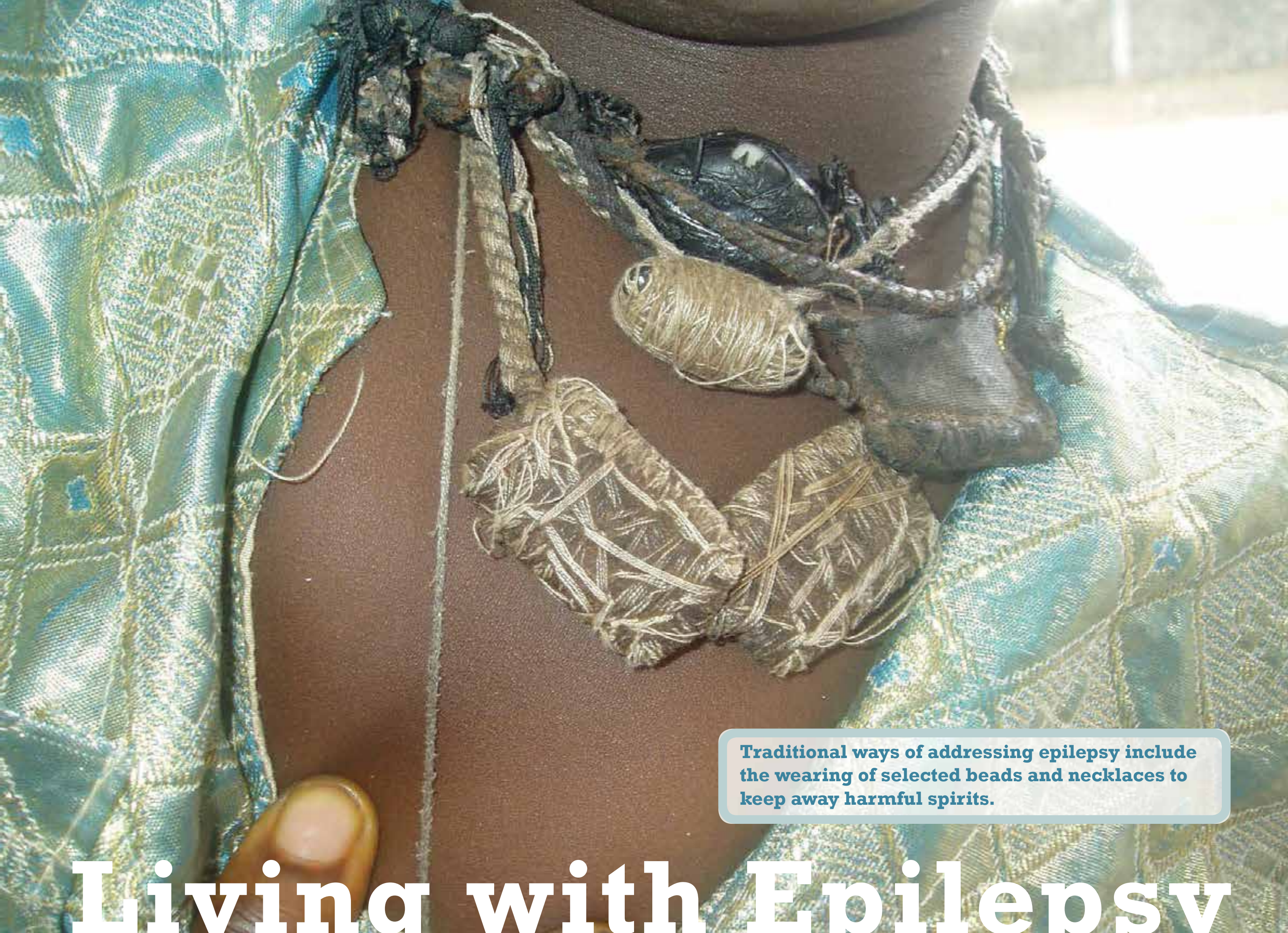




Traditional ways of addressing epilepsy include the wearing of selected beads and necklaces to keep away harmful spirits.

Living with Epilepsy in Sierra Leone



Alhassan Sesay tried several traditional healers before seeking help at the Epilepsy Association of Sierra Leone

Traditional Medicine

Families often spend large sums of money on local healers to try to cure epilepsy. Traditional local medicine employs herbal remedies, rituals, spiritual cures or combinations of all these. Some methods can be dangerous and can result in long-term health complications. Scarification of the arms or the face is very common; this can lead to skin infections, including tetanus. Some 'treatment' involves intense 'fumigation' with smoke from a herb mixture, sometimes leading to respiratory complications. Some of the oral concoctions have been known to be toxic, leading to serious gastrointestinal symptoms.

A survey of patients at the epilepsy clinic in Freetown found that over 75% had tried traditional treatment.





Living with Epilepsy in Sierra Leone

“*Danella was asked to leave school by her teachers because they thought that the epileptic fits that she was experiencing might be contagious. When Danella went to the Epilepsy Association of Sierra Leone to control her seizures, they also worked with the school to get her re-accepted, explaining that epilepsy was not contagious, that her epilepsy can be managed with medication, and offering support on how to help if there was a seizure at school.*”



Education

In Sierra Leone, people with epilepsy are less likely to receive an education than those without the condition. As in most resource-poor settings, the direct and indirect costs associated with attending school - uniforms, transportation, exam fees and the loss of family members' engagement in economic activity - prevent substantial numbers of children from participating. At the newly opened epilepsy clinic in Freetown, it was found that 48% of school-going children discontinued schooling because of their epilepsy. Misunderstandings about epilepsy, its causes and how it may be treated often leads to discrimination in the educational setting.



Living with Epilepsy in Sierra Leone

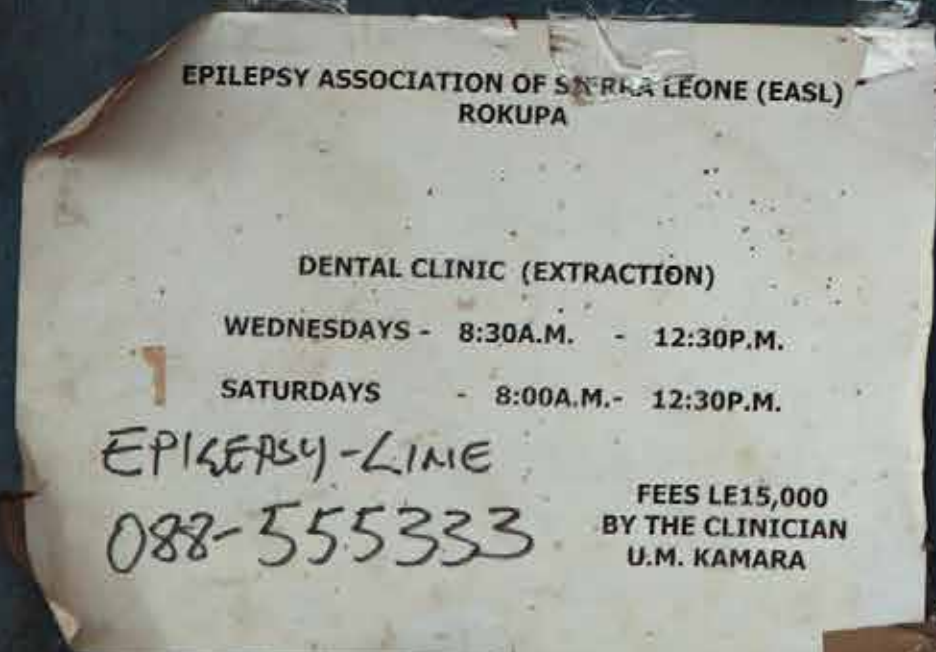
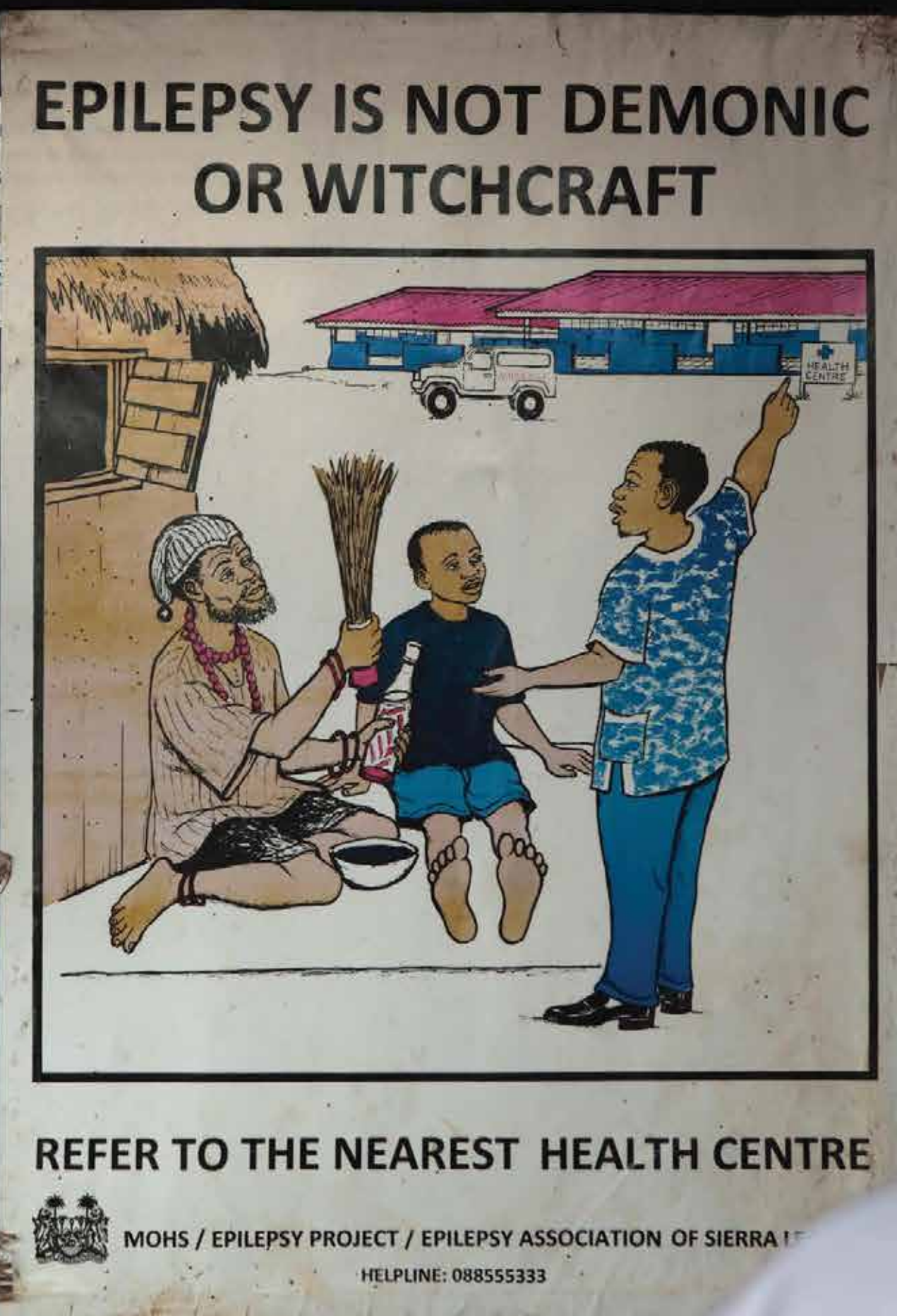
Many people with epilepsy have been excluded from school or college and thus, even when their epilepsy is being controlled by medication, find it difficult to get work. Unemployment, coupled with the medical costs associated with having a chronic disease, place a great financial burden on patients and their families.

Livelihoods

In response to this, the Epilepsy Association of Sierra Leone (EASL) has set up a small training institute to teach members a variety of basic skills with which they can earn a living. Classes are held everyday at the small institute which is attached to the EASL.

There is still though a great need for awareness-raising; many members of the Association report that the stigma of the condition can stop customers from frequenting their businesses for fear of 'contamination'.





Living with Epilepsy in Sierra Leone



Awareness & Support

“Research at the Freetown clinic concluded that there is a lack of knowledge and a reluctance on the part of patients and their families to seek timely medical treatment. The average delay in seeking medical care was found to be 6.5 years after onset.”

Research by Lisk, Moses, Jalloh and Mansaray 2011



The stigma of epilepsy and the resultant isolation of sufferers needs to be addressed systematically if those affected are really to get the support that they require. The Epilepsy Association of Sierra Leone (EASL) has been supporting people affected by epilepsy in Sierra Leone for over ten years.

The Association is run by a small dedicated team of people, led by Coordinator and Founder, Max Bangura.

EASL travels the length of the country every month distributing anti-epileptic drugs to patients as well as educating patients, families and communities to address the disabling stigma associated with epilepsy. EASL has a network of eighteen local educational volunteers who support patients and families in their home environment. The Association runs a helpline offering advice to those affected by epilepsy, manages a drop-in centre and coordinates a skills training programme.

Amara Bangura's epilepsy caused him to collapse whilst playing football with his friends and he suffered serious injuries to his spine. He could not walk for a year.

“ *I didn't like seeing my friends go to school while I stayed at home. Sometimes I would cry, because instead of going to school I would be home, defecating myself because I couldn't even get up to go to the toilet. I felt very sad. My friends would leave the ball and come play indoor games with me, but they would soon go back outside to play football.* **”**

It was through the Epilepsy Association of Sierra Leone (EASL) and the intensive support of a volunteer physiotherapist that Amara was finally able to walk again. However being disabled for that long has had a permanent effect on Amara.

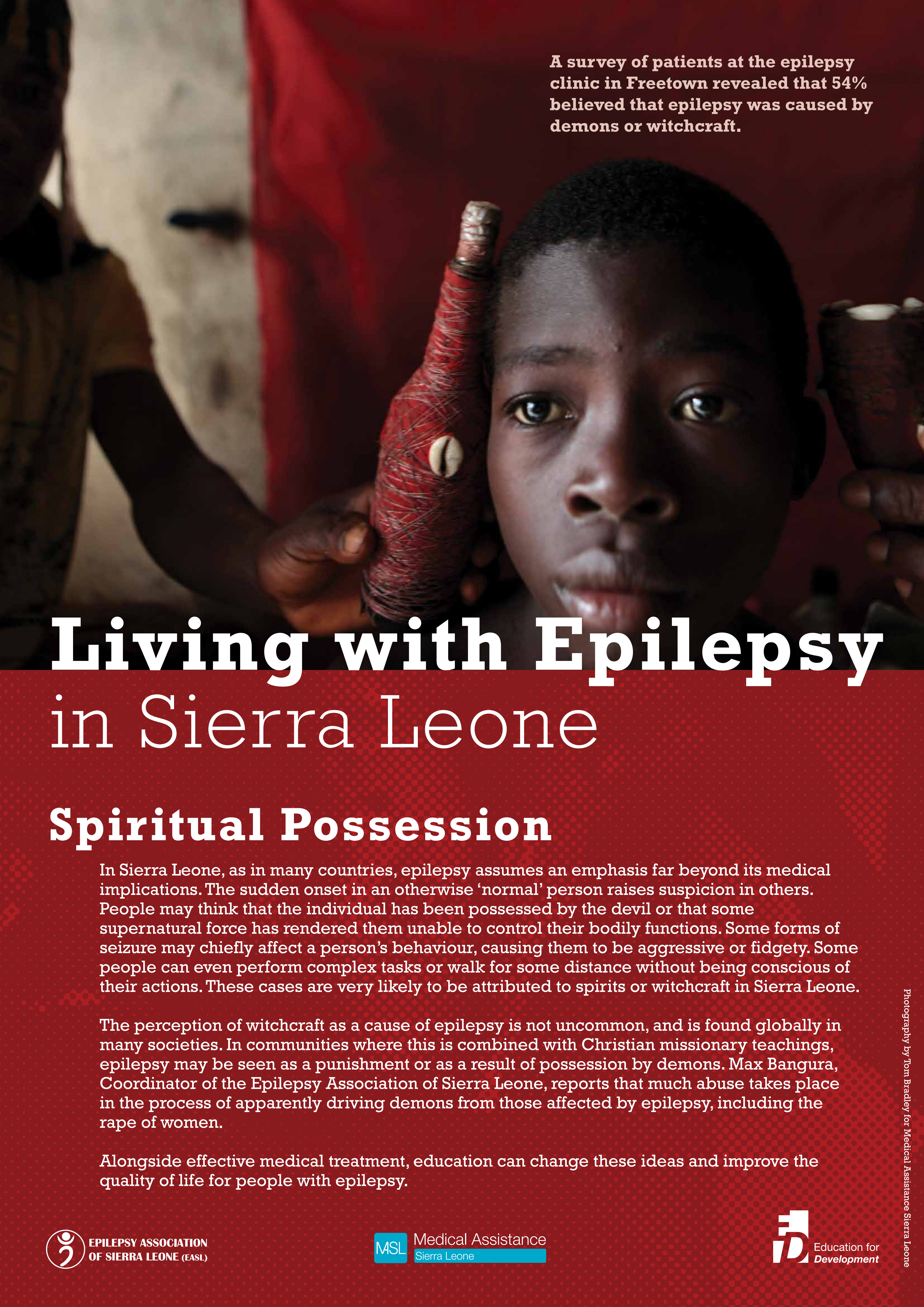


Living with Epilepsy in Sierra Leone

Injury through Seizure

The Epilepsy Association of Sierra Leone (EASL) reports that large numbers of its membership have sustained injuries during seizures. Drowning and burns from open cooking fires present the greatest danger. Indeed, among the Bassá and Bambiliké communities of Central Africa, epilepsy is known as 'the disease of people with burns'.

The country's first epilepsy clinic opened in February 2010 and many of the patients who have come to the clinic have presented with extensive and disabling burns, and other serious injuries. Misunderstandings about the condition can prevent people coming to the aid of someone experiencing an epileptic seizure. Many believe that one should keep clear of a person during these attacks and avoid contact with all body fluids. This is particularly the case with the saliva, which is widely believed to carry contagions. As a result, the person is often left unattended and may sustain severe injuries, such as fractures or burns or even die from avoidable causes, such as obstructed breathing or inhalation of vomit.



A survey of patients at the epilepsy clinic in Freetown revealed that 54% believed that epilepsy was caused by demons or witchcraft.

Living with Epilepsy in Sierra Leone

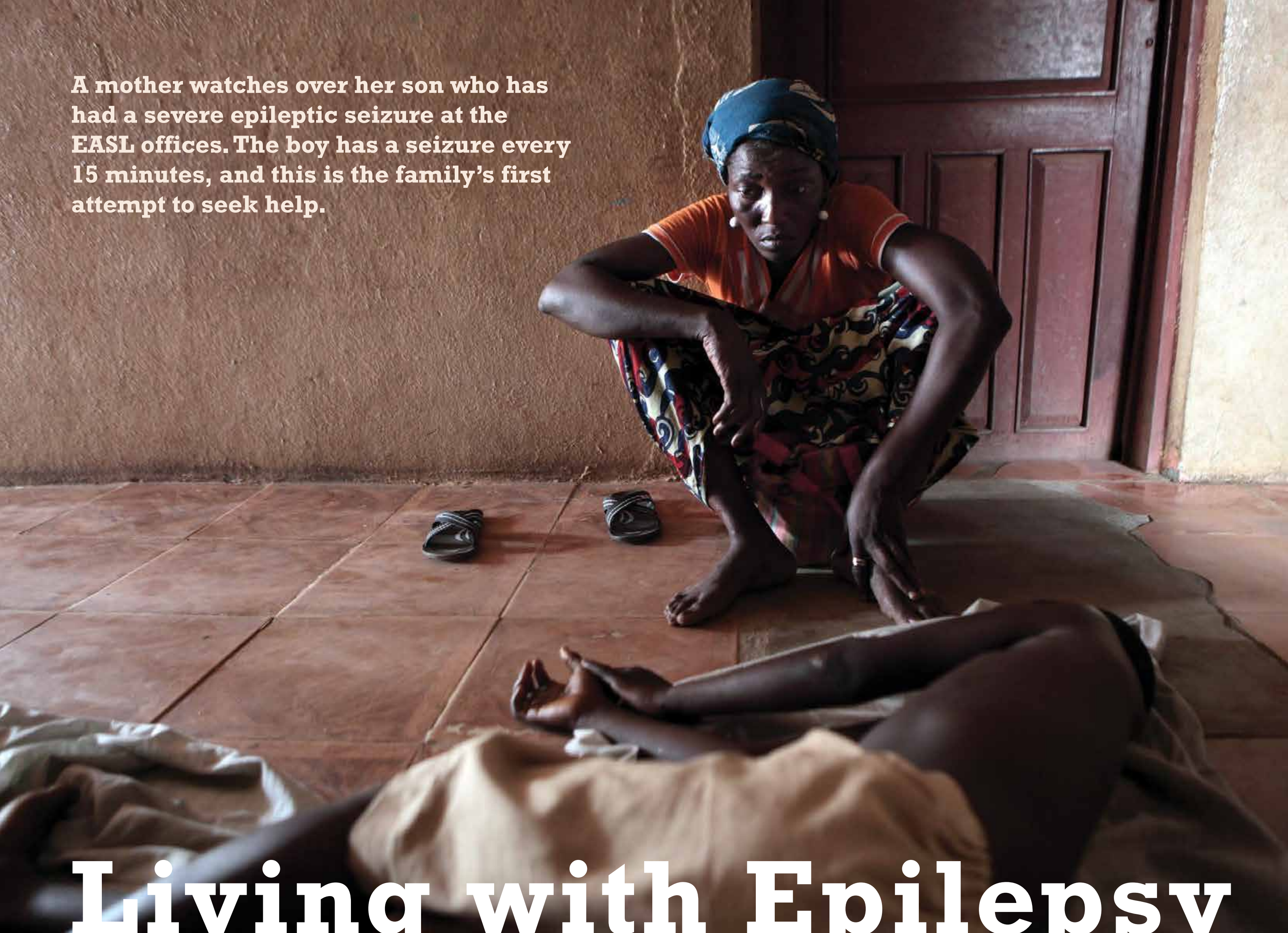
Spiritual Possession

In Sierra Leone, as in many countries, epilepsy assumes an emphasis far beyond its medical implications. The sudden onset in an otherwise 'normal' person raises suspicion in others. People may think that the individual has been possessed by the devil or that some supernatural force has rendered them unable to control their bodily functions. Some forms of seizure may chiefly affect a person's behaviour, causing them to be aggressive or fidgety. Some people can even perform complex tasks or walk for some distance without being conscious of their actions. These cases are very likely to be attributed to spirits or witchcraft in Sierra Leone.

The perception of witchcraft as a cause of epilepsy is not uncommon, and is found globally in many societies. In communities where this is combined with Christian missionary teachings, epilepsy may be seen as a punishment or as a result of possession by demons. Max Bangura, Coordinator of the Epilepsy Association of Sierra Leone, reports that much abuse takes place in the process of apparently driving demons from those affected by epilepsy, including the rape of women.

Alongside effective medical treatment, education can change these ideas and improve the quality of life for people with epilepsy.

A mother watches over her son who has had a severe epileptic seizure at the EASL offices. The boy has a seizure every 15 minutes, and this is the family's first attempt to seek help.



Living with Epilepsy in Sierra Leone

Clinical Treatment: Reaching Out



Dr Lisk studies the EEG

The first functioning clinical epilepsy service in Sierra Leone recently opened, led by Consultant Neurologist, Dr Radcliffe Lisk, of Basildon Hospital and supported by a British Council Health Links grant and Medical Assistance Sierra Leone.

There are an estimated 60,000 people with epilepsy in Sierra Leone. There is very little understanding of epilepsy in the country: it is very rarely diagnosed, and sufferers are often socially excluded from their communities – to devastating effect. Epilepsy rates are substantially higher in Sierra Leone than in Western European countries. This is due to a range of factors, including birth trauma, cerebral malaria and the consequences of meningitis. Around three-quarters of births are unattended by medical personnel in Sierra Leone; as well as resulting in the very high maternal mortality and infant mortality statistics, this also results in increased disabilities related to problems at birth, including lack of oxygen.



Living with Epilepsy in Sierra Leone

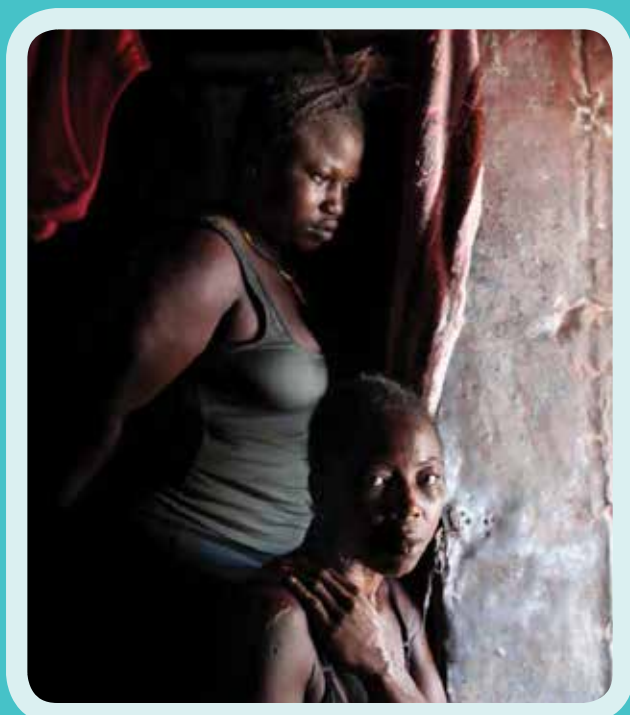
Clinical Treatment: Changing Lives



The good news is that with the right type and dosage of anti-epileptic medication, around 70% of people with epilepsy can have their seizures completely controlled. We have numerous examples from the Freetown clinic of patients in their thirties and forties who have had multiple daily and weekly seizures all their life – and who are now seizure-free as a result of medication.

Treatment is transforming people's lives: most adults who attend the clinic have never been to school, have no source of income and do not have children. Their lives have been lived predominantly in social and economic isolation.

A national initiative is urgently required to reach all those affected by epilepsy and support them to manage their condition.



Baby (above) has burns all over her torso, shoulders and arms from having seizures while cooking over fires. Baby relies on her sister-in-law Isatu to watch over her while she cooks.

Though the stress of worrying about getting mugged, or burnt, or not earning enough to pay for her monthly medication is a heavy burden, it is the thought that no man has the desire to take her as his wife that she most hates about her epilepsy.



Jenaba's epilepsy is successfully controlled by medication, and she now teaches at the EASL.

Living with Epilepsy in Sierra Leone

Women and Epilepsy

Women's experiences of epilepsy can be very different to those of men. There are issues around epilepsy and its treatment which are specific to women, such as the links between epilepsy and hormones, puberty, contraception and the menopause. There are also social factors which affect women with epilepsy - and in resource-poor settings such as Sierra Leone, these factors can become doubly disabling.

The stigma of epilepsy means that many women find it hard to find a partner and often don't have a family of their own. They may rely on family members for support, but as they are unlikely to have gone to school and to have had the chance to develop a skill, it is often not easy for women to contribute to the household income. In the worst cases that are seen at the clinic, a woman may be asked to leave her home or community, and can end up begging on the street.

Because of their roles in the home and community, women are at greater risk of common seizure-related incidents, such as burns and drowning.



Living with Epilepsy in Sierra Leone

Children and young people

Children and young people have particular needs in relation to epilepsy. The average age of onset is 12 years old - but the average delay in seeking medical attention is 6.5 years. This leaves young people very vulnerable and at risk of serious injury during an epileptic seizure. EASL reports that well meaning family and community members often force children to undergo harmful alternative treatments. Some children are made to leave the family home to prevent 'contamination' and it is common for children to be asked to leave school for the same reason.

Those children and young people who commence treatment depend wholly on their caregivers for the continuation of medication. Understanding that treating epilepsy is a process of management and not cure is one of the greatest challenges. Many parents will stop treatment once seizures stop; encouraging parents to assist their children to manage their condition is a key area of activity for the Epilepsy Association of Sierra Leone. This can even involve sending people into the rural areas to track down children with severe epilepsy who have not been seen in clinic for long periods.

Photography by Tom Bradley for Medical Assistance Sierra Leone