



World Health
Organization


Regional Office for
South-East Asia

Global Campaign Against

EPILEPSY:

**Out of the
Shadows**

from
prejudice
to
hope

A large, vibrant yellow sunflower with a dark brown center is positioned behind the text. The word 'hope' is written in a large, bold, green font, with the sunflower's head acting as the letter 'o'. The words 'from', 'prejudice', and 'to' are in a smaller, black font, stacked vertically to the left of 'hope'.

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SEA/Ment/115 Distr: General

Global Campaign Against

EPILEPSY: Out of the Shadows

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Message from the Regional Director

Populations of Member Countries of the World Health Organization's South-East Asia Region have suffered for ages from many communicable diseases. While some of these have been successfully controlled, others continue as serious public health problems. However, recently, it has become increasingly clear that noncommunicable diseases, including mental and neurological disorders, are important causes of suffering and death in the Region. An estimated 400 million people world-wide suffer from mental and neurological disorders or from psychosocial problems such as those related to alcohol and drug abuse. Our Region accounts for a substantial proportion of such people. Thus, the Region faces the double burden of diseases – both communicable and noncommunicable. Moreover, with the population increasing in number and age, Member Countries will be burdened with an ever-growing number of patients with mental and neurological disorders.

As Dr. Gro Harlem Brundtland, the Director-General of the World Health Organization says, "Many of them suffer silently, and beyond the suffering and beyond the absence of care lie the frontiers of stigma, shame, exclusion and, more often than we care to know, death".

While stigma and discrimination continue to be the biggest obstacles facing mentally ill people today, inexpensive drugs are not reaching many people with mental and neurological illnesses. Although successful methods of involving the family and the community to help in recovery and reduce suffering and accompanying disabilities have been identified, these are yet to be used extensively. Thus, many population groups still remain deprived of the benefits of advancement in medical sciences. Dr Brundtland has said, "By accident or design, we are all responsible for this situation today."

The World Health Organization recently developed a new global policy and strategy for work in the area of mental health. Launched by the Director-General in Beijing in November 1999, the policy emphasises three priority areas of work: (1) Advocacy to raise the profile of mental health and fight discrimination; (2) Policy to integrate mental health into the general health sector, and (3) Effective interventions for treatment and prevention and their dissemination. The South-East Asia Regional Office of the World Health Organization is committed to promoting this policy.

Mental health care, unlike many other areas of health, does not generally demand costly technology. Rather, it requires the sensitive deployment of personnel who have been properly trained in the use of relatively inexpensive drugs and psychological support skills on an outpatient basis. What is needed, above all, is for all concerned to work closely together to address the multi-faceted challenges of mental health.

Dr Utom Muchtar Rafei

Regional Director
WHO South-East Asia Region

Preface

Epilepsy, which is probably the oldest recorded medical illness, has evoked varied reactions ranging from mystery to fear. It has even been seen as messages from the supernatural. However, people with epilepsy and their families have suffered ostracism by society and deprived of treatment, leading to frequent injuries and, sometimes, death. It is estimated that there are 35 million people with epilepsy in developing countries, most of them in the South-East Asia Region.

Advances in medical sciences have enhanced the understanding of epilepsy as a medical illness. We now know why it occurs, in some cases what causes it, how to treat it and how best to care for the patient.

Unfortunately, despite the availability of effective and inexpensive medicines and treatment regimens, many patients in the Region are not getting the full benefit of appropriate treatment.

The World Health Organization in partnership with the International League against Epilepsy, and the International Bureau for Epilepsy, has launched a world-wide programme, "Out of the Shadows", to create awareness, remove myths and misconceptions and make available appropriate care and treatment to people with epilepsy world-wide. The South-East Asia Regional Office of the World Health Organization is committed to this partnership. Our objective is to support Countries in the Region to reach even remote and rural areas and marginalized populations, to help people with epilepsy lead normal lives.

As we take courage from the fact that 70 to 80% of people with epilepsy can lead normal lives if properly treated, it is time to introspect as to why 80 to 90% of people with epilepsy are not being treated at all. We must find the answers and take appropriate action now. It is only then that people with epilepsy can emerge from the shadows.

This document prepared by a panel of experts from the Region, provides valuable information for the layman and policy-makers regarding the multifaceted aspects of epilepsy and how to cope with the challenges posed by this mystified and misunderstood illness.

Dr Vijay Chandra

Regional Adviser – Health & Behaviour
South-Asia Regional Office
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Historical Background

First description of epilepsy in India

Apasmara, the Indian equivalent of epilepsy, has been mentioned in the ancient Vedic and post-Vedic literature. Charaka provided a definition of epilepsy almost conforming to the present concept: "Epilepsy is a disease characterized by derangement of the mind and memory. Therefore, victims of this disease experience disturbance in or loss of consciousness and undergo all kinds of ugly scenes." Charaka described the prodromal symptoms of epilepsy as: "Epileptic seizure preceded by aura, a subjective phenomenon denoting the onset of an epileptic attack. During such episodes, a patient perceives some imaginary shapes or figures (visual aura), or hears certain peculiar sounds (auditory aura) before the onset of epileptic attack."

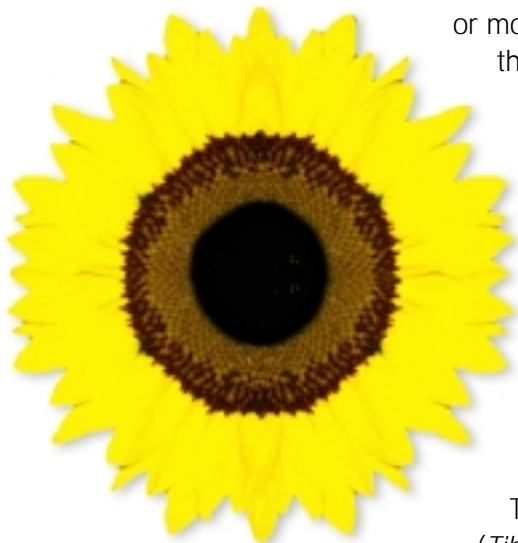
Epilepsy is one of the most common disorders of the brain, and is generally perceived negatively as a lifelong, chronic, incurable disorder.

It is also one of the oldest recorded medical conditions, described by Hippocrates more than 2000 years ago, and recognized by the Ayurvedic system of medicine in India for over twenty centuries. The word "epilepsy" is derived from a Greek term meaning "to possess", "to take hold", "to grab" or "to seize". In Greek mythology, epilepsy was considered a supernatural phenomenon, because only God could knock someone down, cause the body to thrash uncontrollably for some time and bring about a recovery without apparent ill-effects.

Epilepsy is known as *Apasmara* in India and Sri Lanka, as *Mirgee/Lata/Laran* in northern India, *Khichuni* in Bangladesh, *Ayan* in Indonesia, while *Rake Lom Ba Mu* or *Roke Lom Chak* are the lay terms in Thailand. Epilepsy, regardless of its immediate causation, is frequently thought of as a punishment for evil deeds, for instance, the breaking of certain taboos. Epilepsy, like the other diseases mentioned in the *Nidanam sthanam* section of the ancient medical text *Charaka Samhita*, is described as a punishment for participation in the forbidden sacrifice.

Another Hindu belief is that *Apasmara* in this life is the result of cheating in a previous state of existence, and is mentioned along with leprosy, abscess, skin disease and asthma as *pancabadha*. People suffering from these five diseases were prohibited from ordination. *Kamma* is a concept in Buddhist philosophy, but epilepsy is not singled out. The *Culakamma Vibhanga sutta* of the *Majjhimanikaya* states that anyone causing injury to other beings and tormenting them with hands, clubs or weapons may, when reborn as a human, be subject to many diseases as a consequence of this bad *kamma*. The text includes a reference to a *Bikkhu*, whose good *kamma* rendered him free of diseases such as *Apasmara* in numerous rebirths.

Nowhere else has folklore taken so strong a hold on the medical profession as in the matter of a cosmic connection to disease, particularly to the "falling" sickness. Sieveking wrote as late as 1861: "Lunar influences are still upheld by some physicians of repute, and the belief is generally in vogue among the public. People with epilepsy were termed moony



or moon-struck." The belief that epilepsy is dependent upon the phases of the moon is an ancient one, and gave rise to such names as *morbus lunaticus* and *morbus astralis*. The reconstructed Sanskrit title of a text extant in its Tibetan version

(*Tibetan Tripitaka*) states:

"Morning and evenings of the second, fourth, ninth and twelfth days in the part of the month in which phases of the moon increase and the twenty-ninth day of the month falling in the dark half of the month are specified as the times during which hot-tempered people are susceptible to attacks of epilepsy." Subsequently, it lists symptoms and treatment procedures. Even now, many believe that epileptic events are related to moon cycles with the frequency increasing during new moon and full moon days. However, scientific experiments and observations during these days and during eclipses have proved that they have no bearing on the occurrence of epilepsy.

The strange behaviour caused by some forms of epilepsy has led to a rather common rural belief that epilepsy is due to "spirit possession". To date, in some parts of India, Indonesia, Nepal, Sri Lanka and Thailand, people believe in supernatural powers at work and offer worship and animal sacrifice. In Bangladesh, rural people consider epilepsy as the "spell of Satan" locally known as "*batash*" (bad wind).

Epilepsy can affect anyone.

Interestingly, a look at historical records reveals the names of several famous personalities who were believed to have suffered from epilepsy. Great warriors, rulers, painters, artists, scientists – clearly, epilepsy could affect anyone regardless of caste, creed and socio-economic status.

Famous people who have suffered from epilepsy

Vincent van Gogh,
Dutch Painter

G. Julius Caesar,
Roman Statesman

F.M. Dostoyevsky,
Russian Writer

Gustave Flaubert,
French Writer

Saint Paul, Apostle

Hermann von Helmholtz,
German Physicist

Joan of Arc, French Saint

Moliere, French Playwright

Pope Pius IX

Cardinal Richelieu,
French Statesman

Socrates, Greek Philosopher

Alfred Nobel,
Swedish Chemist

Alexander the Great,
Macedonian King

Vladimir Ilyich Lenin,
Russian Revolutionist

Erzherzog Karl,
Austrian Warlord

Heracles, Greek Hero

Karl V, Austrian Emperor

Rudi Dutschke,
German Student Leader

Napoleon Bonaparte,
French Emperor

Lord Byron, English Poet

Source:

German Epilepsy Museum,
8 January 2001
website:
www.epilepsymuseum.net

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Myths & Misconceptions

The communities of South-East Asia continue to perpetuate many myths and misconceptions about epilepsy, passed on from generation to generation. These deprive patients of bonafide treatment and prove extremely detrimental not only to them but also to their families and community.

Myth:

Epilepsy is due to incarceration with evil spirits. Take the person to a sorcerer and have these spirits exorcised.

Fact:

Epilepsy is a medical disease. It is now easy to treat with modern medication. Under no circumstances should patients be taken to sorcerers or faith healers.

Myth:

These patients are possessed by God. They should be worshipped.

Fact:

Patients behave in an uncontrollable manner during an epileptic seizure, but this is not an expression of supernatural powers. They should be given medical treatment and treated like any other human being.

Myth:

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 appropriate care. Epilepsy cannot be passed on to others by touching the patient.

Myth:

Having a person in the family with epilepsy is a stigma, so this fact should be concealed.

Fact:

Unfortunately, the stigma against people with epilepsy and their families continues to be widely prevalent. Every effort should be made to remove this stigma through education.

Myth:

Epilepsy is a form of madness, so it should be treated in a lunatic asylum.

Fact:

Epilepsy is a disease of the brain, so it should be treated by physicians, neurologists or psychiatrists.



Myth:

Children with epilepsy are dull and cannot learn, so they should not be sent to school.

Fact:

Children with epilepsy can be extremely intelligent. There are many examples of high achievers in history who have had epilepsy. Usually it is the stigma against epilepsy which prevents parents from sending their children to school, to learn and achieve their full potential.

Myth:

Women with epilepsy can never have children, so they should not get married.

Fact:

Most women with epilepsy can safely have children, with no adverse effects on the baby. Marriage of women with epilepsy is a delicate and sensitive issue and should be handled appropriately. There is certainly no bar against their getting married.

Myth:

A seizure can be terminated by putting a key in the patient's hand or by making the patient smell onions or a dirty shoe.

Fact:

None of these non-medical measures are of any use. Family members and teachers should be made aware of first-aid measures required during a seizure.

Myth:

Marriage will cure epilepsy.

Fact:

This misconception is widely prevalent in some villages of north-eastern Thailand and South India. It is certainly not true and it is undesirable for a person with epilepsy to marry without the proper consent and knowledge of the partner.

These myths and misconceptions can only be dispelled by proper education of patients, families, communities and policy-makers. We all have a role to play in dispelling these myths, removing stigma and helping patients and their families to lead a normal life.

What is epilepsy? What is not epilepsy?

The first modern definition of epilepsy was given by Hughling Jackson in the second half of the nineteenth century. He defined it as

**the occasional,
sudden, excessive,
rapid and local discharge
of gray matter of the brain**

and this definition still holds. An often-used, current, operational definition of epilepsy is “the occurrence of transient paroxysms of excessive or uncontrolled discharges of neurons (nerve cells), which may be due to a number of different causes, leading to epileptic seizures”. The actual presentation or manifestation differs among individuals, depending upon the location of the origin of the epileptic discharges in the brain and their spread.

The words “seizure” and “convulsion” are used synonymously and colloquially; the manifestation is described as a “fit” or “funny turn”. The term “fit” has a derogatory connotation and is also used by a lay person to describe people who are having a temper tantrum. This term should be avoided. “Seizure” is a better term to describe individual episodes of convulsion.

The word “epilepsy” however, denotes a recurrent manifestation and hence there should be *at least two or more unprovoked similar episodes within a certain period of time*. Hence, the first episode of a seizure is called a “single unprovoked seizure” and not epilepsy. An epileptic seizure is a repetitive event in which an individual is not aware of the surroundings, either completely or partially. Various motor movements, such as shaking of limbs; sensory phenomenon, such as electric shock-like sensation over a specific area; behavioural experiences, such as fear or confusion or autonomic disturbances such as excessive secretion of saliva or bladder/ bowel incontinence could occur in association with this altered sensorium. The epileptic seizure occurs all of a sudden as a “bolt from the blue” and ceases on its own, just as suddenly. Usually it is very brief, lasting from a few seconds to minutes. Only in very rare cases will it be continuous, resulting in “status epilepticus”, i.e. a seizure lasting more than 30 minutes or recurrent seizures without the individual regaining consciousness. However, often patients or their

relatives describe a single attack that lasted for hours. This is invariably due to the fact that patients are drowsy or confused soon after cessation of the seizure, a state described as postictal phenomenon. This phenomenon may last for a few hours, rarely for more than a day, but the eyewitness often confuses this as part of the attack and reports it as a long duration of seizure.

Epilepsy is considered “active” if the patient with epilepsy has had at least one seizure in the preceding two years and is or has been on antiepileptic drugs for the same. Otherwise, it is termed “inactive”.

Seizures occurring only in association with a precipitating or triggering factor are termed “acute symptomatic”, “secondary seizures” or “situation-related seizures”, and even if recurrent, they are **not considered as epilepsy**. In this monograph, the word epilepsy refers to epileptic seizures, and seizures due to other causes are referred to as secondary or provoked seizures.

The commonest example of secondary seizures is febrile convulsion – for instance, a child of less than six years may have seizures at the peak of temperature on the first day. It is estimated that about 5% of children below six years of age have at least one fever-triggered convulsion. Other examples include a seizure that occurs during an acute infection of the brain such as “brain fever”(encephalitis); or due to low blood sugar or low calcium in the blood; or due to excessive alcohol or substance abuse.

Seizures provoked by specific conditions, even if recurrent, are not considered as epilepsy. It is important to clearly differentiate these conditions, as there are medical, social, psychological and economic consequences.

Causes of provoked / secondary seizures

Preventable or treatable

Birth injury and asphyxia
Brain infection
Febrile convulsions
Brain injuries
Alcohol abuse
Drug abuse
Complications of pregnancy
Metabolic disorders
Endocrine disorders
HIV and AIDS*

Not preventable

Genetic factors*
Brain tumours
Hereditary diseases
Degenerative disorders

*Partly preventable

Chances of remission of seizures are high...

In a three-year, hospital-based follow-up study in Bangalore, India, it was found that 57% of patients were seizure-free by one year, 66% by the second year and 75% by the end of the third year if adequately treated. In another follow-up study at the end of four years in India, it was found that nearly 85% were seizure-free while on regular medication.

Natural history of epilepsy

With adequate currently available drug treatment and good compliance, epilepsy remits on its own and the person can be seizure-free for life. In nearly 60–70% of such individuals, epilepsy is short-lived and once remission has occurred, a subsequent relapse is not common. The condition remains active in a small proportion of affected individuals. Such individuals have recurrent seizures, a poor prognosis and require lifelong management. Long-term studies have indicated that the relapse rate over a period of time is about 1% per year for persons who have remained seizure-free for more than two years with adequate treatment.

What is NOT epilepsy?

Since the diagnosis of epilepsy involves long-term management and carries a lot of social and psychological stigma, one needs to differentiate it from other common conditions resembling it.

Conditions mimicking seizures

Syncope or fainting	Emotional outbursts
Some sleep disorders	Low blood sugar
Non-epileptic attacks/ pseudoseizures	Night terrors
Transient ischaemic attacks	Breath-holding spells
Some forms of stroke	Drop attacks
Abnormality of blood flow to the brain	Migraine

More often than not, fainting episodes known as “syncope” are wrongly diagnosed as epilepsy, while in small children breath-holding spells during a temper tantrum are often erroneously classified as being epileptic in origin.

Pseudoseizures (Non-epileptic attacks)

These are also called psychogenic or hysterical seizures. They are more common in women usually during puberty and early adulthood and do not respond to any drugs. Usually, these are “dramatic” and “bizarre”, and last longer than true seizures. Sometimes, a patient suffering from epilepsy may, in addition, start getting pseudoseizures which may be very difficult to differentiate from true seizures. A careful observation of one such attack aids diagnosis, although sophisticated tests may sometimes be required to differentiate the conditions. About 20% of those diagnosed to have epilepsy even in the best of centres may actually have pseudoseizures.

Differences between epileptic seizures and pseudoseizures

Features	Epileptic attacks	Non-epileptic attacks
(A) CLINICAL FEATURES		
Resemble known seizure types	Yes	No
Tongue biting	Yes (sides of tongue)	Rare (tip of tongue)
Duration	Short	Long
Postictal phenomenon	Present	Absent
Injury	Yes, sometimes severe	Rare, less severe
Occurs in sleep	Yes	No
Can be precipitated by suggestion	No	Yes
(B) LABORATORY TESTS		
EEG during the attack	Abnormal seizure discharges	No change
EEG after the attack	Slowing pattern	No change
Antiepileptic drug usage (worsen)	Suppress seizures	No change (may)
Serum prolactin levels (during generalized attacks)	Raised	No change

Some facts and figures on epilepsy

At the global level, it is estimated that there are nearly 50 million persons suffering from epilepsy of which three-fourths, i.e. 35 million, are in developing countries. It is estimated that India alone has approximately 8–10 million people suffering from epilepsy.

Epilepsy is a common health problem which carries with it a variety of medical, social, psychological and economic burdens. The impact of the disease is felt, noticed and experienced in all spheres of the patient's life and by the patient's family.

The exact number of people suffering from epilepsy in the South-East Asia Region (SEAR) Member Countries is not known. As per some studies in the Region, it is known that the problem of epilepsy varies from 2–10 per 1000 population. In other words, for every 1000 persons there will be between 2 and 10 persons suffering from epilepsy. Although all these countries collect, compile and publish health statistics, epilepsy is not included, as it is not a notifiable disorder. It is thus difficult to answer the question: "How many are suffering from epilepsy?" However, various hospital-based and community-based studies have reported that it is a commonly encountered problem. Scientists believe that among all neurological conditions, epilepsy is the second commonest condition after headache, in terms of the number of people affected.

Although epilepsy has been recognised since ancient times, a scientific understanding of the problem is recent. In India, the earliest population surveys were carried out by mental health professionals in 1964 in Pondicherry. Neurologists began to study this problem in 1980.

How common is epilepsy in South-East Asia?

India:

Studies from different parts of India reveal that the problem varies from 9/1000 in Bangalore, 5/1000 in Mumbai, 3/1000 near Calcutta to 4/1000 in New Delhi.

Sri Lanka:

In a survey in the Kandy district of Sri Lanka, it was observed that 9 out of 1000 people had epilepsy.

Thailand:

A survey of nearly 3000 people in Thailand revealed that 50 had probable epilepsy.

Bangladesh:

Though there are no national statistics, it is estimated that there are at least 1.5–2.0 million people with epilepsy.

Other SEAR Member Countries:

The problem will be similar in countries such as Bhutan, DPR Korea, Maldives and Nepal as these countries share similar sociocultural and demographic characteristics. If these figures are applied to any local population, it will be possible to know the approximate number of people requiring help in the given geographical area.

The risk of having epilepsy at some point in the average life span of any individual varies between 2% and 5%.

Unlike many other disorders, instances of death directly due to epilepsy are few. However, serious injury can occur during a seizure, such as falling into a well while drawing water, falling down a mountain, falling into a fire while cooking, or automobile accidents while driving. Such accidents during seizures can be fatal. Deaths from epilepsy occur in larger numbers in distant and remote areas as compared to urban areas, probably due to lack of care.

Epilepsy can occur in all age groups and in both genders. There is no substantial gender difference. Younger age groups are much more susceptible to new onset of seizures. Research indicates that the highest number of people with epilepsy are seen in the first twenty years of life, followed by adults and middle-aged individuals. Recent trends suggest an increasing number of elderly people having epilepsy.

The exact difference in the number of cases and the causes of seizures between urban and rural areas is not clearly known. As secondary seizures are related directly to environmental standards and issues, it is possible that the number of cases will be higher in rural areas as compared with urban areas. From a recent study in Bangalore, India, it is known that the problem is nearly 2½ times higher in rural areas as compared with urban areas. The exact reason for this rural–urban difference is not known; lack of facilities for good antenatal/postnatal care, birth injury, malnutrition and childhood infections are probably responsible. Further, as the rural population is greater in the SEAR Member Countries, the burden of epilepsy may be expected to be higher in rural areas, where access to services is limited.

Epilepsy occurs across all sections of society. While there are

no systematic studies on the subject, it is possible that a greater number of people from the lower socioeconomic sections of society will be affected by epilepsy. With improvement in living standards and environmental sanitation, there may be a shift to other strata of society. It remains unclear whether low social status is a cause or an effect of epilepsy.

Treatment gap noticed in selected SEAR Member Countries

- **Yelandur**, South India
78% untreated at first contact
- **Bangalore**, South India
10% (urban) and **24%** (rural) were not on treatment
- **Kashmir**, North India
75% not on treatment at first contact
- **Kandy**, Sri Lanka
50% initiated on treatment for the first time

Treatment gap in SEAR Member Countries

Epilepsy is eminently treatable with simple drugs in a majority of sufferers. However, there is a substantial treatment gap in many SEAR Member Countries. *The treatment gap is the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point of time, expressed as a percentage.* This definition has been developed by the Commission on Developing Countries of the International League against Epilepsy and includes diagnostic and therapeutic deficits. Studies have revealed that in most SEAR Member Countries, nearly 50%–80% of people with epilepsy either do not receive systematic treatment or do not contact any health care institutions. Among those who are on treatment, nearly 40%–70% drop out at various stages of treatment, resulting in the recurrence of seizures.

The stigma related to epilepsy emanates from the many myths and misconceptions which are being perpetuated. Thus, people with epilepsy do not want to be identified as having epilepsy, and do not come forward to obtain treatment, even in the best of situations.

Knowledge, Attitude and Practice in SEAR Member Countries

There are many studies which use different methods to evaluate knowledge, attitude and practice towards epilepsy, both in the developed and developing countries. The information is usually collected by face-to-face interviews with specific questionnaires. These KAP studies have shown that knowledge is comparable in some developing countries (India and Sri Lanka, where projects have been done) and developed countries. However, the attitude towards epilepsy in India, Indonesia and Sri Lanka is far more negative than it is in developed nations. This is probably related to the prevalent literacy rate and educational status. A contradictory case is

Kerala, a southern Indian state, where despite the high literacy rate, the attitude is extremely poor. Epilepsy is generally believed to be a mental illness there and people object to their children playing with a child with epilepsy.

Comparison of the Responses to Knowledge, Attitude & Practice Inquiry about Epilepsy in Various Countries (%)

	USA	China	North India	Taiwan	South India
Inquiry	1979	1990	1992	1995	2000
Heard or read about it	95	93	92	87	99
Is it an object to play with	6	57	43	18	11
Objection to employment	9	53	-	31	44
Is it mental illness	3	16	15	7	27
Is it hereditary	9	17	18	17	31

Adapted from K. Radhakrishnan *et al. Epilepsia* 2000; 41:1027–1035
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There are reservations about employing people with epilepsy because of the stigma rather than for safety reasons. A significant proportion of the population believe that people with epilepsy cannot pursue their education and gain employment. The educated understand that epilepsy is a treatable condition and that appropriate drugs are available, whereas the uneducated continue to believe that epilepsy is untreatable and is caused by previous bad *karma*. Many people repose their faith in alternative systems of medicine, such as Ayurveda in India and Sri Lanka, and acupuncture in Thailand.

Who treats epilepsy?

Although people in urban areas do contact specialists, family physicians play a major role in providing proper care and direction for people with epilepsy. People contact primary health centres, *taluk* hospitals, district hospitals, nursing homes and tertiary institutions, depending on their accessibility to transportation facilities and socioeconomic factors. An in-depth examination reveals that perception and belief systems of people with epilepsy and their families, availability and accessibility of care, along with utilization of services based on their convenience, often determine their compliance with suggested medication.

Epilepsy is treated by a large number of professionals in the community, for instance, general practitioners, child specialists, obstetricians and neurologists.

Rani was taken to a faith healer for the treatment of epilepsy...

Rani was a beautiful little girl of ten years living in the mountains of Almora district. Unfortunately, she developed epilepsy. Her parents consulted the village leader who said she was possessed by evil spirits and must be immediately taken to a faith healer. Rani and her parents travelled for three days to a remote mountain cave in search of this famous faith healer. The healer tied Rani's feet with a rope and hung her upside down from a tree. Rani cried bitterly but the faith healer explained that the evil spirits would be driven out by her crying. Unfortunately, Rani died after ten minutes of being hung upside down. The faith healer proclaimed it to be the will of God.

Role of faith healer and indigenous systems of medicine

Traditional healers play a major role, as they provide a substantial proportion of care in rural areas. People in Bangladesh and Thailand continue to seek care from faith healers such as "*fakirs*" or "*monks*" before going to a hospital. Patients in Sri Lanka choose to go to a traditional healer, rather than to a modern doctor. These faith healers have strong social and religious connections and they play a very important but negative role in the management of epilepsy. A survey in Sri Lanka revealed that local traditional healers, in spite of the availability of a state-run free health service, were treating nearly 50% of the patients. Epilepsy is also considered an effect of past "*karma*" and 20%–30% of patients and families believe in religious or supernatural powers. In India, it continues to be related to supernatural powers and influences, both in terms of cause and cure. A study in India revealed that 12% believed in this cause, particularly in rural areas. In SEAR Member Countries, practitioners of Ayurvedic, Homoeopathic, Chinese, Siddha and Unani systems are involved to a great extent in epilepsy care. Unfortunately, many unscrupulous healers and manufacturers of indigenous systems of medicine abuse these systems for monetary gains, much to the detriment of the patient.



Why does it happen?

The question uppermost in the patients' mind is the cause of their seizures. The seizure itself is a symptom of the underlying disorder of the brain, and results from the interaction between genetic, environmental and physiological factors.

Epilepsy can be broadly classified into two types depending upon the presence or absence of a known cause:

- (a) Idiopathic, where the cause is not known;
- (b) Symptomatic, secondary or situation-related seizures where the cause is known.

Idiopathic epilepsy

As the name itself suggests, the cause of this type of epilepsy is not known, although there are some risk factors associated with it. These include previous history of repeated febrile convulsions during early childhood and history of epilepsy among close family members.

Epilepsy and heredity

Some forms of epilepsy, but certainly not all, are hereditary, i.e. inherited due to genetic defects. Seizures are an important manifestation of more than 150 single-gene disorders. In certain parts of India, for example, South India, consanguineous marriages (uncle–niece) are in practice, with figures estimated at 33%. This type of marriage should not be encouraged in the event of a family history of epilepsy. Genetic counselling may be necessary for such families.

Possible Risk Factors and Their Contribution

Risk factor	Contribution to risk of seizure
Febrile seizures (repeated)	3–20% develop recurrent seizures (epilepsy)
Family history of seizures	Not known clearly, may increase risk
Brain infections	5–10% will have seizures at the time of infections
Brain injuries	5–10% will have seizures at the time of injury and another 10% during later years
Cerebrovascular disorders	5–15% develop seizures
Mental retardation or cerebral palsy	10–20% have seizures
Brain tumours	The majority will have seizures
HIV/AIDS	60% will have seizures at some time
Alcohol abuse	Heavy usage and withdrawal seizures
Drug abuse	Depends on type and dose of drug
Metabolic conditions	Variable: depends on severity of condition and age of patient
Hypocalcaemia, hyponatraemia, hypoglycaemia	

Secondary or Provoked Seizures

Birth injury

Birth injury and hypoxia (low oxygen concentration in the blood) are very important causes of secondary seizures and mental retardation in SEAR Member Countries where medical care at the time of delivery is often inadequate, especially in rural areas. Even today, many deliveries are conducted at home by traditional birth attendants. Preterm deliveries are twice as common as in developed countries. Chances of neonatal (newborn) infection leading to septicaemia (generalized infection) are very high in children born under these conditions. In the newborn, delay of the first cry, seizures in the first month (neonatal seizures), and infections in the first month (neonatal infections) such as blood infection and brain infection are predictors for later recurrent seizures. Malnutrition and infection in the mother during pregnancy are additional risk factors for injury to the newborn during birth.

Brain infection

Infections affecting the brain (encephalitis) or its coverings (meningitis) may result in seizures both during the acute phase of the illness or long after the infection has subsided. A convulsion in a child may be the first symptom of meningitis/encephalitis. Viral encephalitis due to Japanese B virus (Japanese encephalitis) is commonly reported among children in SEAR Member Countries. It occurs both as an epidemic, i.e. a large number of cases in a particular region at a particular time, or as an endemic, i.e. occurring throughout the year in a localized region.

Meningitis due to bacterial infection occurs following infections in the ear, lungs or elsewhere in the body. Chronic ear infection is common among children in these countries and this could spread to the brain.

Tuberculosis remains a very common disease in SEAR Member Countries. Tuberculosis could affect the coverings of the brain (tuberculous meningitis) or could occur as a collection of pus within the brain (tuberculoma). Early recognition and treatment are essential to prevent brain damage which may lead to mental subnormality and later seizures.

A few common causes of secondary/provoked seizures in different age groups.

Newborn

- Birth injury
- Metabolic abnormalities
- Congenital abnormalities
- Genetic causes

Infant

(less than one year of age)

- Birth injury
- Brain infection
- High fever

School-age child

- Genetic causes
- Brain infection
- High fever
- Brain injury

Young adult

(15–25 years)

- Genetic causes
- Brain infection
- Metabolic abnormalities
- Brain tumour

Adult

(26–50 years)

- Alcohol abuse
- Brain infection
- Brain tumours
- Brain injury
- Stroke.

Elderly citizen

(50 plus)

- Stroke
- Brain tumour
- Brain injury
- Alcohol abuse

Poor sanitation

may be the single most important social factor leading to secondary seizures in SEAR Member Countries. It has been proven that *neurocysticercosis* (a worm infection) is one of the leading causes for symptomatic seizures in India, Indonesia, Sri Lanka and Thailand. Contrary to popular belief, this worm's presence in the body is **not** due to eating pork alone, as it occurs in vegetarians and non-pork-eating communities as well. It is contracted by eating food contaminated with soil containing eggs of the worm. If such food is eaten without proper washing or cooking, the eggs hatch in the body and spread to the brain.

Malaria

Malaria, although preventable, continues to be the commonest infection in South-East Asian countries and could affect the brain (cerebral malaria). Acute symptomatic seizures in the form of generalized convulsions occur in 40% of adults and in a majority of children with cerebral malaria.

Brain Injury

Among adults and the middle-aged population, brain injuries due to road traffic accidents, falls, violence and industrial accidents are common causes of secondary seizures (post-traumatic seizures). Traffic accidents are very common in SEAR Member Countries such as India, Indonesia and Thailand. Some of these are probably due to poor road conditions, poor driving habits and a higher density of two-wheel vehicles. Thailand has specific legislation regarding the compulsory wearing of helmets for two-wheel vehicle travellers and seat-belts for front seat passengers of four-wheel vehicles. Most other countries of the Region have not made these precautions compulsory. Seizures might occur in the acute phase of an injury or much later, secondary to scarring of the brain. Post-traumatic seizures are one of the most common and preventable causes of secondary seizures.

Stroke

It is well known that reduced blood flow to the brain may precipitate seizures. A small, unrecognized cerebral stroke may be enough to cause seizures, especially in people above the age of 40 years.

Alcohol and substance abuse

Alcohol and seizures are closely related. In alcoholics,

intoxication as well as alcohol withdrawal result in seizures. Alcohol use is associated with an increasing number of road traffic accidents and violence. Alcohol and substance abuse are not limited to urban areas but are common among the rural folk in SEAR Member Countries.

HIV infection

HIV and AIDS cases are commonly reported from India and Thailand, placing them second to sub-Saharan Africa. In Thailand, about 34–40% of people with central nervous system complications associated with HIV infection have seizures. It is known that 60% of patients infected with HIV have a seizure at some point in their lifetime and this may soon become a leading cause of seizure disorder in these countries.

Diarrhoea in children

Infantile and childhood diarrhoea may cause seizures in a predisposed child. This may be secondary to electrolyte and fluid imbalance or due to severe infection, e.g. *Shigella* infection. In Bangladesh, diarrhoeal disorders are very commonly reported among children and are a leading cause of emergencies.

Metabolic disturbances

Metabolic disturbances such as hypocalcaemia (low blood calcium), hypoglycaemia (low blood sugar) and hyponatraemia (low blood sodium) cause seizures in children and the elderly. Certain inborn errors of metabolism such as phenylketonuria or other aminoacidurias could cause seizures and mental retardation.

Infancy and epilepsy

Infants below the age of one year may have prolonged seizures, sometimes lasting up to thirty minutes or one hour. Since these seizures may be bizarre and fragmented, it is difficult to make a correct diagnosis. Child specialists need to be knowledgeable about the different types of childhood seizures. This is specially required in developing countries such as those in the SEA Region, where very few trained paediatric neurologists (neurologists specializing in brain disorders of children) are available. The common causes for seizures during infancy are: (i) birth injury; (ii) metabolic disturbances and (iii) brain infections. In addition, there are certain special forms of epileptic syndromes, such as infantile spasms. These



Dos and don'ts for the elderly with epilepsy.

Avoid multiple drug therapy.

Antiepileptic drugs might cause **increased drowsiness**, so be careful, especially when you are outside the house alone.

Kidney and liver damage are not uncommon and hence **proper dosage of the medications** needs to be calculated.

The elderly are prone to **dehydration and electrolyte imbalance**, particularly in tropical countries, which may affect antiepileptic drugs.

More often than not, elderly people are on other medications, hence, **drug interactions need to be considered** before the proper antiepileptic drug can be chosen.

need to be diagnosed and properly treated to prevent the development of mental handicaps and intractable epilepsy.

Febrile convulsions

Children below six years of age are prone to convulsions when they have high fever. These are known as febrile convulsions and are not epileptic. This phenomenon occurs all over the world. Parents are advised to reduce the fever as early as possible by: (1) tepid sponging whenever the temperature touches 100°F, and (2) immediately administering medicines to lower the temperature. Many parents cover their children with a blanket during the fever. It is not unusual to see parents in many parts of Bangladesh, India and Sri Lanka bringing completely covered children to the clinic. This is again due to a misconception that during fever, the patient feels cold. However, covering the child with a blanket makes the body warmer and raises the temperature further. They have to be advised to expose their children rather than cover them during a fever. Apart from this, rectal/oral diazepam should be administered at the onset of fever. Generally, these children do not require antiepileptic drug treatment, since febrile convulsions are a benign condition, disappearing spontaneously after six years of age.



Epilepsy in the elderly

As longevity is increasing in some South-East Asian countries such as India, DPR Korea, Sri Lanka and Thailand, it is not uncommon to find epilepsy among the elderly. Special precautions should be observed when treating epilepsy in the elderly.

Types of Epilepsy

Epilepsy may be of many types. The area of the brain from where the seizure starts and its ability to spread to other parts can further define the type of epilepsy.

People usually think that epilepsy manifests only through motor (muscle) symptoms such as jerks. In fact, epilepsy has a wide range of symptoms, which can be broadly grouped into three types:

- (a) Motor symptoms, such as limb shaking or weakness;
- (b) Sensory symptoms, such as numbness, electrical shock-like sensation over a specific area, and
- (c) Mental symptoms, such as fear, confusion, visual and auditory hallucinations.

Sometimes epilepsy can present as restlessness in a child or inability to learn quickly, with no external manifestations of seizures. This can only be diagnosed by recording the electrical activity of the brain by an electroencephalogram (EEG). Minor twitching of the face and hands may also be due to epilepsy. Thus, a careful diagnosis is essential.

Warning symptoms

Some people with epilepsy get warning or premonitory symptoms (auras) before their attack. These depend upon the region of the brain where the seizure originates. Hence, these auras not only warn patients and provide them with an opportunity to protect themselves but also give a clue to the diagnosis of the specific type of seizure. It is thus essential to note these warning symptoms and report them to the treating physician.

Depending upon the absence or presence of these warning symptoms, epilepsy can be broadly classified into two types: generalized and partial. In the former, warning signs are absent whereas in the latter, warning signs are usually present. Some partial seizures later spread to become generalized, and at this stage the patient loses consciousness completely.

Generalized seizures

In generalized seizures, patients suddenly stop what they are doing, the eyes and head turn to one side and the body becomes stiff. This is usually followed by several jerks of the hands and legs, groaning and frothing from the mouth.

Mama, its about to happen...

Rashmi is an eight-year-old girl, studying in class III, with normal physical and mental development. She has had four or five seizures in the last one year. During these episodes, she complained of a sense of fear, ran to hold her mother, stared at a particular spot and smacked her lips. During this period, she was not responsive and the experience lasted for about one minute. Following this, she remained confused for 10–15 minutes. Later, neither did she remember the incident nor was she able to recollect what had happened.

Rashmi has complex partial epilepsy.

Ajar is a 14-year-old boy who routinely experiences sudden jerking of his hands. These episodes occur after waking up every morning, and cause him to drop items while brushing his teeth. Interestingly, there is no recurrence at other times.

Ajar has myoclonic jerks which are a type of epilepsy.

During the episode, the tongue may be bitten or severe injury can result from a fall or an accident. Sometimes the patient may pass urine or stools. The body relaxes after a few minutes and the patient sleeps for a variable period. The patient is completely unaware of the seizure. Such seizures can also occur in sleep.

Partial seizures

In partial seizures, some patients may experience only motor or sensory phenomena. Such seizures are called simple partial seizures and arise from a specific area of the brain, with the patient being fully or partly aware of the event. However, some patients may experience various complex warning symptoms such as gas rising up from the stomach, fear, a sense of giddiness or involuntary movements such as smacking of the lips, mental confusion or wandering around. These are known as complex partial seizures and are difficult to diagnose, due to the varied manifestations. It is essential that the patient and eyewitnesses note down the symptoms and describe them to the treating physician. Usually, complex partial epilepsy is under-diagnosed because symptoms are very brief and strange.

In addition to the above-mentioned types, children below 15 years of age may experience another type of seizure. This is very brief, lasts only 10–15 seconds, and is repetitive. During this period, children are totally unresponsive, may not fall down, but may experience automatism briefly and return to normal immediately after the episode. The seizure recurs very frequently, perhaps as often as 20–30 times per day. Such episodes are called “absences” and these patients may sometimes also have generalized tonic–clonic seizures. As these are common among school children, they are almost always noticed by the school teacher and then referred to a physician. It is essential to educate school teachers to identify such children, as the seizure is easily amenable to treatment.

Myoclonic jerks are another type of generalized seizure which could occur in children, adolescents and adults. Such seizures could be very mild with occasional jerks of hands or legs or they could be very severe, make the patients fall down and interfere with their daily activities



The Doctor - Patient interview

Ms S: Doctor, I am so worried about my 15-year-old daughter. She has had spells of odd behaviour, following which she loses consciousness. This has happened five times.

Doctor: Ms S, can you please tell me when it started?

Ms S: It happened suddenly about three months ago. She mentioned an odd feeling in her stomach, and before we realized it, she had lost consciousness.

Doctor: Can you please explain a little more? Do you remember the date? What time was it? What was she doing when she complained about that feeling?

Ms S: It was about six in the evening. She had returned from school and was relaxing in a chair with a book in her hand, when all of a sudden she complained of an odd sensation in the stomach. She had a dazed look on her face and started behaving in a strange manner, clutching at the chair and the book. She didn't answer when called, and appeared to be in a dazed state of mind. This was about three months ago. But I don't remember the date.

Doctor: Did you call her by her name? Did she respond? By any chance, did you notice any movements of the lips or jaw?

Ms S: Now that you ask me, I recollect that she was muttering something. She was moving her jaw as if she was eating something! (Ms S proceeds to demonstrate the movements).

Doctor: What happened next?

Ms S: She walked around without any specific purpose, and didn't respond when called. Then suddenly, she fell down unconscious, and started moving both limbs vigorously. It was uncontrollable, like a fit. This went on for two minutes. She was frothing at the mouth, and had soiled her clothes. It was very frightening! We placed a key in her hand, but it didn't help.

Doctor: Did she hurt herself? Did she bite her tongue?

Ms S: We all held her tightly, hence, she didn't get hurt. But saliva, froth and blood were drooling from her mouth. Yes, she had bitten her tongue.

Doctor: When did she regain consciousness?

Ms S: She slept for an hour and when she woke up, she complained of muscular pain and exhaustion. She has had four such episodes in the last three months.

Doctor: When was the last attack?

Ms S: The last attack was about seven days ago.

Doctor: Did your daughter have any convulsions following fever when she was less than six years old?

Ms S: No, she did not have any such convulsions.

Doctor: Does she complain of headaches or vomiting, on and off?

Ms S: Never, but she has vomited sometimes during these episodes.

People who have experienced the above-mentioned episodes should consult a doctor. It is essential that they be accompanied by a witness who can describe the episodes in detail. More often than not, epilepsy can be diagnosed on the basis of patients' and eyewitness' reports. No laboratory test can replace a clear description provided by an eyewitness. Electroencephalography (EEG), which records electrical activity from the surface of the head (similar to the ECG for the heart) can, in some cases, support the diagnosis. Those who develop epilepsy for the first time require investigation to identify the underlying cause. These investigations include EEG, and imaging tests such as CT scan or MRI of the brain.

When epilepsy is diagnosed, it is necessary to document the type of seizure, determine the cause, and evaluate the intelligence and social background. This information is extremely useful for further patient management.

Objectives of treatment

Undoubtedly, people with epilepsy want to live seizure-free lives and be free from the fear of future attacks. It is usually the fear of attacks which interferes with the day-to-day activities of affected people. Hence, management of epilepsy should include:

- (a) Control or prevention of seizures;
- (b) Determining the underlying cause of the seizures if possible, and treating it, and
- (c) Psychosocial support to patients.

Until the mid-nineteenth century, people with epilepsy received many strange remedies without any success. Bromide was the first antiepileptic drug and remained in use till the beginning of the twentieth century. It was effective but was discontinued because of its undesirable side-effects. The first true antiepileptic drug, phenobarbitone, was discovered in 1912. This drug continues to be the mainstay of medical management of epilepsy in SEAR Member Countries. Several drugs have entered the market since, and in the last ten years, many new drugs have been discovered with the objective of finding an “ideal” antiepileptic drug.

The first step in the management of any seizure is to stop the ongoing seizure through specific first-aid measures.

First aid: Generalized convulsion

During this type of seizure, the patient may fall down and experience jerking of the limbs. Hence, first-aid measures should ensure that the patient is safe.

- Help the person into a lying position, preferably on the floor.
- Loosen tight clothing, remove glasses.
- Clear the surrounding area of any objects that may hurt the patient.
- Do not force anything into the patient’s mouth.
- Make the person lie down on the side, so that any secretions from the mouth can flow out freely.
- Do not hold the patient, as the seizures cannot be stopped by restraint.

Once the seizure stops, keep the patient lying on one side to allow saliva to drain out from the mouth. Do not offer any food or drink until the patient is fully alert.

In case the patient has recurrent seizures, i.e. status epilepticus, the following steps need to be taken immediately.

First aid: Status epilepticus

Status epilepticus is a serious emergency. If the patient suffers repeated seizures without regaining consciousness, immediate medical attention is needed. Hence, the patient needs to be shifted to the nearest medical centre. Immediate medical measures include:

- Supportive measures to ensure a clear airway
- Intravenous drugs to stop the ongoing seizure
- Subsequently, the administration of medications to control seizures

Patients experiencing other kinds of seizures also need help.

First aid: Complex partial seizures

During this type of seizure, the patient may remain unresponsive, stare, perform some inappropriate movements/gestures or appear totally confused.

- Such a patient should not be restrained.
- The patient should be moved to a safe place.
- The patient should not be agitated.
- The patient should not be forced to eat or drink anything.

Advice to care-givers

Relatives are often very concerned about their loved ones having seizures. However, they should note the following points:

- Although seizures look frightening, they are not painful and patients often will have no recollection of the episode.
- Seizures are generally self-limiting, i.e. they stop spontaneously.
- Injury to the patient should be prevented.
- There should be no attempt to force open the patient's mouth if clenched. This may damage the teeth.
- Until the patient has regained full consciousness, no drink should be forced into the mouth.
- There is no need for an extra dose of antiepileptic drugs.
- The care-giver needs to stay with the patient and provide reassurance once the patient regains consciousness.
- If the seizure persists for more than 10 minutes or if it recurs, medical assistance should be sought.

Precipitating factors

In some patients, there are certain precipitating or triggering factors, for example:

- *Sleeplessness: Sleep deprivation is a definite precipitating factor for some, and hence needs to be avoided.*
- *Flickering lights: In some patients, flickering bright lights, such as those found in discotheques may precipitate seizures. If a patient's seizures are precipitated by such lights, these should be avoided. However, not ALL people with epilepsy need to avoid bright flickering lights.*
- *Alcohol abuse: Excess consumption of alcohol may lead to seizures. Seizures may also occur when recovering from an episode of excess alcohol consumption.*

Patients should carefully identify their own precipitating factors and report them to the treating physician. Once a triggering factor is recognized, it should be avoided.

Advice to patients:

If seizures are well controlled, patients are encouraged to lead as normal a life as possible, conducting activities of daily living, working and engage in recreation. However, certain precautions must be taken.

- *Driving:* Driving a motor vehicle is an essential part of living and working in urban areas. Each country has its own law about people with epilepsy and driving. Even if the patient is within the law and has a valid driving licence, routine precautions, such as not driving when sleepy or avoiding driving for an extended period, should be taken. This is further dealt with in another section of the monograph.
- *Working with heavy machines:* Although people with epilepsy are encouraged to work, working with heavy and dangerous machines should be avoided.
- *Daily activities:* Simple precautions should be taken while engaging in daily activities and doing chores around the house, such as while cooking. These activities should be avoided when the patient is tired, has not had adequate sleep or when an aura occurs.
- *Rural areas:* Although life is simpler in rural areas compared to urban areas, there are other hazards, such as falling into a well, into an open fire or getting limbs cut while working with machines such as harvesters,

threshers and tractors used in agriculture. Patients and families should take adequate precautions.

Aspects of treatment

Need for regular use of antiepileptic drugs

- (a) Antiepileptic drugs must be taken daily as prescribed. Missing a dose or taking twice the dose are both undesirable. If the patient is unable to take the initiative to take the medicine daily, the family should help to ensure that the drugs are taken as prescribed.
- (b) Patients should be aware of “withdrawal seizures”, i.e. an abrupt discontinuation of antiepileptic drugs may cause an increasing number of seizures. Patients also need to be informed about the necessity of good compliance, with taking medicines keeping an adequate stock of drugs with them, not changing the brand of drugs and storing the daily quota in a small container so that no dose is missed.
- (c) Certain antiepileptic drugs interact with commonly-used drugs such as some anti-asthmatic drugs like theophylline or antibiotics such as erythromycin. Patients should inform their family physicians about the antiepileptic drugs they are taking, so that drug interactions are avoided.
- (d) Some drugs cause undesirable effects if the dose is increased too quickly, hence this should be avoided.
- (e) If the first drug is not effective or not tolerated, a second drug from the commonly used drug list can be tried, and the previous drug withdrawn.

One-drug treatment

About 75-80% of people with epilepsy can be managed easily with one drug. This is called monotherapy, and it prevents interaction between drugs, ensures good compliance with taking medicines and also proves cost-effective. However, the remaining 20–25% of patients may require multiple drugs. This is known as polytherapy. For each type of epilepsy, there is a drug that usually proves to be the most effective. The best drug for the specific type of epilepsy should be started in a low dose, once or twice daily depending upon the nature of the drug. Dose escalation should always be under medical guidance and needs to be undertaken slowly during follow-up, in a gradual process, until either the seizures are controlled or undesirable side-effects appear.

Long-term antiepileptic drug treatment

Epilepsy is a chronic illness as is hypertension or diabetes mellitus and requires long-term treatment. In view of the stigma attached to this disorder and the requirement for long-term administration of medications, it is essential to confirm the diagnosis before treatment commences. Not all seizures require antiepileptic drugs. For example, a young housewife, whose general health, neurological examination and all tests are normal and who has suffered only one seizure, may not require antiepileptic drugs in the first instance. Similarly, a child experiencing convulsions with only high fever is not started on long-term antiepileptic drug treatment.

Systemic disorders

Since people with epilepsy can also suffer from other diseases such as asthma, hypertension, diabetes, renal and liver disorders, it is essential that patients inform their treating physicians of their other illnesses, so that those drugs which interact with antiepileptic drugs can be avoided. As certain kidney and liver disorders interfere with the excretion of some antiepileptic drugs, the doses of these antiepileptic drugs need to be adjusted and some drugs completely avoided. The physician will decide the drug and its dose.

Serum antiepileptic drug estimation

The dose of drug required by each patient depends largely on its effectiveness and is, therefore, based on success in controlling seizures or the appearance of side-effects. This is dependent on the amount of medicine which enters the body through the stomach. One way to assess this is to measure the level of medication in the patients' serum. Only a few major hospitals in SEAR Member Countries offer a facility for serum antiepileptic drug estimation, but it is not necessary to refer all patients there. Serum antiepileptic drug levels need to be estimated only in certain conditions:

- To monitor compliance in patients with uncontrolled/refractory seizures;
- In patients with kidney or liver disorders;
- To assess antiepileptic drug dosage in pregnant women with epilepsy;
- In patients participating in controlled trials of antiepileptic drug safety;

- When the patient is on polytherapy and drug interaction is suspected.

Adverse effects of medications

A few patients experience adverse effects when antiepileptic drugs are administered. These are of four types:

- (a) Acute dose-related effects
- (b) Chronic toxic effects
- (c) Idiosyncratic or allergic reactions
- (d) Teratogenic effects (affecting the unborn child)

Acute dose-related side-effects are similar for most antiepileptic drugs. These include dizziness, gait imbalance, nausea, visual disturbances and excessive drowsiness. Once reported, these can be mitigated by reducing the dose of the drug or by starting with small doses of the drug and gradually building it up.

Chronic toxic effects develop gradually and can be observed during follow-up. The side-effects common to most antiepileptic drugs are drowsiness, lethargy, mental slowing, memory disturbance, irritability and aggression. In addition, there are specific toxic effects of each individual drug.

Idiosyncratic (allergic) side-effects are temporally related to the administration of a particular drug. These are not dose-related, and require a complete, immediate cessation of the drug.

Teratogenic effects (effects on the unborn child) may result if a pregnant woman is on antiepileptic drugs, especially if she is on multiple drugs. Teratogenic effects vary from drug to drug. Some effects noted include cleft lip or palate, congenital heart defects, mental retardation, deformities of the brain and small size of head.

Follow-up evaluation

Follow-up is an essential step in the management of epilepsy. The patient has to maintain a "seizure diary" where every seizure is recorded and report to the treating physician periodically. The interval between follow-up varies, depending upon the frequency of seizures. The treating physician will evaluate the clinical response of the patient with respect to the dose of the drug being administered and any side-effects

Even a minor episode should be reported to the doctor. The doctor will decide whether these were epileptic events or non-epileptic ones. If diagnosed as epileptic events, they will affect the duration of treatment.

noted during follow-up visits. It is essential to note the effect of seizures on the patient's day-to-day activities.

Why does treatment fail?

Despite the best of efforts, some patients fail to respond to medication and continue to suffer from seizures. This is referred to as chronic epilepsy, difficult-to-treat epilepsy or refractory epilepsy. The following factors may be responsible:

- Poor drug compliance;
- Inadequate dosage, i.e. not enough drug levels in the blood;
- Patient cannot afford the medication;
- Non-availability of drugs;
- Inappropriate medication;
- Wrong diagnosis;
- Seizures secondary to an underlying cause.

Most of these causes are preventable and, hence, easily remedied. In developing countries of SEAR, non-availability of the specified drugs and unaffordability play an important role in poor drug compliance. In some cases, patients continue to get seizures subsequent to eliminating the above factors and, thus, further investigations are essential to rule out an underlying cause.

Duration of treatment

Once commenced, antiepileptic drug treatment should be continued till the patient has been totally seizure-free for a minimum of two years. Some physicians treat for three years. Before considering discontinuation, it is necessary to ensure the following:

- The patient has had no major or minor episodes in the last two years;
- The patient has normal mental development;
- The seizures are not due to a progressive brain disorder;
- Periodic EEGs have been normal, and EEG prior to tapering medicines is normal.

If the above-mentioned factors are not met, it is advisable to continue antiepileptic drug treatment for a longer period.

After successful completion of the course of treatment, the drug should not be stopped abruptly; it should be withdrawn slowly over a period of several months. In the case of a

patient taking more than one drug, withdrawal of one drug should be complete before the dose of the other drug is reduced.

Risk of recurrence after stopping the antiepileptic drug

The risk of recurrence remains, even after a seizure-free two-year period on treatment and a gradual reduction and cessation of drug therapy. Patients should be informed about this. The chances of recurrence are about 10% for children and about 20% for adults. In other words, there is still a one in five chance of recurrence. It is believed that patients with symptomatic seizures, associated mental handicaps and initial difficulty in achieving control have a higher susceptibility to recurrence. Risk of recurrence is highest soon after stopping the drug and gradually declines with time. It is essential that patients remain in contact with their doctors during this period.

Under no circumstances should antiepileptic medications be stopped suddenly. This can be life-threatening.

Diet

There are no special dietary restrictions for epilepsy. The belief among rural folk in India that consuming cold items of food such as ice cream or fruits such as banana will cause seizures is a misconception. There is absolutely no truth in this.

Special diets such as the high fat diet known as “ketogenic diet” has been of some help in children with intractable epilepsy. However, this is costly and extremely difficult to follow. Also, the patient may not like this diet.

Surgery for epilepsy

Some people with epilepsy who do not respond to antiepileptic drugs may require brain surgery. This is possible in very few patients. It is essential that the specific area of brain responsible for their seizures is pinpointed by an abnormal MRI scan and correlated with the EEG abnormality. The removal of such a localized area may cure seizures in selected patients. The success of the operation depends upon proper patient selection. The surgery is expensive and labour-intensive, and available at only a few centres in India and Thailand.

Psychotherapy

Psychotherapy cannot cure epilepsy. However, some patients who experience seizures whenever they are tense or emotionally upset can be helped, such as a child who has seizures at the beginning of the school year. Psychotherapy can help such patients to understand the problem, to have a positive attitude and to control stress. Often, parents of children with epilepsy are extremely worried and require psychotherapy themselves.

Women are more prone to certain special situation-related seizures than men.

Catamenial epilepsy

Approximately two-thirds of women with epilepsy complain of an increase in seizure frequency at the time of menstruation. The term “catamenial epilepsy” is applicable if the seizures occur immediately prior to or during the menstrual cycle. This is a worldwide phenomenon. These seizures could be hormone-related, due to fluid and electrolyte imbalance or increased stress during this period. Some additional medications may be prescribed by physicians for women with catamenial epilepsy.

Oral contraceptives and antiepileptic drugs

Women with epilepsy who use oral contraceptives should be warned about the decreased efficacy of these agents, as antiepileptic drugs interact with oral contraceptives. Women who experience breakthrough bleeding need to practice a barrier method for the rest of the cycle, since the bleeding is an indication that the agent may not provide adequate protection.

Pregnancy and epilepsy

Approximately two-thirds of women with epilepsy can safely become pregnant. In some women, the pregnancy has no effect on epilepsy, in some it improves epilepsy, but in one-third of women with epilepsy, there is a worsening of their epilepsy status. This could be due to many reasons.

- (a) There could be a fall in the serum antiepileptic drug levels due to the physiological changes/growth of the foetus.
- (b) Some women may not take antiepileptic drugs regularly because of fear that their unborn child may be harmed.
- (c) A hormone-related cause could be the reason for the worsening of the epilepsy.

Hence, it is essential that women with epilepsy regularly consult their doctors during pregnancy.

Pregnant mothers should be protected from recurrent seizures with adequate medications.

The majority of women with epilepsy give birth to normal, healthy infants.

Foetal malformations

The risk of foetal malformations is higher in pregnant women on multiple drugs and hence women with epilepsy planning to have a child should preferably be treated with a single antiepileptic drug. They should consult a physician who will choose the most appropriate drug and in the right dose. The risk of their having a child with foetal malformations is about three times higher than in the general population. However, they need to continue on a relatively safe antiepileptic drug and understand that if drugs are reduced, there is a risk of seizure recurrence, and frequent seizures in the mother may affect the unborn child.

Women with epilepsy are usually advised to use folate supplementation before and during pregnancy, till delivery. Common malformations seen in children born to women with epilepsy are: cleft lip or palate and congenital heart defects. Other less common effects include mental retardation, deformities of the nervous system and small head size. Premature labour and other obstetric complications are said to be higher in women with epilepsy.

Problems in babies born to mothers with epilepsy

The chances of perinatal problems such as difficult labour, prematurity and low birth-weight are a little higher in the pregnancies of women with epilepsy than in normal pregnancies. The risk of jaundice during the neonatal period (during the first one month) could also be higher in these children.

A majority of women taking an antiepileptic drug can breastfeed their children without any difficulty.

Breastfeeding

Breast feeding should be especially encouraged in SEAR Member Countries to overcome protein–calorie malnutrition among children. As antiepileptic drugs do pass through the breast milk to the child, the latter could be slightly jittery, drowsy and sometimes hyperexcitable. The mother should be cautioned about these possibilities. Only those women who are on some newer antiepileptic drugs are not allowed to breastfeed their babies. The treating physician will be able to provide detailed information.

Status epilepticus

Status epilepticus is a serious medical emergency

Sudden stoppage of antiepileptic drugs can lead to status epilepticus. This can be life-threatening.

If a seizure is allowed to continue for a long duration, there is a great risk of permanent brain damage. It is not uncommon to find patients with seizures lasting for more than 24–48 hours in the emergency wards of hospitals in SEAR Member Countries. There are several reasons for this: ignorance among the general public, who usually practise locally available methods such as native medicines or tattooing, before reaching the hospital; lack of proper hospital facilities, and distant location of major hospitals and poor modes of transport in rural areas.

The most common causes of status epilepticus in developing countries are poor drug compliance and abrupt drug withdrawal. The latter could be caused by the nonavailability of drugs, poverty or ignorance among patients or their caregivers.

Other causes could be: (a) brain infections such as viral encephalitis, which is still common in Bangladesh, India, Indonesia, Sri Lanka and Thailand; (b) clotting of blood in the veins of the brain due to restricting fluids to women just after delivery of a baby. This is practised among the rural folk in some SEAR Member Countries.

It is essential that local physicians, paediatricians or family physicians be educated about the principles of management of status epilepticus. This expertise should be available at least in all district hospitals, so that delay in the proper institution of drug treatment can be prevented. More often than not, guidelines provided by the International League Against Epilepsy cannot be practised in these countries as patients reach hospitals very late. In SEAR Member Countries, future community programmes for epilepsy should emphasize the management of status epilepticus.

Impact of epilepsy

Epilepsy itself should not impair performance.

According to a study in India, 39% of students with epilepsy had difficulty with their studies, while 9% of the employed faced difficulties at work. Work performance was affected in 26% of patients and 39% had personality problems. Surprisingly, 15% had concealed their illness from their employers and colleagues. While the situation will improve over time, it is currently a matter of increasing concern for all.

The role of a medical care provider is not limited to controlling seizures, but extends to helping the patient improve the overall quality of his/her life.

Epilepsy affects every sphere of an individual's life, cutting across age, gender and social differences. The overall quality of life is hampered due to the nature of the illness and associated effects. Major areas of education, employment, marriage and social functioning are affected and the individual experiences personal problems. The discriminating attitude of society makes the situation worse. It is indeed the sociocultural attitudes rather than the illness itself which worsen the quality of life of people with epilepsy.

Impact on education

The fundamental requirement of a growing child is education. Children with epilepsy are not sent to school because of parental fears. In school, teachers display segregational attitude such as separating, neglecting or barring such children from school activities. A seizure in the classroom is regarded as "a horrible scene and a nuisance" by teachers and other children. The major problems encountered by school-going children with epilepsy are coping with studies, difficulty in making friends, fear of seizures occurring at school, disliking school, fear of teachers, drowsiness due to medication, decreased attention and low performance. It should be noted that epilepsy by itself does not impair the intellectual performance of the child. Usually, the impairment is due to the side-effects of medications or the social stigma inflicted on the patient. There is virtually no facility to provide first-aid for children in case of a seizure, and to educate and involve other children in school. These attitudes cause the child to drop out and discontinue education. At such times, parents and society aggravate matters by labelling the child a failure. Due to the precious years of schooling lost, peer groups, parents and neighbours look down on the child, thus creating an inferiority complex. The positive strengths of these children are never brought out, making them possible failures in later life.

Impact on employment

Good education is an essential factor in acquiring gainful employment. Once children lag in education, they will find, as adults, that jobs are not easily available in today's competitive world. Employers do not want to employ a person with epilepsy; when employed and if prone to uncontrolled attacks, the person with epilepsy faces a worsened situation. They are not given normal jobs but placed in sundry peripheral low-income assignments. Often these jobs are terminated. Loss of

a job or low income from a job renders the person to be less productive and a “burden” on the family.

Recent studies indicate a slightly higher risk of accidents at the workplace. The employer’s fear of compensation further segregates the person. At the end of a four-year follow-up study from India, 2% had stopped going to work and the work status had changed for 6% of patients due to uncontrolled seizures. Deterioration was noticed in 25% of the patients when seizures were uncontrolled, leading to a significant drop in work efficiency. The costs of medical management and travel to hospitals added to the existing burden.

Impact on the family

A number of social problems such as interpersonal conflicts and rejection surface later in life, leading to strained relations. Over a period of time, this leads to feelings of helplessness, hopelessness and worthlessness, often driving the person to the extreme step of suicide or running away from home.

The combined effects of epilepsy on the family, the school and in the workplace have a significant impact on the psychosocial functioning of the patient. The family’s reactions vary from mixed feelings of overprotection, to rejection, to using the patient as a scapegoat. Emotional responses include horror, guilt, anxiety, sadness, worry, confusion, depression and even avoidance. These reactions lead to various behaviours such as overindulgence, poor monitoring, sibling jealousy and decreased parental expectations. Further, these cause disturbed family dynamics, leading to guilt and concealment, adoption of a sick role, dependence and low self-esteem. The emotional adjustment and coping strategies for these problems thus begin with the individual and extend to the family, acting as major stressors. These behaviours and limited coping patterns lead to changes in personality, apart from the illness itself. Such personality problems coupled with the disease process and medication lead to difficulties in adjustment in interpersonal areas, education, employment and family life. This results in decreased productivity of the person, both in financial and other areas. The patients are already struggling with seizure problems and must face other difficulties as well, which only serve to aggravate the situation.

In the absence of a sound education and a good job, getting married and leading a healthy family life is much more difficult. In traditional societies, getting a daughter with epilepsy married is an extremely difficult task.

Attitude towards marriage for people with epilepsy...

“Revealing is dangerous and acceptance is risky” sums up the situation for family members.

What can be done about epilepsy?

My true story..

Having petit mal epilepsy from the age of 11, with occasional grand mal seizures, it was instilled in me that nobody should know about my illness. As a result, I began to think that I had a dreadful illness. One that I could not share with even my closest friends, which made me feel very lonely. My self-esteem took a beating. It was only when I started working as a secretary with a small private firm achieving some measure of independence that I started believing that if I worked hard, very hard, I could be good at whatever I put my mind and heart to. This belief worked well for me. While in my first job, I completed my graduation as well as honed my secretarial skills.

Like many women who have epilepsy, I was convinced that no one would marry me. I was scared to death to even think of marriage. It came as a complete surprise to me, a pleasant one, when I found I was not rejected when I confided I had epilepsy. Before having children, I went to my neurologist I was worried about the effects of seizures and medication on the unborn child. He assured me that the chance of something happening to my child was slim. "What can happen?" I asked, and he said "some small malformation like a cleft lip." I thought the risk was worth taking. Today I have two children who are enjoying life. We will have our fears; we are human. But it is important to realize that we are not alone, that others have been there before us. Support from my spouse and family are really what helped me overcome difficulties and fears.

Besides family support, support from another direction or group helped me greatly. Four years ago, I joined SAMMAN, an epilepsy support group in Mumbai. I joined, thinking my experiences could help others. To my amazement and delight I discovered that, by joining, I benefited myself the most! My first impression of the group was "these persons are enjoying life in spite of epilepsy – let me get to know more about them". Since then I've been committed to this group. It's given me the opportunity for all round development in more ways than I could have ever imagined.

It's an eye-opener really, to realize that epilepsy is not always a barrier. And to realize that epilepsy can be treated as just a part of my life and not my whole life.

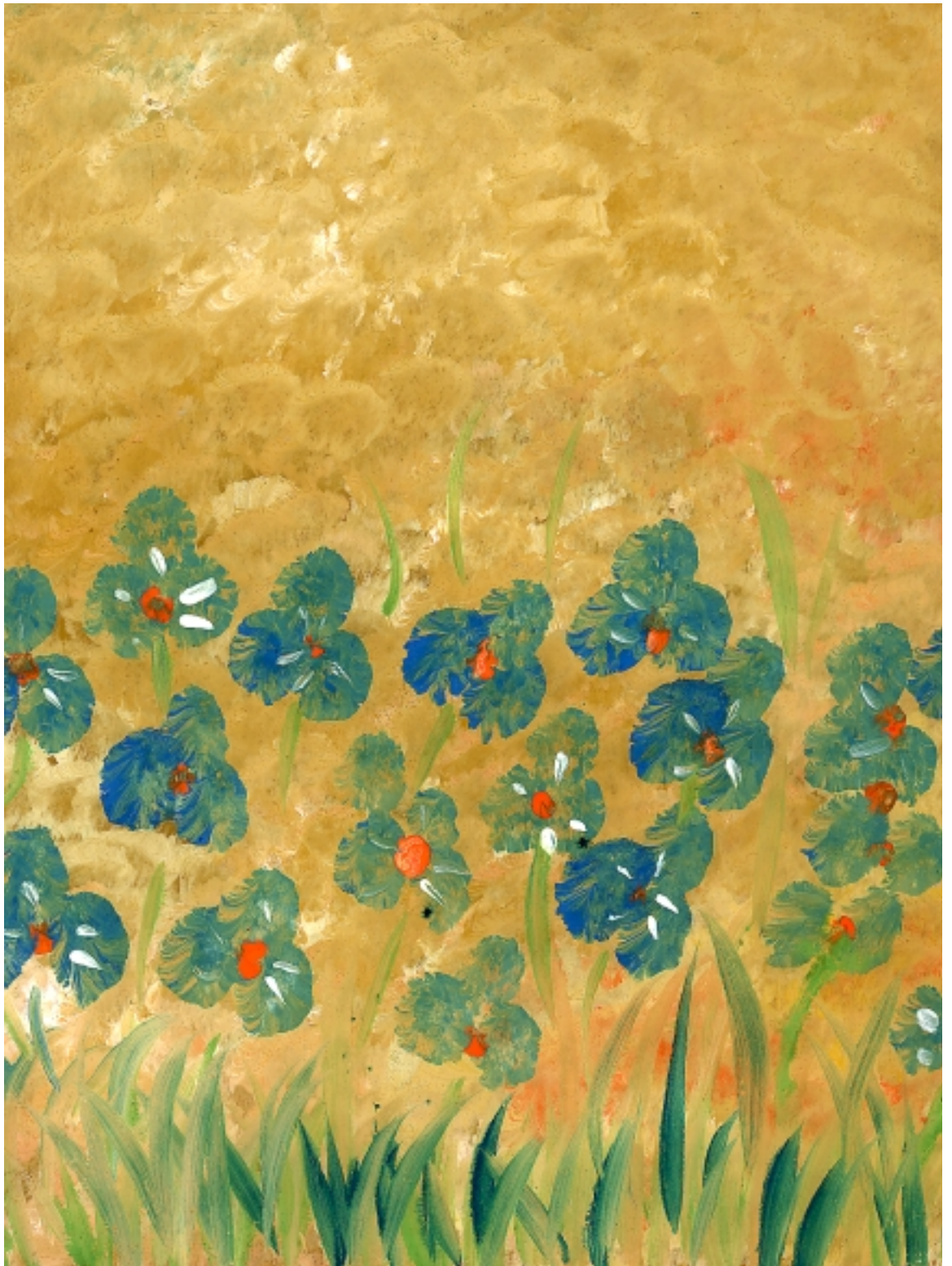
However, let's not go away from here thinking that all is well for people with epilepsy. There is a harsh reality outside. There are many people out there who will tell you they can deal with the seizures but not the stigma; who are suffering because of it. At medical congresses, it is apparent that the medical fraternity and medical researchers are doing an excellent job. However, more has to be done by way of education and awareness to change attitudes. Family members first, and then society, have to be given a proper perspective of what epilepsy is all about, and on the value of support.

At times, it is brought to my notice that persons with my kind of story are in the minority. I wonder if that is true. I am sure there are many people with epilepsy leading successful lives, who are afraid to "come out" and be branded. I am very happy that I have been given this platform to write about my experiences. And I appeal to more likeminded persons to talk of their experiences and challenge the notion that "epilepsy" goes with "inferiority".

Let us make it our mission.

Thank you.

Carol D'Souza



"Valley of Flowers"

Painting by Ms. Yogeeta of India

Some dos and don'ts for patients: Ten Commandments

(Adapted from Indian Epilepsy Association, Bangalore, India)

1. Epilepsy is a controllable disorder.
2. Epilepsy is not a mental illness.
3. If you witness a patient having a seizure, note the details: an accurate description prevents wrong diagnosis.
4. Early treatment is the secret of success.
5. The prescribed antiepileptic drugs have to be taken regularly.
6. The duration of treatment, in general, is about 2 to 3 years after the last episode.
7. Restrictions for people living with epilepsy are very few; the most important thing is to ensure adequate sleep.
8. People with epilepsy can study, work and enjoy life.
9. Women with epilepsy can marry and bear children.
10. Treat people with epilepsy as you would treat people with asthma, diabetes or hypertension. Do not overprotect or ostracize.

What the patients can do for themselves

Everyone can contribute...

While the number of people with epilepsy receiving modern care is gradually increasing in urban areas, those residing in inaccessible and remote areas in SEAR Member Countries are still unidentified and untreated. The responsibility of reaching the unreached rests with the relevant agencies, governments and health professionals. Strategies have to be developed and new mechanisms initiated, if epilepsy is to be taken out of the shadows.

1. There are already several disease control programmes in operation in SEAR Member Countries. They cover diseases such as tuberculosis, Japanese encephalitis, mental disorders, respiratory diseases and reproductive and child health. Many of these stress outreach programmes and epilepsy could be incorporated into the existing programmes.
2. As most of these programmes work with the existing local health staff and professionals, strengthening knowledge, attitudes, beliefs and practices of functionaries at the grass-roots level will enable identification, follow-up monitoring and guidance for people with epilepsy. Simple manuals are already available, replete with information to be disseminated and put into practice.
3. Physicians (including specialists of various disciplines) at various levels of health care should acquire appropriate knowledge about the identification and management of epilepsy. Their work needs to extend beyond prescribing medicines to being agents of change at the community level. Regular in-service training programmes should be arranged in all countries via local professional or voluntary organizations through continuing medical education programmes.
4. Strengthening epilepsy care in SEAR Member Countries requires substantial input. This includes training doctors and related professionals at the undergraduate and postgraduate levels, inculcating greater skills in physicians and others at the formative stage, thereby enhancing their role in society. Apart from the disease process and drugs, health professionals should be well-



“I Am Not Alone”

Painting by Mr. Peera of Thailand, to describe his feeling just before he has a convulsion

- versed in sociocultural issues.
5. Short-term awareness programmes for local resource agencies such as, teachers in schools and colleges, local NGOs active in health and development, industrial employers should be conducted to involve them in the prevention and control of epilepsy.
 6. Various models have already been developed in some countries, for example: District Mental Health Programme in India, Sarvodaya Movement in Sri Lanka, School Teachers' Programme in Indonesia and Thailand. These have provided good insights into the benefits of such programmes and their ability to extend services to those in rural and remote areas. These models must be expanded and integrated into ongoing health programmes.
 7. Apart from the hospital-based approach, various outreach programmes, such as special epilepsy clinics, satellite clinics and monthly camps involving local NGOs should be developed on a large scale, with community participation. Key components of these outreach programmes should incorporate the following features at all levels:
 - Identification
 - Monitoring and follow-up
 - Drug distribution
 - Individual and family education
 - Community education
 - Simple record maintenance
 - Simple reporting methods.
 8. Systematic planning at the regional and local levels should be undertaken for budgeting, drug procurement and distribution to ensure continuous availability of drugs at the local level.
 9. In the rural and remote areas of every country, nearly 70% of epilepsy can be effectively controlled with simple antiepileptic drugs. The remaining 30% of sufferers require further investigation and multiple drugs. To handle this situation, a referral network between peripheral health centres, mid-level district hospitals and apex institutions should be established.
 10. There is an increasing number of road accidents and injuries caused by falls, violence, industrial accidents and sports in SEAR Member Countries. While specific preventive strategies are available for each of these, road accidents should receive greater attention. Many

victims who survive these accidents are severely disabled and may suffer from recurrent seizures.

11. Every country must initiate concerted efforts to remove the stigma associated with epilepsy. Community education and awareness are key steps in this direction, along with improving opportunities for education and employment. People with epilepsy should not be discriminated against.
12. Epilepsy education plays a key role in a number of areas at the individual, family and community levels. Apart from other relevant factors, such education should focus on removal of stigma, improving drug compliance and disseminating information about first-aid measures. In this regard, there is a paucity of education materials in every SEAR Member Country. Resource materials in simple formats should be developed in local languages and disseminated through local communication channels in a people-friendly way. Appropriate and required information should be provided as a continuous activity, and not as a one-time effort.
13. Local professional bodies such as neurological associations, epilepsy associations and medical associations need to network with professionals, NGOs and local groups to undertake epilepsy education programmes.
14. Continuous research is required to augment the understanding about epilepsy. In SEAR Member Countries, research into the efficacy of drugs continues, but other aspects have not received much attention. Operational research about services, drugs, health systems and utilization of services is vital to improve epilepsy care. Studying the prevalent knowledge, attitude, beliefs and practices is crucial to stigma elimination programmes and to improve the psychosocial standards of people. Each country can designate one of their apex institutions as a research centre for epilepsy. Research should also be expanded to cover the number of affected, the causes and susceptibility through simple, practical and inexpensive methods. One or two centres of excellence should be designated for research into advanced management issues.

Some basic information for health professionals ...

Health care providers must be fully aware of the presentation of epilepsy and its identification at first contact.

A case history from an eyewitness should always be obtained.

The patient may be unaware of what exactly happened during a seizure.

Discuss the nature of the illness and potential consequences openly with the patient and family members.

Initiate treatment as per the general and specific guidelines already established.

Emphasize the importance of compliance with drug treatment and regular follow-up.

Highlight the importance of stocking an appropriate amount of drugs.

Discuss the possible side-effects of drugs with the family, as ignorance will

lead to discontinuation.

Reinforce that people with epilepsy can lead normal lives with minimal restriction of daily activities.

Emphasize the dos and don'ts for people with epilepsy.

Educate family members about the illness to remove stigma. Specifically, provide inputs for education of children, employment of adults and marriage of daughters.

Answer specific questions about driving, working with machines and risk environments.

Provide simple and practical first-aid training to local health staff and other important members of society such as teachers, members of NGOs and the local industrial establishments.

Work closely with the media and local press for stigma removal and education.

Role of Health Professionals

There are very few neurologists in SEAR Member Countries. Further, most of the neurologists are concentrated in major urban centres. Thus, a number of other practitioners provide care in different situations. The health care systems in SEAR Member Countries vary greatly and each country has to develop its own individual strategy. However, in every country, the family physician is usually the first stop for a patient with epilepsy.

Role of the pharmaceutical industry

The pharmaceutical industry has a vital role in ensuring a seizure-free life for people with epilepsy. In most countries, antiepileptic drugs are not available on a continuous basis in remote areas, while the cost of some of the newer drugs is high. Adequate supply and distribution is crucial if people are to lead seizure-free lives. Spurious and substandard medication is a serious problem. Governments can work with the industry to reduce taxes and modify laws which effect cost and distribution.

Role of NGOs

Nongovernmental organizations at local levels are involved in a number of health and development programmes. Due to their close proximity with community leaders and members, they are well acquainted with people with epilepsy. NGOs and professionals should organize local programmes on epilepsy. They can also take a lead role in ensuring drug supply and availability, monitoring of persons for drug compliance and removal of stigma.

Role of the Health Sector

The health sector is the key agent of care with regard to epilepsy. Adequate efforts must be made in the areas of prevention, management and rehabilitation.

Epilepsy and the education sector

As epilepsy commonly occurs in younger age groups, teachers have a key role in its management on a day-to-day basis.

The health sector can...

- Provide simple and practical training for medical and paramedical staff;
- Ensure availability of antiepileptic drugs through governmental and nongovernmental agencies;
- Develop and distribute simple training manuals in local languages;
- Support manpower development at different levels;
- Maintain national surveillance of epilepsy and promotion of research.

Teachers can help...

- Learning to recognize seizures.
- Referring people with epilepsy to appropriate health care agencies.
- Emphasize the importance of continuous treatment to the families of affected children.
- Equipping themselves with knowledge and skills regarding first-aid techniques.
- Educating other children and families to remove stigma and misconceptions about epilepsy.
- Not discriminating against or segregating children with epilepsy.

Contrary to popular belief, epilepsy is not equated with insanity in Indian law.

There is a close relationship between epilepsy and the law. Epilepsy has been quoted in many judgments. However, the legal system varies from one country to another. Developed nations have changed their laws towards epilepsy and enlarged the rights of people with epilepsy, whereas in developing countries, age-old laws persist.

Epilepsy and marriage

There is no medical reason for people with epilepsy to remain unmarried. However, in many countries, including some South-East Asian countries, there have been laws in the past preventing marriage for people with epilepsy. In India, there are different marriage laws for Hindus, Christians and Muslims. In legal parlance, the term "Hindu" includes Buddhists, Jains and Sikhs. As per the Marriage Law Amendment Act (1976) promulgated by the Government of India, a person subject to recurrent attacks of insanity or epilepsy cannot have a legally valid marriage and such a marriage can be declared null and void.

Repeated petitions to the Government of India by the Indian Epilepsy Association since 1986 were unsuccessful, hence the Indian Epilepsy Association filed a public interest litigation before the Supreme Court of India. The Government of India amended the above-mentioned draconian law of 1976 in 1999, and on 29 December 1999, the Marriage Law Amendment Act 1999 was enacted. With this, legal rights in marriage have been restored to people with epilepsy.

It is desirable that the marital partner of a person with epilepsy has a full understanding of the medical condition prior to marriage, to prevent legal battles after marriage.

Epilepsy and driving

Laws related to driving vehicles vary from country to country. Indian law with respect to driving has made a complete turnaround. The Motor Vehicle Act of 1939 prohibited any person who had ever suffered a seizure from driving or obtaining a valid driving licence including a learner's licence; patients, however, concealed their condition and easily obtained a driving licence. The Motor Vehicle Act, 1994 has rescinded the word "epilepsy". A person with epilepsy in India can now drive any vehicle, anywhere, as there is no mention

of driving restrictions for people with epilepsy in this amended Act. This is an unfortunate situation, as the patient, passengers and the public can be at risk if a driver were to have a seizure while driving. The Indian Epilepsy Association has started legal proceedings to amend this law. There are no guidelines for epilepsy and driving in Thailand either.

Law in Europe

A close look at the law in Europe is recommended. Accordingly to this law, a patient with a history of epilepsy is allowed to drive if:

- He or she has been free of attacks for one or more years; or
- If attacks have occurred but only during sleep, for a period of three or more years; and
- If “the driving of the vehicle is not likely to be a source of danger to the public”.

In Europe, for purposes of driving, a single seizure is considered a manifestation of epilepsy if there is a high chance of recurrence. In instances where this is not the case, a patient with a single seizure is usually prevented from driving for 3 to 12 months after the episode. The law is much more rigid for driving of public and heavy vehicles.

SEAR Member Countries may take their cue from European regulations.

Epilepsy and health insurance

Health insurance in India is a new phenomenon and covers less than 0.5% of the population. The Insurance Privatization Bill was passed by Parliament in 1999, thereby allowing private entrepreneurs to enter the insurance sector. Previously, state-owned insurance had excluded epilepsy from its ambit, categorizing it with other chronic medical illnesses. Once again, a legal battle is on, to grant equal rights to people with epilepsy with respect to insurance. Only time will identify the benefits of a liberalized insurance policy for people with epilepsy in India. In Thailand, health insurance covers epilepsy in the same manner as any other chronic illness like diabetes or hypertension, and all the expenses of people with epilepsy are covered by social security.

Mr George Burden, the first Secretary-General of the International Bureau for Epilepsy said ...

//

I beseech you
Do not give a
person a job
because he has
epilepsy
Do not deny
him a job
because he has
epilepsy.

//

Education and employment

There is no legal bar to education and employment for any person with epilepsy in India. It is essential to remove injustice towards people with epilepsy. There should be no discrimination against people with epilepsy. Since this is not a disabling illness, there is no need for special privileges.

In India...

Under the aegis of the **National Mental Health Programme, the District Mental Health Programmes** was started in 1982 in Bellary district of Karnataka, India. A series of activities beginning with training of primary health centre workers, evaluation of trained workers, and training of trainers formed the foundation of the Programme.

Drug supply was ensured through continuous planning and budgeting. The training was decentralized, and continued on the job with evaluation activities. Simple records were maintained, including a patient identification card, simple record books and a record of the doctor's care. Monitoring was established through continuous support, district-level (local) meetings of primary health centre staff and constant feedback. The district administrative staff and local communities were involved through awareness and sensitization programmes. Currently, the Programme has been expanded to 22 districts in India.

Encouraged by this response and realizing the magnitude of the problem of epilepsy and the lack of experts in India, the National Institute of Mental Health and Neurosciences (NIMHANS), at Bangalore launched the '*Epilepsy Control Programme*' in 1999 with financial assistance from WHO country funds. This programme involves the training of district medical officers located in various states all over India in the principles of diagnosis and management of common types of epilepsy. The programme envisages further monitoring and feedback of these district medical officers by the identified nodal neurologists located in each of these states. The training is currently in progress and will continue in future to include all the 28 states in India.

Satellite clinics are monthly camps by the Community Mental Health unit of NIMHANS on a fixed day, and at a fixed time and place, held in five *taluk*-level areas within 20–100 km from Bangalore, India. The experience has revealed that a large majority of people with epilepsy can be managed effectively with simple antiepileptic drugs. Free drugs are made available by the local government department on a regular basis and are included in its budget.

This model is an ongoing activity wherein services are provided by specialists in close proximity to the people.

A successful district-level model for mental health in India...

The essential components were: (a) training of health functionaries; (b) continuous and uninterrupted provision of essential drugs; (c) a simple recording and reporting system; (d) continuous support and supervision by technical experts, and (e) community participation and establishment of district units.

An essential outcome was that nearly 70% of people with epilepsy within a 5 km radius of the primary health centre were covered by continuous drug supply, education and supportive activities.

Cooperation works...

Local NGOs in Bangalore, India (Rotary, Lion's Club, schools) are involved in the provision of space, distribution of drugs, awareness-building and publicity programmes. The involvement of the community has helped in reducing stigma and improving awareness, while the involvement of family members has been a key component of education programmes.

In Sri Lanka..

It has been ably demonstrated by the programme that local involvement of health workers, community and governmental agencies can provide efficient and effective care.

Gold medal for film on epilepsy...

The film depicts a young girl with epilepsy and her medical and social hardships. The role played by her elder sister (who becomes a nurse) in improving the situation highlights the role of families in the control of epilepsy.

Evaluation studies have shown significant impact of such community programmes.

The **Indian Epilepsy Association** was started in 1971 and has developed numerous educational materials on epilepsy. It also organizes public awareness programmes and celebrates 17 November as National Epilepsy Day in India.

In Sri Lanka..

Primary health care of epilepsy is possible only if information about epilepsy is disseminated at peripheral levels. An excellent example from Sri Lanka is the **Sarvodaya Shramadana Movement** in Kandy district, involving preschool teachers. Beginning with a well-illustrated handbook on epilepsy in Sinhalese and Tamil, which was expanded over a period of time, the preschool teachers were trained in first-aid methods, identification of epilepsy, effects of drugs (role and side-effects), and education regarding social problems. It was followed by a survey in the area which identified nearly 700 people with epilepsy. A total of 19 health workers and 214 teachers were trained on issues related to epilepsy. The local government hospitals were involved from the inception of the programme

"Gangulaen Egodata" or "The Story of Saba" is a television drama in four half-hour episodes written in 1988 by a medical specialist and directed by a leading film personality in Sri Lanka. This documentary won the Gold medal in the drama section at the Epilepsy International Congress at Hamburg, Germany. The film was shown on the national television network "Rupavahini" and has been repeatedly telecast on public demand.

In Thailand...

The Epilepsy Society of Thailand has developed a number of activities since its inception in 1996. The society conducts short-term programmes for general practitioners once a year. A **Teachers' Training Programme** is also in operation in metropolitan Bangkok. Public awareness programmes are held regularly to spread information about epilepsy. The society has brought out colourful brochures on various aspects of the illness. Outreach programmes are being conducted in Lampang (northern Thailand) and Krabi (south Thailand). The society plans to publish epilepsy management guidelines for general practitioners in the future.

The Department of Mental Health Policy in Thailand enlists the support of village volunteers to identify and follow-up on people with epilepsy. Started in 1995, this innovative approach has proved useful for epilepsy care in Thailand.

Thailand has introduced legislation since 1997, making it compulsory to wear a helmet when driving a motor cycle, to reduce head injuries and subsequent development of seizures. This is a step in the right direction and should be followed in other countries.

In Indonesia...

In Indonesia, teachers have been trained to identify children with epilepsy. In the early part of the programme, a physician visited each school at least once a month to detect possible cases of epilepsy. Subsequently, teachers became a reliable source of referral of children with epilepsy.

Mission statement..

"To improve acceptability, treatment, services and prevention of epilepsy worldwide".

Overall, 70 to 80% of people with epilepsy could lead normal lives if properly treated, but 80-90% of people with epilepsy are not being treated at all.

The International League Against Epilepsy (ILAE) was founded in 1909. The objectives of the International League Against Epilepsy are to advance and disseminate knowledge about epilepsy, promote research, education and training, and to improve medical services and care.

The International Bureau for Epilepsy (IBE) was created in 1961 to deal more specifically with the social aspects of epilepsy, focusing on quality of life and welfare of people with epilepsy.

The International League Against Epilepsy and the International Bureau for Epilepsy both have local chapters, i.e. national epilepsy associations affiliated to the international bodies in over 70 countries.

The three partners, the World Health Organization, the International League Against Epilepsy and the International Bureau for Epilepsy, launched the **Global Campaign Against Epilepsy "Out of the Shadows"**, from Geneva as well as Dublin, during the 22nd International Congress of Epilepsy in 1997.

Campaign objectives

- (1) To increase public and professional awareness of epilepsy as a universal and treatable brain disorder;
- (2) To raise epilepsy to a new plane of acceptability in the public domain;
- (3) To promote public and professional education about epilepsy;
- (4) To identify the needs of people with epilepsy at the national and regional levels, and
- (5) To encourage governments and departments of health to address the needs of people with epilepsy including awareness, education, diagnosis, treatment, care, services and prevention.

Campaign Strategy

In 1999 the Cabinet and Director-General of WHO approved the Paper to the Cabinet on the Campaign, thus raising activities under the Campaign to the highest level within WHO. According to the WHO Cabinet Paper, the strategy of the Campaign includes two parallel and simultaneous tracks:

- (1) Raising of general awareness and understanding of epilepsy, and
- (2) Supporting Departments of Health in identifying needs and promoting education, training, treatment, services, research and prevention nationally.

Following this strategy, the Campaign provides a framework for concerted action at the global, regional and national levels to bring epilepsy "*Out of the Shadows*". Programmes were developed:

Globally: Activities were developed in order to recognize the diagnosis and treatment of epilepsy as a health care priority

Regionally: IBE and ILAE are developing Regional Associations and Commissions in cooperation with all six WHO Regions and setting up demonstration projects. In the South-East Asia Region of WHO, a Regional Commission of ILAE and a Regional Association of IBE have already been set up.

Nationally: The main thrust of the Campaign is at a local/national level, where local solutions to local needs are best understood and from where support for the global and regional aspects of the Campaign also need to be developed, for example through national governments.

During the initial stage, the strategy of the Campaign was essentially focussed on advocacy and awareness activities. According to the plans of action for the Campaign and following the recommendations of the WHO Cabinet, regional conferences on public health aspects are to be organized in all six regions of WHO. In 1998, the first one took place in Heidelberg, Germany where over 100 representatives of professional and lay bodies, WHO representatives and health experts from governments and universities unanimously approved the European Declaration on Epilepsy. During the year 2000, four regional conferences took place:

May	Africa (Dakar, Senegal)
September	Latin America (Santiago, Chile)
November	South-East Asia (New Delhi, India)
December	North America (Los Angeles, USA)

Experience of the initial stage of the Campaign created the rationale for the suggestion of a launch of the second phase of the Campaign with new and more ambitious goals; to improve health care services, treatment, prevention and social acceptance of epilepsy worldwide. The main activities towards these goals are the demonstration projects, which will be initiated in a number of selected countries during the second phase of the Campaign. Countries will be selected in the SEA Region soon.

A report from India

EPILEPSY



out of the shadows

By our Special Correspondent

November, 2000: A meeting on “Epilepsy: A Public Health Priority in Asian and Oceanian Region” was held in New Delhi in November 2000. The countries represented were: Bangladesh, Chile, China, India, Indonesia, Japan, Korea, Nepal, the Netherlands, New Zealand, Pakistan, the Philippines, Senegal, Sri Lanka, UK and USA. Over 600 professionals from the health and social sciences sectors and representatives from many other organizations of the Region participated. The Asian and Oceanian Declaration on Epilepsy was formally announced and unanimously adopted.

Asian-Oceanian Declaration on Epilepsy

New Delhi, November 13, 2000

CONSIDERING THAT IN ASIA/OCEANIA:

- At least 30 million people have the common brain disorder epilepsy. This compares with approximately 50 million people with epilepsy worldwide.
- Epilepsy can have serious medical, psychological, social and economic consequences for people with epilepsy and their families.
- Epilepsy affects people with epilepsy and their families, irrespective of race, religion, gender, age or socioeconomic status.
- Although epilepsy is a brain disorder, it is often mistakenly believed to be a mental illness, or to be caused by supernatural powers.
- It is erroneously, yet widely, believed that epilepsy is an infectious disease and seizures are contagious.
- It is often not realized that epilepsy is treatable, and that most people with epilepsy can lead productive lives with relatively inexpensive, cost-effective treatment.
- The majority of people with epilepsy are treated inadequately and inappropriately because of ignorance, discrimination and limited health resources.
- Good quality standard antiepileptic drugs are not available regularly in many countries.
- Disability and mortality are greater because epilepsy is inadequately treated.
- Epilepsy impacts most severely on the period of greatest development, namely childhood, adolescence and young adulthood. Yet it is during this time of life that it is most readily and successfully treated.
- The preventable causes of epilepsy such as poor perinatal care, infectious diseases, parasitic infestations, head trauma and consanguineous marriages are particularly prevalent.
- Epilepsy has not been included in most national health care plans.

PROCLAMATION

We call on the governments and other health providers of the Asian and Oceanian Region, to join us in taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy launched by the World Health Organization, the International League Against Epilepsy and the International Bureau for Epilepsy.

Specifically, we urge every government in this Region to:

- Educate people with epilepsy, their families and the general public about epilepsy as a widespread, noncommunicable and treatable chronic brain disorder. Educational means appropriate to all levels of literacy should be used.
- Educate and train health care and other relevant professionals about epilepsy, its prevention and its treatment.
- Provide access to trained personnel, modern diagnostic equipment and appropriate medication and/or surgical treatment for epilepsy.
- Promote and support research in Asia and Oceania into the basic processes, clinical aspects, and psychosocial consequences of epilepsy.
- Promote social integration and eliminate discrimination against people with epilepsy in all spheres of life, especially school, work and marriage.
- Include epilepsy in their national health plans, just as they do maternal and child health, mental health, infections and immunization.
- Encourage cooperation between modern medical, traditional and other healing systems for the treatment of epilepsy.
- Encourage the public and private sectors, as well as relevant nongovernmental organizations to actively support local activities related to the Global Campaign Against Epilepsy.
- Raise public awareness of epilepsy by proclaiming a National Epilepsy Day, and supporting the establishment of a World Epilepsy Day.
- Encourage regional and global cooperation in dealing with epilepsy.



The magnitude of the problem of epilepsy and its care, as well as its considerable social and psychological impact in SEAR Member Countries makes it imperative for all countries to develop a national strategy for the prevention and control of epilepsy. The programme must have political commitment, professional support and public participation.

Tasks for the future

1. To place epilepsy on the public health agenda;
2. Develop national guidelines for prevention and management of epilepsy and improve the quality of life of people with epilepsy;
3. Develop relevant manpower at all levels through sensitization and awareness programmes;
4. Establish treatment mechanisms within existing health services;
5. Ensure regular, continuous, uninterrupted drug supply even at peripheral levels with planning and budgeting;
6. Increase public awareness to remove stigma;
7. Develop systematic referral services within defined geographical areas;
8. Expand services to cover inaccessible and remote areas;

WHO/SEARO, national governments, professional organizations and NGOs should work together in removing prejudice and creating hope for people with epilepsy. Epilepsy organizations and their addresses

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