

Epilepsy

mhGAP Training of Health-care Providers
Training manual
Supporting material



World Health
Organization

EPI supporting material

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

Activity 3: mhGAP EPI module – assessment

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

EPI person stories

This is a personal story describing what it feels like to live with epilepsy. This story should last between three to five minutes maximum. The story can be adapted as required to fit the context and setting of the training.

You can choose to read out the story in a creative and engaging manner. Or, where available, you can show videos of the person story by downloading the video.

If suitable, seek permission to use a person's story from the local area. If there are service users that you know well who have lived with epilepsy and would like to share their experiences, then ask them to share their story with you. Ask them to describe to you how it feels to live with epilepsy and how it has impacted on their life. You can write this down and use their story, with their consent, to teach other participants.

Person story 1

When I was six years old, I started getting these attacks. My family and I did not understand what was happening to me. When I was walking around the city the attacks would come. If I sat and did nothing they would still come. It felt like there was nothing I could do to control them or stop them.

It was really tough for me. As I started to go to school these attacks would still come, and when they happened in school the other children grew more and more scared of me and started to avoid me. None of the kids wanted to sit next to me in the classroom. In fact they would all move their chairs and tables as far away from me as possible. They thought that they would catch the illness by touching me. People avoided me for so long that I started to believe that I was bad and contagious as well.

(continued)

Person story 1 (continued)

I grew up a very lonely child and never really understood what was happening to me. I tried to help my mother and sisters do the chores in the household, but because of these attacks there were so many things I could not be trusted to do. I couldn't be trusted to cook because of the fire and I never felt free in my own home.

When I had an attack in the streets and I was on my own, I was so vulnerable anyone could have done anything to me, taken me anywhere. I was often found after an attack uncovered or having soiled myself and everyone would know my shame. I was so embarrassed and was afraid to leave the house on my own.

My father would always protect me but my mother was ashamed of me and would get very angry with me. She and my aunts would say that because of the epilepsy I would never be able to get married or have children. I believed that no man would want to marry me and I would often sit down and have a conversation with myself and say, "What kind of life am I going to have?" Some days I would feel so sad that I could not force myself to get out of bed.

After my father, my protector, died, I did meet a nice man and I married him. I was surprised when I became pregnant and I started to understand that what my mother and aunts had told me growing up was wrong. I was nervous about having children and I questioned how well I would be able to look after my babies. I wondered if I would drop them and hurt them if I had an attack. During pregnancy, the attacks were more frequent so I asked for help. I learned about the attacks and understood more about the condition. Now I have two daughters and they know that I have epilepsy and they know that it is not contagious. They have learned my triggers and understand when I am about to have an attack, and when that happens, they help me. They often remind me to take my medication and I am so proud when I hear them educating other children about epilepsy.

It is still hard and my attacks are worse when I am tired and stressed but in general I am able to manage them. The medication has helped a lot and once I got used to taking it regularly it just feels normal now.

I don't feel embarrassed about my epilepsy anymore and I feel sorry for ignorant people who do not take the time to understand me or the condition. As my girls grow up I will start to think about finding a job, but all I can do is take it one day at a time.

Adapted from WHO: Treating and defeating epilepsy in Ghana
<https://www.youtube.com/watch?v=gFxbNO02ok>

EPI role plays

Note: Role plays 3, 4 and 5 are additional to those supplied for the activities – as an option for those wanting to change the role play scenarios and help participants develop different skills.

Role play 1: Assessment

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

Duration: 25 minutes.

Situation: **PERSON SEEKING HELP**

- You did not want to come and seek help.
- You believe that you fainted because you have been feeling very tired recently.
- You do not remember fainting and you do not know how long you fainted for, but your spouse has told you that you were shaking for one minute and unresponsive for five minutes.
- This has happened before, about six months earlier, but you were on your own.
- Again, you do not remember how it happened but you do remember waking up and feeling very stiff and achy.
- You do not have a fever, headache, or any symptoms of a neuroinfection. You do drink alcohol, but not very much. You have never used drugs.
- After you fainted you felt very tired and sleepy. Your muscles were aching and you felt weak.
- You do not have a family history of seizures, your birth was normal and you have not had a head injury or suffered any physical trauma.
- You do not have any concurrent MNS conditions.

Instructions:

Let your spouse start the conversation.

Role play 1: Assessment

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

Duration: 25 minutes.

Situation: **CARER SEEKING HELP**

- You saw your spouse collapse in the garden. You rushed over and watched her shaking on the floor for about one minute.
- You were scared and did not know what to do.
- After the shaking stopped your spouse was unresponsive for five minutes even though you were shouting loudly in her ear.
- You noticed that your spouse had been incontinent of urine during the event.
- You asked your spouse to seek help but she would not.
- You noticed how drowsy your spouse was after the event and it took her some time to recover to normal.
- You are very worried that there is something seriously wrong with her.

Instructions:

You are to start the conversation by talking about how worried you are.

Role play 1: Assessment

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

Duration: 25 minutes.

Situation: **HEALTH-CARE PROVIDER**

- 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.
- Conduct an assessment using the mhGAP-IG page 58 to establish whether the person has epilepsy.
- Use effective communication skills with the person and their spouse to establish:
 - Was the seizure convulsive?
 - Did the seizure have an acute cause?
 - Does the person have epilepsy?
 - Are there concurrent MNS conditions?

Instructions:

- The carer seeking help will start the conversation.
- You are to conduct an assessment and then explain your findings.

Role play 1: Assessment

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

Duration: 25 minutes.

Situation: **OBSERVER**

- 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.

Instructions:

Please keep to time:

- 3 minutes reading
- 10–15 minutes' interview
- 5–10 minutes for feedback and small-group discussion.

Please assess the following competencies:

4. Uses effective communication skills
5. Performs assessment
6. Assesses and manages physical condition

Grade the level of competency the health-care provider achieves.

Role play 2: Management

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

Duration: 40 minutes.

Situation: **PERSON SEEKING HELP**

- A health-care provider assessed you and your spouse and decided that you have epilepsy.
- React in a way you think people would upon learning they had epilepsy (including showing any shock, fear, judgement and stigma, resistance, questioning the skills of the health-care provider etc.).
- Listen to the psychoeducation delivered by the health-care provider and ask any questions you may have.
- Ask the health-care provider what you can do to get better. Work with the health-care provider to help you manage the condition.

Instructions:

The health-care provider will start the conversation.

Role play 2: Management

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

Duration: 40 minutes.

Situation: **CARER SEEKING HELP**

- A health-care provider assessed your spouse and decided they have epilepsy.
- Ask any questions you believe a spouse may have upon hearing that their spouse had a diagnosis of epilepsy (including showing any shock, fear, judgement or stigma).

Instructions:

The health-care provider will start the conversation.

Role play 2: Management

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

Duration: 40 minutes.

Situation: **HEALTH-CARE PROVIDER**

- You have just assessed this person and their spouse and diagnosed them with epilepsy.
- You now have 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:

- Start by explaining the results of the assessment and explaining that the person has a condition called epilepsy.
- Ensure that you give appropriate psychoeducation to the person with epilepsy and their spouse.
- Explain that you would like to start the person on antiepileptic medication
- Describe the medication, possible risks and benefits, dosage etc.
- Create a care plan with the person using strategies to promote functioning in daily activities and community life.

Role play 2: Management

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

Duration: 40 minutes.

Situation: **OBSERVER**

- 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:

Please keep to time:

- 3 minutes reading
- 15–20 minutes' consultation
- 5–10 minutes for feedback and small-group discussion.

Please assess the following competencies:

8. Provides psychosocial intervention
9. Delivers pharmacological intervention

Grade the level of competency the health-care provider achieves.

Ensure that the health-care provider discusses ways to promote the person's functioning in daily activities. Ensure the health-care provider mentions risks of driving, cooking on an open fire, swimming alone, excessive use of alcohol etc.

Role play 3: Emergency management

Purpose: To enable participants to practise emergency assessment and management of epilepsy.

Duration: 30 minutes.

Situation: **PERSON SEEKING HELP**

- You are Nikolaj, a 17-year-old boy.
- In the past, you have had “episodes” where you felt strange and noticed a funny smell, then blacked out. When you wake up you have been incontinent of urine.
- People have told you that during these episodes you shake. You often wake up feeling confused and sore.
- It happened at school two years ago and you were told not to come back so that you did not make the other children sick. You have not been back since. Your family has put you to work making things to sell in their shop instead.
- You are otherwise well.
- Today, you felt the strange feeling and funny smell coming on, and your mother has taken you to the health clinic which is nearby.

Instructions:

- You will start the conversation by saying that you do not feel well and you want to lie down.
- When you lie down on the floor you will “pass out” and then start shaking.
- You black out for a long period. You may stop shaking intermittently but then you start again.
- You only wake up once the health-care provider has stated that they are going to give you an anticonvulsant intravenously. When you wake up you are still quite confused.

Role play 3: Emergency management

Purpose: To enable participants to practise emergency assessment and management of epilepsy.

Duration: 30 minutes.

Situation: CARER SEEKING HELP

- You are Siti, 44-year-old mother to Nikolaj.
- Nikolaj has had these funny episodes for a few years now.
- The episodes are frightening – he will pass out, then start shaking, be incontinent of urine, and then be confused for a while afterwards.
- He had to leave school a few years ago, which made you very sad. You are also worried that he will never get a wife because of these episodes.
- People have told you different things – that maybe he is possessed, or that you will “catch” the same condition and start having the episodes too.
- Today he has told you he thinks one of the episodes is coming on. You have taken Nikolaj to the health clinic.
- You have explained to the health-care provider what has happened in the past.

Instructions:

- You accompany Nikolaj and assist. When he starts to become more unwell you become very upset.
- Once the emergency is over, the health-care provider may ask you some questions about Nikolaj’s health. You should answer in the negative or say that you do not know, and that he is fine apart from these episodes.

Role play 3: Emergency management

Purpose: To enable participants to practise emergency assessment and management of epilepsy.

Duration: 30 minutes.

Situation: HEALTH-CARE PROVIDER

- You are a local health-care provider in a small community.
- A lady called Siti and her son Nikolaj rush in.
- Nikolaj looks unwell.
- Siti tells you she is worried he is going to have another episode. The episodes sound to you like epilepsy – she describes that he falls down, starts shaking and becomes incontinent. He is often confused when he wakes up.

Instructions:

- Nikolaj will start the conversation.
- Perform emergency assessment and management of Nikolaj for suspected epilepsy as per page 57 of mhGAP-IG Version 2.0.
- You will get extra information on physical assessment as you proceed through the role play.
- If a medication or other invasive treatment is needed, say verbally what you would like to give.

Role play 3: Emergency management

Purpose: To enable participants to practise emergency assessment and management of epilepsy.

Duration: 30 minutes.

Situation: **OBSERVER**

- Nikolaj is a 17-year-old boy who seems to have a history of seizures.
- His mother, Siti, has run to the health-care provider as Nikolaj feels a seizure coming on.
- The health-care provider will perform emergency assessment and management of Nikolaj for suspected epilepsy.

Instructions:

- You will need to provide the following extra information to the health-care provider as they proceed through the examination.
- If they check ABCs, report that Nikolaj has nothing in their airway, is breathing fine and has a stable pulse.
- If they check vital signs, tell them the following (on every occasion):
 - BP 148/102
 - Pulse 127
 - O2 saturation 96%
 - Temp. 36.4 degrees
 - RR 10.

Nikolaj is in status epilepticus so will not wake up until intravenous anticonvulsants are administered. The role play should end once the health-care provider assesses/evaluates for an underlying cause of the convulsions, as per page 57 of mhGAP-IG Version 2.0.

Please keep to time:

- 3 minutes reading
- 10–15 minutes' consultation
- 5–10 minutes for feedback and small group discussion.

Please assess the following competencies:

7. Assesses and manages emergency presentation

Grade the level of competency the health-care provider achieves.

Role play 4: Management

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

Duration: 40 minutes.

Situation: **PERSON SEEKING HELP**

- You are Nikolaj, a 17-year-old boy.
- An hour ago, you had a witnessed seizure, and the health-care provider has now diagnosed you with epilepsy.
- You still feel quite groggy and out of it, but you are interested to know what epilepsy means and what the treatment will be. You are particularly interested to know if this means you can go back to school.

Instructions:

- Let the health-care provider start the conversation.
- You ask a few questions on anything you are not sure about.

Role play 4: Management

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

Duration: 40 minutes.

Situation: **CARER SEEKING HELP**

- You are Siti, 44-year-old mother to Nikolaj.
- He has just had another seizure, which the health-care provider has told you is “epilepsy”. You do not know what this means but you are worried.
- Nikolaj has had a few episodes before and you have had to pull him out of school. You are worried he will never get married. People have told you he might be possessed.
- The health-care provider is about to tell you what the treatment will be.

Instructions:

Let the health-care provider start the conversation.

Role play 4: Management

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

Duration: 40 minutes.

Situation: **HEALTH-CARE PROVIDER**

- You are a health-care provider working in a local clinic.
- You have just witnessed Nikolaj, a 17-year-old boy, have a seizure after being brought in by his mother, Siti.
- You have diagnosed epilepsy.
- You learn that Nikolaj has been taken out of school because of previous seizures, and that Siti has been very worried about him. Neither of them knows what epilepsy is.
- You now have the responsibility to develop a treatment plan with the person.
- The treatment plan should include psychosocial and pharmacological interventions as well as instructions to Siti on how to help Nikolaj if he has a convulsive seizure at home.

Instructions:

- You are to start the conversation.
- Start by explaining the results of the assessment and explaining that Nikolaj has a condition called epilepsy.
- Ensure that you give appropriate psychoeducation to Nikolaj and Siti.
- Explain that you would like to start the person on antiepileptic medication.
- Describe the medication, possible risks and benefits, dosage etc.
- Create a care plan with Nikolaj and Siti using strategies to promote functioning in daily activities and community life.

Role play 4: Management

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

Duration: 40 minutes.

Situation: **OBSERVER**

- The health-care provider has just assessed and managed Nikolaj, a 17-year-old boy who has had a seizure.
- The health-care provider has diagnosed him with epilepsy.
- The health-care provider will now need to develop a treatment plan, including psychosocial and pharmacological interventions, as well as instructions to Siti on how to help Nikolaj if he has a convulsive seizure at home, and appropriate psychoeducation.

Instructions:

Please keep to time:

- 3 minutes reading
- 15–20 minutes' consultation
- 5–10 minutes for feedback and small group discussion.

Please assess the following competencies:

4. Uses effective communication skills
8. Provides psychosocial intervention
9. Delivers pharmacological intervention

Grade the level of competency the health-care provider achieves.

Ensure that the health-care provider discusses ways to promote the person's functioning in daily activities, particularly encouraging Nikolaj to return to school and giving reassurance that he can live a normal life. Ensure the health-care provider mentions the risks of driving, cooking on an open fire, swimming alone, excessive use of alcohol etc.

Role play 5: Follow-up

Purpose: To enable participants to practise performing follow-up for a person with epilepsy.

Duration: 30 minutes.

Situation: **PERSON SEEKING HELP**

- You are Nikolaj, a 17-year-old boy who was diagnosed with epilepsy.
- It is now six months later, and you are attending for a follow-up review with the health-care provider.
- You started taking the medication the health-care provider gave you after the witnessed seizure, and it seemed to work well – you had no more seizures and managed to go back to school, which you are very happy about.
- You have had no more seizures since then.

Instructions:

Let the health-care provider start the conversation.

Extended version (only read this if instructed by facilitator)

Option 1: As per above, but you are having terrible side-effects with the medication. You feel sleepy and unsteady on your feet, and you have fallen over and also fallen asleep at school.

Option 2: You actually stopped the medication two weeks ago as your mother wanted to save some money to pay for your schooling. Since then, you have had two seizures, but you have not told anyone as you are worried you will not be able to go to school.

Role play 5: Follow-up

Purpose: To enable participants to practise performing follow-up for a person with epilepsy.

Duration: 30 minutes.

Situation: **CARER SEEKING HELP**

- You are Siti, 44-year-old mother to 17-year-old Nikolaj.
- Six months ago Nikolaj was diagnosed with epilepsy by the health-care provider.
- He has been taking medication since then and the seizures have stopped.
- He has returned to school.
- You are attending for follow-up.

Instructions:

Let the health-care provider start the conversation.

Extended version (only read this if instructed by facilitator)

Option 1: As per above, but Nikolaj is having terrible side-effects with the medication. You often notice he is sleepy and unsteady on his feet. He has fallen over and fallen asleep when he should be helping you around the house.

Option 2: Two weeks ago, you asked Nikolaj to stop the medication. Now that he is back at school there is less money in the house, and you thought that because he has been so well and not had any seizures that he must be cured and no longer needed the medication.

Role play 5: Follow-up

Purpose: To enable participants to practise performing follow-up for a person with epilepsy.

Duration: 30 minutes.

Situation: **HEALTH-CARE PROVIDER**

- You are about to review Nikolaj, a 17-year-old boy, with his mother, Siti.
- You diagnosed Nikolaj with epilepsy six months ago after you witnessed him having a seizure.
- They have returned for follow-up.

Instructions:

- Turn to page 67 of mhGAP-IG Version 2.0 and perform follow-up for Nikolaj.
- You are to start the conversation.

Extended version (only read this if instructed by facilitator)

An extended version option is available for this role-play. Even if instructed to complete this, continue to perform follow-up using page 67 of your mhGAP-IG Version 2.0.

Role play 5: Follow-up

Purpose: To enable participants to practise performing follow-up for a person with epilepsy.

Duration: 30 minutes.

Situation: **OBSERVER**

- Nikolaj is a 17-year-old boy, accompanied by his mother, 44-year-old Siti.
- Nikolaj was diagnosed with epilepsy by this health-care provider six months ago after a witnessed seizure.
- He was commenced on medication and has been seizure-free since then.
- Nikolaj and his mother are attending for follow-up.

Instructions:

Please keep to time:

- 3 minutes reading
- 15–20 minutes' consultation
- 5–10 minutes for feedback and small group discussion.

Please assess the following competencies:

- 4. Uses effective communication skills
- 10. Plans and performs follow-up

Grade the level of competency the health-care provider achieves.

Extended version (only read this if instructed by facilitator)

Option 1: As per above, Nikolaj is having terrible side-effects with the medication. He feels sleepy and unsteady on his feet, has have fallen over and also fallen asleep at school.

Option 2: Nikolaj actually stopped the medication two weeks ago as Siti wanted to save some money to pay for his schooling. She thought he must be cured as he has not had any seizures. Since then, Nikolaj has had two seizures, but has not told anyone as he is worried he will not be able to go to school.

EPI multiple choice questions

1. Which of the following is a common presentation of epilepsy? Choose the best answer:
- A Delayed developmental milestones.
 - B Slow respiratory rate and pinpoint pupils.
 - C Tremor in hands, sweating and vomiting.
 - D Convulsive movements or fits.
-
2. Which of the following is a common presentation of epilepsy? Choose the best answer:
- A Loss of consciousness, stiffness/rigidity, tongue-biting and urinary incontinence.
 - B Marked behavioural changes and neglecting usual responsibilities.
 - C Bleeding from a self-inflicted wound.
 - D Smell of alcohol on breath, slurred speech and uninhibited behaviour.
-
3. Which of the following statements concerning epilepsy is correct? Choose the best answer:
- A Epilepsy is a communicable disorder of the brain.
 - B Epilepsy is a sign of spirit possession.
 - C Epilepsy is always genetic in cause.
 - D Epilepsy is one of the most common neurological disorders.
-
4. Which of the following statements concerning epilepsy is correct? Choose the best answer:
- A Epilepsy can often cause people to be dangerous to others.
 - B Epilepsy does not occur in children or adolescents.
 - C Epilepsy can be well-controlled in the majority of people with proper treatment.
 - D Epilepsy does not present as an emergency situation and does not always require medication.
-
5. Which of the following is a common cluster of symptoms in epilepsy? Choose the best answer:
- A Eclampsia and fever, followed by head injury.
 - B Signs of poisoning and self-harm, followed by loss of consciousness.
 - C Loss of consciousness and tongue-biting, followed by confusion.
 - D Nausea and headache, followed by increased pulse.
-
6. Which of the following is a common cluster of symptoms in epilepsy after a seizure? Choose the best answer:
- A Drowsiness, confusion, abnormal behaviour.
 - B Extreme hopelessness and despair, thoughts of self-harm or suicide.
 - C Excessive crying, clinging to a carer, sleeping and eating difficulties.
 - D Dilated pupils, abdominal cramps, diarrhoea.

-
7. Which of the following is an important step in the emergency treatment of someone with epilepsy having a convulsion? Choose the best answer:
- A Use a calm voice when talking with the patient and listen carefully.
 - B Check airway, breathing and circulation.
 - C Give intramuscular or subcutaneous naloxone.
 - D Give thiamine injection.
-
8. Which of the following is the best combination treatment for epilepsy? Choose the best answer:
- A Seeing a traditional healer and taking herbal products as advised by them.
 - B Pharmacological interventions and herbal products.
 - C Psychosocial interventions and antiepileptic medication.
 - D Psychosocial interventions and magnesium sulphate.
-
9. Which of the following might you say to a carer of someone with epilepsy? Choose the best answer:
- A Epilepsy is contagious – they should be careful of touching the person when they are having a seizure.
 - B When the person is having a seizure they should try and restrain them.
 - C The person only needs medication if they feel that a seizure is imminent.
 - D Epilepsy is the recurrent tendency for convulsions.
-
10. Which of the following requires emergency medical treatment? Choose the best answer:
- A When someone starts to feel that a seizure is imminent.
 - B If the seizure lasts for more than one minute.
 - C If the seizure lasts for more than five minutes.
 - D If the person is drowsy once the seizure is over.

EPI multiple choice answers

- | | |
|--------|---------|
| 4. = C | 8. = C |
| 3. = D | 7. = B |
| 2. = A | 6. = A |
| 1. = D | 5. = C |
| | 9. = D |
| | 10. = C |