

Module: Epilepsy

Overview

Learning objectives

- Promote respect and dignity for people with epilepsy.
- Know common presentations of epilepsy.
- Know the assessment principles of epilepsy.
- Use effective communication skills in interactions with people with epilepsy.
- Know the management principles of epilepsy.
- Perform an assessment for epilepsy.
- Assess and manage physical health in epilepsy.
- Assess and manage emergency presentations of epilepsy.
- Provide psychosocial interventions to persons with epilepsy and their carers.
- Deliver pharmacological interventions as needed and appropriate in epilepsy considering special populations.
- Plan and perform follow-up for epilepsy.
- Refer to specialists and link with outside agencies for epilepsy as appropriate and available.

Key messages

- Epilepsy is not inherited or contagious.
- Assessment includes:
 - Assessing and managing an acute/emergency presentation.
 - Assessing for epilepsy and any other underlying causes of the seizures.
- Seizures are symptoms and not the cause, therefore underlying causes should always be explored and assessed.
- To be considered epileptic there must be two or more unprovoked, recurrent seizures.
- Epilepsy can be treated effectively with antiepileptic drugs in non-specialized health settings.
- Psychoeducation and psychosocial interventions to promote functioning in daily activities are empowering for the person with epilepsy to enable them to manage their condition.
- Adherence to treatment and regular follow-up are critical.
- People with epilepsy can lead normal lives.
- Children with epilepsy can go to a normal school.

Session	Learning objectives	⌚ Duration	Training activities
1. Introduction to epilepsy	Know the common presentations of Epilepsy	20 minutes	Activity 1: Person's story followed by group discussion Tell the person's story to introduce participants to what it feels like to live with epilepsy
	Understand the impact of epilepsy on a person's life Promote respect and dignity for people with epilepsy	20 minutes	Presentation on epilepsy <ul style="list-style-type: none"> • Signs and symptoms of epilepsy • Causes of epilepsy • How epilepsy impacts a person's life • Why it is a public health priority
2. Assessment of epilepsy	Know the assessment principles for epilepsy	30 minutes	Activity 2: Group discussion: Emergency presentations
	Perform an assessment for epilepsy	40 minutes	Activity 3: Video demonstration: Assessment Use videos/demonstration role play to show an assessment and allow participants to note: <ul style="list-style-type: none"> • Principles of assessment (all aspects covered) • Effective communication skills (what and how this is done)
	Use effective communication skills in interactions with people with epilepsy	30 minutes	Activity 4: Role play: Assessment Feedback and reflection
	Assess and manage emergency presentations of epilepsy		
Assess and manage physical health in epilepsy			
Refer to specialists and links with outside agencies for epilepsy, as appropriate and where available			
3. Management of epilepsy	Know the management principles of epilepsy	45 minutes	Presentation on interventions for emergency presentation (acute convulsions, status epileptics)
	Provide psychosocial interventions to persons with epilepsy and their carers	30 minutes	Presentation on psychosocial and pharmacological interventions for people epilepsy
	Deliver pharmacological interventions, as needed and appropriate in epilepsy, considering special populations		Activity 5: Role play: Management Feedback and reflection
4. Follow-up	Plan and perform follow-up for epilepsy	10 minutes	Presentation on the principles of follow-up
		30 minutes	Activity 6: Group discussion: How to reduce stigma and discrimination
5. Review		15 minutes	Multiple choice questions and discussion
Total duration (without breaks) = 4 hours 30 minutes			

Step-by-step facilitator's guide

Session 1. Introduction to epilepsy

 40 minutes

Session outline

- Introduction to epilepsy.
- Assessment of epilepsy.
- Management of epilepsy.
- Follow-up of a person with epilepsy.
- Review of materials and skills.

Begin the session by briefly listing the topics that will be covered.

Activity 1: Person's story followed by group discussion

Activity 1: Person's story

- Present a person's story of what it feels like to live with epilepsy.
- First thoughts.

Using the person's story to:

- Introduce the activity and ensure participants have access to pens and paper.
- Tell the person's story – be creative in how you tell the story to ensure the participants are engaged.
- Immediate first thoughts – give participants time to give their immediate reflections on the story.

Ask participants to think about people they have cared for in the past with epilepsy? Can they think of any cases? How did the person with epilepsy behave, how did their family and carers cope?

Local descriptions and understanding of epilepsy

- What are the names and local terms for epilepsy?
- How does the community understand epilepsy? What causes seizures and epilepsy?

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Write a list of local terms and descriptions for epilepsy and compare those with common presentations described in the mhGAP-IG.

(Maximum five minutes.)

World Health Organization

Overview of Priority MNS Conditions

1. These common presentations indicate the need for assessment.
2. If people present with features of more than one condition, then all relevant conditions need to be assessed.
3. All conditions apply to all ages, unless otherwise specified.
4. For emergency presentations, please see the table on page 18.

COMMON PRESENTATION	PRIORITY CONDITION
<ul style="list-style-type: none"> Multiple persistent physical symptoms with no clear cause Low energy, fatigue, sleep problems Persistent sadness or depressed mood, anxiety Loss of interest or pleasure in activities that are normally pleasurable 	DEPRESSION (DEP)
<ul style="list-style-type: none"> Marked behavioural changes, neglecting usual responsibilities related to work, school, domestic or social activities Agitated, aggressive behavior, decreased or increased activity Fixed false beliefs not shared by others in the person's culture Hearing voices or seeing things that are not there Loss of awareness that one is having mental health problems 	PSYCHOSES (PSY)
<ul style="list-style-type: none"> Convulsive movement or fits/seizures During the convulsion: loss of consciousness or impaired consciousness, stiffness, rigidity, tongue bite, injury, incontinence of urine or faeces After the convulsion: fatigue, drowsiness, sleepiness, confusion, abnormal behaviour, headache, muscle aches, or numbness on one side of the body 	EPILEPSY (EPI)

Read through the common presentations of people with epilepsy.

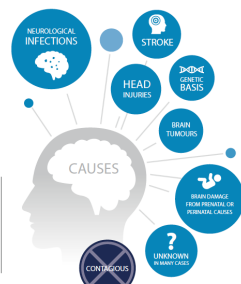
WHAT IS epilepsy?

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



Talk through the points on the slide by explaining that epilepsy is a neurological condition characterized by recurrent seizures.

Seizures are brief disturbances in the electrical functions of the brain.

There are potentially many different causes of epilepsy but it is not always easy to identify one.

Talk through the possible causes.

Signs and symptoms of epilepsy

- Epilepsy is a chronic disorder of the brain.
- It is characterized by recurrent unprovoked seizures (at least 2 in the past 12 months).
 - Recurrent = usually separated by days, weeks or months.
 - Unprovoked = there is no evidence of an acute cause of the seizure (e.g. febrile seizure in a young child).

Explain the signs and symptoms of epilepsy. It is typified by seizures.

In order to receive a diagnosis of epilepsy, there needs to have been two or more recurrent unprovoked seizures (in the past 12 months):

- Recurrent = usually separated by days, weeks or months.
- Unprovoked = there is no evidence of an acute cause of the seizure (e.g. febrile seizure in a young child).

Seizures are brief disturbances of the electrical function of the brain.

Characteristics of seizures vary and depend on where in the brain the disturbances first start and how far it spreads.

Types of epilepsy

- There are two types of epilepsy: convulsive and non-convulsive.
- **Convulsive epilepsy** has features such as sudden abnormal movements including stiffening and shaking the body (due to a convulsive seizure).
- **Non-convulsive epilepsy** has features such as changes in mental status (due to non-convulsive seizures).

Describe the two types of epilepsy as described on the slide.

Explain that this module will focus on **convulsive epilepsy**, as that is the type associated with more fear, stigma and discrimination.

What are seizures?

- Seizures are episodes of brain malfunction due to abnormal surges of electrical activity.
- A seizure usually affects how a person appears or acts for a short time.
- 70% of all seizures are convulsive.

Talk through the points on the slide and briefly explain what a seizure is.

Highlight again that in this module we will concentrate on convulsive seizures as 70% of all seizures are convulsive.

Convulsive seizures have a high mortality rate, but they can be treated.

Signs and symptoms of a convulsive seizure

During the seizure:

- Loss of awareness or consciousness.
- Convulsive movements (involuntary shaking of the body).
- Incontinence of urine or stool.
- Tongue-biting.
- Loss of vision, hearing and taste.

After the seizure:

- Low mood, anxiety, worry.
- Injuries sustained during seizures.
- Muscle aches.
- Tiredness/sleepiness.
- Abnormal behaviour.
- Confusion.
- Fatigue.
- Pains on one side of the body.

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Use the slide to explain:

- What a person is likely to experience during a seizure.
- What the person is likely to experience after the seizure.

Causes of epilepsy

- Brain damage from prenatal or perinatal injuries (e.g. a loss of oxygen or trauma during birth, low birth weight).
- Congenital abnormalities or genetic conditions with associated brain malformations.
- A severe head injury.
- A stroke that restricts the amount of oxygen to the brain.
- An infection of the brain such as meningitis, encephalitis, neurocysticercosis.
- Certain genetic disorders.
- Brain tumour.

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Explain that epilepsy is **not** contagious.

Talk through the points on the slide.

Facilitate a brief discussion about which of these conditions is a common cause of epilepsy in their local community.

It is important to know and discuss local environmental factors that could contribute to seizures and epilepsy.

Encourage participants to participate in the discussion to make sure they are aware of the local causes.

Epilepsy and non-specialized health settings

- **70%** of children and adults with epilepsy can be successfully treated (i.e. their seizures completely controlled with anti-epileptic medication).
- **Two to five years:** After two to five years of successful treatment and being seizure-free, medication can be withdrawn in 70% of children and 60% of adults.
- **US\$ 5:** This medication costs US\$ 5 per year.

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Emphasize the first point on the slide indicating that epilepsy can be treated effectively in non-specialized health settings.

When people are treated they have a good prognosis. Two to five years' successful treatment and being seizure-free means medication can be stopped in 70% of children and 60% of adults.

Antiepileptic medication is affordable – US\$ 5 per year.

In low- and middle-income countries about 75% of people with epilepsy may not receive the treatment they need.

In fact, in low- and middle-income countries there is a low availability of antiepileptic drugs (AEDs) – this may act as a barrier to accessing treatment.

Local names for epilepsy

- Are the names/local descriptions of epilepsy negative?
 - Some of the local terms may imply a person is mad, possessed, stupid or cursed.
 - How might this impact on a person and their family?
 - How might this impact on their likelihood to seek help?

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Here are some other reasons (although not exhaustive) for the high treatment gap:

- Epilepsy is a low priority for many countries.
- Limited capacity of health-care systems to address epilepsy and inequitable distribution of resources.
- Lack or severe shortage of appropriately trained staff.
- Inadequate and inconsistent access to affordable medicines.
- Societal misconceptions.
- Poverty.

Generate a brief discussion. Revisit the list of local names and terms produced for a person with epilepsy.

Ask the group if some of the names and terms are negative?

How might that make the person/family feel?

How might that impact on their likelihood to seek help?

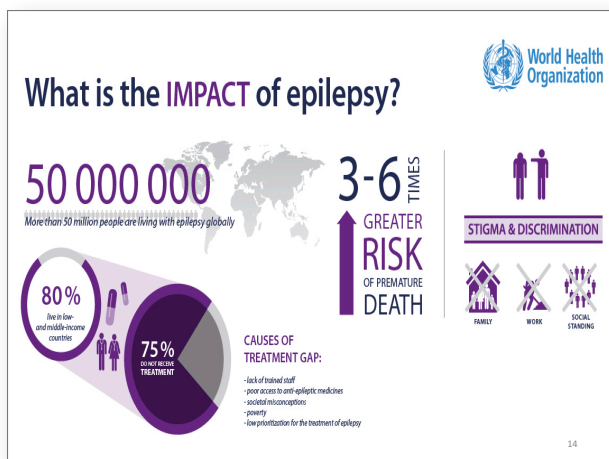
Explain that people living with epilepsy around the world are quite often stigmatized and discriminated against.

Common misconceptions about epilepsy are that it is contagious, and people must be avoided and feared; and that they are possessed by evil spirits and/or bad in some way.

People are denied access to health care and treatment, or they are too afraid to seek help.

Often children are withdrawn from schools. People with epilepsy are overlooked for jobs (impacting on their ability to earn money and support themselves and their family). People with epilepsy are often unable to get married and sometimes prevented from driving.

To summarize, even though epilepsy is a very treatable condition, people with epilepsy are not receiving the help they need and instead are being stigmatized and discriminated against.



Approximately 50 million people worldwide have epilepsy, making it one of the most common neurological diseases globally.

Nearly 80% of the people with epilepsy live in low- and middle-income countries.

People with epilepsy respond to treatment approximately 70% of the time.

Nearly 75% of people with epilepsy living in low- and middle-income countries do not get the treatment they need. In some regions of the world, like Africa, this can be as high as 85%.

Those with epilepsy have a three to six times greater risk of dying prematurely **but** epilepsy can be treated effectively in primary health care.

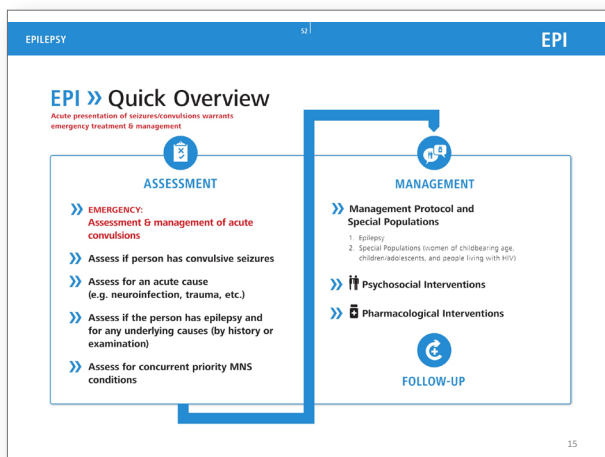
Treatment is simple, inexpensive and effective. Some 70% can be seizure-free for life after two years of treatment.

Session 2.

Assessment of epilepsy

🕒 1 hour 40 minutes

The first part of the session focuses on the management of acute seizures and emergency presentations. The second half of the session focuses on how to assess someone for epilepsy.



Explain that there are two ways that people with epilepsy enter health care services:

- During a seizure – as an emergency presentation.
- After a seizure.

Have participants read through the assessment principles for epilepsy.

mhGAP-IG has an assessment algorithm for both and in this training we will start with how to manage seizures which present as emergencies.

Why are seizures treated as an emergency?

- Treatment can end seizures or shorten seizure duration, which limits the damage they can cause.
- Prolonged or repeated seizures can result in brain injury.
- Prolonged or repeated seizures can result in death if not treated immediately.
- Seizures can be a symptom of a life threatening problem, like meningitis.

Emphasize why managing seizures is an emergency.

Talk through the points on the slide.

Activity 2: Group discussion: Emergency presentations

Group discussion

A person is brought into the clinic and is unconscious after a reported seizure.

What are your first actions?

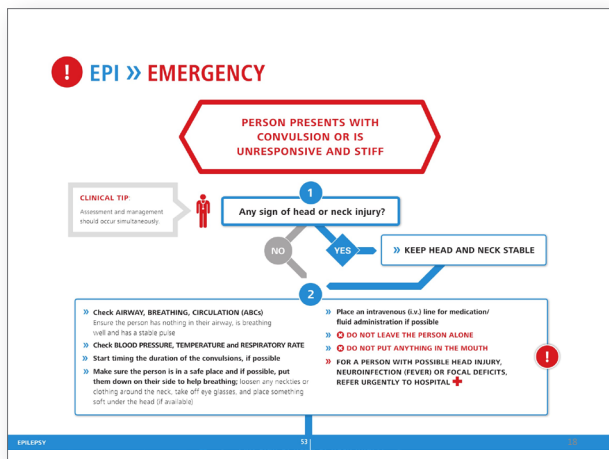
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Duration: 10 minutes.

Purpose: To learn how much participants know about managing acute seizures.

Instructions:

- Give individuals a few minutes to think individually about what they would do in this situation.
- Facilitate a group discussion and seek group consensus to create a comprehensive list of steps they would take to help the person.



Talk through steps 1 and 2 in the algorithm as shown on page 53 of mhGAP-IG Version 2.0.

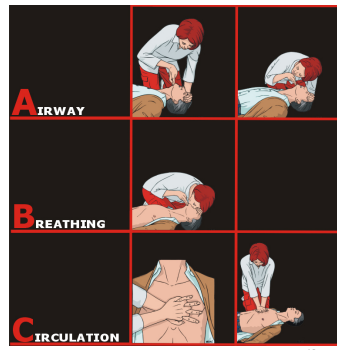
Emphasize that participants need to understand that they cannot wait until they establish a complete diagnosis to start managing the seizure. Management and assessment must happen at the same time.

Ensuring the A, B, C (airways, breathing, circulation) is crucial, even if they do not have a clear idea about the cause yet.

First action in all cases: Check ABCs

- Airway
- Breathing
- Circulation

- DO NOT leave the person alone.
- Place in recovery position.
- Make sure NOTHING is in the mouth.

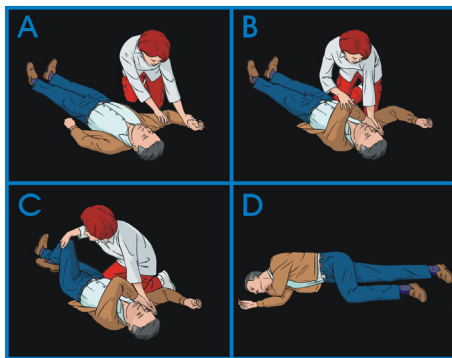


Check with participants if they've already had training on this topic.

If this is a new topic then ensure you give sufficient time to ensure participants understand how to manage acute seizures.

If they have received training in this then explain that this is an opportunity for them to refresh their knowledge.

If the person is still unconscious, use the recovery position



Ask participants to explain and then demonstrate how they put a person in the recovery position (20 minutes).

Divide the participants into pairs and have them practise putting each other into the recovery position (15 minutes).

Recovery position

- Kneel on the floor to one side of the person. Place the person's arm that is nearest you at a right angle to their body, so it is bent at the elbow with the hand pointing upwards. This will keep it out of the way when you roll them over.
- Gently pick up their other hand with your palm against theirs (palm to palm). Now place the back of their hand onto their opposite cheek (for example, against their left cheek if it is their right hand).
- Now use your other arm to reach across to the person's knee that is furthest from you, and pull it up so that their leg is bent and their foot is flat on the floor.
- Now, with your hand still on the person's knee, pull their knee towards you so they roll over onto their side, facing you.

Measure and document vital signs

1. Blood pressure.
2. Temperature.
3. Respiratory rate.

These must be measured and documented.

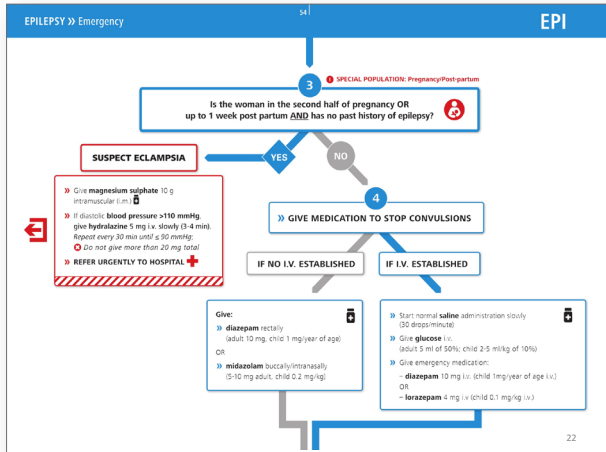
In particular, the respiratory rate should be counted. You may be using drugs that cause respiratory depression.

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Emphasize that these vital signs need to be **measured and documented**.

Respiratory rate actually needs to be counted, not estimated, since trends in respiratory rate become quite important if the person has recurrent seizures and requires aggressive treatment with multiple doses of medications, which can suppress the respiratory drive.

- Time the duration of the convulsions.
- Make sure the person is in a safe place – ensure that nothing is likely to fall on them and/or they can't hit anything if they convulse.
- If possible place in an i.v. line for medication/fluids.
- Know when to **refer** – if a person has a head injury, a neuroinfection or focal neurological deficits then **refer to hospital**.



Direct participants to page 54 of mhGAP-IG Version 2.0.

Talk through the next steps highlighting the special population: pregnancy/post-partum and when to suspect eclampsia.

A pregnant woman who has no history of epilepsy and presents with seizures may have **eclampsia**.

Eclampsia is a condition in which one or more convulsions occur in a pregnant woman suffering from high blood pressure.

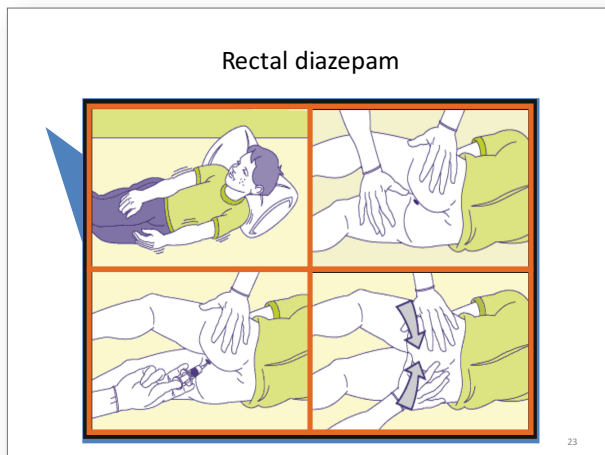
The condition poses a threat to the health of the mother and the baby.

If there is a midwife in your clinic call them to assist. They may have training in how to support people with eclampsia.

Refer immediately to a hospital.

Step 4 (give medication to stop convulsion) – if you cannot establish an i.v., **do not give diazepam intramuscularly (i.m.)**. Ask participants if they know why they should not give i.m. diazepam?

Explain that i.m. diazepam is poorly and unpredictably absorbed and diazepam should only be given rectally.

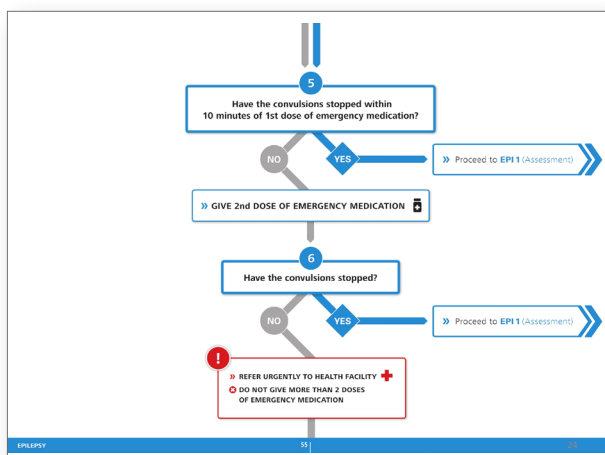


Explain how to give rectal diazepam. Mention to participants that they need to teach this to the carers of people with seizures for them to be able to do it at home.

Instructions:

- Draw up the dose from an ampoule of diazepam into a tuberculin (1 ml) syringe.
- Base the dose on the weight of the child, where possible.
- Remove the needle.
- Insert the syringe into the rectum 4 to 5 cms and inject the diazepam solution.
- Hold buttocks together for a few minutes.
- If the convulsion continues after 10 minutes, give a second dose of diazepam rectally (or give diazepam intravenously (0.05 ml/kg) if i.v. infusion is running).

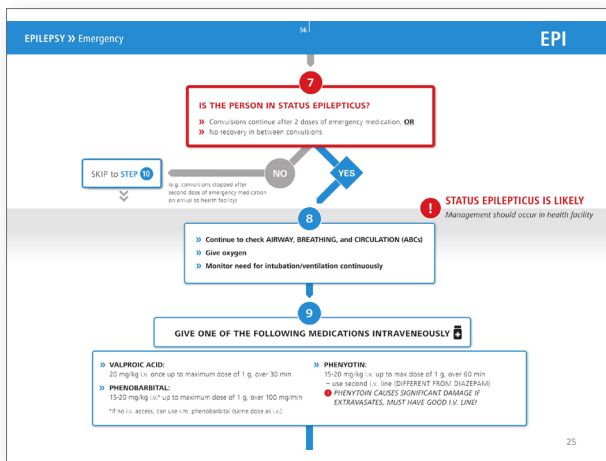
Ask participants what should they do if the convulsions have not stopped within 10 minutes of the first dose of medication?



Direct the participants to page 55 mhGAP-IG Version 2.0. Talk through steps 5 and 6.

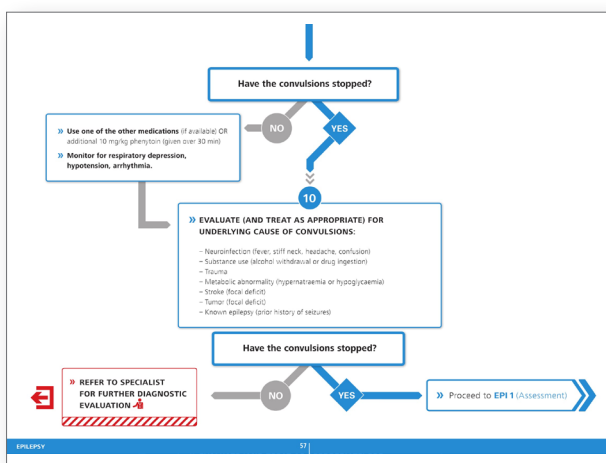
Explain that we will look at the management protocols in the next session but for now we will concentrate on the assessments.

Ask participants if they know when a person is in status epilepticus?



Direct the participants to page 56 mhGAP-IG Version 2.0.

- Explain the definition of status epilepticus and emphasize that management should occur in a health facility.
- Continue talking through the steps of the algorithm if a person is in status epilepticus.
- Explain that i.v. antiepileptic medicines such as i.v. phenytoin and phenobarbital should always be administered in a health care setting.



Once the convulsions have stopped, take step 10 (page 57 mhGAP-IG) – evaluate (and treat as appropriate) for underlying cause of convulsions.

Remind participants that seizures are symptoms not causes, so you always need to **look for the cause**.

If the person presents convulsing, it is an emergency and needs to be treated urgently as:

- Seizures can be a sign of a life-threatening problem.
- Seizures can result in brain injury or death.

Explain that we are now going to look at some possible causes in more detail.

What if you suspect a brain infection?

- If there are signs and symptoms (e.g. fever, vomiting, rash):
 1. Manage the seizure as we have discussed.
 2. Initiate treatment for the underlying brain infection (such as i.v. antibiotic for meningitis).
 3. Refer to hospital as this is an emergency.

Underlying causes

Explain that if you suspect a **brain infection** is causing the seizures, establish if there is a fever, vomiting or a rash.

If there are then manage the seizure as discussed.

Initiate treatment for underlying brain infection (such as i.v. antibiotic for meningitis).

Briefly mention specific treatments or national guidelines for common infections such as cerebral malaria, meningitis, neurocysticercosis (WHO is currently developing guidelines for the treatment of neurocysticercosis), etc.

What if you suspect trauma?

1. Manage the seizure as we have discussed.
2. Stabilize the neck:
 - DO NOT move the neck.
 - There could be a cervical spine injury.
 - Log roll the person when moving.
3. Assess for other evidence of trauma.
4. Refer to the hospital as this is an emergency.

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Explain that another cause of the seizure could be **trauma**.

If they suspect trauma they should talk through the points on the slide.

This may be a good opportunity to ask participants which methods they might use to stabilize the neck.

If there seems to be some confusion or inappropriate ideas, find a volunteer and show them with a hands-on example.

Ask the group what they have available to stabilize the neck or what they might be able to make with local materials. The participants may be able to offer each other advice.

How to check for other evidence of trauma ?

1. Remove all clothing and check whole body for evidence of trauma.
2. Look/feel for deformity of the skull.
3. Check if pupils are not equal or not reactive to light.
4. Check for blood/fluid from the ears or nose.
5. Look for associated traumatic injuries (spine, chest, pelvis).

From: IMAI District Clinician Manual: Vol 1, section 2 page 7.

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Ask participants how they would check for evidence of trauma before revealing the answers.

Ask participants how they would check for evidence of trauma:

- stroke and tumour
- drug ingestion or alcohol withdrawal
- metabolic abnormality.

What if the person is a child with fever?

- It could be a febrile seizure.
- Febrile seizures are events occurring in children (three months to five years of age), who are suffering from fever and don't have any neurological illness or brain infection.
- There are two types of febrile seizure:
 - Complex (these need to be ruled out).
 - Simple febrile seizures.

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Remind participants that we have already discussed what to do if we suspect eclampsia in pregnant or post-partum women.

But ask the participants what they would do if the person is a child with fever?

Then reveal the answers.

Febrile seizures are common in primary health-care settings.

Ask the participants to explain the difference between febrile seizures and epilepsy.

What is a complex febrile seizure?

It is a complex febrile seizure if one of the following criteria is present:

- **Focal:** Starts in one part of the body.
- **Prolonged:** More than 15 minutes.
- **Repetitive:** More than one episode during the current illness.

A complex febrile seizure needs to be referred to hospital.

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Answer: In epilepsy the person has recurrent, unprovoked seizures **without** fever.

Febrile seizures occur when the child has a high fever.

Make it clear that febrile seizures are not epilepsy.

Clarify that it is important to rule out complex febrile seizures as these are at a higher risk of serious underlying pathology and generally need hospital admission, CT scan and lumbar puncture.

Explain the criteria for complex febrile seizures:

- **Focal:** For example, the seizure starts in the arm and then generalizes to the entire body.
- **Prolonged:** Even if it is due to fever with no signs and symptoms suggestive of neurological illness or brain infection, if the duration is more than 15 minutes, it is considered a complex seizure.
- **Repetitive:** If seizures are repetitive, it is considered to be complex.

Emphasize that you **must refer the person to hospital**.

Management of simple febrile seizures

1. Look for possible causes and manage fever according to the local IMCI guidelines.
2. Observe for 24 hours.
3. Follow-up in one to two months to assure no further seizures.

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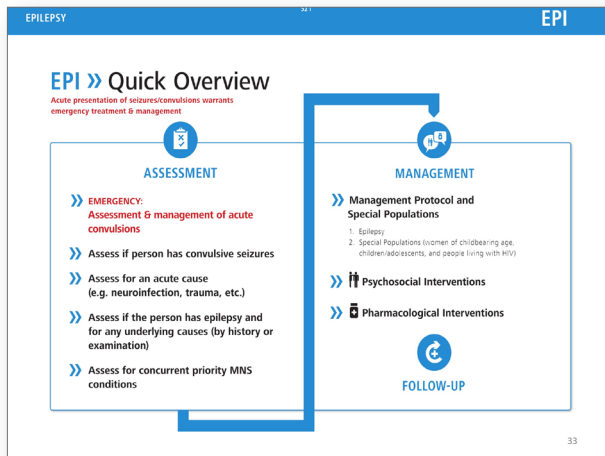
Talk through the points on the slide.

Simple febrile seizures usually last for less than five minutes. The child will:

- Become stiff and their arms and legs may begin to twitch.
- Lose consciousness and may wet or soil themselves.
- If there is only one seizure, it can leave the child feeling sleepy for up to an hour afterwards.

A simple febrile seizure like this will only happen once during your child's illness.

Refer to the WHO Integrated Management of Childhood Illness (IMCI) guidelines, if needed, for more details. If the community does not use or is not aware of the IMCI guidelines, refer to:
http://whqlibdoc.who.int/publications/2008/9789241597289_eng.pdf



Explain to participants that they have looked at the emergency assessment and management of acute convulsions.

Once the convulsions have stopped and the person has had sufficient time to rest and recover, the next step is to assess for epilepsy.

Activity 3: Video demonstration: Assessment

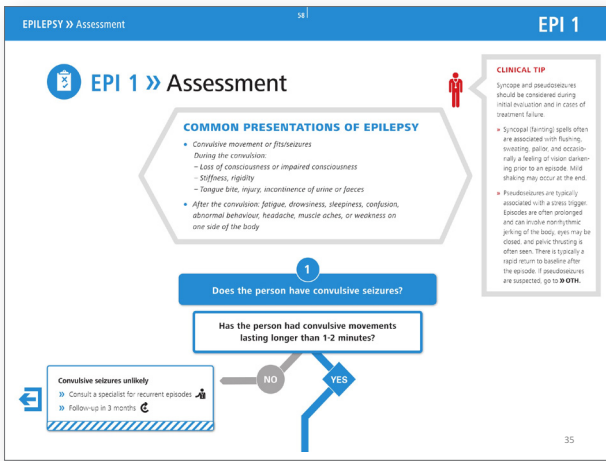
Activity 3: Video demonstration

- Watch the mhGAP-IG video.
- During the video follow the epilepsy assessment algorithm on page 58 mhGAP-IG Version 2.0.

Explain to the participants that they are about to watch a video of a person being assessed for epilepsy by a primary health-care professional.

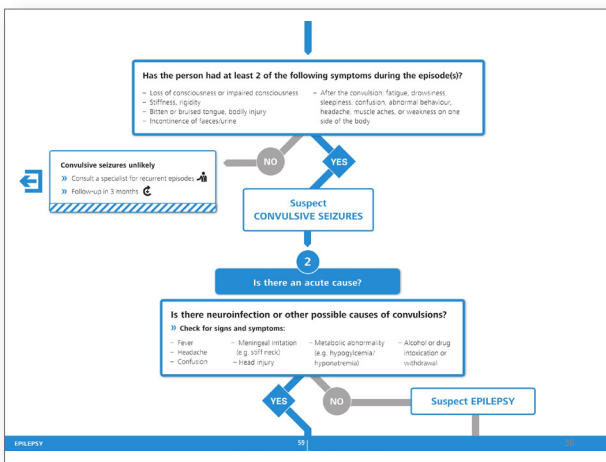
During the video participants should look at the epilepsy assessment on page 58 of the mhGAP-IG Version 2.0 and use the clinical decision-making points to decide if the person has epilepsy.

<https://www.youtube.com/watch?v=RUIRg555xI0&index=6&list=PLU4ieskOli8GicaEnDweSQ6-yaGxhes5v>



- After watching the video ask participants:
- Does Faten’s presentation match that described in the common presentation of epilepsy?
 - Does Faten have convulsive seizures?

Seek a group consensus.



- Ask the participants:
- Has Faten had at least two of the symptoms described during an episode?

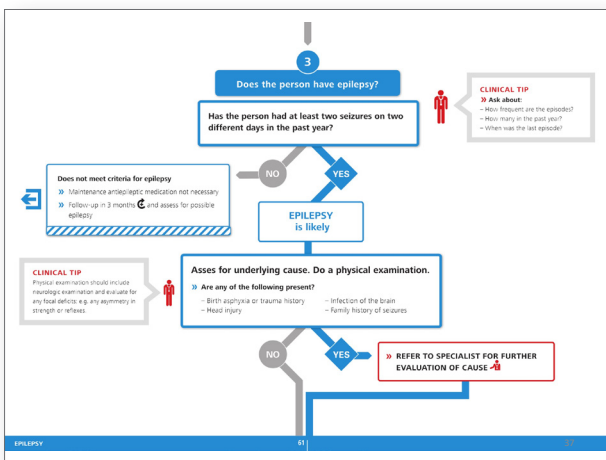
Seek group consensus.

If yes, then suspect convulsive seizures.

Explain that the next step in the assessment is to find out if there is an acute cause?

How did the health-care provider assess if there was a neuroinfection or other possible cause?

Note: Replay the video as many times as necessary to ensure participants provide an answer.



- Ask the participants:
- Does Faten have epilepsy?
 - How did the health-care provider assess if Faten had had at least two seizures on two different days in the past year?
 - How did the health-care provider do a physical examination? What did he look for?

What to look for on physical examination?

- Signs of head and/or spinal trauma.
- Pupils: Dilated? Pinpoint? Unequal? Unreactive?
- Signs of meningitis: stiff neck, vomiting.
- Weakness on one side of body or in one limb.
 - In unconscious people who are unresponsive to pain, you may notice that one limb or side of the body is “floppy” compared with the other.

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Talk through the points on the slide.

If there are conditions in the region especially likely to cause seizures, discuss these here, e.g. cerebral malaria or Japanese encephalitis, neurocysticercosis.

Ask about other medical conditions

1. Are they diabetic? Are they on any medications?
 - Could this be low blood sugar?
2. Are they HIV positive? Are they on any medications?
 - Could this be an infection (e.g. meningitis)?
3. Is there any chance of poisoning?
4. Is this person a drug user or a heavy drinker?
 - If yes, in addition to managing their acute seizures, you will need to do an assessment according to the drug and alcohol use sections of the mhGAP-IG.

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Talk through the points on the slide and ask these questions to try and find out about any other medical conditions that could be causing the seizure.

Mention common causes of poisonings and drugs used in the environment, e.g. in farming communities organophosphate poisoning is common.

It may be worthwhile discussing other signs and symptoms of common exposures in the environment.

EPILEPSY » Assessment
EPI 1

4

Are there concurrent MNS conditions?

» Assess for other concurrent MNS conditions according to the mhGAP-IG Master Chart (MC)

• Please note persons with EPILEPSY are at higher risk for DEPRESSION, DISORDERS DUE TO SUBSTANCE USE. CHILDREN AND ADOLESCENTS MAY HAVE ASSOCIATED MENTAL AND BEHAVIOURAL DISORDERS. SUBSTANCE USE DISORDERS

» Go to PROTOCOL 1

• IF THERE IS IMMINENT RISK OF SUICIDE, ASSESS AND MANAGE before continuing to Protocol. Go to 95U.

40

Ask the participants:

- Did the health-care provider assess for concurrent priority MNS conditions?
- Do you suspect Faten has any symptoms of different MNS conditions?
- Does Faten show any imminent risk of suicide?

Activity 4: Role play: Assessment

Activity 4: Role play

- A person comes to a primary health-care clinic for the first time after they had a fainting spell the week before.
- The person comes with their spouse.
- The health-care provider conducts an assessment using the algorithm on page 58 of the mhGAP-IG Version 2.0.

See EPI supporting material role play 1.

Print off four different instruction sheets for the participants playing different roles.

Ensure the person playing the role of the observer also has a competency assessment form (see ToHP training forms) in order to assess the participants.

Duration: 30 minutes.

Purpose: This role play enables participants to practise conducting an assessment to establish if someone has epilepsy.

Situation:

- A person comes to a non-specialized health setting for the first time after they had a fainting spell the week before.
- The person comes with their spouse.
- The health-care provider conducts an assessment using the algorithm on page 58 of the mhGAP-IG Version 2.0.

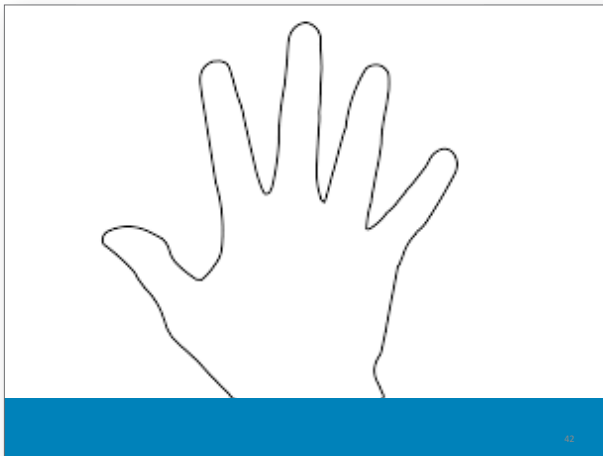
Instructions:

- Divide the participants into groups of four.
- Instruct one person to play the role of the health-care provider, one the person seeking help, one person the spouse and one the observer.
- Distribute the role play instructions to each person depending on their role.
- Ensure that the participants keep to the allotted time.

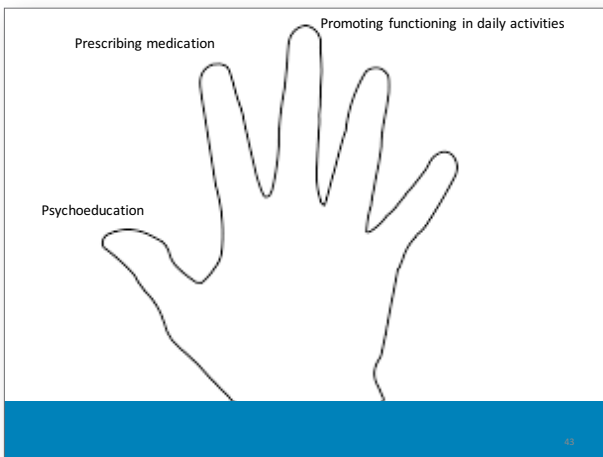
Session 3.

Management of epilepsy

🕒 1 hour 15 minutes



Begin by asking participants what management intervention strategies they think might be appropriate for people suffering with epilepsy.



Explain that if the person and the family are also experiencing high levels of discrimination and/or stress then relaxation strategies and strengthening social support strategies can also be used.

EPI 2 » Management
PROTOCOL

1

- Provide **psychoeducation** to the person and carers (2.1)
- Initiate **antiepileptic medications** (2.3)
- Promote **functioning in daily activities** (2.2)

Special populations
Note that interventions are different for EPILEPSY in these populations

WOMAN OF CHILDBEARING AGE
Concern: Risk of teratogenic medication to foetus

- Advise folic acid (5 mg/day) to **prevent neural tube defects, in ALL women of childbearing age.**
- AVOID VALPROATE.**
- CAUTION if Pregnant:**
 - Most AEDs therapy: Multiple medications in combination increase the risk of teratogenic effects during pregnancy. If medications are stopped during pregnancy, they should always be tapered.
 - Administer delivery in hospital.
 - An epidural given 7 mg intrathecal LiCl to the newborn to prevent haemorrhagic disease.
- If **breastfeeding**, carbamazepine preferred to other medication.

CHILD/ADOLESCENT
Concern: Effect of antiepileptic medication on development and/or behaviour

- For those with a **developmental disorder**, manage the condition. Go to **9 CDMH**.
- For children with behavioural disorder, avoid phenytoin if possible. Manage the condition. Go to **9 CDMH**.

PERSON LIVING WITH HIV
Concern: Drug interactions between antiepileptic medications and antiretrovirals

- When available, refer to specific drug interactions for person's antiretroviral regimen and antiepileptic medication.
- Valproate** is preferred due to fewer drug-drug interactions.
- AVOID PHENYTOIN AND CARBAMAZEPINE (WHEN POSSIBLE)**

Explain that managing epilepsy with pharmacological interventions and in special populations will be discussed soon, but first psychoeducation will be considered.

EPILEPSY » Management **EPI 2**

PSYCHOSOCIAL INTERVENTIONS

2.1 Psychoeducation

Provide information on: "What is a convulsion/epilepsy" and the importance of medication.

- "A convulsion is caused by excess electrical activity in the brain - it is not caused by 'witchcraft' or 'spirits'."
- "Epilepsy is the recurrent tendency for convulsions."
- "It is a chronic condition, but if you take your medicines as prescribed, in the majority of people it can be fully controlled."
- The person may have several people helping them take care of their convulsions. Discuss this with the person.
- Ask the person to let you know if they are using a traditional or a faith healer, showing respect for this, but emphasizing the need for being seen at a health care facility. The person should also be informed that medicines and herbal products can sometimes have adverse interactions, so the health care providers must know about everything they take.

CLINICAL TIP:

- Seizures lasting greater than 5 minutes are a medical emergency - one should seek help immediately.
- Most people with epilepsy can have normal lives with good adherence to treatment.

Provide information on: How carers can manage convulsions at home.

- Lay person down, on their side, head turned to help breathing.
- DO NOT PUT ANYTHING IN THEIR MOUTH OR RESTRAIN THE PERSON.**
- Ensure the person is breathing properly.
- Stay with person until the convulsion stops and they wake up.
- Sometimes people with epilepsy know that a convulsion is imminent. They should lie down somewhere safe if they have that feeling.
- Epilepsy is not contagious. You cannot catch the disorder by assisting the person experiencing convulsions.

Provide information on: When to get medical help.

- When a person with epilepsy appears to have trouble breathing during a convulsion, they need immediate medical help.
- When a person with epilepsy has a convulsion lasting longer than 5 minutes outside of a health facility, they need to be taken to one.
- When a person with epilepsy is not waking up after a convulsion, they need to be taken to a health facility.

2.2 Promote functioning in daily activities and community life

Refer to Essential Care and Practice (ECP) for interventions that promote functioning in daily living and community life.

- In addition, inform carers and people with epilepsy that:**
 - People with epilepsy can lead normal lives. They can marry and have children.
 - Parents should not remove children with epilepsy from school.
 - People with epilepsy can work in most jobs. However, they should avoid jobs with high risk of injury to self or others (e.g. working with heavy machinery).
 - People with epilepsy should avoid cooking on open fires and swimming alone.
 - People with epilepsy should avoid excessive alcohol and recreational substances, sleeping too little, or going to places with flashing lights.
 - Local driving laws related to epilepsy should be observed.
 - People with epilepsy may qualify for disability benefits.
 - Community programs for people with epilepsy can provide assistance in jobs and support for both the person and family.

Ask participants to read through page 64 mhGAP-IG Version 2.0 (psychosocial interventions).

Clarify any concerns/questions participants may have.

Group activity: In plenary, ask participants to adapt any psychoeducation messages to be culturally appropriate in the local context.

Example of a seizure diary

Ask the person (and carer) to keep a record of seizure history

What happened? (description of seizure)	When? (day, time)	What medication did the person take?	
		Yesterday	Today

Emphasize that a seizure diary can be very helpful in managing epilepsy.

It is useful because it gives a clear idea about the person's problems and how they are progressing.

It also empowers the individual to gain some control over their epilepsy and learn:

- When their seizures happen and what triggers them.
- How medication is having an effect on them.

Make it clear that the diary does not have to be exactly as displayed.

Any record will suffice as long as it includes the details of the event:

- Whether the person was taking the medicines regularly.
- What happened.
- When it happened.
- What/if any triggers were present.

Explain that people with epilepsy can also learn to manage their seizures and understand them better by seeking witness accounts of their seizures. Also, discussing the lead up to their seizures with carers, family members etc. can help.

Group discussion: First, ask participants what medications they use to manage epilepsy and discuss in the group.

Give the participants five minutes to read through point 2.3 (Initiate antiepileptic medication) and look at Table 1.

Ask participants to share what key messages they found most important?

Point out the risks of prescribing medication to special populations.

Highlight that once the appropriate medication has been chosen, ensure that it is consistently available.

- Only start one medication.
- Start at the lowest dose.
- “Go slow”, increase the dose slowly until convulsions are controlled.
- Consider monitoring blood count, blood chemistry and liver function, if available.

PHARMACOLOGICAL INTERVENTIONS

2.3 Initiate antiepileptic medications

- ▶ Choose a medication that will be consistently available.
- ▶ Special populations (infants, women of childbearing age, person living with HIV), use relevant section of this module.
- ▶ Start with only one medication at lowest starting dose.
- ▶ Increase dose slowly until convulsions are controlled.
- ▶ Consider monitoring blood count, blood chemistry and liver function tests, if available.

CAUTION!

- ▶ Check for **drug-drug interactions**. When used together, antiepileptics may **enhance** or **reduce** the effect of other antiepileptics. Antiepileptics may also **reduce** effect of hormonal birth control, immunosuppressants, antiwarfarin, methotrexate, and some antiarrhythmics.
- ▶ Parity can cause severe bone marrow depression. Hypersensitivity reactions including Stevens-Johnson syndrome, altered Vitamin D metabolism and vitamin B-deficient haematologic causes of leucopenia.
- ▶ Where possible, avoid use of sodium valproate in pregnant women due to **risk of neural tube defects**.
- ▶ All anticonvulsant medications should be discontinued slowly as stopping them abruptly can cause severe breakthrough.

TABLE 1: Antiepileptic medications

MEDICATION	ORAL DOSING	SIDE EFFECTS	CONTRAINDICATIONS / CAUTIONS
CARBAMAZEPINE	Adults: Start 100-200 mg daily in 2-3 divided doses (increase by 200 mg each week/one 1400mg daily). Children: Start 5 mg/kg daily in 2-3 divided doses. Increase by 3 mg/kg daily each week (max 40mg/kg daily 20 mg/kg daily). Women who are pregnant or breastfeeding: Use with caution.	Common: Rash/fever, dizziness, nausea, double vision, nausea, diarrhea, benign leukopenia & neutropenia. Serious: Hypersensitivity, cardiac conduction delay, low sodium levels.	Caution in patients with history of blood disorders, kidney, liver or cardiac disease. Dose may need to be adjusted after 2 weeks due to induction of its own metabolism.

EPILEPSY Management **EPI 2**

TABLE 1: Antiepileptic medications (cont.)

MEDICATION	ORAL DOSING	SIDE EFFECTS	CONTRAINDICATIONS / CAUTIONS
PHENOBARBITAL	Adults: Start 60 mg daily in 1-2 divided doses (increase by 20 mg (max 180 mg daily)). Children: Start 2-3 mg/kg daily in 2-3 divided doses. Increase weekly by 1-2 mg/kg daily depending on tolerance (maximum 6mg/kg daily).	Common: Sedation, hypotension, incontinence, ataxia, polydipsia, sexual dysfunction, depression. Serious: Liver failure (hypersensitivity reactions decreased bone marrow density).	Contraindicated in patients with acute intermittent porphyria. Lower doses for patients with kidney or liver disease.
PHENYTOIN	Adults: Start 150-200 mg daily in two divided doses (increase by 20 mg daily every 2-4 weeks (max 400 mg daily)). Children: Start 3 mg/kg daily in 2-3 divided doses. Increase by 3 mg/kg daily every 3-4 weeks (maximum 300 mg per day). Women who are pregnant or breastfeeding: Avoid. Older adults: Use lower doses.	Common: Rash/fever, parotiditis, ataxia, nystagmus, blurred vision, double vision, hysteresis, slurred speech, nausea, vomiting, constipation. Serious: Hematology abnormalities, hepatitis, polymycocystitis, gum hyperplasia, acne, lymphadenopathy. Increase in suicidal ideation.	Lower doses for patients with kidney or liver disease.
SODIUM VALPROATE	Adults: Start 400 mg daily in 2 divided doses (increase by 200 mg daily each week (maximum 3000 mg daily)). Children: Start 15-20 mg/kg daily in 2-3 divided doses (increase each week by 15 mg/kg daily (max 540 mg/kg daily)). Women who are pregnant or breastfeeding: Avoid. Older adults: Use lower doses.	Common: Rash/fever, headache, tremor, ataxia, nausea, vomiting, diarrhea, weight gain, transient hair loss. Serious: Impaired kidney function, thrombocytopenia, leukopenia, acute liver failure (idiosyncratic), hepatotoxicity, hyperammonemic encephalopathy, a sign of toxic colic, liver failure, hemorrhagic pancreatitis.	Use with caution if underlying or suspected hepatic disease. Drug-drug interactions: valproate levels decreased by carbamazepine, increased by aspirin.

Group discussion

- What drugs are available in your setting?
- How much does the medication cost?
- How can you ensure medication adherence?
- What can you do if the medication is not consistently available?

Remind participants of the instruction in the mhGAP-IG to choose a medication that will be **consistently available**. Ask them to reflect whether that is realistic in their settings?

Facilitate a discussion about:

- What drugs are available in your setting?
- How much does the medication cost?
- How can you ensure medication adherence?
- What can you do if the medication is not consistently available?

Psychoeducation for medication management

Explain to the person and the family:

- The need for prompt medical treatment.
- Explain that this is a chronic condition and the medication must be taken as prescribed.
- If you take the medication as prescribed then the majority of people find that the seizures are fully controlled.
- Explain the potential side-effects and what to do if they occur.
- Explain the risk of further seizures if doses are missed
- Plan for regular follow-ups.

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Psychoeducation for medication management

Talk through the points on the slide and use the below for extra emphasis.

Key messages:

- Explain to the person and the carer the need for medication.
- Explain the importance of taking the medication as prescribed.
- Explain that if they take the medication as prescribed they can expect to control the seizures.
- Explain the potential side-effects and what to look out for and what to do.
- Explain the risk of further seizures if doses are missed.
- Plan for a follow-up session to show that you are still there to support them.

Ask participants to read through the management options for special populations.

Ask participants:

- Why these groups are considered special populations?
- What are the concerns for:
 - Women of childbearing age?
 - Children and adolescents?
 - Persons living with HIV?

EPI 2 » Management

PROTOCOL

1 Provide psychoeducation to the person and carers (2.1)

2 Initiate antiepileptic medications (2.3)

Special populations
Note that interventions are different for EPILEPSY in these populations

WOMAN OF CHILDBEARING AGE	CHILD / ADOLESCENT	PERSON LIVING WITH HIV
<p>Concern: Risk of teratogenic medication to foetus/child</p> <ul style="list-style-type: none"> ➤ Advise folic acid (5 mg/day) to prevent neural tube defects, in ALL women of childbearing age. ➤ AVOID VALPROATE. ➤ CAUTION if Pregnant: <ul style="list-style-type: none"> – Avoid polytherapy. Multiple medications in combination increase the risk of teratogenic effects during pregnancy. – If medications are stopped during pregnancy, they should always be resumed. – Advise delivery in hospital. – At delivery, give 1 mg vitamin K₁ to the newborn to prevent haemorrhagic disease. ➤ If breastfeeding, carbamazepine preferred to other medication. 	<p>Concern: Risk of antiepileptic medication on development and/or behaviour</p> <ul style="list-style-type: none"> ➤ For those with a developmental disorder, manage the condition. Go to 3.CMH. ➤ For children with behavioural disorder, avoid phenobarbital if possible. Manage the condition. Go to 3.CMH. 	<p>Concern: Drug interactions between antiepileptic medications and antiretrovirals</p> <ul style="list-style-type: none"> ➤ If/when available, refer to specific drug interactions for person's antiretroviral regimen and antiepileptic medication. ➤ Valproate is preferred due to fewer drug drug interactions. ➤ AVOID PHENYTOIN AND CARBAMAZEPINE WHEN POSSIBLE.

EPILEPSY 63

Activity 5: Role play: Management

Activity 5: Role play

- A health-care provider assessed this person and their spouse and decided that the person has epilepsy.
- The health-care provider now has the responsibility of developing a treatment plan with the person.
- The treatment plan should include psychosocial and pharmacological interventions as well as instructions to the spouse on how to help the person if they have a convulsive seizure at home and when to refer for medical help.

See EPI supporting material role play 2.

Print off the four different instruction sheets for the participants playing the different roles.

Ensure the person playing the role of the observer also has a competency assessment form (see ToHP training forms) in order to assess the participants.

Duration: 40 minutes.

Purpose: To enable participants to practise using recommended psychosocial and pharmacological interventions for epilepsy.

Situation:

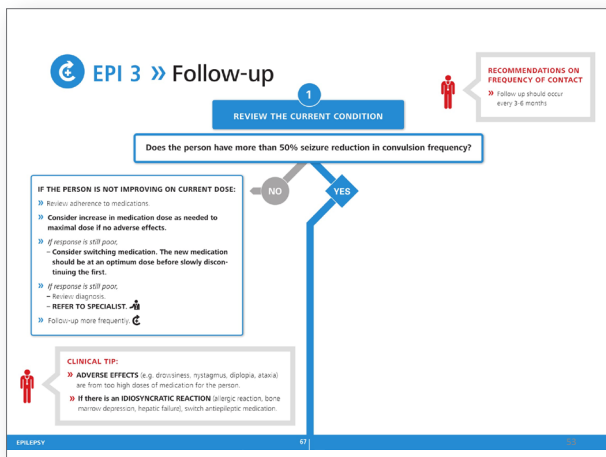
- A health-care provider assessed this person and their spouse and decided that the person has epilepsy.
- The health-care provider now has the responsibility to develop a treatment plan with the person.
- The treatment plan should include psychosocial and pharmacological interventions as well as instructions to the spouse on how to help the person if they have a convulsive seizure at home and when to refer for medical help.

Instructions:

- Divide the participants into groups of four.
- Instruct one person to play the role of the health-care provider, one the person seeking help, one the spouse and one the observer.
- Distribute the role play instructions to each person depending on their role.
- Ensure that the participants keep to the allotted time.

Session 4. Follow-up

 40 minutes



Highlight the recommendations on frequency of contact (page 67 mhGAP-IG Version 2.0) and explain that follow-up should occur every three to six months.

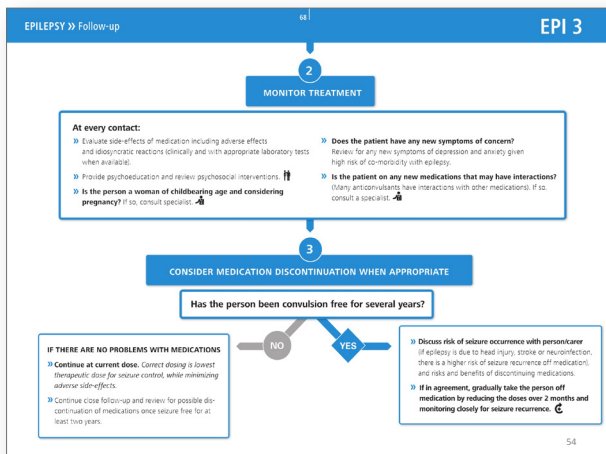
Ask participants why they think that is?

Talk through step 1 of the follow-up algorithm and ask participants to brainstorm what questions they could ask at follow-up?

Possible questions could include:

- Has the person been keeping a seizure diary?
- Have there been any drug specific side-effects?
- Are they taking their medication as prescribed? If not, why not?
- Are they having any other issues?

Describe what to do if the person is not improving on their current dose, highlighting when they should refer.



Describe what should be monitored at regular follow-ups.

Focus on asking about how well they are being accepted and treated by the community.

Describe when to consider stopping medication and why.

Activity 6: Group discussion: How to reduce stigma and discrimination

How to reduce stigma and discrimination?

1. Why is it important that you respect, protect and promote the rights of people with epilepsy?
2. Can you think of some concrete actions that you could undertake to make the rights of people with epilepsy a reality?
3. What would be the positive impact of these actions for all the groups concerned?

Duration: 30 minutes.

Purpose: To have participants reflect and plan what they can do to help reduce stigma and discrimination against a person with epilepsy and their carer.

Instructions:

- Divide the participants into three groups.
 - One group will represent people with epilepsy.
 - One group will represent non-specialized health-care providers.
 - One group will represent the family and carers of people with epilepsy.
- Give each group three pieces of flip chart paper and pens.
- You are going to ask the groups three different questions.
- They should write down their answers to the questions on three separate pieces of flip chart paper.
- Instruct the participants to write down their answers imagining that they are a person from the group they represent.

Question 1: Why is it important that **you** respect, protect and promote the rights of people with epilepsy?

Question 2: Can you think of some concrete actions that you could undertake to make the rights of people with epilepsy a reality?

Question 3: What would be the positive impact of these actions for all the groups concerned?

Possible answers to look for:

Question 1: Why is it important that **you** respect, protect and promote the rights of people with epilepsy?

Potential answers from people with epilepsy:

- We can contribute a wide array of expertise, skills and talents and these can benefit everyone.
- We are human beings and should have the same opportunities as everyone else.
- We know what is best for us; what is helpful and what is not helpful.
- We have the right to participate in all actions and issues that affect us.

Potential answers from health-care providers:

- I want to give the people under my care the respect they deserve.
- It is my legal obligation.
- This is part of my job and responsibility.
- It is the right thing to do.
- By providing care and support that respects people's rights, people are more likely to accept the service we provide, respond well to our care and support and to recover.

Potential answers from family members and carers:

- I can help voice the wishes and preferences of my relative and help explain these to others when needed.
- I want what is best for my relative and these rights give them the best opportunities to live a good life.
- I can have an important role in enabling my relative to live a more fulfilling life by respecting their rights, being more accepting and changing some of my own actions.

Question 2: Can you think of some concrete actions that you could undertake to make the rights of people with epilepsy a reality?

Potential answers from people with epilepsy:

- I can learn my rights and understand them.
- I can explain my rights to my peers, family and the community members.
- I can speak with local officials about the need to change.
- I can help other people in the same situation as me.
- I can talk about my experience to raise awareness about disability and human rights.

Potential answers from health-care providers:

- I can make sure that my clinical practice promotes respect and dignity and the rights of people with epilepsy.
- I can train and inform other staff about human rights and make sure that my colleagues also promote respect and dignity.
- I can talk to people about epilepsy in my work place so that they understand.
- I can speak to service management about taking action to improve treatment for people with epilepsy.
- I can speak with local officials about the need to change.
- I can make sure that people with epilepsy are involved and participate in decisions concerning running services for them.

Potential answers from family members and carers:

- I can explain their rights to my relative.
- I can make my relative feel that I respect them.
- I can try not to over protect my relative.
- I can make sure I listen and respect their views and decisions.
- I can support and encourage my relative to make decisions and become independent.

- I can make sure other family members/community members respect the rights of my relative.
- I can speak with local officials about the need for change and for the creation of the services that meet the needs of my relative and other people with epilepsy.
- I can raise awareness in the community to break down stigma, stereotypes and prejudices.

Question 3: What would be the positive impact of these actions for all the groups concerned?

Potential benefits for people with epilepsy:

- I would have greater independence and be less dependent on my family, friends and health-care provider.
- I would feel more empowered to take control of my own life and recovery.
- I would feel stronger.
- I would be able to develop new skills.
- I would be able to contribute my skills and talents to society and be more included.

Potential benefits for health-care providers:

- I would be able to provide better quality of care for individuals.
- I would see better outcomes for people so I would feel happier in my job.
- I would be able to improve services provided.
- The people to whom I provide care and support would be empowered.
- Relapse and dependency would be reduced.
- I can make the service a better place to work.
- People to whom I provide care would lead more fulfilling and independent lives.

Potential benefits for family members and carers:

- I would feel better and happier because my relative was better and had a better quality of life.
- I would have more time to pursue my own goals as I would need to spend less time caring for my relative.
- I would feel empowered to be able to support my relative and start breaking down prejudice and stereotypes.
- I would feel less stressed and have better mental well-being.
- I would feel empowered to be able to talk to local community leaders and decision-makers about respecting the rights of people with epilepsy.
- I would have a happier family as my relative would be able to engage more in family life.

Session 5. Review



15 minutes

Duration: Minimum 15 minutes (depends on participants' questions).

Purpose: To review the knowledge and skills gained during this training session by delivering MCQs and facilitating a discussion.

Instructions:

- Administer the MCQs (see EPI supporting material) to participants.
- Discuss the answers as a group.
- Facilitate a brief discussion answering any queries or concerns the participants may have.

EPI PowerPoint slide presentation



PowerPoint slide presentation available online at:
http://www.who.int/mental_health/mhgap/epi_slides.pdf

EPI supporting material

- Person stories
- Role plays
- Multiple choice questions
- Video links

Activity 3: mhGAP EPI module – assessment

<https://www.youtube.com/watch?v=RUIRg555xl0&index=6&list=PLU4ieskOli8GicaEnDweSQ6-yaGxhes5v>



Supporting material available online at:
www.who.int/mental_health/mhgap/epi_supporting_material.pdf