

NSA Project – Internal guide on Epilepsy/NS awareness messages

QUICK FACTS / MESSAGES

- 1) “Epilepsy is a common brain disorder that affects men, women and children of all ages, ethnicities, origins, socioeconomic conditions”
- 2) “Epilepsy is a disorder that varies in severity and causes – its clearest manifestation being seizures”
- 3) “Epilepsy is not contagious - you cannot get epilepsy from another person in any way”
- 4) “More than 50 million people worldwide have epilepsy – so, if you are a PWE, you are not alone!”
- 5) “Nearly 8 out of 10 people with epilepsy live in low- and middle-income countries, like South Sudan; although there are no figures available for South Sudan, it can be estimated that approximately 1 out of 100 South Sudanese (120,000 people) suffer from epilepsy in the country”
- 6) “Epilepsy can (but does not have to) be a serious, life-threatening disorder with great impact on health and quality of life, including increased risk of injury and death”
- 7) “With daily, regularly taken and inexpensive antiepileptic medicines, 2 out of 3 people with epilepsy can be seizure free after 2 years” + “Antiepileptic medicines treat epilepsy symptoms (e.g. seizures), but cannot cure it” + “Antiepileptic treatment is beneficial to all people with epilepsy, regardless of the severity of epilepsy”
- 8) “Taking antiepileptic medicines can have side effects. These can be managed, for instance by changing antiepileptic treatment” + “If a person with epilepsy taking antiepileptic medicines is experiencing side effects, s/he should seek care at a health facility”
- 9) “People with epilepsy and their families often suffer from stigma and discrimination from their own community” + “The stigma associated with epilepsy can cause serious harm to the physical, mental, and social well-being of a person with epilepsy” + “Socialization and social integration greatly help a person with epilepsy live a safer, happier and healthier life”
- 10) “Anyone can learn basic first aid to help someone when a seizure occurs”

- 11) “Nodding Syndrome is a form of epilepsy, whose cause is not fully known; it has been associated with “river blindness” which is caused by the bites of the black fly, but there is no clear evidence yet that river blindness can lead to the development of Nodding Syndrome”
- 12) “Nodding Syndrome, being a form of epilepsy, can be treated quite effectively with daily and inexpensive antiepileptic medicines”
- 13) “If you think that you or a member of your family may have epilepsy, seek care at a PHCC or a Hospital”

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EPILEPSY/NODDING SYNDROME MYTHS DEBUNKED

Myth 1: Epilepsy is contagious.

→ **Fact:** Epilepsy is not contagious. You cannot get epilepsy from another person in any way.

Myth 2: Epilepsy is caused by spiritual possession or punishment.

→ **Fact:** Epilepsy does not have any spiritual or supernatural cause. It is a medical condition, a chronic neurological disorder that can happen to anyone.

Myth 3: People with epilepsy cannot work.

→ **Fact:** People with epilepsy can and should be supported to work. In South Sudan they are water vendors, cleaners, firewood vendors, etc. They only require some additional supervision, due to their risk of experiencing seizures. Unfortunately, they tend to be unequally remunerated and to be forced to work longer hours.

Myth 4: People with epilepsy cannot get married or have children, and if they do then their children will also have epilepsy.

→ **Fact:** People with epilepsy can get married and maintain stable, supportive relationships. Epilepsy is not transmitted from parents to their children. Women with epilepsy can have healthy pregnancies, however they should consult a trained health care provider if they are pregnant or planning to become pregnant.

To be more effective, recur to TESTIMONIES of real couples and parents with epilepsy.

Myth 5: Children with epilepsy cannot go to school.

→ **Fact:** Children with epilepsy should not be prevented from going to school. They are not a danger to other children. Teachers should be educated about epilepsy and what to do in the event of a seizure. The latter can be handled with basic, first aid assistance – even by teachers.

To be more effective, recur to TESTIMONIES of real children attending school and learning institutions.

Myth 6: People with epilepsy cannot participate in recreational activities - such as going to church, doing sport, etc.

→ **Fact:** People with epilepsy can safely participate in recreational or sporting activities if their seizures are under control. Activities involving heights or water require specific safety considerations.

To be more effective, recur to TESTIMONIES of real children / adults participating in recreational or sporting activities.

Myth 7: Never touch a patient having a seizure. The disease will be passed on to you.

- ➔ **Fact:** The patient having a seizure needs your help and should be given immediate and appropriate care. Please do not hesitate to do so. Seizures cannot be passed on to others by touching the patient – Epilepsy is not contagious!

Myth 8: Having a person with seizures is a stigma on the family, so this should be concealed.

- ➔ **Fact:** Having seizures, epilepsy, Nodding Syndrome is like having any other disease. Every effort should be made to remove this stigma through awareness. Parents and relatives should be encouraged to seek early treatment!

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