their families also have the opportunity to advance knowledge about epilepsy and its treatment when they participate in clinical research, surveys, and other studies that investigate ways to improve care and increase understanding of how epilepsy affects individuals' lives.

## Conclusion

Given the current gaps in epilepsy knowledge, care, and education, the committee believes there is an urgent need to take action—across multiple dimensions—to improve the lives of people with epilepsy and their families. The committee provides research priorities to further develop the evidence base, and it recommends realistic, feasible, and action-oriented steps for a variety of stakeholders to enable short- and long-term improvements for people with epilepsy. 

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