

First Aid (FA) and First Guidance (FG) for epilepsy seizures: key considerations and recommendations for developing regions of the world

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How to cite using ASWNet style

Mugumbate J. R., Kissani, N., Acevedo, K. ... (2022). First Aid (FA) and First Guidance (FG) for epilepsy seizures: key considerations and recommendations for the developing world. *Journal of Social Issues in Non-Communicable Conditions & Disability*, 1(1), 11-24.

Abstract

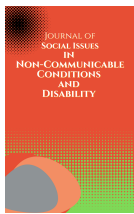
Seizures happen unexpectedly, therefore, there is a need for first aid (FA) and first guidance (FG) to help the person experiencing them. FA for seizures has medical goals while FG has social goals. The medical goals are to prevent injury, save life and get help, if needed. The social goals include protecting the person's dignity, their possessions and guiding them about assistance, if needed. The person giving help is called the first aider or first guider. The one being helped is the aidee or receiver. In this article, we provide and discuss 14 key considerations and six recommendations when providing FA and FG for seizures in developing countries. We answer the questions, what should be done or not done and why? We also provide a FA reassurance scale and a FG assessment tool. To the best of our knowledge, there was no other publication addressing this knowledge gap. This article can be used for FA and FG training or developing educational material but can also be used as a resource by people with epilepsy and their caregivers to gain knowledge about their condition and to teach others. If used appropriately, the key considerations, recommendations, scale and tool provided in this article will increase and better epilepsy FA and FG (EFAFG), reduce hospitalisations and social exclusion.

Key words

developing regions, epilepsy, first aid (FA), first guidance (FG), seizures

Key points

1. In most countries of the developing regions, relevant FA and FG information and training is scarce.
2. In this publication, we provide 14 key considerations and six recommendations when providing FA and FG.
3. We also provide a FA reassurance scale and a FG assessment tool.
4. The information in this article is useful for FA and FG training and for creating FA and FG educational material such as posters, fliers, videos, fact sheets and cartoons.



Introduction

Seizures happen unexpectedly. As such, there is need for first aid (FA) and first guidance (FG) to help the person experiencing seizures. FA for epilepsy has medical goals while FG has social goals. The medical goals are to prevent injury, save life and get help if needed. The social goals include protecting the person's dignity, their possessions and guiding them about assistance, if needed. The person giving help is called the first aider or first guider. The one being helped is the aidee or receiver. In this article we provide and discuss 14 key considerations and six recommendations when providing FA and FG for epilepsy in the developing world. We answer the question, what should be done or not done and why? To the best of our knowledge, at the time of writing this article, there was no publication that details the key considerations and recommendations when providing first aid to a person experiencing a seizure in the developing world. This gap has motivated us to write this article. This article can be used for FA and FG training but can also be used as a resource by people with epilepsy and their caregivers to gain knowledge about their condition and to teach others.

Background

Epilepsy seizures

Epilepsy is a health condition that results from excessive electrical activity in the brain (Shorvon, 2009). When there is excessive electrical activity, the coordination of the brain and the body is disturbed, and this results in seizures (Dekker, 2002; International League Against Epilepsy (ILAE), 2022). Some seizures include jerking of a body part, for example a limb but some involve jerking of the whole body. For other people, seizures are not easy to perceive. When a person is experiencing a seizure, so they usually lose consciousness, meaning, they won't know what is happening. This can result in them being injured, for example, by a fire or losing control of a vehicle or machine if they are using one. They won't be able to stop the seizures, in fact, the seizure will run its course. Even if you hold the person tightly, the seizure will continue increasing the chances of the person being harmed. Because of these reasons, it is crucial that people around know how to help a person experiencing seizures.

Burden of epilepsy

Epilepsy can be a huge burden to families and health systems (Mugumbate and Mushonga, 2013; Newton and Garcia, 2012). Stigma and ignorance are common issues (Fandiño, 2020). Uncontrolled epilepsy impacts education, employment and social life, at the end, it reduces the quality of life of the individual and their family (Birbeck et al, 2006). In developing regions of the world, there is a huge treatment and knowledge gap (Ndoye et al 2005). This means that very few people with epilepsy are on treatment while knowledge of the condition is limited. Through FA and FG, treatment gap can be reduced while the knowledge gap is lessened. If correct and persuasive information could be provided when someone has a seizure, this could encourage them to seek medical treatment (if they do not receive medication yet), adhering to treatment (if they had defaulted) and having knowledge to manage their situation (Mushi et al, 2011; Mugumbate, Riphagenn and Gathara, 2017).

FA and FG for epilepsy

For most people with epilepsy FA could be an ongoing requirement. Besides FA, FG is also a useful strategy, especially when it is the first seizure or if the person is not receiving medical treatment and social support. FA and FG have these stages:

1. Aid or help to deal with the current emergency situation
2. Guidance to provide immediate help
3. Guidance for medium to long-term needs

FA and FG can be offered by bystanders who have no experience or training in first aid. It can also be offered by trained people. At times FA and FG are provided by two or more people at the same time.

In developing regions of the world, when a person gets into a seizure, they may not get first aid or first guidance for several reasons (Nuhu et al, 2010; Eze and Ebuehi, 2013). One reason is the stigma associated with epilepsy (Obeid, 2008), another is the lack of knowledge of helping (Eze and Ebuehi, 2013). To solve these challenges, epilepsy awareness and training have been recommended (Chilean League against Epilepsy, 2022; Epilepsy South Africa, 2022; Epilepsy Care Ethiopia, 2021; Epilepsy Support Foundation Zimbabwe, 2000).

Other countries in the developing regions have done well, nonetheless. Chile is an example. The Chilean League against Epilepsy has been working not only in education, but also with the different aspects related with the social issues of epilepsy (Chilean League against Epilepsy, 2022). Annually more than 10,000 people are trained through different courses that address epilepsy issues like stigma, first aid and learning difficulties, among others. Over the years new material has been posted in the website and are available for education, including a journal, pamphlets, videos and fact sheets. Of special value are the videos “Story of Juanito” a short story with puppets, that has been translated to several languages and has become a useful tool to teach not only children but also general public, or others teaching how to manage a seizure, among others (Chilean League against Epilepsy, 2022). During 2022, efforts have been made to organize material for teachers and health personal in a friendly and accessible way, the so-called tool kits, with the sponsorship of local and government authorities. Even though the majority of the material is written in Spanish, most of the people living in Latin America can access it. The Chilean League is a World Health Organisation/Pan-American Health Organisation (WHO/PAHO) Collaborating Centre for Education in Epilepsy (WHO, 2022), and all these activities are free, being it possible to share and translate the educational contents in order to be used in other countries or languages.

First aid approaches

The most known model of first aid addresses the physical aspects of health and wellbeing. However, other models have emerged, for example, mental health models such as the Mental Health First Aid (MHFA) (Kitchener and Jorm, 2002). Developed in 2000, the MHFA is a course that teaches first-aid skills in the community to help increase support for mental health

patients. MHFA was developed by an academic, researcher and a mental health consumer who was also an educator. This model does not vary much from physical first aid training for injuries and emergencies. They define mental health first aid as ‘the help provided to a person who is developing a mental health problem or who is in a mental health crisis, until appropriate professional help is received or the crisis resolves’ (Morgan, Ross, and Reavley, 2018, p. 1). The course teaches recognition of symptoms, how to offer initial help and how to guide a person to treatments and support. This process of offering this aid and guidance is called the ALGEE Action Plan which means ‘Approach the person, assess and assist with any crisis; Listen and communicate non-judgmentally; Give support and information; Encourage the person to get appropriate professional help; and Encourage other supports (Morgan, Ross, and Reavley, 2018, p. 1). The MHFA model is used in several countries, and has reached millions of people through training. It now has two versions, one for adults and one for young people (Morgan, Ross, and Reavley, 2018).

Methodology

This article was written by seven authors from Zimbabwe, Morocco, The Gambia, Mexico, Chile and Colombia. Authors were motivated to write this article by their work with people with epilepsy while some authors were motivated by having family experience with epilepsy. All authors have worked in the area of epilepsy as medical or social professionals and they are leaders of epilepsy associations in their respective countries.

Over the years, some of the authors provided first aid training using different methods and modules. The modules used, however, focussed on the medical aspects and most of them were designed in the developed world. While these modules were useful, they did not adequately address the situation in developing countries. Some examples are the recommendations of ‘calling an ambulance’, ‘timing the seizure’, ‘seeking medical help’ or ‘calling a doctor’ – actions that would not be practical for a first aider or guider in a village or small town in a developing country. In most developing settings, access to resources such as ambulances, telephone services and doctors is limited (Kissani et al, 2022).

Before writing the article we searched for related literature but we could not find any. Outside Africa, we found a study that focused on people’s knowledge and attitudes towards providing first aid and considerations when developing a first aid program.

The considerations and recommendations were co-designed with health professionals, people with epilepsy, community workers in the area of epilepsy and carers. This process involved soliciting information from people affiliated to the Epilepsy Alliance Africa (EAA). The people involved were first contacted through a WhatsApp group. The group had, at the time, 124 participants from 34 African countries. Those who responded to the question were six (6) medical doctors, five (5) nurses, one (1) public health worker, (thirteen) 13 community workers, eight (8) people with epilepsy and four (4) care givers. In addition, three (3) first aid posters and fliers of epilepsy associations were located and used: Epilepsy South Africa (2022), Epilepsy Care Ethiopia (2021) and Epilepsy Support Foundation Zimbabwe (2000). The information from WhatsApp was copied, pasted into a word processing document,

categorised into do's and don'ts and discussed with a small group that included medical doctors, nurses, people with epilepsy and community workers. The first aid posters and fliers were included in the discussion. The resultant document was used to create a first aid poster and to inform this article.

Results and Discussion

Key considerations when providing FA to a person experiencing seizures

The 14 key considerations when providing FA to a person experiencing seizures are:

1. Keeping calm
2. Protecting the head
3. Putting nothing in their mouth
4. Not restraining movements as a result of seizures
5. Timing
6. Removing hazards and potentially harmful objects
7. Dealing with injuries, burns or drowning
8. Emergency help and rescue medication, if needed
9. Putting in recovery position
10. Securing the person and their valuables
11. Protecting the person's dignity of the person
12. Observing for injury or pain
13. Where there is no ambulance, nurse or doctor
14. Reassuring the person

These considerations are discussed below.

It is important to keep calm

Most people become afraid and run away or cause panic. While this is happening, the person with epilepsy having a seizure might be harmed by objects around them.

Protect from injury

The person is very vulnerable during a seizure. For example, the person having the seizure will not be able to protect their head, they can actually unconsciously bang their head on the ground, floor or objects. Putting a pillow, cushion or folded blanket under the head will protect them. But at times these soft things are not there or are not near, what could be done when a person starts experiencing seizures? An option is to put your palms under the person's head or put them on your laps while you are seated, is safe for you and the person experiencing seizures. Remove eyeglasses and loosen tight clothing, for example a tie. Turn the person on his or her side, and provide ample space. Remain calm and time how long the seizure lasts.

Do not put anything in their mouth

Putting anything in the mouth when someone is unconscious can be very dangerous and life threatening. Food, water or drink can choke the person. Giving oral medicines while having a seizure is not recommended but medicines given through the tissues of the nose or mouth (intrabuccal or intranasal) may be recommended, for example, to prevent status epilepticus. At times someone having a seizure can bite their tongue because they do not feel pain or their gums are stiff. If you put a stick or rubber between the teeth to avoid tongue biting, the object can break and block the airway which compromises breathing or injure the person. The stick can break their teeth. It is better to let them bite their tongue, which heals very soon, than breaking a tooth or getting choked. Sometimes the person putting their fingers inside the patient's mouth could have a severe injury.

Do not restrain seizure movements

If a seizure is happening, do not restrain the movements that occurs. This may result in the person breaking a bone. Instead, make sure you put a soft thing where their body is hitting.

It is important to time

It is important to time the seizure when it starts, however, this should not delay removing harmful objects. Looking for a watch or clock to time the seizure is not more important than removing harm. Why is timing important? It is important to know how long a seizure has gone for seeking help. If a seizure goes repeatedly for more than five minutes, then emergency medical assistance will be required.

It is important to look for hazards, and remove them if any

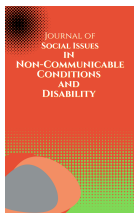
The person having a seizure usually will be unconscious, and they temporarily lose the sense of touch or feeling, smell, sight or taste. If there is anything harmful, they will not sense it.

Dealing with injuries, burns or drowning

In case the person is bleeding from an injury, apply pressure until bleeding stops. If they are bleeding from the mouth, give them water with salt to wash their mouth. If the person is ablaze, that is they are in flames or their have caught flames, roll them or cover with a blanket to put off the flame. If there is an extinguisher, use it. If the person has burns, put cold water on the wound. If the person has nearly drowned, and their breathing or heartbeat has stopped, apply cardiopulmonary resuscitation (CPR) through chest compressions, breathing for the person or doing both starting with compressions.

Emergency help and rescue medication

If not recovered, or if seizures repeat again, or one seizure goes for more than five minutes, this will now be an emergency. You can deal with it by using rescue medication if necessary, and calling for help from the nearest health or emergency centre.



Recovery position

During and after the seizure has finished, it is important to put the person lying them on their side. This helps to avoid accumulation of secretions in the throat and mouth and let them to come out, allowing the person to breath normally and replenish their body with air.

Security of the person and their valuables

Thieves and pick pocketers can take advantage of a person having a seizure and steal their possessions. They can also search their pockets or bags for money, wallets, mobile phones or food. As a first responder, it is your duty to protect their valuables. You should not also take advantage of their situation.

Dignity of the person

Having a seizure can result in people urinating on themselves, have saliva all over the face and dirty on their body and clothes. They can also sleep in the open. All these impact their dignity as a person. There are simple steps first aiders can take to ensure that you protect their dignity. Cover them with a blanket, cloth, jacket or anything else accessible until they wake up to ensure that their body is not exposed, which is important because at times their body may be half naked, and they will not realise it if they are still unconscious. Covering the body also gives them warmth or protect them from the sun and wind, if any. Give them a towel to wipe their face and body. Cover their pants if they are wet. If people have started gathering, find ways to disperse them, assure them everything will be fine. Having a few people to help is ok, by far many people can result in the person feeling ashamed, and they may fail to open up when you speak with them. If there are many people around when they wake up, they usually just want to leave the place immediately. In some cases, people with epilepsy were sexually abused during seizures or soon after, so it is important to ensure they are safe.

Observation for injury or pain

It is important to know if the person is in pain or has been seriously injured. This can be achieved by asking the person or observing them. Observe for wounds, bleeding, swelling, crying, guarding, glimpsing facial expression, rising temperature, inability to walk or confusion.

Where there is no ambulance, nurse or doctor

In most developing communities, ambulances, nurses and doctors are not readily available or accessible. They may be far away or contact details may not be there. In such cases, it is important to know who else can provide support as follows:

- In the village, you might find village health workers
- Local health worker where you live or where the incident happened
- You can also find people experienced in providing first aid, ask for their help or information

- At work places, there may be some people trained in first aid
- Because of telehealth, there may be services available over the phone or internet, if available
- If the person has a medical alert bracelet, though this is not usual in most communities, phone the number that is there
- If there is a contact number of a relative or workplace, call it because they may have more knowledge about helping the person

Reassurance

When the seizure stops, and the person has gained consciousness, ask the mandatory questions in the reassurance scale (Table 1).

Table 1: FA reassurance scale

Mandatory questions	Responded correctly	
	Yes	No
1. What is your name?		
2. Where are you?		
3. Where do you live?		
4. What do you think just happened to you?		
5. Are you in pain? Or Pain observed		
6. What help do you need? Or Is there anything I can do for you?		
Total points		
Additional questions		
7. Where are you going? (question applicable if they seem to be going somewhere)		
8. What is the time? Or What day is today?		
9. What were you doing just before this happened? (question applicable if you do not know what the person was doing)		
10. Are you able to continue with what you were doing or Are you able to go home etc?		
11. Have you done this before or has this happened before? (question applicable if you do not know their history)		

If the person gets:

- All six (6) mandatory questions correct (6 points), then they have recovered and they are likely to be able to continue with what they were doing. If they have a phone, it is

good to take their phone number or that of a relative so that you check afterwards that they arrived safely.

- If four (4) responses from the mandatory questions are correct (4 points), consider waiting a bit more so that they recover or consider calling a family member to be with them or offer to take them home.
- If two (2) responses from the mandatory questions are correct, they have not recovered. Do not leave them alone. Contact their family or close contact person or medical help.

The additional questions may not be applicable to everyone, and they are not part of the scale. These questions will help the first aider if they are not sure of any one of the responses provided.

Most seizures do not require emergency medical attention. Call a doctor, a nurse or ambulance when:

- A seizure lasts more than five minutes
- She is pregnant
- He or she does not regain consciousness
- He or she does not breathe after one minute
- He or she has one seizure after another
- He or she is injured
- He or she asks for help

Key recommendations when providing FG to a person who experiences seizures

The six key recommendations are:

1. Helping the person if it is their first seizure
2. Responding to their spiritual needs
3. Referring to social welfare for services like assistance and counselling
4. Using correct language
5. Using contextually appropriate first aid literature
6. Partnerships between FA/FG providers and support groups or organisations

Each of these recommendations is discussed in the proceeding sub-sections.

Helping the person if it is their first seizure

If it is the first time, they may be afraid and inexperienced to deal with a seizure. They may not even know that they had a seizure. For first time seizures, we suggest you tell the person what happened, do not interpret, just describe what happened clearly to get medical assessment and help. It is not important to tell them 'this is epilepsy' because the diagnosis of epilepsy, usually needs more than one seizure. However, saying 'it could be epilepsy' is ok. The word epilepsy carries a lot of stigma, and can result in people getting worried especially if it is their first

seizure. There are seizures that are not symptoms of epilepsy, some seizures occur once as a result of heat, trauma, shock or drugs.

It is important to educate people with epilepsy and carers to avoid stress when there is only a single seizure. If it is the first seizure, the person usually recovers easily without need to call an ambulance or taking them to hospital. Usually for single generalized seizures there is no need for admitting the patient in an emergency or intensive care unit. Physicians called by their patients in such situations should reassure them to reduce unnecessary stress.

Responding to their spiritual needs

Often, other people will also want to seek assessment or treatment from cultural or spiritual experts who provide counselling, psychological and social support. These include family, community and cultural leaders, healers, church leaders or prophets. We recommend that you leave the person to decide how they want to get treatment but inform them that at a clinic or hospital, they will be nurses and doctors trained to manage the medical aspects of epilepsy.

Referring to social welfare for services like assistance and counselling

Epilepsy is a life-long condition that is very costly to manage. Often medication is required every day. Many times tests are required including EEG, MRI, CT scan, blood tests and others. In other cases, ability to work is reduced. It is important for families, communities and nations to put aside assistance or welfare to cover some of these costs. One question to ask is if they are getting any support from family, community and government. If not, and if you have details, inform them how they can get support especially from government social welfare or assistance. Another important support is counselling, this helps people to deal with their situation and to get more information about epilepsy. It gives people self-confidence and the power to face their situation. In most countries, there is a community or national organisation that helps or works with people with epilepsy. Refer the person to this organisation if you have the details or information.

Using correct language

We recommend the appropriate language below when communicating with the person and others. It is important to use nouns and words that are respectful to give people with epilepsy dignity.

- Use local language that the person understands, English nouns like epilepsy, seizures, brain and neurology are not understood by everyone and are not the best to use.
- Avoid using the word fits because not all people with epilepsy will 'fit'.
- Avoid using the noun epileptic, rather use 'person with epilepsy'.
- You can refer to epilepsy as a brain disorder, seizure disorder, neurological disorder or health condition.
- Avoid using disabled person because not all people with epilepsy will have a disability.

Using contextually appropriate first aid literature

Lastly, we want to comment on FA and FG literature (posters, fliers, videos and web pages) that is usually available in developing countries. Most of the literature comes from outside and is developed for developed settings. It is important to translate to local languages, and use relevant images and pictures of local people. In one of the submissions we received during the discussions, one participant said ‘when someone with epilepsy becomes blue then seek medical help’. But our knowledge is that Black people do not turn blue, perhaps White people do. This shows the importance of contextually relevant literature.

Partnerships between FA/FG providers and support groups or organisations

We strongly recommend partnership between FA/FG providers and recognised epilepsy social groups can help improve treatment outcome and reduce treatment gap. At the point of FA/FG, there is a great opportunity to lower health inequities within our local communities by referring patients to epilepsy support groups or organisations where FA/FG is being provided by a healthcare, social care worker or experienced members of the group. Support groups and organisations can be helpful in addressing social issues and problems such as food, housing, education, transportation, neighbourhood and employment. These are among key social determinants of health in epilepsy globally.

FG assessment tool

Table 2: FG assessment tool

When all FA processes have finished, ascertain the needs of the person. We suggest seven questions from the assessment tool.

Questions	Response	
	Yes	No
1. Does your family know that you experience seizures?		
2. Are you getting support from the government?		
3. Are you getting support from the community, including organisations and helping groups?		
4. Are you getting support from your family?		
5. Are you getting support from your school, college or university?		
6. Are you getting support from your employer or co-workers, if employed or self-employed?		
7. Do you know enough about your condition?		
Total points	Yes responses	
0-3 - Immediate support is required, refer for assistance		

4 - Optimum level, support may be required	
5-7 - Adequate, no support required	

Appreciating what the person is doing, their resilience and the strengths they have

Epilepsy is a challenging disorder, and often people feel ashamed of their condition. People with the condition and their family will not usually disclose because of the stigma that usually follow. When you speak with someone with epilepsy, try to be appreciative of what they are already doing to deal with their condition, including the resilience they have, their strengths. Assure them of the potential they have to overcome epilepsy if they seek help, if they need treatment.

Next steps

Training, implementation validation and continuous assessment are essential steps. Epilepsy FA and FG (EFAFG) training involves the general public. The syllabus for the training could follow the FA and FG content in this article. We suggest that the FA scale and the FG assessment tool be translated to local languages. Following training, the tools could be implemented. However, where training is not feasible, self-directed learning is encouraged. Both our FA scale and FG assessment tool could benefit from validation to determine their feasibility and effectiveness. To validate, we suggest getting views of both aiders and guiders and those who received first aid and guidance but also those of medical and social professionals. They could be asked to share their views through an *indaba* (African version of a focus group), *baliono* (African version of a Delphi study) an interview or other locally relevant methods. Continuous assessment would involve seeking new knowledge to improve the tools.

Conclusion

When someone experiences a seizure, they are at risk to injure themselves or others. It is therefore important that everyone is able to provide first aid to prevent injury, save lives and ensure dignity for people with epilepsy. Those who provide first aid often provide guidance. In this article, we provided and discussed 14 key considerations and six recommendations to assist in providing the first aid for a seizure and guiding people with epilepsy. We also created a FA reassurance scale and FG assessment tool. The key considerations, recommendations, scale and tool that we provided in this article are important for informing and training medical and non-medical community about epilepsy. They are also important for developing educational and awareness material such as posters, fliers, videos, fact sheets and cartoons. If used appropriately, these resources will increase and better EFAFG, reduce hospitalisations and social exclusion.

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