Helping mothers feel confident about breastfeeding

There will be less stigma against people with epilepsy breastfeeding when families and communities have correct information about epilepsy. Help people learn that breastfeeding cannot cause epilesy and seizures. Let others know that epilepsy cannot be passed through breastmilk to the baby. Encourage mothers with epilepsy to have confidence in their ability to breastfeed.

One way to build confidence is to bring together a group of mothers with epilepsy and their babies and encourage them to enjoy each other's company. As they share experiences and tips about breastfeeding and parenting, they can also share ideas about how to challenge epilepsy myths and stigma. For more information about other ways to challenge stigma, see Chapter 5.

Caring for your baby

Bathing and changing your baby. If you have seizures that make you lose consciousness or control over your movements, or your seizures are not controlled by medicine, try to have another person around when you bathe or change your newborn baby. Having assistance ensures both you and your baby are safe if a seizure happens. A support person can move you and your baby away from danger, provide any needed first aid, or get help in an emergency.

Change your baby's diapers (nappies) on a mat or blanket on the floor, to avoid any problems if you have a seizure.

Sleeping with your baby. After having a baby, getting enough sleep can be hard, especially when you are feeding your baby every few hours at night. Try to prevent lack of sleep from triggering your seizures. Rest when your baby sleeps and ask family and friends for help so you can get as much rest as possible.

If you have sleep seizures, movements caused by a seizure might injure your small baby sleeping next to you. Instead, have your baby sleep nearby in a bassinet or crib.

Carrying your baby in a sling. If your seizures are well-controlled, a sling for your small baby can be used safely. The sling should keep the baby secure and close to your body, but make sure the baby's face is visible so they have no difficulty breathing. Because babies do not have neck control until they are about 3 months old, avoid carrying very young babies on your back. Babies carried in front get bounced around less and have less trouble breathing.

If your seizures are not well-controlled, consider using a stroller or pram instead.

Improving local epilepsy care for mothers

When health services, education, and antiseizure medicines are made available nearby, pregnant people with epilepsy can get the care they and their babies need. Local programs get information out more quickly and help the community help itself.

Neurology on Wheels takes epilepsy care to the village

In India, the community health program Neurology on Wheels delivers care for people with epilepsy to support safer and healthier pregnancies.

Neurology on Wheels is a traveling clinic that visits villages in the state of Andhra Pradesh to provide services to people who cannot easily get to hospitals or clinics. A medical team led by a neurologist offers epilepsy checkups and gives free medicines. The program includes education for families to correct common misunderstandings, like the belief that women with epilepsy should not get married or have children, or that epilepsy is not treatable.

Neurology on Wheels works with the government's ASHA network of community health workers. ASHAs are trained female community health activists already involved with pregnancy care and women's health. By teaming up with ASHAs, the program adds epilepsy care and follow-up to the support available to rural women during pregnancy.

Neurology on Wheels shows how access to the right medicine and support enables women with epilepsy to have safe pregnancies and healthy babies:

- They get the medicines and health attention they need.
- They reduce fear and shame about epilepsy and pregnancy.
- Community health workers are trained to provide them with basic care and support before, during, and after pregnancy.

In rural areas where there is little or no organized government support for health, local health workers often step up to provide care. Then they need to involve the community in finding ways to make the care sustainable.

Epilepsy care far from cities

Nuru's labor pains had already started when she knocked on the door of the birth center in a small village in Uganda. Aisha was the midwife on call that night. She welcomed Nuru, gave her a little food and drink, helped her walk around and keep moving, and comforted her when her water broke. By sunrise, Nuru was the mother of a baby girl, Tomanika. She was exhausted by the delivery and quickly fell asleep.

Aisha noticed Nuru made jerking movements in her sleep. Even after she woke up, Nuru's face and arms moved uncontrollably. She had trouble holding and breastfeeding Tomanika because she felt so poorly. She was afraid she would drop her baby. Aisha saw Nuru was having different types of seizures—sometimes she lost consciousness, but other times she did not. She asked Nuru about her seizures.

Nuru explained her seizures began a few years ago after she fell and hit her head while working. When a health camp was held near her village, she talked to a visiting doctor. She even showed the doctor burn scars on her arm that she got during a seizure while cooking. The doctor gave her medicine to take every day—once in the morning and once at night.

The medicine made Nuru sleepy. Still, she took it every day as the doctor said. After some days, Nuru felt better. Her seizures happened less often. But her medicine ran out. Travel to the district health center was costly and Nuru had no money to buy medicine. All she could do was to wait for the next health camp.

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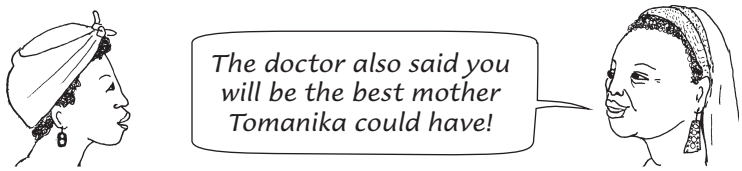
Epilepsy care far from cities *(continued)*

During the months she waited, Nuru's seizures returned. At the next health camp, she was given a different medicine. The new medicine slowed her seizures but gave her such terrible headaches that she stopped using it.

Shortly after this, Nuru got pregnant.

After hearing Nuru's story, Aisha phoned a doctor at the government hospital in the capital city who knew about epilepsy. She described Nuru's seizures—what they looked like, how many times they happened in a day, and how they left her feeling. She also told the doctor about Nuru's experiences with the 2 different medicines and how important it was that she be able to breastfeed her newborn.

The doctor agreed to send a 3-month supply of a different medicine by motorcycle to the birth center, at no charge. She explained the initial dose and then how to adjust it until it worked best.



Nuru's seizures lessened and then stopped with medicine. She began to sleep through the night, and her health improved. Tomanika was breastfeeding and gaining weight. But Aisha was worried. She knew that Nuru's farm work would not allow her to pay for more medicine, even though the medicine did not cost very much.

Aisha decided to offer Nuru work at the birth center tending the garden, caring for the chickens, and sweeping the compound. The person doing these jobs was away for a few months and Nuru could take over until they returned. This would help cover the cost of Nuru's medicine for some months. Tomanika could stay in the nursery while her mother worked.

But how could they ensure Nuru continued to get the antiseizure medicine she needed every day? After all, the job at the birth center was temporary, and there were few opportunities for women in the village to work and earn enough to pay for the medicine.

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