

16 Taking action against epilepsy stigma

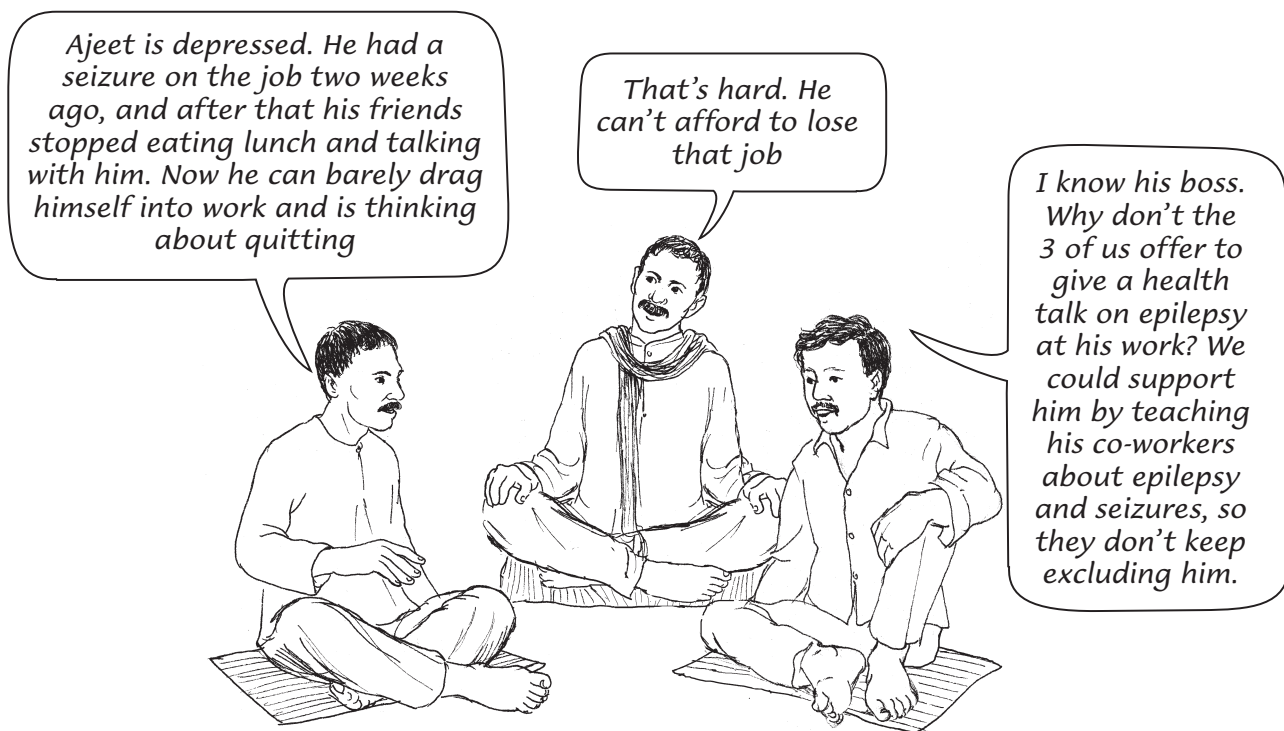
## Raising awareness in the community challenges stigma

Forming a support group for people living with epilepsy and getting comfortable talking about its daily challenges and joys helps to reduce self-stigma. As group members gain comfort and confidence about speaking up, it can also be a stepping stone towards raising awareness in the larger community about epilepsy and addressing interpersonal and institutional stigma.

### People with epilepsy can drive community education

Helping communities understand epilepsy and seizures is key to reducing stigma and the harm it causes. Because stigma keeps people from talking about epilepsy, one way to act against stigma is to do the opposite—support communities to learn about epilepsy.

When people with epilepsy or their family members lead community discussions and education sessions on the topic, their words carry the strength of lived experience. They are more likely to speak not just from knowledge but from the heart. Their stories and explanations are strengthened by real experiences of fear, courage, and resilience. Their personal conviction helps others listen more closely, ask questions more openly, and begin to challenge their own ideas and actions which may reflect interpersonal stigma and discrimination. Interacting personally with people affected by epilepsy breaks down fear and builds empathy and understanding, all necessary ingredients for people to take action against stigma.



## Sharing correct information reduces stigma and harm

No matter what beliefs exist about epilepsy in a community, and no matter how stigma is showing up, community education can always help. Sharing correct information about what does and does not cause epilepsy and seizures, and how people with epilepsy can be helped, is one way to begin educating your community.

### ACTIVITY

#### Epilepsy quiz: True or False?

When people refuse to talk openly about something, all sorts of ideas and explanations can develop that may or may not be true. This is certainly the case with epilepsy. This activity can help a group raise and talk about the many commonly held beliefs about epilepsy and if they are true. By identifying which are false and harmful, we can undermine the ones that cause stigma. This activity can work with any number of people.

To prepare, create a deck of cards where each card has one of the statements below on it.

#### Statements:

- Epilepsy can be caused by a head injury.
- You can get epilepsy by touching someone who had a seizure.
- Seizures are a punishment from a past life.
- A woman who has seizures should not get married or have children
- Epilepsy is a medical condition and can be treated.
- Rubbing animal blood on a person with epilepsy will help them heal.
- Taking daily medicine can help control seizures.
- A nail must be hammered into the head to release the spirit causing seizures.
- People with epilepsy should be avoided.
- A baby can develop epilepsy if the brain is injured during birth.
- Sharing food with a person who has epilepsy is dangerous.
- Stress or trauma can sometimes lead to seizures.
- Smoke from burnt herbs will stop a seizure.
- Rest, exercise, and good food can help control seizures.
- Epilepsy is caused by a curse.
- Sometimes people get seizures, and no one knows why.
- A baby can get seizures from a high fever. *Continues*

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ACTIVITY

**Epilepsy quiz: True or False?** *(Continued)*

- Some children “grow out of” having seizures.
- If a mother has epilepsy, her children will also.
- You can get epilepsy by kissing.
- Some people can tell when they are going to have a seizure.

Add other beliefs common in your community to the deck.

**1 Introduction**

Start the activity by pointing out that many people have likely heard different things about what causes seizures or how to treat epilepsy. Some of the ideas are true and helpful, and others are false, based on myths, rumors, or fear, and often contribute to stigma. The purpose of this activity is to learn about epilepsy and identify beliefs that are wrong and can lead to stigma and harm.

**2 Play the cards**

People form a line and one at a time pick a card, read it aloud, and say whether they think it is true or false. After they decide, invite the group to briefly discuss whether they agree. If they are unsure or raise other questions, clarify the information as necessary.

**3 Group reflection**

After all the cards have been read and discussed, ask questions like these and others that flow from your discussion.

- What surprised you?
- How do these beliefs affect people with epilepsy in our community?
- How do some of the beliefs promote epilepsy stigma?
- What can we do to share helpful information that will reduce stigma?

As you lead the group in talking about these issues, remind them that while we may not always be able to change a person’s beliefs, we can try to keep wrong information and harmful beliefs from hurting people with epilepsy. Beliefs should never be used to shame, isolate, or harm anyone.