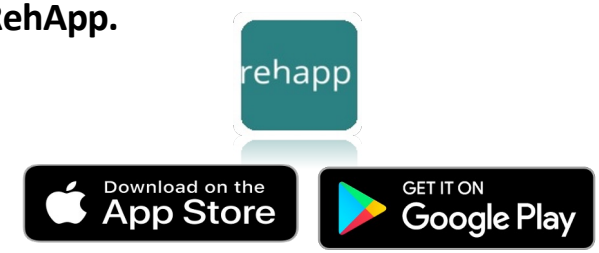
# Flashcards Epilepsy



- **These flashcards contain information about working with people with Epilepsy in low resource areas.**
- **These Flashcards are made for the use of fieldworkers.**
- **These flashcards are based on the information about Epilepsy from the RehApp.**




**The goals of the flashcards are:**

- To meet the needs of people with disabilities and their families.
- To improve knowledge and skills of fieldworkers in providing basic (functional) rehabilitation services for people with disabilities and their families.
- To enhance participation in daily, family and community life.
- To improve the quality of life of people with disabilities and their families.
- To support you (as fieldworker) in the process of guiding a family by providing you with a resource you can keep with you on your phone (offline) or in your bag.

**What can you do with these flashcards:**

- To help guide your visits to families that have a family member with Epilepsy.
- Make an inventory of the needs of the person with Epilepsy and his/her family.
- Learn about the implications of a disability for the person and their family.
- Use them to do an assessment.
- Use them to set goals for a person with Epilepsy.
- Use them to help you discuss interventions with the family.
- Use them to help you keep client records.
- Use them to help you monitor process.

**Index:**

*Note: These flashcards contain information about* Epilepsy. *The content is organised according to the ICF domains. These cards don't replace the knowledge and skills of doctors and therapists. We advice you to seek their advice first.*


| Information about Epilepsy | |
|---|---|
| | Introduction |
| | Body functions & structures |
| | Activities & participation |
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Epilepsy

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Card 1

Introduction

**Introduction Epilepsy**

Epilepsy is a chronic or long-lasting disability. It is characterised by recurrent, unprovoked seizures. Seizures are also called fits. A seizure, or fit, is a sudden change in electrical activity in the brain, affecting a person's appearance and behaviour.

There are many forms of epileptic seizures and, hence, many forms of epilepsy. Recurrent epileptic seizures may come apart in hours, days, weeks, or months. The cause of epileptic seizures is often not known. Risk factors include:

- Prolonged labour
- Parasitic brain infections
- Severe malaria
- Meningitis

More severe forms of epilepsy result in:

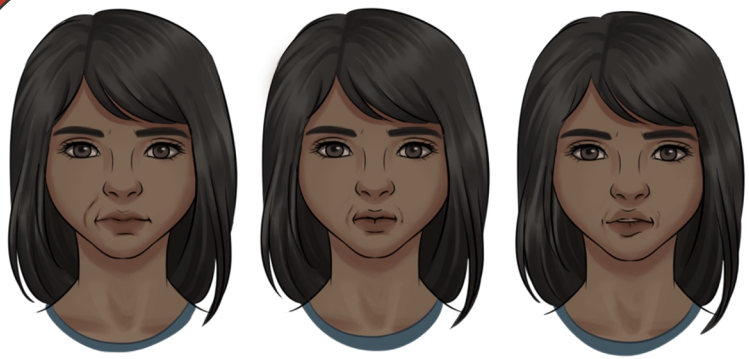
- Sudden unconsciousness during a seizure and violent movements of arms and legs.
- The eyes often roll back.

In mild types of epilepsy, the person:

- may suddenly 'blank out' for a moment
- make strange movements, or
- behave oddly.

Epilepsy can thus be dangerous during driving, working, traveling, fetching water, and cooking on an open fire.

Frequent seizures also have a negative effect on cognitive brain functions. Epilepsy often results in social stigma, low self-esteem, and relational difficulties. This, however, depends on the perception of epilepsy in the community. Despite common beliefs, none of the forms of epilepsy is contagious.











# Body functions and structures:

Information and actions to take







Card 2

Body functions and structures

**Causes of seizures**

Seizures come from damage to or an abnormal brain condition.

Common causes are:

- *Injury to the brain.* This causes at least one-third (33%) of epilepsies. Injuries may be before birth, during birth, or at any time after. The same causes of brain damage that result in cerebral palsy can cause epilepsy. In fact, cerebral palsy and epilepsy often occur together.
- *High fever*. Children who have once had a seizure with a high fever often will have seizures again when they have a fever, especially if other persons in the family have had seizures with fever. Be sure to check for infections of the ears and throat, as well as bacterial dysentery (diarrhoea with blood and fever), and treat the cause. Seizures that come only with fever usually stop occurring when the child is seven years old. Sometimes they may develop into 'non-fever-related epilepsy', especially if the child has signs of brain damage.
- *Meningitis*. A meningitis infection may result in scar tissue and, consequently, recurrent seizures.
- *Cerebral malaria*. Malaria is one of the most common parasitic diseases worldwide. If malaria affects the brain, there is a risk of developing epilepsy.
- *Brain tumour.* Epilepsy that steadily gets worse, especially if other signs of brain damage begin to appear, may be a sign of a brain tumour. Seizures caused by a tumour usually affect one side of the body more than the other.
- *Tapeworm.* Larvae from pork tapeworms may cause cysts in the brain. Subsequent cyst calcification is a major cause of epilepsy in low-middle countries.
- *Hydrocephalus.* High pressure in hydrocephalus children may result in recurrent seizures.
- *Hereditary.* There is a family history of seizures in a minority of persons with epilepsy. This is mainly caused by genetic susceptibility.
- *Unknown causes.* In about one-third (33%) of epilepsies, no family history or history of brain damage can be found. Even with modern magnetic resonance brain imaging, the causes cannot be determined.

**Note:** the spasms of tetanus can be mistaken for recurrent seizures. In the case of tetanus infection, the jaw shuts tightly (lockjaw), and the body suddenly bends back. Learn to spot early signs of tetanus. This is not epilepsy.

Seizures can also be due to 'Nodding Syndrome' and are often accompanied by repetitive nodding (dropping down) of the head and/or staring spells. Nodding Syndrome is infectious, and its cause is unknown. This condition can affect physical and intellectual growth and lead to injuries or death related to seizures. **In case of Nodding Syndrome symptoms, consult a doctor.**

**Warning signs or 'aura'**

Depending on the kind of seizure, the person or witness may be able to sense when a seizure is about to begin.

<u>Possible warning sings</u>

- A person can see flashes of light or colours.
- The person may suddenly cry out.
- Another 'warning' may be fear or imagined sights, sounds, smells, or tastes.

In the majority of seizures, there is no 'warning'. The person's body may suddenly jerk or be thrown violently. These people with epilepsy may need to continuously wear some kind of safety hat or other head protection.

**Timing of recurrent seizures**

Recurrent seizures may happen weeks or months apart or very often.

- Minor seizures or 'absences' may come in groups—often in the early morning and late afternoon. Seizures are usually short. Minor seizures may last only a few seconds.
- Big seizures seldom last more than ten or fifteen minutes. Rarely, however, a person with epilepsy may enter into a long 'epileptic state' which may last hours. This is a medical emergency.

Some kinds of seizures may appear at any age. Others begin in early childhood and usually disappear or change to other patterns as the child ages.

Many persons have epilepsy all their life. However, some young people with epilepsy stop having seizures after a few months or years. Usually, there is no need to know the exact kind of seizures a child has. However, some kinds of seizures require different medicines.

**Note:** Consult a medical expert on medication use.

Card 3

Body functions and structures

Card 4

Body functions and structures

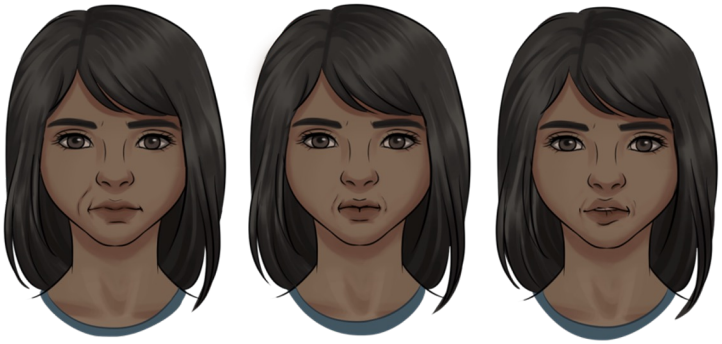
**Signs and symptoms of seizures**



**SHAKING**



**FUMBLING**



**CHEWING & BITING**



**CONFUSED SPEECH**



**BLANK STARING**



**WANDERING**

People with epilepsy have seizures in different severities and forms.

<u>The most common variants are the following:</u>

- 'Big' or 'major' seizures with strong, uncontrollable movements, incontinence, and loss of consciousness.
- 'Minor' seizures can be 'brief spells' with strange movements of some part of the body. They can be sudden, unusual behaviour such as lip-sucking or pulling at clothes.
- Brief 'absences' in which the person with epilepsy suddenly stops and stares—perhaps with blinking or fast movement of the eyelids.
- People with epilepsy can have both minor and 'big' seizures, or they may first have minor ones and later develop big ones.

Card 5

Body functions and structures

## How to act during a seizure



1.Block Hazards



2. Loosen tight clothing



3. Don't put anything in the mouth



4. Roll the person to the side



5. Cushion the head with a pillow or clothes





6. Time the seizure with a clock or watch (most seizures should end in a few minutes)



7. Do not grab and hold the person



8. Speak calmly



9. Explain to others



10. Stay with the person till they are awake and alert






**VISIT A CLINIC TO SEE A DOCTOR**

Card 6

Body functions and structures

**Treatment of seizures**

Treatment of epilepsy aims at eliminating the seizures. If that does not fully work, the aim is to reduce seizure severity. While antiepileptic drugs are the mainstay of epilepsy treatment, other approaches may be necessary. This should be determined with medical advice.

Although antiepileptic drugs do not cure epilepsy, they may effectively prevent epileptic seizures. Often, the medicine must be taken for life. Given that medicine is not always readily available, it is important to have a valid prescription and monitor medicine intake.

**Note:** combining drugs with an herbal treatment should be avoided as there could be unknown interactions between the drugs and the herbs.

With appropriate medication, a person can function normally, attend school or work, play, and be included in the community.

- Give appropriate, prescribed epileptic medication at the right time
- Make sure to refill the epilepsy medication in time so there are no gaps in taking the medication
- Keep the medicine in a safe and dry place

Keep an eye on the changing behaviour of the person with epilepsy. This might mean there is a problem.

- X Irregular bedtime
- X Swimming alone
- X Climbing high things

**Drug withdrawal**

Sometimes, suppressing seizures with drugs for a long time seems to stop the epilepsy permanently. For this reason, if the person has had many seizures in the past, it is usually wise to keep taking anti-epileptic drugs regularly for at least one year after the last seizure. Only then should the dose gradually be lowered and stopped if the person wants to stop taking drugs.





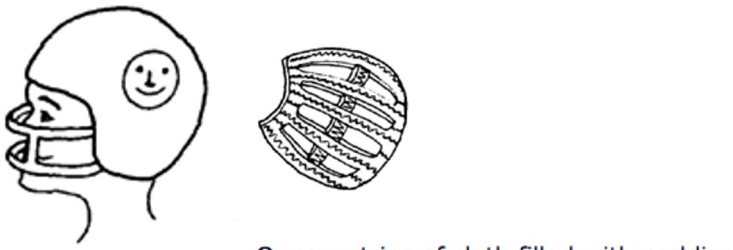


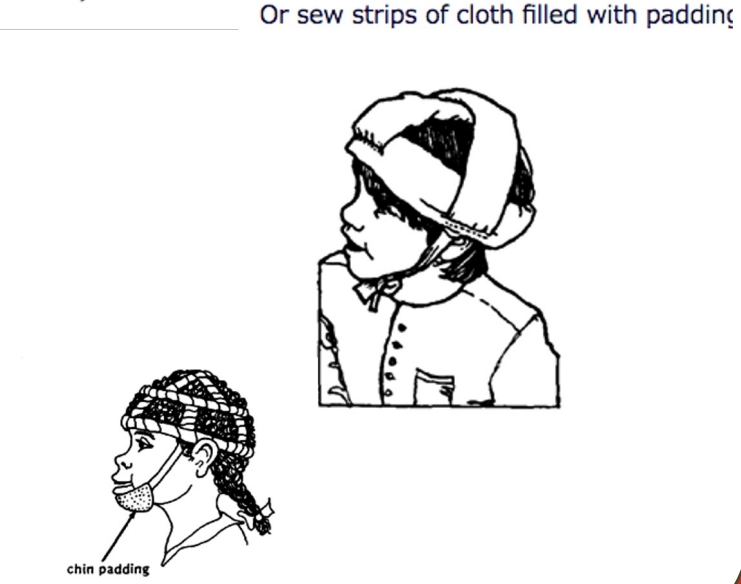
**Actions to take**

- Anti-epileptic drugs are best taken at bedtime because they often cause sleepiness.
- Give the right dose of medicine.
- To prevent choking, do not give medicines to a person while she is lying on the back or if the head is pressed back. Always make sure the head is lifted forward during drug administration. Never give anti-epileptic drugs by mouth to a child while he or she is having a seizure or while he or she is asleep or unconscious.



- A person who often injures his or her face with seizures may need a 'hard hat' helmet with a face mask. You can make a 'cage' of stiff wire and wrap it with strips of inner tube, soft cloth, or sponge rubber. Or cut a piece of old car tire something like this. Or sew strips of cloth filled with chin padding.




Card 7

Body functions and structures









**Activities and Participation:**
Information and actions to take







Card 8

Activities and participation

**Activities of daily living**

It is important for people with epilepsy to continue attending school or work, as well as taking part in day-to-day activities, even if the seizures are not entirely under control. When this is the case, overprotection is not useful, but it is important to take some precautions when carrying out activities such as swimming, bathing, cooking, or climbing high things. It is also preferable to have others around and to avoid locking doors when going to the toilet, for example. Regulations regarding epilepsy and driving are not uniform across countries. Thus, the person with epilepsy should consult a doctor to discuss whether she can drive or not.











Card 9

Activities and participation

**Community inclusion**

Discrimination due to epilepsy is found in all spheres of life, from health care and educational systems or employment to social and family life. Yet, people with epilepsy have the right to participate in society like others, as stated in the Universal Declaration of Human Rights and specified in the UN Convention on the Rights of Persons with Disabilities. To foster people's participation in society, attention can be paid to the following issues:

- Change family and community attitudes by counselling and awareness-raising. In particular the notion that epilepsy is not a contagious disease.
- Identify myths about epilepsy in the community you work in. For example, some may believe that putting the person's feet into a fire will "frighten them back to life", but in fact, it will severely burn them. Make sure you address and debunk these through discussion and explanation.
- Make the physical environment safe for people with epilepsy.



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**Personal factors:**

Information and actions to take







Card 10

Personal factors

**Self-management**

A person with epilepsy needs to handle the uncertainty and risk of recurrent seizures to live a proper daily life. This will most likely be in cooperation with one or more caregivers, family, and friends. Following the diagnosis of epilepsy, the person has to live with the chronic disorder. This involves choices on work, relationships, and personal goals. The person with epilepsy has to adjust personal goals and find the proper resources and support to reach those goals. The person has to do self-management. What does this self-management involve?



The following suggestions are given:

- Record the number of seizures together with the caregiver.
- Get sufficient and regular sleep.
- Keep stress levels low and avoid seizure triggers such as alcohol consumption.
- Exercise and work in a preventive manner
- Prevent the social stigma from isolating from family and friends.
- Do not hide away when in need of help.
- Tell others about the condition and how they can help.
- Take your medication as prescribed, and take sufficient tablets at all times.

Stable and faithful medicine intake will prevent so-called withdrawal seizures. Monitoring the patterns of seizures will help community-workers to decide on the dose of drugs. Avoiding seizure triggers will reduce risks and lower social stigma.







Card 11

Personal factors

**Caregiver role**

People with epilepsy often need support from caregivers to get a stable drug treatment. They also need a sparring partner, a true friend, and someone to watch after them.

As a fieldworker, you can coach the caregiver to do the following things in case of an epileptic seizure:

- Learn to recognize any ‘warning signs’ that a seizure is about to begin, such as sudden fear or a cry. Quickly protect the person with epilepsy by lying him or her down on a soft mat or other place where he or she cannot hurt herself.
- Refer to Card 5 of these flashcards for the 10-pointers on how to act during a seizure.
- After the epileptic seizure is over, the person may be very sleepy and confused. Give him or her sufficient rest.
- Headache is a common complaint following a seizure. Give the person a painkiller such as acetaminophen (Paracetamol).



Card 12

Personal factors

**Family and Community**

Seizures can be frightening to those who see someone having them. For this reason, people with epilepsy sometimes have a hard time gaining acceptance in the community. Everyone in the community should, therefore realise that epilepsy is not:

- the result of witchcraft or the work of evil spirits
- a sign of madness
- the result of bad actions by the child or parents or ancestors
- an infectious disease

It is important that children and youth with epilepsy go to school and take part in day-to-day work, play, and adventures in family and social (village) life. This is true even if seizures are not completely under control. The schoolteachers and other children or students should learn about epilepsy and how to protect a peer when he or she has a seizure. If they learn more about epilepsy, it will help them to be supportive rather than afraid or cruel.

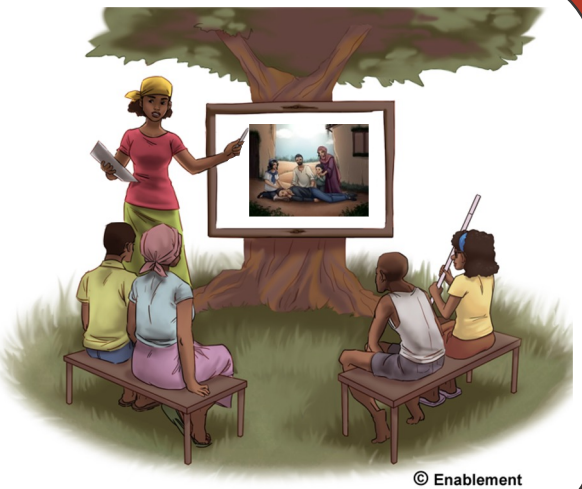
Although children with epilepsy should be encouraged to lead active, normal lives, certain precautions are needed, especially for children who have sudden seizures without warning.

Village children can learn to help in the safety of such a child, especially at times when danger is greatest.









Card 13

Personal factors

**Mental support**

Many factors may affect the person with epilepsy and his/her family emotionally. Counselling can be as necessary for children as adults, and they may require special advice and help with the choice of work. For example, they should only become professional drivers or do a job requiring standing on ladders, climbing trees, or using heavy machinery once seizures have been controlled (no seizures at all) for at least two years. Otherwise, nearly any type of work is open to people with epilepsy.

**Actions to take**

- Be sensitive to the stages of emotional distress and provide mental support and courage to hold on. Refer if needed!
- Provide the child and family practical and mental support for developing resilience, learning to live with their seizures, and finding alternative ways to achieve their full potential.
- Listen to their stories, encouraging them to seek assistance from family and friends and provide a positive sense of the future.
- Make sure the person and the caregivers have some form of social support (e.g., from caregiver(s), family members, friends/peers, community members, or others).
- Pay attention to whether the person or caregiver(s) shows signs of emotional distress (e.g., exhaustion, worry, depression, anger).









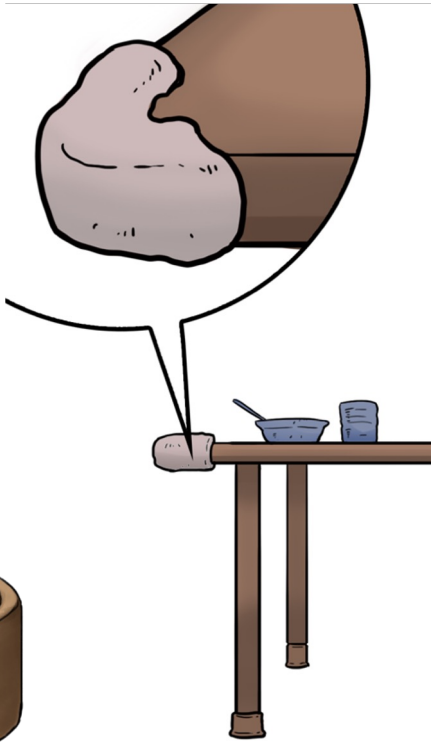





**Environmental factors:**

Information and
actions to take











Card 14

Environmental factors

Epilepsy is largely underdiagnosed in low-income and middle-income countries due to a lack of medical specialists and expensive electroencephalography (EEG) hardware. Over 90% of all people who suffer from epilepsy in low-middle-income countries remain undiagnosed and, hence, untreated. This is known as the epilepsy diagnostic gap. The limited diagnostic tools and healthcare resources in these countries can explain the epilepsy diagnostic gap. In many of these places, the acquisition of clinical-grade electroencephalography is not available, and the clinical experts to interpret the data are few and mostly concentrated in the larger cities. A proper diagnosis may also be obtained by taking a proper history and keeping a simple seizure calendar.



**Attitudes**

Every society may have its myths surrounding epilepsy. It is often considered a supernatural happening that could be a consequence of witchcraft, curses, possession, and so forth. It is also often thought to be contagious. All these elements lead to people having negative responses to those experiencing a seizure, resulting in no help, which can have extremely dangerous consequences (e.g., drowning, death, burning, and other injuries). Such beliefs can also isolate the person with epilepsy as well as her family. Stigma and prejudice can also discourage people from seeking treatment.



Card 15

Environmental factors

**Household safety measures**

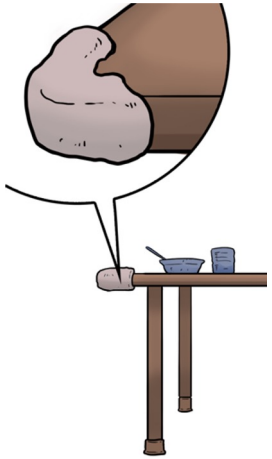
The greatest risk for people affected by epilepsy is to get injured while having a seizure. This makes some everyday activities within the household dangerous as they can cause injuries and more impairments.

- Undertake the following safety measures in and around the house:

Protect or fence off cooking places.



Remove sharp edges of, e.g., tables that can possibly hurt someone when falling.



Use stable pots for cooking.



Remove loose items one can easily stumble upon/bump into.

Card 16

Colophon

For the development of the Epilepsy chapter of the RehApp, we particularly want to express our gratitude for the valuable contributions of Frank van der Maas, Willem M. Otte, Hanne Marit, and Annemarie Gindorfer.

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