Epilepsy Alliance africa

Muungano wa Kifafa Afrika
Alliance Africaine contre l'Epilepsie
تحالف الصرع الأفريقي
Epilepsia áfrica aliança

# GUIDELINES TO FORM A GROUP, ASSOCIATION OR ORGANISATION TO IMPROVE THE LIVES OF PEOPLE WITH EPILEPSY (2020)

## What is epilepsy?

It is a condition of the brain that results in repeated seizures and stigma. It is not contagious. It is largely manageable with medication and other modalities. You can learn more about epilepsy here or here.

## What challenges do people with epilepsy face?

Challenges include lack of knowledge about epilepsy and lack of medicines. While it is the responsibility of governments to ensure that these challenges are resolved, families and communities can play a part by forming support groups, community-based organizations and associations. This document gives some important suggestions.

## What is a group?

This is when 3 to 20 people come together to solve some of the challenges people with epilepsy face. However, a good support group should have between 5 and 15 people. Three (3) are too few and 20 are too many. As we know, a group is better than an individual, it means more brains, more energy, more resources and a louder voice. A group can operate from home, village, community centre, school, church, health centre or even under a tree. They usually operate at local level but online groups go beyond. We recommend that you register your group with the Alliance, join others and get a certificate.

## What is a community association?

This is when individuals or people in a group have an oral or written agreement or constitution. They may be registered or not. Their work is usually limited to one community. Usually an association has elected leaders and keeps records. It can operate from home, community centre, school, church, health centre or even under a tree. Associations operate at local, county, district or national level. We recommend that you register your association with the Alliance, join others and get a certificate.

## What is an organisation?

This is when groups or associations have a formally written constitution and they are registered. Some organizations may operate without formal registration, but registration is important. Usually an organisation has elected leaders, keeps records and books of accounts. It needs an office. The office can be shared or located at a community centre, school, church or health centre. Organizations operate at local, county, district or national level. We recommend that you register your organisation with the Alliance, join others and get a certificate.

## 10 types and objectives of groups, associations or organizations

Below are 10 types of groups and their objectives. These groups can meet face-to-face, by phone, online or both.

1. Social support or self-help group – these are groups to promote acceptance in families and in society and solve other social problems like stigma and discrimination through awareness or lobbying for better policies.
2. Psychological support group – these groups solve psychological problems like stress, anxiety, depression, mental health and stigma.

3. Income generating group or association – these are groups to improve the income of members and their families.
4. Carers or parents' group – these groups are for parents or care givers.
5. Children's group or community club – these groups are for children with epilepsy but can also include those without epilepsy.
6. School or college/university educational group or club – these groups ensure that students with epilepsy learn better.
7. Clinic or hospital group – these are groups for patients with epilepsy or other related conditions. They discuss medication, side-effects and coping mechanisms.
8. Professionals' group, association or organisation – these are for doctors, nurses, social workers and other professionals.
9. Work-based group – these are for workers with epilepsy, and can include those without.
10. General group, association or organisation – these groups usually have one of more objectives and some includes members from different backgrounds.

## 10 steps to form a support group, association or organisation

1. First understand epilepsy, how it is managed and what challenges people with epilepsy face.
2. Do needs analysis. Research what services, groups, associations and organizations are available and what they are offering to address the needs. Identify if there is a gap that exists, if there is no gap it is better to work with existing groups, associations or organizations. If there is a gap, then come up with an aim, that is what do you want your group to do?
3. Identify people who can support your aim including people with epilepsy, and identify those who can benefit from your work. People with epilepsy must be your main beneficiaries but it is ok to have programs that benefit families, communities, health workers, employers, education or social workers.
4. Invite people to your first meeting face-to-face or online. In the meeting make an agreement or constitution that includes the selected name, logo, leaders, objectives, activities and rules about ethical fundraising and managing resources etc. It is important to have people with epilepsy in leadership positions. Leaders include Group Coordinator, Chairperson and Vice, Secretary and Vice and Treasurer. Others will have President instead of Chairperson.
5. Register your group with the relevant community, area, local and country authorities. If there is an umbrella organisation or national association, join or partner them. In Africa, there is one regional association that you can register with, this is the Epilepsy Alliance Africa (EAA).
6. Where possible and relevant, inform and work with the leaders of your village, chiefdom, community, suburb, county, district, province, relevant government ministries and country about your group, association or organisation. Inform other organizations providing health or social services. You can do this by organising an official launch or writing them letters or both.
7. Put your resources together and if they are not enough, ask other people in the community, businesses, churches, funders etc to help or donate. Help is not only cash but volunteering, printing, speaking or medicines.
8. Record everything: list of members, minutes of meetings, funds/resources received or given to members etc. Keep your records safe.
9. Have regular meetings with your leaders and members. Each year have an annual meeting where you discuss all things, report and plan.
10. If your support group grows, think of creating an association. If the association groups, think of becoming an organisation.

## Do you need further information?

If you need help, please contact us. Email: epilepsyallianceafrica@gmail.com