

## Where to find more information

In writing this book, we reviewed many resources, published research, websites, and training guides. Here is a selection of epilepsy materials on education, care, and advocacy that we found helpful. Many are online and free to use.

To access this list of resources on Hesperian’s website, scan the QR code on the right with your mobile phone camera or use this link:

- [en.hesperian.org/hhg/Other\\_Resources:Epilepsy](https://en.hesperian.org/hhg/Other_Resources:Epilepsy)



### Hesperian’s online resources

Hesperian’s HealthWiki provides free access to our resources on many health topics, in many languages (see: [en.hesperian.org/hhg/HealthWiki](https://en.hesperian.org/hhg/HealthWiki)). After opening each page, click “In this chapter” to see related pages.

#### Disabled Village Children

Many children with disabilities also have epilepsy or seizures; and many children with epilepsy also have other disabilities. This book offers a broad understanding of many disabilities and how to help children where resources are limited.

- [bit.ly/disabled-village-children](https://bit.ly/disabled-village-children)

#### Promoting Community Mental Health

Explanations and tools that people can use to improve the emotional health of their communities, including information about stress, anxiety, depression, and trauma.

- [bit.ly/promoting-community-mental-health](https://bit.ly/promoting-community-mental-health)

#### Pocket First Aid

Provides basic first aid information covering a range of emergencies, including what to do if a person has a seizure.

- [bit.ly/pocket-first-aid](https://bit.ly/pocket-first-aid)

#### A Book for Midwives

Covers the essentials of care before, during, and after pregnancy and birth.

- [bit.ly/a-book-for-midwives](https://bit.ly/a-book-for-midwives)

### Helping Children Live with HIV

Includes information about child development and support for communicating with children of all ages.

- [bit.ly/helping-children-live-with-HIV](https://bit.ly/helping-children-live-with-HIV)

## Epilepsy organizations

**The International League Against Epilepsy (ILAE)** has chapters in 120 countries. Their website and newsletters provide up-to-date information on medical and social aspects of epilepsy. While the main language is English, information is available in many languages.

- [ilae.org](https://www.ilae.org)

**The International Bureau for Epilepsy (IBE)** has chapters throughout the world which focus on advocacy for social and legal rights for people with epilepsy.

- [ibe-epilepsy.org](https://www.ibe-epilepsy.org)

IBE also maintains a website focusing on women and epilepsy:

- [womenandepilepsy.org](https://www.womenandepilepsy.org)

There are many national, local, and special focus epilepsy organizations. Here are two listings you may find useful:

- [epilepsyfoundation.org.au/understanding-epilepsy/international-links](https://www.epilepsyfoundation.org.au/understanding-epilepsy/international-links)
- [ilae.org/patient-care/resources/links](https://www.ilae.org/patient-care/resources/links)

## General epilepsy information

### Epilepsy: A public health imperative (2019)

This World Health Organization (WHO) report, done in collaboration with the ILEA and the IBE, explores the impact of epilepsy worldwide and outlines public health actions needed to improve care.

- [who.int/publications/i/item/epilepsy-a-public-health-imperative](https://www.who.int/publications/i/item/epilepsy-a-public-health-imperative)

### **Intersectoral global action plan (IGAP) on epilepsy and other neurological disorders, 2022-2031**

This WHO document sets policy goals to improve access to epilepsy treatment and reduce epilepsy stigma internationally. It is accompanied by an implementation toolkit for people working to turn the plans into reality.

- [bit.ly/WHO-IGAP-document](https://bit.ly/WHO-IGAP-document)
- [bit.ly/WHO-IGAP-toolkit](https://bit.ly/WHO-IGAP-toolkit)

### **Free Access Epilepsy Journals**

Many medical sources with research and information about epilepsy are very expensive to read. The 10 scientific journals listed on this website are free for everyone to read, although some may be difficult to understand.

- [gfmer.ch/Medical\\_journals/epilepsy.htm](https://gfmer.ch/Medical_journals/epilepsy.htm)

## **Seizure first aid**

### **Seizure first aid videos**

From the British Red Cross:

- [bit.ly/BRC-seizure-first-aid-video](https://bit.ly/BRC-seizure-first-aid-video)

From the Apollo hospital group in India:

- [bit.ly/Apollo-seizure-first-aid-video](https://bit.ly/Apollo-seizure-first-aid-video)

### **Seizure first aid posters**

Downloadable posters with simple, step-by-step guidance in multiple languages.

- [epilepsy.com/tools-resources/forms-resources/first-aid](https://epilepsy.com/tools-resources/forms-resources/first-aid)

### **Online seizure first aid training**

An on-demand seizure first aid training designed for school settings but appropriate for anyone seeking to learn the basics of epilepsy and how to recognize and respond to a seizure. From Epilepsy Alliance America.

- [bit.ly/online-seizure-first-aid-training](https://bit.ly/online-seizure-first-aid-training)

## Identifying seizure types

### Epilepsy and Seizures

Developed by the US National Institutes of Health, this resource explains the different seizure types and includes information on childhood epilepsy, nonepileptic seizures, treatments, and more.

- [ninds.nih.gov/health-information/disorders/epilepsy-and-seizures](https://ninds.nih.gov/health-information/disorders/epilepsy-and-seizures)

### Types of Seizures

An explanation of the new ILAE system for classifying types of seizures designed to support better recognition and management of epilepsy and seizures. For medical professionals.

- [epilepsy.com/what-is-epilepsy/seizure-types](https://epilepsy.com/what-is-epilepsy/seizure-types)

### Psychogenic Nonepileptic Seizures (PNES)

A set of resources on seizures not caused by epilepsy, with links to articles, webinars, books, and films for patients, families, and health professionals. The FAQs (Frequently Asked Questions) are available in both English and Spanish.

- [nonepilepticseizures.com/epilepsy-psychogenic-nes-reading-materials](https://nonepilepticseizures.com/epilepsy-psychogenic-nes-reading-materials)

## Advocacy tools

### IBE Advocacy Toolkits

Guidance, ideas, and inspiration for organizations working to:

Make Epilepsy a Priority in Africa:

- [bit.ly/IBE-toolkit-Africa](https://bit.ly/IBE-toolkit-Africa)

Make Epilepsy a Priority in the Americas:

- [bit.ly/IBE-toolkit-Americas](https://bit.ly/IBE-toolkit-Americas)

Reduce Epilepsy Stigma in Africa:

- [ibe-epilepsy.org/stigmatoolkitafrika](https://ibe-epilepsy.org/stigmatoolkitafrika)

### The Community Health Worker's Training Curriculum for Epilepsy Self-Management

Developed by the Managing Epilepsy Well Network to train CHWs with some medical knowledge to support people with epilepsy in community settings.

- [managingepilepsywell.org/community-health-worker](https://managingepilepsywell.org/community-health-worker)

### **The Curse of Stigma (video)**

A documentary film that shares stories of living with epilepsy and the pain, isolation, and harm suffered because of discrimination and deeply-embedded cultural beliefs.

- [thecurseofstigma.org](http://thecurseofstigma.org)

### **What's Wrong with How We See Epilepsy**

This short article reviews and counters 10 harmful myths about epilepsy.

- [bit.ly/whats-wrong-with-how-we-see-epilepsy](http://bit.ly/whats-wrong-with-how-we-see-epilepsy)

## **Living well**

### **Exercise and epilepsy: Research and myths (audio)**

An ILAE podcast episode that discusses current research and myths about exercise for people with epilepsy.

- [bit.ly/ILAE-podcast-research-and-myths-exercise](http://bit.ly/ILAE-podcast-research-and-myths-exercise)

### **Self-Management Tools**

These resources from the Managing Epilepsy Well Network explain epilepsy self-management as a team effort between the person with epilepsy, their family and friends, and doctors.

- [managingepilepsywell.org/patients-families-nav](http://managingepilepsywell.org/patients-families-nav)

### **Ketogenic Diet Explained**

The Charlie Foundation promotes ketogenic diets to treat epilepsy and other conditions. This webpage explains how and why a ketogenic diet helps control seizures for some people.

- [charliefoundation.org/learn-about-ketosis](http://charliefoundation.org/learn-about-ketosis)

### **Peer support groups by and for people with lived experience**

A WHO booklet to guide you in setting up and running a peer support group.

- [bit.ly/WHOresource-list](http://bit.ly/WHOresource-list)

## **Pregnancy and birth**

### **Epilepsy and Pregnancy Medical Consortium**

This organization's website provides helpful, regularly updated information and links useful for people with epilepsy and for their doctors and midwives.

- [epilepsypregnancy.com](http://epilepsypregnancy.com)

### **Pregnancy and Epilepsy (video)**

A video produced by Epilepsy Action in the UK to answer common questions about epilepsy and pregnancy.

- [epilepsy.org.uk/living/starting-a-family/pregnancy-birth-and-epilepsy](http://epilepsy.org.uk/living/starting-a-family/pregnancy-birth-and-epilepsy)

### **Women and Epilepsy**

Hosted on the IBE website, these resources address multiple issues faced by women with epilepsy, including information about pregnancy.

- [womenandepilepsy.org](http://womenandepilepsy.org)

## **Children and young people**

### **Anti-Bullying Poster**

Children for Health's free, downloadable anti-bullying poster.

- [childrenforhealth.org/sdm\\_downloads/anti-bullying-poster](http://childrenforhealth.org/sdm_downloads/anti-bullying-poster)

### **Teacher Tool Kit to Promote Well-being in Students with Epilepsy**

This Canadian resource for teachers includes 2 videos (English) and 2 booklets (in 6 languages) that explain what epilepsy is, how it affects school achievement, and use of emergency medicines.

- [epilepsyswo.ca/teacher-toolkit](http://epilepsyswo.ca/teacher-toolkit)

### **Improving the management of prolonged convulsive seizures for children in schools: An advocacy toolkit**

An IBE guide, including videos and checklists, to support schools to develop policies that promote inclusion for children with epilepsy.

- [ibe-epilepsy.org/advocating-better-epilepsy-management-schools](http://ibe-epilepsy.org/advocating-better-epilepsy-management-schools)

### **La Historia de Juanito/ Juanito's Story (video)**

This Chilean video (Spanish, with subtitles in many languages) of a puppet show educates about epilepsy, how to help during a seizure, and dispels fears and myths to promote understanding and support.

- [bit.ly/la-historia-de-juanito-video](http://bit.ly/la-historia-de-juanito-video)

### **My Thinking Cap: A Coloring Book about Epilepsy**

Massachusetts General Hospital produced this free, downloadable coloring book to help children understand how the brain works and what an EEG is.

- [bit.ly/epilepsy-coloring-book](http://bit.ly/epilepsy-coloring-book)

### **Seizures and Epilepsy in Children: A Comprehensive Guide, 4th edition**

This comprehensive, parent-focused book covers the practical, emotional, physical, and psychological aspects of epilepsy, including medicines, side effects, testing, diets, and digital resources. Your local library may have a copy.

- [bit.ly/seizures-and-epilepsy-in-children-4th-edition](https://bit.ly/seizures-and-epilepsy-in-children-4th-edition)

### **Warriors of Light: Kids Yoga in Color (videos)**

These 20 short videos show age-appropriate yoga techniques for self-calming through fun exercise, meditation, and relaxation.

- [bit.ly/kids-yoga-in-color](https://bit.ly/kids-yoga-in-color)

## **Violence**

### **Violence in a Structural and Cultural Context (video)**

Emory University produced this 7 ½ minute talk to discuss structural and cultural violence.

- [bit.ly/violence-in-context-video](https://bit.ly/violence-in-context-video)

### **Violence and injury (VIP) short courses**

WHO offers these free, short (2 to 5 day) trainings-in-a-box that facilitators and trainers can deliver on violence and injury topics, such as child injury prevention, intimate partner and sexual violence prevention, and trauma care.

- [bit.ly/WHO-VIP-courses](https://bit.ly/WHO-VIP-courses)