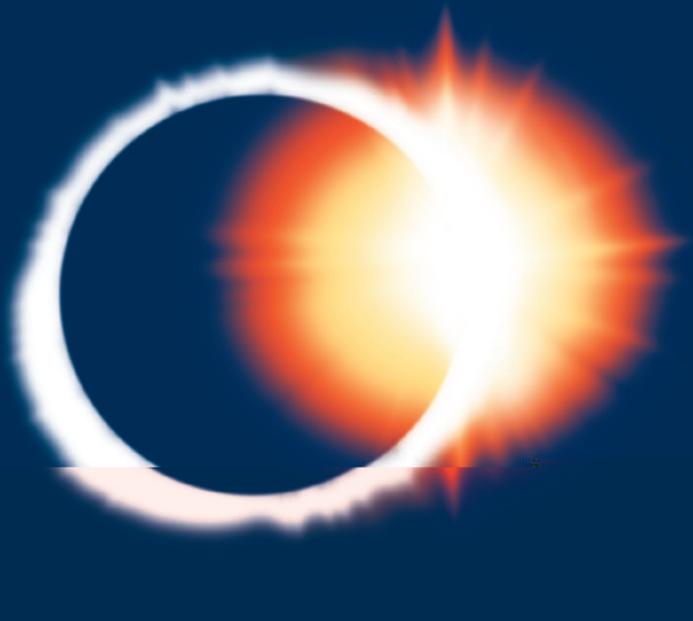


# Epilepsy in the WHO South-East Asian Region



## Bridging the Gap



World Health Organization  
Regional Office for South-East Asia



International Bureau  
for Epilepsy



**WORLD HEALTH ORGANIZATION**

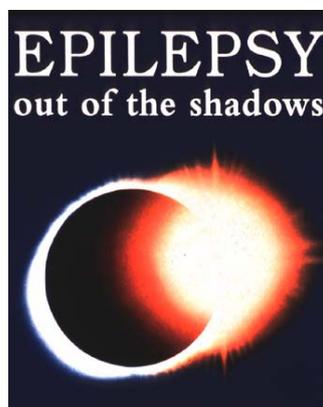
**Regional Office for**

**South-East Asia**



**EPILEPSY IN THE SOUTH-EAST ASIA REGION**

**Bridging the Gap**



***The Global Campaign Against Epilepsy***

***“Out of the Shadows”***

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## FOREWORD

Epilepsy affects about 1% of the population of the South-East Asia Region of WHO thus there are approximately 15 million people with epilepsy in the Region. Despite global advances in modern medicine, epilepsy continues to be surrounded by myths and misconceptions. Patients with epilepsy may be taken to faith healers rather than medical doctors, and only 10-20% of all patients with epilepsy receive appropriate treatment. People with epilepsy and their families have suffered ostracism by society and deprived of treatment, leading to frequent injuries and sometimes, death. The situation is particularly bad in rural and remote areas where almost no services for epilepsy are available.

However, 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 answers and take appropriate action now.

In cooperation with the governments of Member Countries, SEARO hopes to launch nationwide projects in each country to reduce the treatment gap in epilepsy. To carry forward this ambitious project, SEARO recognizes that the support of multiple partners is needed. One of the important partnerships is the collaboration between WHO, the International League Against Epilepsy and the International Bureau for Epilepsy through the Global Campaign Against Epilepsy.

This publication which is a comprehensive review of epidemiology and available services in the Region, aims at further strengthening WHO's initiative to assist Member States to deliver at least the minimum services for neuropsychiatric conditions, using community-based health care providers. It provides valuable information regarding multi-faceted aspects of epilepsy and how to cope with the challenges posed by this mystified and misunderstood disorder.

It is only then that people with epilepsy can emerge from the shadows.

Global Campaign Secretariat

Epilepsy in the South East Asian Region

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## ABBREVIATIONS

AED: Antiepileptic drug  
CBZ: Carbamazepine  
CNS: Central Nervous System  
CT: Computerised tomography  
DALY's: Disability Adjusted Life Years  
EEG: Electroencephalogram  
GCAE: Global Campaign Against Epilepsy  
GTCS: Generalised Tonic Clonic Seizure  
HQ: Headquarters  
IBE: International Bureau for Epilepsy  
ILE: International League Against Epilepsy  
KAP study: Knowledge, Attitude and Practice study  
LTG: Lamotrigine  
MRI: Magnetic Resonance Imaging  
NIMHANS: National Institute of Mental Health and Neurosciences  
NGO: Non-governmental Organisation  
PB: Phenobarbital  
PHT: Phenytoin  
PWE: People with Epilepsy  
RMP: Registered Medical Practitioner  
SEARO: Regional Office for South East Asia  
US: United States  
VPA: Valproate  
WHO: World Health Organization

## 1. INTRODUCTION

Historically, public health policy and priority have been based on mortality statistics. However, these statistics do not adequately reflect the burden from non-fatal conditions, such as neuropsychiatric disorders which, although not usually immediate causes of death, can cause a substantial amount of suffering during a life-span. The estimate of the burden from mental and neurological disorders is huge when disease burden measurement includes years lived with disability. Currently about 450 million people worldwide suffer from these disorders - one in four people will be affected at some point during their lifetime. In the South-East Asia Region of WHO, 27 percent of disability is due to neuropsychiatric disorders, including epilepsy.

Epilepsy occurs in men and women and can begin at any age, but is most frequently diagnosed in early in life or in old age. Up to 5% of the world's population may have a single seizure at some time in their lives, but a diagnosis of epilepsy is reserved for those who have recurring seizures, i.e. at least two unprovoked seizures.

*Dr. Gro Harlem Brundtland former Director-General of WHO stated the following about people with neuropsychiatric disorders and epilepsy:*

*"Many of them suffer silently. Many of them suffer alone. Beyond the suffering and beyond the absences of care lie the frontiers of stigma, shame, exclusion and more often than we care to know, death."*

### 1.1. Historical background

Epilepsy is one of the most common serious brain disorders. It is also one of the oldest recorded medical conditions, described by Hippocrates more than 3,500 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 epilambanein, meaning "to be seized" or "to be overwhelmed by surprise". 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.

### ***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 seizures 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 an epileptic attack.”

### ***1.2 Many names of epilepsy***

Epilepsy is known as *Apasmara* in India and Sri Lanka, as *Mirgee/Lata/Laran* in northern India, *Khichuni* in Bangladesh, as *Ayan* in Indonesia, while *Rake Lom Ba Mu* or *Roke Lom Chak* are the lay terms in Thailand.

### ***1.3 Myths and misconceptions about epilepsy***

The communities of South-East Asia continue to perpetuate many myths and misconceptions about epilepsy. Epilepsy, regardless of its immediate causation, is frequently thought of as a punishment for evil deeds or the breaking of certain taboos. These myths and misconceptions often prevent people with epilepsy from seeking medical treatment.

The strange behaviour caused by some forms of epilepsy has led to a common rural belief that epilepsy is due to “possession by spirits”. In some parts of India, Indonesia, Nepal, Sri Lanka and Thailand, people believing in supernatural powers at work offer worship and animal sacrifice. In Bangladesh, rural people consider epilepsy as the “spell of Satan” locally known as “*batash*” (bad wind). In some rural areas of India, attempts are made to exorcise evil spirits from people with epilepsy. In Indonesia, epilepsy is often considered as a punishment from unknown dark forces. In Nepal, epilepsy is associated with weakness, possession by an evil spirit or the reflection of a red colour.

### ***Some myths prevalent in South-East Asia...***

**Myth:** Epilepsy is due to possession by evil spirits. Take the person to a sorcerer and have these spirits exorcised.

**Fact:** Epilepsy is a medical disorder. It is now easy to treat with modern medication, so patients should be taken to doctors.

**Myth:** Never touch a patient having a seizure. The disorder 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:** Someone with epilepsy brings stigma to the family, so this 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 disorder of the brain, so it should be treated by physicians, neurologists or psychiatrists.

**Myth:** Women with epilepsy can never have children, so they should never marry.

**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 marriage.

These myths and misconceptions can only be dispelled by proper education of patients, families, communities and policy-makers.

#### ***1.4 Knowledge, Attitude and Practice (KAP) of Epilepsy in SEAR Member Countries***

There are many studies which use different methods to evaluate knowledge, attitude and practice towards epilepsy, both in developed and developing countries. The information is usually collected by face-to-face interviews and 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 possibly related to the higher illiteracy rate. However, in Kerala, a southern Indian state, with a high literacy rate, the attitude is extremely negative, and epilepsy is generally believed to be a mental illness.

In some Member Countries of SEAR/WHO, there are reservations about employing people with epilepsy because of the stigma rather than for safety reasons. A significant proportion of the population believes that people with epilepsy cannot pursue education and gain employment. Many people seek treatment from alternative systems of medicine, such as Ayurveda in India and Sri Lanka, and acupuncture in Thailand.

**Table 1.1 Comparison of the responses to the Knowledge, Attitude and Practice inquiry about epilepsy in various countries (% yes)**

Question	USA 1979	China 1990	North India 1992	Taiwan 1995	South India 2000
Have you heard or read about epilepsy?	95	93	92	87	99
Is it an object to play with?	6	57	43	18	11
Is there objection to employment for people with epilepsy?	9	53	-	31	44
Is it a mental illness?	3	16	15	7	27
Is it hereditary?	9	17	18	17	31

Source: Adapted from K. Radhakrishnan *et al.* *Epilepsia* 2000; 41:1027–1035

### **1.5 Psychosocial aspects of epilepsy in the Region**

During the last few decades greater attention has been paid to the quality of life for people with epilepsy, although the progress is slow and services are still poor.

The overall quality of life of people with epilepsy is hampered, both by the nature of the disorder and its associated effects. Education, employment, marriage and social functioning may all be affected and the individual may experience personal problems. The discriminating attitude of society makes the situation worse. It is often particularly the socio-cultural attitudes that worsen the quality of life of people with epilepsy.

Fear, misunderstanding and the resulting social stigma and discrimination surrounding epilepsy often force people with this disorder "into the shadows". The social effects may vary from country to country and culture to culture, but it is clear that all over the world the social consequences of epilepsy are often more difficult to overcome than the seizures themselves. These problems may in turn undermine the treatment of epilepsy.

### **1.5.1 Impact on education**

Some children with epilepsy are not sent to school because of parental fears. In school, teachers may separate children with epilepsy, or bar them from school activities. Seizures in the classroom may be viewed negatively, and are often not treated appropriately, with few schools having first-aid facilities available. The major problems encountered by children with epilepsy attending school are coping with studies, difficulty in making friends, fear of seizures occurring at school, fear of teachers, drowsiness due to medication, decreased attention and low performance. Epilepsy itself does not impair intellectual performance, but children with epilepsy may have a comorbid learning disability. These negative attitudes may cause the child to discontinue education, and the child may be labelled by society as a failure.

### **1.5.2 Impact on employment**

Many employers are reluctant to employ people with epilepsy. Those with epilepsy may be given low-income jobs, with little job security. Loss of, or low, income may cause the person to feel a “burden” on the family.

Seizures or drowsiness due to medication may cause a slightly higher risk of accidents at the workplace, particularly while working with heavy machines. As a result, the employer’s fear of compensation due to work-related injury may further impact on the employment opportunity for people with epilepsy. At the end of a four-year follow-up study from India, 2% had ceased work and the work status had changed for 6% of patients due to uncontrolled seizures.

***Mr. George Burden the first Secretary-General of International Bureau for Epilepsy said:***  
“I beseech you, do not give a job to a person because he has epilepsy.  
Do not deny him a job because he has epilepsy.”

In rural areas of India, people with epilepsy are generally looked after by their families and they usually help with their family’s trade, although perhaps with fewer responsibilities and less strenuous roles than people without epilepsy.

In a recent research survey, nearly a quarter of Nepali people with epilepsy believed that they were unable to work; they had been culturally conditioned to underrate themselves.

### 1.5.3 Impact on the family

Problems surrounding getting married and leading a healthy family life may be compounded by the absence of a sound education and a good job. In traditional societies, marriage is particularly difficult for women with epilepsy.

***Attitude towards marriage for people with epilepsy...***

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

The combined effects of epilepsy on the family, school and in the workplace may have a significant impact on the psychosocial functioning of the patient. Family’s reactions can vary from mixed feelings of overprotection, to rejection. These can disturb 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.

## 2. ABOUT THE SOUTH-EAST ASIA REGION

The Regional Office of WHO South-East Asia compiles basic health indicators of Member Countries. The most recent publication is from the year 2002. Selected tables from this publication are reproduced below.

### 2.1 Demographic indicators

Demographic Indicators													
Indicator	Year	Bangladesh	Bhutan	DPR Korea	India	Indonesia	Maldives	Myanmar	Nepal	Sri Lanka	Thailand	Timor-Leste	SEAR
Total population (thousands)	2002	143,364	805	22,586	1,041,144	217,534	309	48,956	24,153	19,287	64,344	850	1583332
Surface area (thousands of sq km)	2000	144	47	121	3,287	1,905	0.3	677	147	66	513	15	6,922.3
Population density (per sq km)	2002	996	17	187	317	114	1,030	72	164	292	125	58	229
Population growth rate (%)	2000-05	2.09	2.55	0.68	1.52	1.21	1.96	1.16	2.32	0.94	1.14	3.93	1.50
Crude birth rate (per 1000 pop)	2000-05	29.9	34.09	16.7	23.8	20.0	20.0	23.2	34.0	17.3	17.8	25.4	23.6
Crude death rate (per 1000 pop)	2000-05	8.7	8.64	9.9	8.4	7.1	4.0	11.6	9.9	6.3	6.2	13.2	8.2
Urban population (%)	2000	24.5	14.5	60.2	28.4	40.9	27.4	27.7	11.9	23.6	21.6	15.0	29.6
Average annual growth rate of the urban population (%)	2000-05	3.98	5.95	1.62	2.81	3.57	3.52	2.86	5.07	2.84	2.67	2.21	3.02

**Source:** Health Situation in South-East Asia, Basic Indicators 2002. World Health Organization, South-East Asia 2003

## 2.2. Socio-economic indicators

Socio-economic indicators												
Indicator	Year	Bangladesh	Bhutan	DPR Korea	India	Indonesia	Maldives	Myanmar	Nepal	Sri Lanka	Thailand	Timor-Leste
Gross national income per capita (US\$)	2001	370	640	n/a	460	680	2,040	n/a	250	830	1,970	478
Gross domestic product per capita growth rate (%)	2000-01	3.3	4.0	n/a	2.7	1.8	4.5	n/a	3.4	1.0	0.9	n/a
Human Development Index	2001	0.502	0.511	n/a	0.590	0.682	0.751	0.549	0.499	0.730	0.768	n/a
Dependency ratio												
Total	2000	72	89	48	62	55	89	61	81	48	47	84
Old-age(65+)	2000	5	8	9	8	7	7	7	7	9	8	5
Young (0-14)	2000	67	81	39	54	48	83	53	74	39	39	79
Adult literacy rate(%)												
Total	2000	40.0	47.3	100	57.2	86.8	96.9	84.7	41.7	91.6	95.5	n/a
Male	2000	49.4	61.1	100	68.4	91.8	97.0	88.9	59.4	94.4	97.1	n/a
Female	2000	30.2	33.6	100	45.4	81.9	96.8	80.5	24.0	89.0	93.9	n/a

Source: Health Situation in South-East Asia, Basic Indicators 2002. World Health Organization, South-East Asia 2003

### 2.3 Health resources indicators

Health Resources Indicators												
Indicator	Year	Bangladesh	Bhutan	DPR Korea	India	Indonesia	Maldives	Myanmar	Nepal	Sri Lanka	Thailand	Timor-Leste
Total expenditure on health (as % of GDP)	2000	3.8	4.1	2.1	4.9	2.7	7.6	2.2	5.4	3.6	3.7	9.4
Public share to total health expenditure (%)	2000	36.4	90.6	77.3	17.8	23.7	83.4	17.1	29.3	49.0	57.4	n/a
Per capita total health expenditure (international dollars)	2000	47	64	33	71	84	254	24	66	120	237	n/a
Physicians per 10,000 population	2001	2.51	1.6	29.7	5.2	1.1	8.4	3.0	0.54	4.1	3.0	n/a
Hospital beds per 10,000 population	2001	3.36	16.0	136.1	6.9	6.03	17.4	6.3	1.5	29	22.3	n/a

Source: Health Situation in South-East Asia, Basic Indicators 2002. World Health Organization, South-East Asia 2003

## 2.4 Primary health care coverage indicators

Primary Health Care Coverage Indicators												
Indicator	Year	Bangladesh	Bhutan	DPR Korea	India	Indonesia	Maldives	Myanmar	Nepal	Sri Lanka	Thailand	Timor-Leste
Infants immunized (%)												
	DPT3	70.2	88.0	37.4	52.1	95.0	98.0	89.0	80.0	88.0	94.6	58.0
	OPV3	69.1	89.0	76.5	59.2	88.4	98.0	93.0	80.0	88.0	94.8	84.0
	BCG	90.0	93.0	63.9	69.1	93.1	99.5	95.0	95.0	100.0	100.0	n/a
Measles	2001	62.1	79.0	34.4	41.7	86.8	99.0	90.0	75.0	81.0	88.1	n/a
Pregnant women immunized with tetanus toxoid (%)	2001	63.7	73.0	4.6	66.8	73.4	94.0	77.0	24.2	90.0	76.3	n/a
Attended by trained personnel: (% of live births)												
Pregnant women	2001	33.7	72.0	100.0	65.1	71.9	93.0	60.1	35.0	98.0	83.4	n/a
	Deliveries	21.8	23.7	98.6	42.3	62.3	97.0	77.5	13.5	97.0	94.5	n/a
Women of child-bearing age using contraceptives (%)	2001	53.8	30.7	67.0	48.2	66.4	42.0	55.1	38.9	71.0	72.2	n/a
Population with access to safe water (%)												
	Total	97.3	77.8	99.9	77.9	n/a	76.5	71.5	59.0	75.4	92.7	n/a
	Urban	99.2	97.5	n/a	92.6	88.2	n/a	89.2	61.0	96.0	n/a	n/a
Rural	2001	96.7	73.2	n/a	72.3	71.9	n/a	65.8	59.0	74.6	n/a	n/a
Population with access to adequate sanitation (%)												
	Total	54.1	88.0	99.2	36.0	n/a	85	63.1	23.0	72.6	97.7	n/a
	Urban	2001	74.6	n/a	n/a	80.7	86.9	n/a	74.0	87.0	n/a	n/a
Rural	2001	49.3	n/a	n/a	18.9	54.2	n/a	18.0	68.3	n/a	n/a	

Source: Health Situation in South-East Asia, Basic Indicators 2002. World Health Organization, South-East Asia 2003

## 2.5 Health status indicators

<i>Health Status Indicators</i>													
Indicator	Year	Bangladesh	Bhutan	DPR Korea	India	Indonesia	Maldives	Myanmar	Nepal	Sri Lanka	Thailand	Timor-Leste	SEAR
Life expectancy at birth (years) :													
	Both	62.6	61.3	65.8	61.0	66.4	64.6	62.3	60.1	70.3	69.3	57.5	62.2
	Male	62.6	60.2	64.4	60.1	64.9	64.5	60.7	59.9	67.2	66.0	54.8	61.1
Female	62.6	62.4	67.1	62.0	67.9	65.0	63.9	60.2	60.2	74.3	72.7	60.5	63.3
Healthy life expectancy at birth (years):													
Total	2002	54.3	52.9	58.9	53.4	58.2	56.8	51.6	51.8	61.3	60.0	49.7	54.4
Male	2002	55.3	52.9	58.0	53.3	57.4	57.4	49.9	52.5	59.2	57.7	47.9	54.1
Female	2002	53.3	52.9	59.7	53.6	58.9	56.3	53.5	51.1	64.0	62.5	51.8	54.7
Infant mortality rate (per 1000 live births)	2001	51.0	60.5	21.8	68.0	41.4	21.0	59.8	64.2	15.4	21.5	70-95	n/a
Under-five mortality rate (per 1000 live births)													
Male	2002	71	93	56	87	45	38	78	81	20	32	142	79
Female	2002	73	92	54	95	36	43	78	87	16	26	108	83
Total fertility rate (per woman)	2001	3.6	5.2	2.1	3.1	2.4	5.5	3.0	4.6	2.1	2.0	n/a	n/a
Maternal mortality ratio (per 100,000 live births)	2000	230	258	105	407	373	100	100/180	415	59.6	13.2	800	n/a
Low birth weight newborns (%)	2000	19.5	15.1	9.0	23.0	7.7	17.6	15.0	23.2	16.7	8.1	n/a	n/a
Children with low weight-for-age (%)	2000	47.7	18.7	60.6	47.0	20.3	30.0	35.5	47.1	29.4	11.3	45.0	n/a

Source: Health Situation in South-East Asia, Basic Indicators 2002. World Health Organization, South-East Asia 2003

### 3. EPIDEMIOLOGY

#### 3.1 Prevalence

“Prevalence” is the proportion of existing cases of a disorder in a defined population at a given point or over a brief period in time.

Many studies around the world together estimate that the mean prevalence of active epilepsy (i.e. continuing seizures or the need for treatment) is approximately 8.2 per 1000 of the general population. However, this may be an underestimate as some studies in developing countries suggest a prevalence of more than 10 per 1000.

It is estimated that around 50 million people in the world currently have epilepsy, of whom about 40 million live in developing countries. The number of people in the world who will ever have at least one seizure is estimated to be approximately 100 million people.

#### ***Global Magnitude of epilepsy***

- Up to 5% of people in the world may have at least one seizure in their lives.
- Currently about 50 million people in the world have epilepsy, of whom 40 million live in developing countries.
- In up to 70% of people with epilepsy, it responds to treatment.
- In developing countries 80-90% of people with epilepsy do not receive appropriate treatment.

**India:** Studies from different parts of India reveal that the prevalence varies from 8.8/1000 in Bangalore to 3/1000 near Calcutta.

**Sri Lanka:** In a survey in the Kandy district of Sri Lanka, 9 out of 1000 people had epilepsy.

**Thailand:** A survey of rural Thailand reported a prevalence of 7.2/1000.

**Bangladesh:** Though there are no national statistics, it is estimated that there are at least 1.5–2.0 million people with epilepsy in Bangladesh, ie about 12 people with epilepsy per 1000 population.

**Other SEAR Member Countries:** The prevalence is probably similar in other SEAR countries as they share similar socio-cultural and demographic characteristics. By applying these figures to local populations, it is possible to know the approximate number of people requiring treatment in any given geographical area.

**Table 3.1 Prevalence of epilepsy in selected SEAR member countries**

Author	Year	Country	Community	Location	Prevalence (per 1000)
Gourie-Devi et al	1996	India	Urban	Bangalore,	7.8
Mani et al	1991	India	Rural	Yelandur,	3.9 – 4.6
Koul et al	1988	India	Rural	Kashmir (Kuthar Valley)	2.5
Bharucha et al	1988	India	Urban	Bombay Parsis	3.6
Asawavocjoemkomda. T et al	2002	Thailand	Rural	Talardkav	7.2

### **3.2 Incidence rate**

The incidence rate of a disorder is the number of new cases in a population at a given time. A meta-analysis of incidence studies reported that developing countries have a higher incidence rate of epilepsy (median, 68.7/100,000) than industrialized countries (median, 43.4/100,000). (Kotsopoulos et al. 2002)

One of the main reasons for the higher incidence rate of epilepsy in developing countries is the higher incidence of conditions which can lead to permanent brain damage. These conditions include neurocysticercosis, meningitis, cerebral malaria, pre and peri-natal complications and malnutrition.

### **3.3 Risk factors**

Risk factors for idiopathic epilepsy include pre or peri-natal risk factors (obstetric complications, toxemia, preeclampsia, prematurity, low birth weight, neonatal seizures or asphyxia, small for gestational age, delivery problems and maternal haemorrhage, caesarean section), previous spontaneous abortion in the mother, positive family history of epilepsy, febrile convulsions in the subject, head trauma and smoking by the mother. (Hauser 1990, Sidenvall 2001, Casetta 2002, Matuja 2001)

Risk factors for secondary epilepsy include excess alcohol intake, severe head trauma, history of stroke, and neurocysticercosis. (Leone 2002, Carpio 1998)

### **3.4 Remission rates**

The British National General Practice Study of Epilepsy reported that, after 9 years, 86% of patients with definite epilepsy had achieved a remission of 3 years, and 68%, had achieved a remission of 5 years. (Cockerell OC et al, 1997) A longitudinal study of patients with epilepsy in

Rochester, Minnesota, found that the probability of being in 5 year remission at 20 years after diagnosis was 70%. (Annegers et al, 1979) Thus data suggest a good outcome of seizure control in the majority of patients with treatment. In developing countries where many people with new onset seizures do not receive treatment, remission rates are not clear.

### **3.5 Mortality**

The risk of premature death in people with epilepsy is 2-3 times higher than the general population. Some of the increased risk is related to the cause of epilepsy, a smaller number of people die in circumstances around a seizure and some die a sudden unexpected death for which no cause can be identified. (Cockerell OC, 1996) The standardised mortality ratio for people with idiopathic epilepsy has been estimated to be 1.6. (Cockerell OC, 1994)

***Epilepsy is associated with an increased risk of mortality...***

*Death may be related to:*

- An underlying brain disease, such as a tumour or infection;
- Seizures in dangerous circumstances, leading to drowning, burns or head injury;
- Status epilepticus;
- Sudden and unexplained causes, or a possible respiratory or cardiorespiratory arrest during a seizure;
- Suicide.

### **3.6 Disability Adjusted Life Years (DALYs)**

Epilepsy is a leading cause of disability and disease burden in the world, contributing 5.77 million (discounted but not age-weighted) Disability-Adjusted Life Years (DALYs) to the Global Burden of Disease in 2001 (Global Burden of Disease database: [www.who.int/evidence/bod](http://www.who.int/evidence/bod)). This burden is greatest in developing countries because of the lower rate of treatment provided to those in need, the 'treatment gap'. Epilepsy imposes a large economic burden on health care systems of countries, and there is also a hidden burden associated with stigma and discrimination. Many people with epilepsy suffer severe emotional distress, behavioural disorders and extreme social isolation.

### **3.7 Comparisons with other Regions**

Most of the advances in epilepsy care in developed countries are not available to the 80% of people with epilepsy who live in developing countries. However, even in the developed countries the disorder is still shrouded in secrecy and people prefer not to reveal or discuss their condition.

## **4. MANAGEMENT OF EPILEPSY**

Misunderstandings about epilepsy, combined with the economic and financial barriers to availability of treatment in developing countries, play an important role in preventing treatment being available to millions of people in these countries.

### **4.1 Treatment Gap**

The difference between the number of people with active epilepsy and the number of people who are being appropriately treated in a given population at a given point in time, expressed as percentage, is known as the “treatment gap” (Meinardi 2001). It has been estimated that 80-90% of people with epilepsy in developing countries are inadequately treated. Fear of stigmatization, cultural beliefs, lack of knowledge and illiteracy all contribute to the treatment gap, as people with epilepsy or their proxies do not seek treatment (Scott 2001, Shorvon 1998, Wange 2003, Coleman 2002). Other potential contributing factors include economic issues, distance to health facilities, supply of antiepileptic drugs and lack of prioritization by health authorities.

Poor seizure control contributes substantially to the disability of epilepsy and therefore should be included in the estimates of DALYs. Social isolation, dependence, low educational performance, poor employment opportunities, loss of productivity, and personal injury are all intangible costs which should also be included in the estimate of the burden of epilepsy. (Meinardi 2001)

### **4.2 Who treats epilepsy**

Although people in urban areas may contact medical specialists, family physicians play a major role in providing care and direction for people with epilepsy. They may contact primary health centres, *taluk* hospitals, district hospitals, nursing homes or tertiary institutions, depending on their accessibility to transportation facilities and socioeconomic factors.

In SEAR Member Countries, practitioners of Ayurvedic, Homoeopathic, Chinese, Siddha and Unani systems are also involved in epilepsy care.

#### **4.2.1 Role of faith healers, religious healers and traditional healers**

Faith healers or religious healers provide a substantial amount of care to people with epilepsy in many countries. Often there is substantial cost to these services which can be paid in cash or in kind.

In a prevalence study in Turkey, 65% percent had visited religious figures at some time during the course of the disorder (Karaagac 1999). A more recent study from Gambia found that all people with epilepsy had used traditional treatment i.e. that originating from a set of cultural beliefs (Coleman 2002). A study from rural India, where only 12% of children with epilepsy were on treatment, found that 62% of these children had sought help from a qualified medical practitioner, 44% from traditional practitioners and approximately one third had received help from both (Pal et al 2002). People in Bangladesh and Thailand continue to seek care from faith healers such as “*fakirs*” or “*monks*” before going to a hospital. A survey in Sri Lanka revealed that, in spite of the availability of a state-run free health service, local traditional healers were treating nearly 50% patients. (Satishchandra et al 2001)

Faith healers have strong social and religious connections and play an important role in the management of epilepsy in some countries. Unfortunately some of these healers can indulge in practices which are harmful to the patient. However, on the whole, medical practitioners treating epilepsy in developing countries try to collaborate with faith healers, combining modern medicine with some rituals. The aim of this collaboration is to eliminate harmful practices and to encourage traditional healers to recognize epilepsy as a medical illness and to refer patients to doctors for treatment. Some faith healers also provide valuable services in terms of counselling and prayer, which can be considered as a form of psychotherapy.

#### **4.3 Patient compliance**

Compliance with prescribed medication is often influenced by the perception and belief systems of people with epilepsy and their families, and by the availability and accessibility of care.

In rural Thailand, 57% of people with epilepsy were totally compliant with treatment. However, in an out-patient clinic in Brazil, 40% patients reported non-compliance at any time in the previous week. Approximately 60% either changed the medication dose or stopped the medication, and 48% changed prescription without approval from a doctor (Gomes and Maia Filho 1998). Reasons most frequently reported for non-compliance are misunderstanding (48%), forgetfulness (16%) and economic limitation (13%) (Asawavichienjinda, Sitthi-Amorn et al. 2003). In an attempt to improve compliance in a rural African community, visits by medical

personnel every 6 months and long-term supply of medications lead to a substantial increase in compliance at 20 months (Kaiser, Asaba et al. 1998). In India, availability of free treatment has been shown to influence compliance (Desai, Padma et al. 1998). Inadequate communication between doctors and patients influences compliance negatively.(Gopinath, Radhakrishnan et al. 2000)

#### **4.4 Anticonvulsant medications**

The pharmacological treatment of epilepsy has been extensively studied primarily in high-income countries. Many controlled clinical trials have tested the efficacy of the older antiepileptic drugs (AEDs) (such as phenobarbital and phenytoin) and newer AEDs (such as carbamazepine and valproic acid) in controlling seizure frequency and their safety when prescribed in monotherapy or in combination. However, there is a lack of definitive evidence on the differences between phenytoin and carbamazepine (Aldenkamp, De Krom et al. 2003). In some low-income countries phenobarbital or phenytoin are not available, and even when available, continuity of supply may be irregular. Frequently, economic issues lead to the interruption of treatment.

Recently introduced AEDs, such as lamotrigine, topiramate, or gabapentin, are practically impossible to access by rural populations in most developing countries.

Phenobarbital is a cost-effective drug in the management of epilepsy whose benefit far exceed its side-effects; it remains the drug of choice for large-scale community-based programmes, particularly in rural and remote areas. Unfortunately, its abuse potential and minimal side-effects have been given too much prominence, and the drug has fallen into disrepute. Alternative but more expensive AEDs such as carbamazepine and valproic acid have become the first-line choice of drug treatment in developed countries due to the perceived lower risk of long-term side-effects, including cognitive impairment in children. Unfortunately, these are also being extensively promoted in developing countries.

The Global Campaign Against Epilepsy, a partnership between WHO, the International League Against Epilepsy and the International Bureau for Epilepsy advocates the use of phenobarbital for closing the treatment gap in low-income countries. In resource-poor countries, it can be provided for as little as US\$ 5-10 per annum.

#### **4.4.1 The Choice of Antiepileptic Drugs**

*(Extracted from Development of Strategies for Community-Based Neuropsychiatric Services - Report of an Intercountry Consultation, Bangkok, Thailand, 2001 from a presentation by Dr. William H Theodore MD, Chief Epilepsy Branch, National Institutes of Health, USA)*

The proper choice of AEDs depends on several factors, including efficacy, toxicity, and ease of use. Effective therapy requires compliance, which is influenced by all of these. Pharmacokinetic variables, such as half-life and drug interactions, must be considered as well. Finally, drug cost has to be taken into account.

There are relatively few studies comparing AED efficacy. The US Veteran's Administration Cooperative Study (Mattson 1985), showed that phenytoin (PHT) and carbamazepine (CBZ) had comparable effectiveness, as measured by a combination of seizure control and toxicity, while phenobarbital (PB) was slightly, and primidone definitely, less effective. In contrast several other studies performed in the developing world comparing these drugs showed no difference between CBZ and PB in children or adults, (Placencia et al 1993) or between PB and PHT (Pal et al 1998; Mani et al 2001). A trial comparing CBZ and valproic acid (VPA) (Mattson et al 1992) showed a slight superiority for the former for both complex partial and generalized tonic-clonic seizures, but the differences were small.

Recently some anticonvulsants (lamotrigine, topiramate, gabapentin) have been approved in developed countries. Generally these are recommended as "add on" drugs for better seizure control in patients already on anticonvulsants. These are very expensive. Long-term studies have shown a disappointing tendency of patients to abandon these AEDs: only 30% of patients continued on topiramate or lamotrigine (LTG), and 10% on gabapentin after three years, due to toxicity or lack of efficacy (Lhatoo et al 2000).

Comparisons of AEDs showed in general that comparably effective doses for seizure control lead to comparable toxicity (Brodie et al 1995; Chadwick et al 1998). Side effects of AEDs include neurological toxicity, such as lethargy, impaired thinking, sleepiness, depression, diplopia, dystaxia, or peripheral neuropathy. Systemic side effects, potentially more dangerous, are often related to hypersensitivity reactions, and include haematological, hepatic, ophthalmologic, and endocrine complications. The most severe of these, such as aplastic anaemia, can occur without warning, and may not respond to stopping the drug. They can lead to prolonged illness, require complex medical interventions, and can be fatal.

Limited data suggest that some but not all of the recently introduced AEDs may have slightly less cognitive toxicity than older drugs. Lamotrigine and possibly gabapentin may have

5-10% less cognitive toxicity than CBZ, VPA or PHT at comparably effective doses (Meador et al 1991, 1995, 1999, 2001; Aldenkamp et al 2000). On the other hand, topiramate may lead to greater cognitive impairment. Systemic and idiosyncratic side effects are harder to evaluate, as they usually do not appear among the limited number of patients enrolled in clinical trials. Several dramatic side effects of new AEDs have appeared recently, such as rash due to lamotrigine, felbamate-induced aplastic anaemia, vigabatrin-related visual field constriction, and topiramate-induced glaucoma.

Pharmacokinetic considerations can also affect the choice of AEDs. Phenytoin, for example, shows interpatient metabolism differences between slow and rapid metabolizers. It has rate-limited metabolism, which is close to saturation at therapeutic dose. Thus, blood level monitoring is more important than with other drugs. The short half-life of CBZ and VPA make multiple daily dosing imperative.

AED formulations may vary, and manufacturing problems may create differences among batches of the drug even from the same factory. This is particularly true of drugs that are hard to manufacture, such as phenytoin. Dissolution and absorption can vary, leading to changes in peak concentration.

PB has many advantages for epilepsy treatment. Its cost is very low and it can be given once daily. It has simple, well-understood kinetics, and there is little evidence for interpatient variability. Thus, blood level monitoring is usually not necessary. There are few serious systemic side effects, and they are well known.

The disadvantages of PB include a slightly increased incidence of cognitive side effects, including hyperactivity in children. These side effects usually respond to a decrease in the dose. PB is a hepatic enzyme inducer, which can lead to drug interactions if a patient is taking other medications (such as treatment for cysticercosis). PB, like other barbiturates, benzodiazepines, and drugs such as CBZ, can cause a transient increase in seizures if the drug is stopped abruptly.

No AED has a perfect combination of high efficacy, low toxicity and cost, and a good pharmacologic profile. Among the older drugs, PB appears to have the best combination of advantages, and the fewest disadvantages.

#### ***4.5 Surgery for epilepsy***

In recent years selected centres in developed countries have been performing surgery on patients with intractable epilepsy with varying degrees of success in seizure control. In one series of 21 operated patients, 57% became seizure free while 29% had less than 50%

reduction of seizure frequency.(Malmgren K et al 1996) Evaluation of patients for surgery requires the availability of very high technology, and the surgical procedure itself requires a highly skilled team. Moreover the costs are extremely high. It has been estimated that the total cost of evaluating a person for surgery and the surgical procedure is about US \$ 47000.(Malmgren K 1996) However, in Colombia the direct costs of epilepsy surgery were 5.5% of the cost in Switzerland, with similar postoperative seizure outcome at both places (Tureczek et al 2000). The costs and effectiveness need to be evaluated at other centres performing epilepsy surgery before surgery can be recommended for treatment of epilepsy in developing countries.

#### ***4.6 Creating awareness to reduce treatment gap***

As described, the myths and misconceptions prevalent in most communities of SEAR and the lack of awareness regarding the medical nature of epilepsy amongst patients and their families, lead many patients to seek the help of unconventional sources. Patients and their families need to be educated regarding the medical nature of epilepsy, its characteristics, causes and prognosis. They should also be educated about the importance of compliance in treatment, the potential side effects of drugs and the duration of treatment.

Communication specialists may be used to develop educational materials (booklets, posters, plays, television and radio messages) on epilepsy to inform the community, thereby reducing the social stigma attached to epilepsy. Involvement of community leaders and schoolteachers, in these activities should be encouraged.

#### ***4.7 Legal issues related to epilepsy***

There are many laws that impact the lives of people with epilepsy. However, the legal system varies from one country to another.

##### ***4.7.1 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 preventing marriage for people with epilepsy. In India, a person subject to recurrent attacks of insanity or epilepsy was not able to have a legally valid marriage, and a marriage of such a person could be declared null and void. However, after petitions by the Indian Epilepsy Association, the Marriage Law Amendment Act 1999 was enacted and legal rights in marriage restored to people with epilepsy.

#### **4.7.2 Epilepsy and driving**

Laws related to driving vehicles vary from country to country. In India, it used to be illegal for a person who had ever had a seizure to drive. In 1994 the law was changed and there are now no restrictions on people with epilepsy driving any vehicle. There are no guidelines for epilepsy and driving in Thailand. Accordingly to the European 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 one year or more; and If seizures are without influence on driving ability (e.g. myoclonic, simple partial as only seizure type).*

#### **4.7.3 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 (1999), allows private entrepreneurs to enter the insurance sector. Previously, state-owned insurance had excluded epilepsy from its ambit, categorizing it with other chronic medical disorders. In Thailand, the government sponsored health programme covers epilepsy in the same manner as any other chronic disorders like diabetes or hypertension, and social security pays for all the expenses of people with epilepsy. In addition private foundations also support epilepsy care in Thailand

### **5. RESOURCES FOR EPILEPSY IN SEAR**

*(This section compiled by Dr. Satish Jain, under contract with WHO/ SEARO)*

The World Health Organization (WHO), the International League Against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE) have identified epilepsy as an underserved need of the community and have launched a Global Campaign Against Epilepsy (GCAE) in mid 1997.

The GCAE aims to “improve the acceptability, diagnosis, treatment, services and prevention of epilepsy worldwide”. One of the activities of the GCAE in the South-East Asian Region of the WHO has been the compilation of data on resources for epilepsy, using a pre-designed questionnaire distributed to representatives of Member Countries. The respondents were mainly prominent clinicians and/or public health officials actively involved in the treatment of people with epilepsy. Representatives of 8 countries responded to the questionnaire. Results of this survey are summarized below.

### **5.1 Contents of Questionnaire**

A Questionnaire on Country Resources for Epilepsy prepared by the WHO, ILAE and IBE was used for the survey in the WHO SEA Region. The questionnaire comprised nine sections with one additional section for comments.

The areas of inquiry were:

- Presence of professional associations of epilepsy specialists
- Presence of other organizations dealing with epilepsy
- Five most common causes of epilepsy in the country
- Issues related to epilepsy care and services
- Availability of human resources dealing with epilepsy in the country
- Availability of training programmes in epileptology
- Issues related to financing and budget for epilepsy control in the country
- Presence of information/data collection system in the country
- Availability of drugs and other treatments in the country

### **5.2 Professional associations of epilepsy specialists**

One professional organization exists in each of 5 countries:

- Indian Epilepsy Society, India
- Nepal Epilepsy Association, Nepal
- Indonesian Society Against Epilepsy, Indonesia
- Epilepsy Society of Thailand, Thailand
- The Epilepsy Task Force, Sri Lanka

The exact number of professionals/specialists registered as members of the organizations in most countries was not available. The Indian Epilepsy Society and Epilepsy Society of Thailand each have about 200 registered professionals members.

The main activities of these associations were:

- Organizing professional meetings and conferences on epilepsy
- Publishing guidelines and recommendations on epilepsy
- Advocacy on epilepsy-related issues
- Advising Government on epilepsy and epilepsy-related issues.

Other activities of these organizations included treatment of patients (Nepal) and teacher education/public awareness programmes (Sri Lanka).

### ***5.3 Other organizations dealing with epilepsy***

There are other organizations dealing with epilepsy in 3 countries:

- Epilepsy Association of Sri Lanka
- Indian Epilepsy Association
- Epilepsy Society of Thailand

The organizations in India and Sri Lanka are affiliated to the IBE; the Epilepsy Society of Thailand is a chapter of IBE and of ILAE.

These organizations are mainly involved in:

- Awareness and advocacy of epilepsy
- Treatment of epilepsy
- Rehabilitation for people with epilepsy
- Prevention of epilepsy
- Education on epilepsy

### ***5.4 Causes of epilepsy***

The five most common causes of epilepsy were:

- Idiopathic (hereditary)
- Birth trauma
- CNS infections and infestations
- Head trauma/traffic accidents/war injuries
- Brain tumours.

Other causes listed included cerebral strokes, congenital anomalies of the brain and multi-factorial aetiology.

### ***5.5 Issues related to epilepsy care and services***

**5.5.1 The major problems encountered by health professionals involved in epilepsy care in this Region were:**

- Lack of awareness/knowledge and ignorance about epilepsy
- Poverty interfering with seeking professional help and purchasing medication
- Poor social support for patients and families
- Myths and stigma associated with epilepsy
- Poor availability and compliance with drugs used in the treatment of epilepsy
- Delayed treatment after onset of seizures

- Lack of trained specialist for treatment of epilepsy and poor availability of investigative facilities.

Other problems identified by health professionals involved in epilepsy care included

- Lack of a national epilepsy control programme
- Patients seeking advice of faith/traditional healers and
- Severe disruption of social life

#### **5.5.2 The most common problems encountered by PWE in this Region were:**

- Lack of awareness and ignorance about epilepsy
- Myths, misconceptions and stigma associated with epilepsy
- Discrimination in the society
- Cost of drugs used in the treatment of epilepsy and investigations when required
- Exploitation by quacks and faith healers
- Difficulty in finding jobs and marriage partner.

Other problems identified by people with epilepsy included

- Lack of rehabilitation facilities and
- Emotional burden of chronic disorder

#### **5.5.3 The five main tasks of primary health care workers involved in epilepsy care were reported as:**

- Case identification
- Proper referral
- Follow-up and monitoring the treatment initiated at the referral centres
- Health education at various levels
- Reporting the adverse effects of AEDs

Other tasks in which primary health care workers were involved included fund raising.

**5.5.4 Epilepsy specialists:** 8 countries answered the questionnaire; epilepsy specialists were available in 7 countries but not in Bhutan.

#### **5.5.5 Services provided by epilepsy specialists:**

The five most important services that the epilepsy specialists were providing in the Region included:

- Consultation, diagnosis and treatment
- Education of physicians, health care workers and care-givers
- Counselling
- Government advocacy
- Research activities.

Other activities of epilepsy specialists include attending seminars/conferences on epilepsy and writing research publications on epilepsy.

### 5.5.6 Hospital beds for epilepsy:

The estimated number of hospital beds was provided by only 3 countries – Bangladesh, Myanmar and Thailand. No data was available from India and Indonesia while there were no specific beds for epilepsy in Nepal and Sri Lanka. In Bangladesh 30 beds (out of an estimated 150 beds for patients with neurological disorders) were for residential epilepsy care, in Myanmar 25 beds were for short-term epilepsy care (out of 75 beds for neurological disorders) while in Thailand there were 500 beds for neurological disorders and 200 beds for residential care of the mentally handicapped.

### 5.5.7 Availability of diagnostic procedures for epilepsy

Diagnostic procedures like EEG, CT Scanning and MRI were available in all countries apart from Bhutan. AED level estimations were available in all countries except Bhutan and Myanmar. In India and Thailand investigative facilities for epilepsy surgery were available in three centres.

### 5.5.8 Types of sub-specialized epilepsy services available in the Region (table 5.1)

**Table 5.1 Types of Sub-Specialized Epilepsy Services available in SEAR countries**

Service	Countries available
Therapeutic drug monitoring	Bangladesh, India, Nepal, Sri Lanka, Thailand
Long-term Video-EEG monitoring	India, Bangladesh, Thailand
Epilepsy Surgery	India, Thailand
Neuropsychological services	Bangladesh, India, Indonesia, Nepal, Sri Lanka, Thailand, Myanmar
Psychiatric counselling	Bangladesh, Bhutan, India, Indonesia, Myanmar, Nepal, Sri Lanka, Thailand
Social rehabilitation	Nepal, Sri Lanka, Thailand
Special education	Nepal, Sri Lanka, Thailand

Research on epilepsy was available in India.

### **5.5.9 Epilepsy services in private sector**

In the four countries (Indonesia, India, Nepal and Thailand) that responded, about 50-60% of epilepsy services were privately run. In Sri Lanka no epilepsy service was available in the private sector.

### **5.6 Human resources**

The distribution of professionals involved for 50% or more time in epilepsy care was as follows:

- Specialist Neurologists: India 50 and Myanmar 7.

Data about other specialists were available only from Myanmar: Psychiatrists 50, Neurosurgeons 7, Neurological nurses 15, Psychologists 1, Social workers 2 and EEG technicians 3.

### **5.7 Training in epileptology**

No country in the region had facilities for specialist training in epileptology.

### **5.8 Financing and Budget:**

No country in the Region had a separate budget for epilepsy care in the Ministry of Health's budget or any other official document.

In absence of a separate budget for epilepsy in the Region, rough estimates of the percentage of overall budget of the government spent on epilepsy varied from 0.20% to less than 1 %.

Epilepsy services were mostly financed through out-of-pocket payments (6 countries). Government funding was also available to some extent in most (5 countries). Private insurance provided for health care costs in India, private foundations also helped in Thailand, while community contributions, mutual donations and trust funds were available in Myanmar

There were no disability benefits available for people with epilepsy in regards to epilepsy related social impairments in the region. Some disability funding was available in Thailand, while disability benefit were available only for mentally ill patients in Sri Lanka.

### **5.9 Information/Data Collection System**

Epilepsy was included in the annual health reporting systems in 5 countries and not included in the remaining 3 countries (Bangladesh, India, Indonesia). Epilepsy was not sub-classified in any country's annual health system. Epidemiological or service data collection system that included people with epilepsy was available only in Thailand.

The estimate of the number of people with epilepsy varied from about 1% in Nepal and Sri Lanka to about 1.3% in Thailand. There are an estimated 10 million people with epilepsy in India.

### 5.10 Drug and other treatments

A General Practitioner's prescription was needed for most AEDs in all countries except Sri Lanka and Nepal. A specialist's prescription was required for AEDs in Bhutan, Myanmar and Thailand.

Phenobarbital was included in the list of essential drugs in five countries, carbamazepine in 6 countries, phenytoin in 4 countries and sodium valproate in two countries. Information on essential drugs was not available from India and Sri Lanka.

**Table 5.2 Types of anticonvulsants available in SEAR countries**

Country	Drugs Available
Bangladesh	Carbamazepine, phenytoin, phenobarbital, sodium valproate
Bhutan	Carbamazepine, phenytoin, phenobarbital
India	Carbamazepine, phenytoin, phenobarbital, sodium valproate, lamotrigine, topiramate, clobazam, gabapentin
Indonesia	Carbamazepine, phenytoin, phenobarbital, sodium valproate
Myanmar	Carbamazepine, phenytoin, phenobarbital, sodium valproate
Nepal	Carbamazepine, phenytoin, phenobarbital, sodium valproate
Sri Lanka	Carbamazepine, phenytoin, phenobarbital, sodium valproate, lamotrigine, topiramate, clobazam, gabapentin
Thailand	Carbamazepine, phenytoin, phenobarbital, sodium valproate, lamotrigine, topiramate, clobazam, gabapentin

**Table 5.3 Details of cost of AEDs per unit (price of one tablet, one pill, one capsule calculated approximately in USD)**

Country	PB 60 mg	PHT 100 mg	CBZ 200 mg	VPA 200 mg	Fifth Drug
Bangladesh (1 USD=65 Taka)	-	0.01	0.07	0.04	Clonazepam 0.09
Bhutan (1 USD=48 Ngultrum)	-	-	-	-	-
India (1USD=46 Rupee)	0.003	0.02	0.025	0.045	Lamotrigine 0.10
Indonesia ( 1 USD=Rp 8,400)	-	-	-	-	-
Myanmar (1 USD=600K)	-	-	0.10	0.10	-
Nepal (1 USD=75 Rupee)	0.01	0.20	0.40	-	-
Sri Lanka (1 USD=95 Rupee)	0.003	0.006	0.01	0.02	Topiramate 0.15
Thailand (1 USD=40 Baht)	0.002	0.045	0.10	0.27	Vigabatrin 0.80

**Table 5.4 Services available free-of-cost or without special condition in SEAR countries**

Service	Countries where available free-of- cost
Therapeutic drug monitoring	Nepal, Sri Lanka, Thailand
Neuropsychological services	Myanmar, Nepal, Sri Lanka, Thailand
Psychiatric counselling	Bhutan, Myanmar, Nepal, Sri Lanka, Thailand
Social rehabilitation	Nepal, Sri Lanka, Thailand
Special education	Nepal, Sri Lanka, Thailand

No epilepsy related service was available free of cost in India. Neuropsychological services were available free of cost or without special conditions to PWE in 4 countries (Myanmar, Nepal, Sri Lanka and Thailand); Psychiatric counselling was free in 5 countries (Bhutan, Myanmar, Nepal, Sri Lanka and Thailand); therapeutic drug monitoring, special school education and social rehabilitation was free in Nepal, Sri Lanka and Thailand.

#### **5.11 Comments or any other information**

The major concerns were no separate beds for PWE (Bangladesh), need for a National Epilepsy Control Programme (India), efforts directed at removing social stigma/ignorance and enhanced international support (Indonesia), and availability of cheaper drugs and community based services (Myanmar)

## **6. STRATEGIES FOR EPILEPSY CONTROL IN SEAR**

### **6.1 Global Campaign Against Epilepsy (GCAE)**

The Global Campaign Against Epilepsy launched in Geneva on 19 June 1997 and in Dublin, Ireland on 3 July 1997 during the 22nd World Congress on Epilepsy is a joint initiative of WHO, ILAE and IBE to bring epilepsy "Out of the Shadows" by improving the acceptability, treatment, services and prevention of epilepsy worldwide. Together WHO, ILAE and IBE are trying to raise epilepsy to a level of awareness that has not been achieved yet, despite all efforts from each of the separate organizations and their affiliates.

The first phase of the GCAE was launched in 1997 and was devoted primarily to increasing public and professional awareness of epilepsy as a universal treatable brain disorder and raising epilepsy to a new plane of acceptability in the public domain.

*"The collaboration between the International Bureau for Epilepsy, the International League Against Epilepsy and WHO has shown that when people with different backgrounds and roles come together with a shared purpose, creativity is released and expertise is used in innovative and constructive ways".*

**- Dr. Brundtland, former Director General WHO**

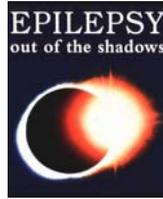
The second phase of the GCAE was launched in 2001 and is devoted primarily to activities that promote public and professional education about epilepsy, identify the needs of people with epilepsy on a national and regional basis, and encourage governments and departments of health to address the needs of people with epilepsy.

**Recommendations of the GCAE for the future:**

- Intensify and boost the status and activities of the Campaign
- Develop a partnership with WHO Regional Offices in all Regions
- Develop and implement demonstration projects in all Regions
- Organize regional conferences on public health aspects of epilepsy in all Regions,
- Organize meetings with appropriate United Nations agencies and relevant WHO departments
- Jointly with WHO representatives, organize meetings with possible donors
- Continue efforts in priority setting for research in epilepsy, including epidemiology and prevention of epilepsy
- Organize technical consultative meetings and workshops on various topics dealing with epilepsy.

**6.2 Asian-Oceanian Declaration on Epilepsy**

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. It reads as follows:



## 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 as a result of 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.
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### **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.



## **7. SEARO PROGRAMME ON EPILEPSY**

Traditionally, in SEAR Member Countries, services for neuropsychiatric disorders have been concentrated in tertiary care mental hospitals. Thus large segments of the population, particularly those who live in rural and remote areas, have been deprived of such services, despite the common occurrence of both neurological and psychiatric disorders in these communities.

SEARO's priority is to concentrate on community-based projects and programmes. Priority is being given to developing projects and programmes which are capable of delivering at least the basic minimum level of services for neuropsychiatric disorders to everyone regardless of where they live; such services should be delivered within the community rather than tertiary care hospitals. The primary health care system should be utilized. Health manpower delivering health care in the community should be trained to identify and manage these conditions and affordable and appropriate medications should be made available to the community. Finally, the programmes should address psychosocial issues such as stigma and rehabilitation.

Epilepsy is a common disorder in all parts of the world. In SEAR there are approximately 15 million people with epilepsy. Epilepsy has high morbidity not only from injuries during a seizure but also from the social stigma attached with the disorder which affects both patients and their families. It is also well accepted that the treatment of patients with "epilepsy" is best done at community level as it helps with the social rehabilitation of the patient. It is also essential to bring epilepsy "Out of the Shadows".

### ***7.1 Issues related to the delivery of neuropsychiatric services (including epilepsy) in SEAR***

The SEARO strategy on neuropsychiatric disorders which aims to reach out to the community addresses several important issues:

- What is the basic minimum level of service for neuropsychiatric disorders which must be available to every one in the community?
- Who will deliver this basic minimum level of service?
- How will the health care providers be trained to deliver these basic minimum services?
- What medications will be used in the treatment of these disorders?
- Who will bear the cost of these medications?

- How will all community-based health care providers who treat people with epilepsy be identified to take the training programme?
- Other issues to be addressed, e.g. stigma, myths, social support, rehabilitation etc.

### **7.1.1 What is the basic minimum level of service for neuropsychiatric disorders which must be available to every one in the community?**

Ideally, complete and comprehensive services for all neuropsychiatric disorders should be available to all members of the community. However, such comprehensive services cannot be delivered to all within the community, especially in rural and remote areas. Thus, projects and programmes for delivery of such services can address only select disorders. Selection of disorders could be guided by the following principles:

- High prevalence of the disorder in the community
- High morbidity from the disorder
- Easy to diagnose with resources available in the community
- Availability of effective and low cost medication
- Good prognosis with treatment

Many neuropsychiatric disorders meet the above criteria e.g. epilepsy, psychosis, depression etc. Some communities may have their own unique problems which meet the above criteria. In order to select neuropsychiatric conditions to be addressed by SEARO in the first phase of this programme, a workshop was held in Bangkok (Inter-country consultation on development of strategies for community-based neuropsychiatric service, Bangkok, Thailand, 19-22 November, 2001). Delegates recommended that SEARO should target two disorders (epilepsy and psychosis) in the first phase of this project to deliver community-based services. This publication specifically addresses epilepsy.

### **7.1.2 Who will deliver this basic minimum level of service?**

Different countries could use a different health care providers as long as the health care provider is based in the community and is willing to serve rural and remote areas. Some countries have made available qualified doctors at primary health care centres even in rural areas. These doctors support a team of trained health care providers who go door-to-door in the community. However, all these staff members will need training in the identification and management of epilepsy.

In some countries faith healers provide a substantial proportion of care especially in neuropsychiatric disorders. Efforts have already been successfully made in these countries to

educate such providers. If approved by governments of these countries, these health care providers could be further trained using the SEARO programme on epilepsy.

### **7.1.3 How will the health care providers be trained to deliver these basic minimum services?**

The health care providers will be trained using a structured written manual and video-based demonstration of patients with epilepsy and psychosis. These modules will address the identification and management of epilepsy and differentiation from similar conditions. They will also show which patients should be referred for further management. Training will include social issues such as removal of myths and misconceptions about epilepsy, care, rehabilitation, and community education.

### **7.1.4 What medications will be used in the treatment of epilepsy?**

Phenobarbital is probably the optimum drug for widespread use in the treatment of epilepsy in developing countries. However, phenobarbital is banned in certain countries and some people may not tolerate it or be allergic to it, so at least one alternative should be available.

### **7.1.5 Who will bear the cost of these medications?**

Ideally, patients should pay for the medication they use. However, in some countries patients are too poor even to pay small sums of money for medication. Thus, each country will have to decide on a mechanism of funding medication.

### **7.1.6 Other issues to be addressed**

Many other issues, including stigma and social issues, are important for the care of patients with neuropsychiatric disorders. Thus the project deals with comprehensive needs of patients with neuropsychiatric disorders.

## **7.2 Development of the SEARO programme on epilepsy control**

The diagnosis of epilepsy is complex and requires a high level of sophistication on the part of a physician specializing in neurosciences, supported by high technology laboratory tests such as CT and MRI scans and EEG. On the other hand, tonic-clonic seizures, sometimes known as “major seizures”, are easy to identify by simple observation. The workshop in Bangkok (see below) recommended that “major seizures” should be the focus of the SEARO programme.

To illustrate what happens in real life in rural and remote areas of the South-East Asia Region of WHO consider the following vignette:

*“A girl aged 15 years, who has been in good health, suddenly has an episode of violent jerking of her limbs and body at night. Her family is extremely frightened, and would like to take the patient to a hospital. However, it would take more than 3 days to reach the nearest hospital. Thus they take the patient to the health care provider in their village. The health care provider must decide how to manage the patient.*

*The health care provider has to determine whether the patient has had an episode of Generalized Tonic-Clonic Seizure (major seizures) or pseudoseizure. In order to do this, he/she needs a simple questionnaire which can be administered to the family and the patient to assist in reaching a conclusion.”*

Thus, a simple questionnaire was developed which could assist community-based health care providers to determine whether a person with an episode of jerking of the body and limbs has had a generalized tonic-clonic seizure. It is important to have a standard validated clinical case definition of epilepsy for use by the community-based health care providers.

### **7.2.1 Recommendations of the Epilepsy Working Group in Bangkok (Intercountry consultation on development of strategies for community-based neuropsychiatric services, Bangkok, Thailand, 19-22 November, 2001)**

The epilepsy Working Group of the workshop in Bangkok made the following recommendations:

- The Project at this stage should aim at identifying and managing only Generalized-Tonic-Clonic Seizures (GTCS). These have the highest morbidity, and a good outcome if treated with easily available and effective anticonvulsant medication.
- Strategies must be developed to provide care to all affected by GTCS, including those in rural and remote populations. The service must be provided in the community and be of acceptable quality.
- In order to reduce the treatment gap, efforts need to be made to increase the availability and accessibility of services in the community.
- Projects should be aimed at four levels of health care providers:
  - Qualified medical practitioners, both in government service and private practice
  - Doctors who practice other officially recognized systems of medicine such as Ayurveda
  - Government employed multi-purpose health workers

- Other community-based health care providers who practise medicine in rural and remote communities where there are no qualified doctors
- The programme should be divided into:
  - Training to identify GTCS
  - Training to provide care to patients including medical treatment of GTCS
- Identifiers could be any person including community members, teachers, faith healers, rural private practitioners etc.
- The health care providers will be expected to prescribe antiepileptic medications and follow up the patients after identification. Those permitted to prescribe medication will depend on Government policy and vary from country to country.
- The project should pilot test the feasibility of this strategy in some Member Countries.
- The first task is to validate the criteria to be used by lay health workers in identifying GTCS. Thus, the criteria to be used by the most basic level of community health care provider should be tested first.

### **7.2.2 Development of a protocol for the identification and management of GTCS**

The questionnaire for identification of GTCS was tested at the following sites:

- Epilepsy clinic, All India Institute of Medical Sciences, New Delhi, India
- Epilepsy clinic, Ballabgarh hospital of the Comprehensive Rural Health Services Project, Haryana, India
- Community sample in Ballabgarh area, Haryana, India

At each of the first two clinical centres, the questionnaire was administered by lay health workers to epilepsy patients, patients with pseudoseizures and patients with other neurological conditions. A neurologist verified the diagnosis of each patient. In the community sample, one member of each household was interviewed and information was obtained from the entire family. Those who screened positive completed the complete questionnaire and also seen by a neurologist to reach a diagnosis of GTCS or other disorders.

The same questionnaire was also tested in the epilepsy clinic of the National Institute of Mental Health and Neurosciences, Bangalore, India. Data obtained from this Centre were compared with data obtained in New Delhi and Ballabgarh.

The revised draft of the questionnaire (one screening question and 6 detailed questions) was administered to 100 patients with GTCS, 25 patients with pseudoseizures and 50 patients with other neurological conditions in both Sri Lanka and Myanmar. These data were presented at the Yangon workshop. The questionnaire was also sent to all countries participating in the

Yangon workshop, and each was asked to test the questionnaire on at least 5 patients with GTCS. Data from all countries were pooled and discussed at the Yangon workshop.

### **7.2.3 Finalization of the SEARO protocol on the identification and management of GTCS in the community (Intercountry Workshop to finalize protocol for identification and management of “major seizures” in the community, Yangon, Myanmar, 13-15 August 2002)**

During the workshop all countries presented their data, based on the questionnaire sent to them prior to the workshop. The experiences of all Member Countries were discussed and the questionnaire finalized. The final questionnaire is attached (Annex 1).

Patients identified by the questionnaire will be treated either by the physicians or the community-based health care provider, or referred for treatment, dependant on the practice of the country.

A “best practice guideline” for the management of GTCS has also been developed based on advice from experts. These guidelines take into account the cost-effectiveness of medication, their availability, toxicity and possibility of compliance. This best practice guideline is attached. (Annex 2).

### **7.2.4 Development of a clinical case definition for GTCS**

A total of **six questions** were tested in the 3 sites in India for the development of a **clinical case definition** of GTCS. The scoring system developed gave one point to an affirmative answer for each question (minimum score zero, maximum six.) We examined the sensitivity and specificity for each score from zero to six in the same data set. With the essential requirement of a minimum specificity of 90%, the best sensitivity was achieved at a cut-off point of four. The sensitivity and specificity at this score were 56.9 % and 96.3% respectively. Combinations of the questions using “AND” or “OR” did not improve on the sensitivity and specificity.

This clinical case definition was then tested in the third and final phase of clinical case definition development by recruiting patients from other SEAR Member Countries (Bhutan, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka and Thailand). The pooled analysis of 197 patients with GTCS and 26 patients with other neurological diagnosis revealed a sensitivity of 72% and specificity of 100%. (Anand, Jain S et al.2005)

Based on these criteria, we recommend that all patients with a history of two or more episodes of jerking or rigidity of limbs, with a score of four or more in the case definition be

identified as having GTCS and started on AEDs. Those scoring below four may need to be followed up, especially those with borderline scores of two or three.

### **7.2.5 Community testing of the finalized questionnaire and clinical case definition**

The final protocol (one screening question and 6 detailed questions) has been tested at a community level in collaboration with experts in New Delhi and Yangon. In India 77 cases of GTCS were identified in three months from one district, while in Myanmar 168 cases of GTCS were identified in a similar setting. In these districts the video on stigma removal has also been tested in group meetings.

### **7.3 Impact of SEARO program on identification and management of epilepsy**

There are about 15 million people with epilepsy in the 11 SEAR Member Countries with an existing treatment gap of 80-90%. In rural areas almost nobody gets appropriate treatment. 75% of those with epilepsy have GTCS i.e. 11.25 million patients.

The sensitivity of the screening instrument developed by SEARO to identify people with major seizures is 72%. Thus, ***this instrument should identify approximately 8 million patients.*** Treatment of these patients should reduce the treatment gap by 50% by the year 2008.

#### **SEARO motto:**

With the availability of cost-effective medication for epilepsy, even one patient with uncontrolled seizures is unacceptable.

### **7.4 Indicators for success of programme**

Success of the programme will be estimated by reduction of treatment gap as measured by the declining difference between the number of patients with active epilepsy (based on the presumed prevalence of the disease) and the number of patients whose seizures are being appropriately treated.

#### **Process indicators**

Successful implementation of the programme will be assessed as follows:

- Number of training sessions held for each category of community-based health care providers

- Number of community-based health care providers trained
- Regular availability of medication to patients and delivery of medication to patients
- Number of stigma removal campaigns conducted

### ***Impact indicators***

The ultimate measure of the success of the programme should be based on assessment of the impact on the control of GTCS in the community. Specifically the following will be assessed:

- Number of patients identified
- Number of patients treated
- Seizure control in identified patients over one year
- Satisfaction of treatment amongst patients/family

Efficacy of stigma removal campaign will be judged by increase in the number of people seeking medical treatment for GTCS.

## **8. PARTNERSHIPS TO REDUCE THE TREATMENT GAP FOR EPILEPSY IN SEAR**

The number of people with epilepsy receiving modern care is gradually increasing in urban areas in SEAR Member Countries. However, those residing in inaccessible and remote areas are still unidentified and untreated. A broader sense of a community working towards the same goal of reducing the treatment gap should be encouraged. The responsibility of reaching the unreached rests with the partnerships formed with all those involved in working with epilepsy.

Figure 1 illustrates the key stakeholders (partners) involved in achieving the goal of ***reducing the treatment gap by 50% by the year 2008.***

### **• World Health Organization**

WHO/SEARO can support national governments, professional organizations and NGOs in creating hope for people with epilepsy and removing prejudice. Specifically SEARO can assist in:

- Development of technical material for identification and management of epilepsy
- Provision of training in administration of technical material
- Promotion of inter-agency collaboration
- Advocacy with governments
- Updating country resources on epilepsy
- Provision of coordination/leadership for multiple partners working on epilepsy
- Creation of opportunities for the implementation of the GCAE in all SEAR Member Countries

- **International League Against Epilepsy (ILAE) & International Bureau for Epilepsy (IBE)**

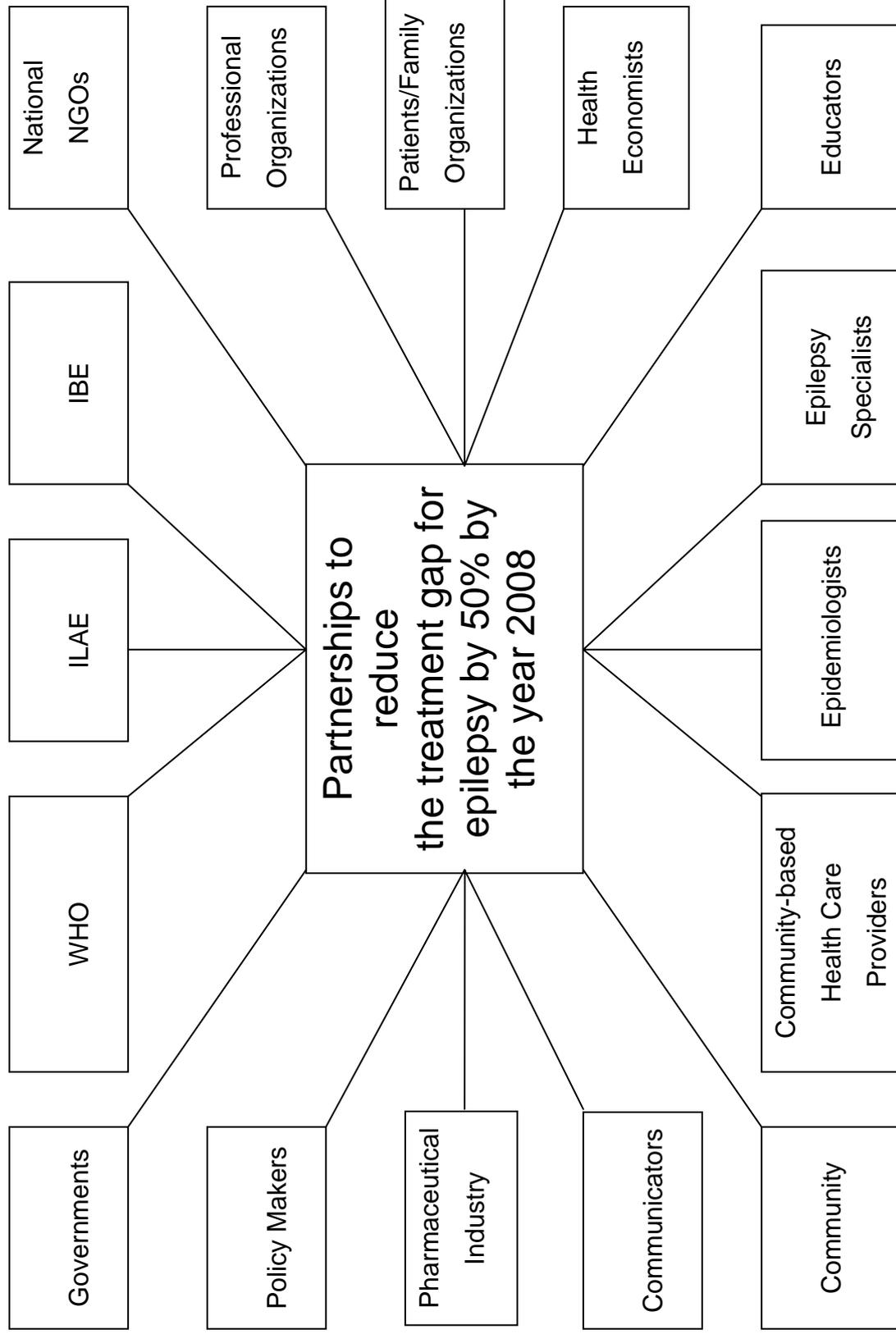
ILAE and IBE can actively collaborate and cooperate with regional organizations by:

- Advancing and disseminating knowledge about epilepsy
- Promoting research, education and training
- Improving services and care for patients, especially on prevention, diagnosis and treatment
- Suggesting measures to improve the quality of life and welfare of people with epilepsy

- **Governments**

Governments have a major role to play in:

- Developing appropriate legislation (epilepsy and employment, epilepsy and marriage, epilepsy and driving etc.)
- Developing appropriate policies for programmes dealing with epilepsy (e.g. manpower training, dissemination of technical material in local languages)
- Working with the pharmaceutical industry to ensure availability and wide spread distribution of high quality anti-epileptic medication at a reasonable price
- Promoting inter-sectoral collaboration (e.g. WHO, NGOs, private health care providers, public health care providers)
- Incorporating epilepsy control activities in existing disease control programme which are already operational in SEAR Member Countries
- Research in enhancing the understanding about epilepsy. Each country can designate one of its apex institutions as a research centre for epilepsy specifically dealing with locally applicable issues.



- **Policy makers and politicians**

Policy makers and politicians should:

- Ensure that all the governments in the SEAR make a commitment towards epilepsy control and specifically to reduce the treatment gap
- Ensure that budgets are provided and resources allocated so that measures to reduce the treatment gap in epilepsy are in place and there is continuous monitoring of the situation.

- **Epilepsy Specialists**

Although scarce in most Member Countries epilepsy specialists can be involved in the following activities:

- Regular training of other health professionals at all levels (primary care physicians, community health workers etc.)
- Providing backup clinical services to other medical and paramedical personnel for difficult to treat epilepsy cases
- Increasing awareness of local resource agencies such as :
  - teachers in schools and colleges
  - local NGOs active in health and development
  - industrial employers

- **Epidemiologists**

Epidemiologists should be involved in:

- Conducting prevalence, incidence and risk factor studies to obtain reliable data for policy development
- Conducting operational research about services, drugs, health systems and utilization of services which is vital to improve epilepsy care
- Studying the knowledge, attitude, beliefs and practices about epilepsy which is crucial to stigma elimination programmes and to address psychosocial issues related to epilepsy
- Projects involving risk factor control such as promotion of good hygiene to prevent neurocysticercosis, optimum ante-natal and peri-natal care to prevent brain injury.

- **Community-based health care providers**

There are very few neurologists in SEAR Member Countries, and most are concentrated in major urban centres. Thus, a number of other practitioners provide care in different situations, including general practitioners qualified in allopathic medicine, practitioners of other systems of medicine, community health care workers and other community-based health care providers

who provide care in the community. All these community-based health care providers should acquire appropriate knowledge about the identification and management of epilepsy. Their work needs to extend beyond prescribing medication 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. The health care systems in SEAR Member Countries vary greatly and each country will have to develop its own individual strategy.

- **Pharmaceutical Industry**

The pharmaceutical industry has a vital role in ensuring a continuous supply of antiepileptic drugs for people with epilepsy. In most countries, antiepileptic drugs not available on a continuous basis particularly in remote areas, and the cost of some of the newer drugs is too high. Spurious and substandard medication is a serious problem. Governments can support the industry by reducing taxes and modifying laws to rationalize cost and improve distribution of drugs.

- **Communicators**

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.

Communication specialists may be used to develop resource materials (booklets, posters, plays, television and radio messages) in simple formats in local languages to be disseminated through local communication channels in a people-friendly way.

- **Educators**

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

- Learning to recognize seizures
- Referring people with epilepsy to appropriate health care agencies
- Emphasizing 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
- Practicing non-discrimination against children with epilepsy

- **Professional organizations working on epilepsy**

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.

- **Health Economists**

Health economists should:

- Estimate and create awareness about the economic burden of epilepsy on the patient, family and the community
- Conduct scientific cost analysis of various medical conditions, including epilepsy, to enable policy makers to make informed decisions on resource allocations.

- **NGOs working for epilepsy control**

NGOs at local levels are involved in a number of health and development programmes. They have a close proximity with community leaders and people of the community. NGOs could be involved in setting up satellite clinics, monthly camps with community participation for management of epilepsy and education of the community regarding epilepsy. They can also take a lead role in ensuring drug supply and availability and monitoring of people for drug compliance.

- **Community**

Awareness of the community of the medical nature of epilepsy will help in removal of the stigma associated with epilepsy. The community can also play an important role in social support of the patients/families when in need. Community awareness would also help in providing equal opportunities for employment for people with epilepsy. The community can advocate to policy makers and politicians to make a commitment towards epilepsy control activities.

- **Organizations of patients and families suffering from epilepsy**

They can help in creating public awareness about epilepsy. They can provide support groups for patients and families suffering from epilepsy and advocate equal opportunity in education and employment.

## **9. INNOVATIVE COMMUNITY PROGRAMMES IN SEAR MEMBER COUNTRIES**

### **9.1 India**

Under the aegis of the National Mental Health Programme, the District Mental Health Programmes were started in 1982 in Bellary district of Karnataka, 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. 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 run 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.

Local NGOs in Bangalore 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. This model provides an ongoing activity wherein services are provided by specialists in close proximity to the people. Evaluation studies have shown significant impact of such community programmes.

## **9.2 Sri Lanka**

Care of epilepsy at the primary health care level 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, which began with a well-illustrated handbook on epilepsy in Sinhalese and Tamil. The preschool teachers were

trained in first-aid methods, identification of epilepsy and 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. The local government hospitals were involved from the inception of the programme. It has been clearly demonstrated by the programme that local involvement of health workers, community and governmental agencies can provide efficient and effective care.

“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 Award in the drama section at the Epilepsy International Congress at Hamburg, Germany. The film was shown on the national television network and has been repeatedly telecast on public demand. 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.

### **9.3 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 disorder. Outreach programmes are being conducted in Lampang (north Thailand) and Krabi (south Thailand). The society plans to publish “Epilepsy Management Guidelines” for general practitioners in the future.

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

### **9.4 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.

## **10. FUTURE PLANS FOR EPILEPSY CONTROL IN SEAR MEMBER COUNTRIES**

The magnitude of the problem of epilepsy and the huge treatment gap, 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 ultimate objective is to improve the quality of life of people with epilepsy. The programme must have political commitment, professional support and public participation.

### **Tasks for the future:**

- To place epilepsy on the public health agenda of all Member Countries;
- To develop locally appropriate national guidelines for prevention and management of epilepsy;
- To develop relevant manpower at all levels specifically trained for epilepsy care (using already developed SEARO protocol on identification of people with epilepsy);
- To establish treatment mechanisms within existing health services (using already developed SEARO protocol on “good practice guidelines”);
- To ensure regular and uninterrupted medication supply even at peripheral levels with planning and budgeting;
- To increase public awareness to remove stigma through sensitization and awareness programmes (using the already developed SEARO video entitled “Epilepsy – Myth and Reality”);
- To develop systematic referral services for people with uncontrolled seizures within defined geographical areas;
- To expand services to cover inaccessible and remote areas (using the already developed SEARO technical material);

***The project will attempt to reach at least 8 million of the 15 million people with epilepsy by gradually scaling up the reach of the programme. With this the treatment gap in SEAR should be reduced by 50% by the year 2008. This will be a major step in reducing the morbidity amongst people with epilepsy.***

## Country data from the SEARO Region<sup>1</sup>

### **BANGLADESH<sup>1</sup> Demographic Indicators:**

Total population (thousands) 143,364,  
Surface area (thousands of sq km) 144,  
Population density (per sq km) 996,  
Population growth rate (%) 2.09, Crude birth rate (per 1000 pop) 29.9, Crude death rate (per 1000 pop) 8.7, Urban population (%) 24.5. **Socio-economic indicators:** Gross national income per capita (US\$) 370, Gross domestic product per capita growth rate (%) 3.3, Adult literacy rate(%) Total 40.0, Male 49.4, Female 30.2

**Health Resources Indicators:** Total expenditure on health (as % of GDP) 3.8, Public share to total health expenditure (%) 36.4, Per capita total health expenditure (international dollars) 47, Physicians per 10,000 population 2.51, Hospital beds per 10,000 population 3.36 **Primary Health**

**Care Coverage Indicators:** Population with access to safe water (%) Total 97.3, Urban 99.2, Rural 96.7, Population with access to

adequate sanitation (%) Total 54.1, Urban 74.6, Rural 49.3. **Health Status Indicators:**

Life expectancy at birth (years) : Both 62.6, Male 62.6, Female 62.6, Infant mortality rate (per 1000 live births) 51.0, Under-five mortality rate (per 1000 live births) Male 71, Female 73. **Available manpower:**

Neurologists (per 100,000 population): 0.02. Psychiatrists (per 100,000 population) : 0.06 Neurosurgeons (per 100,000 population):

0.01 Epilepsy specialists are available in

the country. **Training in epileptology:**

There is no postgraduate specialist training in epileptology in the country. **Services for**

**epilepsy:** No separate hospital beds for epilepsy, patients are admitted either in the neurology ward or general medical ward.

Diagnostic procedures available are: EEG, MRI and CT scan. Sub-specialized epilepsy services available are: Therapeutic drug monitoring, long-term video/Monitoring, neuropsychological services and psychiatric counselling. Major causes of seizures are idiopathic, birth trauma, cerebral encephalitis, head injury and brain tumor.

The available antiepileptic drugs are:

Phenobarbital,, Phenytoin (0.01 US\$ /100 mg tablet), Carbamazepine (0.07 US\$ /200 mg tablet), Sodium Valproate (0.04 US\$/200 mg tablet) and Clonazepam (0.09 US\$/2mg tablet). Phenobarbital and Carbamazepine are included in the list of essential drugs in the country. **Health**

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<sup>1</sup> Countries having completed the Questionnaire on Country Resources for Epilepsy. Cost and presentation of AEDs are indicated as given in the Questionnaire by the responding country.

**budget for epilepsy:** No separate budget for epilepsy care in the Ministry of Health's budget. Epilepsy services are financed through out-of-pocket payments. Epilepsy is not included in the annual health reporting system.

**IBE/ILAE Chapter:** There is no IBE or ILAE chapter.

## **BHUTAN<sup>1</sup>**

**Demographic Indicators:** Total population (thousands) 805, Surface area (thousands of sq km) 47, Population density (per sq km) 17, Population growth rate (%) 2.55, Crude birth rate (per 1000 pop) 34.09, Crude death rate (per 1000 pop) 8.64, Urban population (%) 14.5, Average annual growth rate of the urban population (%) 5.95

**Socio-economic indicators:** Gross national income per capita (US\$) 640, Gross domestic product per capita growth rate (%) 4.0, Adult literacy rate(%) Total 47.3, Male 61.1, Female 33.6

**Health Resources Indicators:** Total expenditure on health (as % of GDP) 4.1, Public share to total health expenditure (%) 90.6, Per capita total health expenditure (international dollars) 64, Physicians per 10,000 population 1.6, Hospital beds per 10,000 population 16.0

**Primary Health Care Coverage Indicators:** Population with access to safe water (%) Total 77.8, Urban 97.5, Rural 73.2, Population with access to adequate sanitation (%) Total 88.0, Urban n/a, Rural n/a

**Health Status Indicators:**

Life expectancy at birth (years) : Both 61.3, Male 60.2, Female 62.4, Infant mortality rate (per 1000 live births) 60.5, Under-five mortality rate (per 1000 live births) Male 93, Female 92

**Available manpower:** Neurologists (per 100,000 population) : 0.

Psychiatrists (per 100,000 population): 0.3

Neurosurgeons (per 100,000 population): 0

**.Training in epileptology:** There is no postgraduate specialist training in epileptology in the country.

**Services for epilepsy:** Epilepsy is not included in the annual health reporting system..

No separate hospital beds for epilepsy – cases are managed in general medical wards. Diagnostic procedures available are: EEG, MRI and CT scan were not available. Sub-specialized epilepsy services available are: Psychiatric counselling. Major causes of seizures are idiopathic, birth trauma, CNS infections and infestations, head injury and brain tumor. The available antiepileptic drugs are: Phenobarbital,, Phenytoin, Carbamazepine. Phenobarbital, Phenytoin and Carbamazepine are included in the list of essential drugs in the country.

**Health budget for epilepsy:** No separated budget for epilepsy care in the Ministry of Health's budget. Epilepsy services are financed through government funding.

**IBE/ILAE Chapter:** There is no IBE or ILAE chapter.

## **DPR KOREA**

**Demographic Indicators:** Total population (thousands) 22,586, Surface area (thousands of sq km) 121, Population density (per sq km) 187, Population growth rate (%) 0.68, Crude birth rate (per 1000 pop), 16.7, Crude death rate (per 1000 pop) 9.9, Urban population (%) 60.2, Average annual growth rate of the urban population (%) 1.62 **Socio-economic indicators:**

Gross national income per capita (US\$) n/a, Gross domestic product per capita growth rate (%) n/a, Adult literacy rate (%) 100, Male 100, Female 100

**Health Resources Indicators:** Total expenditure on health (as % of GDP) 2.1, Public share to total health expenditure (%) 77.3, Per capita total health expenditure (international dollars) 33, Physicians per 10,000 population 29.7, Hospital beds per 10,000 population 136.1 **Primary Health Care Coverage Indicators:**

Population with access to safe water (%) Total 99.9, Urban n/a, Rural n/a, Population with access to adequate sanitation (%) Total 99.2, Urban n/a, Rural n/a **Health Status Indicators:**

Life expectancy at birth (years) : Both 65.8, Male 64.4, Female 67.1, Infant mortality rate (per 1000 live births) 68.0, Under-five mortality rate (per 1000 live births) Male 56, Female 54 **Available**

**manpower:** Neurologists (per 100,000 population) : NA. Psychiatrists (per 100,000

population): NA Neurosurgeons (per 100,000 population): NA

## **INDIA<sup>1</sup>**

**Demographic Indicators:** Total population (thousands) 1,041,144, Surface area (thousands of sq km) 3,287, Population density (per sq km) 317, Population growth rate (%) 1.52, Crude birth rate (per 1000 pop) 23.8, Crude death rate (per 1000 pop) 8.4, Urban population (%) 28.4, Average annual growth rate of the urban population (%) 2.81

**Socio-economic indicators:** Gross national income per capita (US\$) 460, Gross domestic product per capita growth rate (%) 2.7, Adult literacy rate (%) Total 57.2 Male 68.4, Female 45.4 **Health**

**Resources Indicators:** Total expenditure on health (as % of GDP) 4.9, Public share to total health expenditure (%) 17.8, Per capita total health expenditure (international dollars) 33, Physicians per 10,000 population 5.2, Hospital beds per 10,000 population 6.9. **Primary Health Care Coverage Indicators:**

Population with access to safe water (%) Total 77.9, Urban 92.6, Rural 72.3, Population with access to adequate sanitation (%) Total 36.0, Urban 80.7, Rural 18.9 **Health Status Indicators:**

Life expectancy at birth (years) : Both 61.0, Male 60.1, Female 62.0, Infant mortality rate (per 1000 live births) 68.0, Under-five mortality rate (per 1000 live births) Male 87,

## Female 95 Available

**manpower:**Neurologists (per 100,000 population) : 0.05. Psychiatrists (per 100,000 population): 0.4. Neurosurgeons (per 100,000 population): 0.06. . **Training in epileptology:** Epilepsy specialists are available in the country. There is no postgraduate specialist training in epileptology in the country, but at a few places unstructured training is available. **Services for epilepsy:** Epilepsy is not included in the annual health reporting system No separate hospital beds for epilepsy, patients are admitted either in the neurology ward or general medical ward. Diagnostic procedures available are: EEG, MRI and CT scan. Investigations for epilepsy surgery are available in 3 places. Sub-specialized epilepsy services available are: Therapeutic drug monitoring, long-term video/Monitoring, epilepsy surgery, neuropsychological services and psychiatric counselling. Major causes of seizures are hereditary, CNS infections and infestations, perinatal brain insults, traffic accidents, multifactorial causes. The available antiepileptic drugs are: Phenobarbital (0.003 US\$/60 mg tablet),, Phenytoin (0.20 US\$/100mg tablet) Carbamazepine (0.025 US\$/200 mg tablet), Sodium Valproate (0.045 US\$/200 mg tablet), Lamotrigine, Topiramate, Clobazam and Gabapentin. **Health budget for epilepsy:** No separate budget for epilepsy care in the Ministry of

Health's budget. Epilepsy services are financed through out-of-pocket payments, tax-based funding and private insurance.

**IBE/ILAE Chapter:** Indian Epilepsy Association is a chapter of IBE. Indian Epilepsy Society is a professional association of epilepsy specialist.

## INDONESIA<sup>1</sup>

**Demographic Indicators:**Total population (thousands) 217,534, Surface area (thousands of sq km) 1,905, Population density (per sq km) 317, Population growth rate (%)1.52, Crude birth rate (per 1000 pop), 20.0, Crude death rate (per 1000 pop) 7.1, Urban population (%) 40.9, Average annual growth rate of the urban population (%) 3.57 **Socio-economic indicators:** Gross national income per capita (US\$) 680, Gross domestic product per capita growth rate (%) 1.8, Adult literacy rate(%)Total 86.8, Male 91.8, Female 81.9 **Health Resources Indicators:** Total expenditure on health (as % of GDP) 2.7, Public share to total health expenditure (%) 23.7, Per capita total health expenditure (international dollars) 84, Physicians per 10,000 population 1.1, Hospital beds per 10,000 population 6.03 **Primary Health Care Coverage Indicators:** Population with access to safe water (%) Total n/a, Urban 88.2, Rural 71.9, Population with access to adequate sanitation (%) Total n/a, Urban 86.9, Rural 54.2 **Health Status Indicators:**

Life expectancy at birth (years) : Both 66.4, Male 64.9, Female 65.0, Infant mortality rate (per 1000 live births) 41.4, Under-five mortality rate (per 1000 live births) Male 45, Female 36

**Available manpower:** Neurologists (per 100,000 population) : 0.06. Psychiatrists (per 100,000 population): 0.21 Neurosurgeons (per 100,000 population): 0.01 **Training in epileptology:** Epilepsy specialists are available in the country. There is no postgraduate specialist training in epileptology in the country. **Services for epilepsy:** Epilepsy is not included in the annual health reporting system. Diagnostic procedures available are: EEG, MRI and CT scan. Sub-specialized epilepsy services available are: Neuro-psychological services and psychiatric counselling. Major causes of seizures are idiopathic, birth trauma, CNS infections and infestations, head injury and brain tumor. The available antiepileptic drugs are: Phenobarbital,, Phenytoin, Carbamazepine and Sodium Valproate, **Health budget for epilepsy:** No separate budget for epilepsy care in the Ministry of Health's budget. Epilepsy services are financed through out-of-pocket payments and government subsidy through primary health care. **IBE/ILAE Chapter:** There is no IBE or ILAE chapter. Indonesian Society Against Epilepsy is a professional association of epilepsy specialist.

## MALDIVES

**Demographic Indicators:** Total population (thousands) 309, Surface area (thousands of sq km) 0.3, Population density (per sq km) 114, Population growth rate (%) 1.21, Crude birth rate (per 1000 pop) 20.0, Crude death rate (per 1000 pop) 4.0, Urban population (%) 40.9, Average annual growth rate of the urban population (%) 3.52.

**Socio-economic indicators:** Gross national income per capita (US\$) 2,040, Gross domestic product per capita growth rate (%) 4.5, Adult literacy rate(%) Total 96.9, Male 97.0, Female 96.8

**Health Resources Indicators:** Total expenditure on health (as % of GDP) 7.6, Public share to total health expenditure (%) 83.4, Per capita total health expenditure (international dollars) 254, Physicians per 10,000 population 8.4, Hospital beds per 10,000 population 17.4. **Primary Health**

**Care Coverage Indicators:** Population with access to safe water (%) Total 76.5, Urban n/a, Rural n/a, Population with access to adequate sanitation (%) Total 85, Urban n/a, Rural n/a

**Health Status Indicators:** Life expectancy at birth (years) : Both 64.6, Male 64.5, Female 65.0, Infant mortality rate (per 1000 live births) 21.0, Under-five mortality rate (per 1000 live births) Male 38, Female 43 **Available manpower:** Neurologists (per 100,000 population) : 0. Psychiatrists (per 100,000 population): 0.36 Neurosurgeons (per 100,000 population): 0.36

## MYANMAR<sup>1</sup>

**Demographic Indicators:** Total population (thousands) 48,956, Surface area (thousands of sq km) 677, Population density (per sq km) 72, Population growth rate (%) 1.16, Crude birth rate (per 1000 pop) 23.2, Crude death rate (per 1000 pop) 11.6, Urban population (%) 27.7, Average annual growth rate of the urban population (%) 2.86 **Socio-economic indicators:** Gross national income per capita (US\$) n/a, Gross domestic product per capita growth rate (%) n/a, Adult literacy rate(%) Total 84.7, Male 88.9, Female 80.5 **Health Resources Indicators:** Total expenditure on health (as % of GDP) 2.2, Public share to total health expenditure (%) 17.1, Per capita total health expenditure (international dollars) 24, Physicians per 10,000 population 3.0, Hospital beds per 10,000 population 6.3 **Primary Health Care Coverage Indicators:** Population with access to safe water (%) Total 71.5, Urban 89.2, Rural 65.8, Population with access to adequate sanitation (%) Total 63.1, Urban 83.6, Rural 56.5 **Health Status Indicators:** Life expectancy at birth (years) : Both 62.3, Male 60.7, Female 63.9, Infant mortality rate (per 1000 live births) 59.8, Under-five mortality rate (per 1000 live births) Male 78, Female 78 **Available Manpower:** Neurologists (per 100,000 population) : 0.02. Psychiatrists (per 100,000 population):

0.2. Neurosurgeons (per 100,000 population): 0.02

Epilepsy specialists are available in the country

**Training in epileptology:** There is no postgraduate specialist training in epileptology in the country. **Services for epilepsy:** Epilepsy is not included in the annual health reporting system.. Separate beds for short-term epilepsy care are available. Diagnostic procedures available are: EEG, MRI and CT scan are available. Sub-specialized epilepsy services available are: Neuropsychological services and psychiatric counselling. Major causes of seizures are brain tumor, intra cerebral haematoma, cerebral infarction, head trauma, CNS infection. and infestations. The available antiepileptic drugs are: Phenytoin, Phenobarbital, Carbamazepine (0.10 US\$/20mg tablet) and Sodium Valproate (0.10 US\$/200mg tablet). Carbamazepine is included in the list of essential drugs in the country.

**Health budget for epilepsy:** No separated budget for epilepsy care in the Ministry of Health's budget. Epilepsy services are financed through out-of-pocket payments and government funding.

**IBE/ILAE Chapter:** There is no IBE or ILAE chapter

## NEPAL<sup>1</sup>

**Demographic Indicators:** Total population (thousands) 24,153, Surface area (thousands of sq km) 147, Population density (per sq km) 164, Population growth rate (%) 2.32, Crude birth rate (per 1000 pop) 34.0, Crude death rate (per 1000 pop) 9.9, Urban population (%) 11.9, Average annual growth rate of the urban population (%) 5.07

**Socio-economic indicators:** Gross national income per capita (US\$) 250, Gross domestic product per capita growth rate (%) 3.4, Adult literacy rate (%) Total 41.7, Male 59.4, Female 24.0

**Health Resources Indicators:** Total expenditure on health (as % of GDP) 5.4, Public share to total health expenditure (%) 29.3, Per capita total health expenditure (international dollars) 66, Physicians per 10,000 population 0.54, Hospital beds per 10,000 population 1.5

**Primary Health Care Coverage Indicators:** Population with access to safe water (%) Total 59.0, Urban 61.0, Rural 59.0, Population with access to adequate sanitation (%) Total 23.0, Urban 74.0, Rural 18.0

**Health Status Indicators:** Life expectancy at birth (years) : Both 60.1, Male 59.9, Female 60.2, Infant mortality rate (per 1000 live births) 59.8, Under-five mortality rate (per 1000 live births) Male 81, Female 87

**Available Manpower:** Neurologists (per 100,000 population) : 0.02. Psychiatrists (per 100,000 population): 0.09 Neurosurgeons (per 100,000

population): 0.02 Epilepsy specialists are available in the country

**Training in epileptology:** There is no postgraduate specialist training in epileptology in the country. **Services for epilepsy:** Epilepsy is included in the annual health reporting system. No separate hospital beds for epilepsy, patients are admitted either in the neurology ward or general medical ward. Diagnostic procedures available are: EEG, MRI and CT scan. Sub-specialized epilepsy services available are: Therapeutic drug monitoring, neuropsychological services, psychiatric counselling, social rehabilitation and special education. Major causes of seizures are idiopathic, CNS infections and infestations, neurocysticercosis, head trauma and brain tumors. The available antiepileptic drugs are: Phenobarbital (0.01 US\$ /100 mg tablet), Phenytoin (0.20 US\$ /100 mg tablet), Carbamazepine (0.40 US\$ /200 mg tablet) and Sodium Valproate.

Phenobarbital, Phenytoin and Carbamazepine are included in the list of essential drugs in the country. **Health budget for epilepsy:** No separated budget for epilepsy care in the Ministry of Health's budget. Epilepsy services are financed through out-of-pocket payments and government funding. **IBE/ILAE Chapter:** There is no IBE or ILAE chapter. The Nepal Epilepsy Association is the professional association of epilepsy specialists.

## **SRI LANKA<sup>1</sup>**

**Demographic Indicators:** Total population (thousands) 19,287, Surface area (thousands of sq km) 66, Population density (per sq km) 292, Population growth rate (%) 0.94, Crude birth rate (per 1000 pop) 17.3, Crude death rate (per 1000 pop) 9.9, Urban population (%) 23.6, Average annual growth rate of the urban population (%) 2.84 **Socio-economic indicators:** Gross national income per capita (US\$) 830, Gross domestic product per capita growth rate (%) 1.0, Adult literacy rate(%) Total 91.6, Male 94.4, Female 89.0

**Health Resources Indicators:** Total expenditure on health (as % of GDP) 3.6, Public share to total health expenditure (%) 49.0, Per capita total health expenditure (international dollars) 120, Physicians per 10,000 population 4.1, Hospital beds per 10,000 population 29 **Primary Health Care**

**Coverage Indicators:** Population with access to safe water (%) Total 75.4, Urban 96.0, Rural 74.6, Population with access to adequate sanitation (%) Total 72.6, Urban 87.0, Rural 68.3 **Health Status Indicators:**

Life expectancy at birth (years) : Both 70.3, Male 67.2, Female 74.3, Infant mortality rate (per 1000 live births) 15.4, Under-five mortality rate (per 1000 live births) Male 20, Female 16 **Available Manpower:** Neurologists (per 100,000 population) : 0.06. Psychiatrists (per 100,000 population):

0.2 Neurosurgeons (per 100,000 population): 0.03

Epilepsy specialists are available in the country

**Training in epileptology:** There is no postgraduate specialist training in epileptology in the country. **Services for epilepsy:** Epilepsy is included in the annual health reporting system. No separate hospital beds for epilepsy, patients are admitted either in the neurology ward or general medical ward. Diagnostic procedures available are: EEG, MRI and CT scan. Sub-specialized epilepsy services available are: Therapeutic drug monitoring, neuropsychological services, psychiatric counselling, social rehabilitation and special education. Major causes of seizures are idiopathic, CNS infections and infestations, peri natal injuries, head trauma and brain tumors. The available antiepileptic drugs are: Phenobarbital (0.003 US\$ /60 mg tablet), Phenytoin (0.006 US\$ /100mg tablet), Carbamazepine (0.01 US\$/200mg tablet), Sodium Valproate (0.02 US\$/200mg tablet), Topiramate, Llamotrigine, Gabapentin and Clobozam. **Health budget for epilepsy:** No separated budget for epilepsy care in the Ministry of Health's budget. Epilepsy services are financed through out-of-pocket payments and government funding.

**IBE/ILAE Chapter:** The Epilepsy Association for Sri Lanka is affiliated to IBE.

## THAILAND<sup>1</sup>

**Demographic Indicators:** Total population (thousands) 64,344, Surface area (thousands of sq km) 513, Population density (per sq km) 125, Population growth rate (%) 1.14, Crude birth rate (per 1000 pop) 17.8, Crude death rate (per 1000 pop) 6.2, Urban population (%) 21.6, Average annual growth rate of the urban population (%) 2.67 **Socio-economic indicators:**

Gross national income per capita (US\$) 1,970, Gross domestic product per capita growth rate (%) 0.9, Adult literacy rate(%) Total 95.5, Male 97.1, Female 93.9

**Health Resources Indicators:** Total expenditure on health (as % of GDP) 3.7, Public share to total health expenditure (%)57.4, Per capita total health expenditure (international dollars) 237, Physicians per 10,000 population 3.0, Hospital beds per 10,000 population 22.3 **Primary Health Care Coverage Indicators:**

Population with access to safe water (%) Total 92.7, Urban n/a, Rural n/a, Population with access to adequate sanitation (%) Total 97.7, Urban n/a, Rural n/a **Health Status Indicators:**

Life expectancy at birth (years) : Both 69.3, Male 66.0, Female 72.7, Infant mortality rate (per 1000 live births) 21.5, Under-five mortality rate (per 1000 live births) Male 32, Female 26 **Available Manpower:**

Neurologists (per 100,000 population) : 0.. Psychiatrists (per 100,000 population): 0.6

Neurosurgeons (per 100,000 population): 0.4

Epilepsy specialists are available in the country

**Training in epileptology:** There is no postgraduate specialist training in epileptology in the country. **Services for epilepsy:** Epilepsy is included in the annual health reporting system. Epidemiological or service data collection system is available..

No separate hospital beds for epilepsy, patients are admitted either in the neurology ward or general medical ward. Diagnostic procedures available are: EEG, MRI and CT scan. Sub-specialized epilepsy services available are: Therapeutic drug monitoring, neuropsychological services, psychiatric counselling, social rehabilitation and special education. Major causes of seizures are CNS infections and infestations, idiopathic, head trauma , birth injury and brain tumors.

The available antiepileptic drugs are:

Phenobarbital (0.002 US\$/60 mg tablet),

Phenytoin (0.045 US\$/100mg tablet),

Carbamazepine (0.01 US\$/200mg tablet),

Sodium Valproate(0.27 US\$/200mg tablet),

Topiramate, Lamotrigine, Gabapentin and

Clobazam. **Health budget for epilepsy:** No

separated budget for epilepsy care in the

Ministry of Health's budget. Epilepsy

services are financed through out-of-pocket payments and government funding.

**IBE/ILAE Chapter:** The Epilepsy Society of Thailand is affiliated to IBE

## **TIMOR-LESTE**

**Demographic Indicators:** Total population (thousands) 850, Surface area (thousands of sq km) 15, Population density (per sq km) 58, Population growth rate (%) 3.93, Crude birth rate (per 1000 pop) 25.4, Crude death rate (per 1000 pop) 13.2, Urban population (%) 15.0, Average annual growth rate of the urban population (%) 2.21

**Socio-economic indicators:** Gross national income per capita (US\$) 478, Gross domestic product per capita growth rate (%) n/a, Adult literacy rate(%) Total n/a, Male n/a, Female n/a

**Health Resources Indicators:** Total expenditure on health (as % of GDP) 9.4, Public share to total health expenditure (%) n/a, Per capita total health expenditure (international dollars) n/a, Physicians per 10,000 population n/a, Hospital beds per 10,000 population n/a

### **Primary Health Care Coverage**

**Indicators:** Population with access to safe water (%) Total n/a, Urban n/a, Rural n/a, Population with access to adequate sanitation (%) Total n/a, Urban n/a, Rural n/a

**Health Status Indicators:** Life expectancy at birth (years) : Both 57.5, Male 54.8, Female 60.5, Infant mortality rate (per 1000 live births) 70-95, Under-five mortality rate (per 1000 live births) Male 142, Female 108

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## **12. APPENDICES**

### **Appendix 1**

**TRAINING MANUAL  
FOR  
COMMUNITY-BASED HEALTH CARE PROVIDERS  
ON  
IDENTIFICATION AND CARE  
OF  
GENERALIZED TONIC-CLONIC SEIZURES (MAJOR FITS)**

## 1. INTRODUCTION

Perhaps some patients have been brought to you by the family with the complaint that he/she had an attack of vigorous shaking of the body and limbs. Such attacks are called “major fits”. These occur due to some malfunction in the brain that results in a sudden generation of excessive current in the brain. This current runs through the body causing the body to shake violently. Major fits are estimated to occur in 8 to 10 persons per 1000 population at any time.

We are confident that we can work along with you all and try to help people afflicted with this disease.

You are the health worker for the community. The community has faith in you. Thus, we wish to enhance your knowledge and skills so that you can help the community in health matters even more

This manual aims to orient you to identify and manage major fits in your setting. We fully realize that you work under difficult conditions and therefore, the manual has been written to suit your needs.

The manual is divided into three sections:

### 1. Identification of major fits

- a. Identification questionnaire
- b. Definition and features of major fits
- c. Identifying cases needing special care.

### 2. Care, Community Education and Social Issues

- a. Care during an acute episode of major fit
- b. Educating the community on myths and facts about major fits
- c. Issues of importance to persons with major fits

### 3. Instructions for administering the questionnaire

## 2. IDENTIFICATION QUESTIONNAIRE FOR MAJOR FITS

Date \_\_/\_\_/\_\_\_\_

***If a person is brought to you with the complaint that he/she had an attack of vigorous shaking of the body, administer the questionnaire below to the next-of-kin.***

*Note: The questions apply to the current episode or any similar episodes in the past*

No	Questions	Yes/No/ Don't Know
	Name of the patient:	
	Address	
	Age	
	Sex	
1.	Was the patient completely unconscious during an episode?	
2.	Did he/she pass urine or stool in his/her clothes during an episode?	
3.	Did he/she ever injure himself/herself or have tongue/cheek bite during an episode?	
4.	Was there any frothing from the mouth during an episode?	
5.	Did he/she ever have such an episode while asleep?	
6.	Has an episode ever occurred WITHOUT preceding mental/emotionally stressful events?	
How many of the above questions have been answered "YES"		
Is this episode of jerking of the body a major fit? <b><i>Code YES if 4 or more of the above questions are answered YES</i></b>		
How many such episodes has the patient had?		
Does the patient need medical treatment for major fits? <b><i>Code YES if 2 or more such episodes have occurred on different days</i></b>		

### **3. IDENTIFICATION OF “MAJOR FITS”**

Based on the above questionnaire, if any four of the six questions are answered in the affirmative, the person can be considered to have had a major fit.

If two or more such major fits occur on different days, the condition is called EPILEPSY. (i.e. two seizures occurring on the same day do not constitute the diagnosis of epilepsy, they must occur atleast 24-48 hours apart. If a person has only one such episode, it is not to be called EPILEPSY. It is sometimes seen that people have only one fit and do not ever have a second major fit. People who have only one major fit do not need treatment.

As you can see, identification of major fits is based only on observation of events during the episode. Therefore, it is essential to elicit a very good and clear description of the episode from family members and neighbours who have seen the episode. It is important to talk to the family members or neighbours of the patient since the patient is usually not aware of what happened during the episode.

### **4. FEATURES OF MAJOR FITS**

- Some people often have a special feeling before having a major fit. If so, the person can usually tell when he or she is going to have a major fit. These feelings can consist of irritability, anxiety, confusion, a strange sensation in a part of the body, etc. The feeling usually occurs just before the fit and lasts less than about one minute. However, in some people the major fit may start completely without warning and make the patient suddenly fall down. Sometimes, the affected person may suddenly cry at the onset of the major fit. The important thing to realize is that either the fit with strange feelings or the fit when there is no strange feeling, starts suddenly.
- At the onset of the major fit the patient falls down. At first, the body becomes stiff and then it becomes loose. There are jerking movements of one or both sides of the body. The movements may be violent at times. There may be froth from the mouth, and the tongue has been bitten, the froth can be blood-stained.
- The eyes of the patient are usually open but turned to one side as if he is trying to look away. The head also turns to one side.
- The shaking lasts for about one to two minutes. However, the family will usually say that the fit lasted “for ever” or “for hours”. This is because the family is usually so frightened that they lose track of time. Also, they tend to include the period after the major fit in which the person may sleep, as being a part of the fit.

- The person usually sleeps for a variable period of time which can be from a few minutes upto an hour. On waking, they have pain all over the body and may be confused. Their tongue may have been bitten. They have no memory of the event. They could be injured during the fall by hitting sharp objects.
- Sometimes the major fit is so strong, that the shoulder can be dislocated, bones broken, person can sustain a burn, or a serious injury.

## **5. IDENTIFYING CASES REQUIRING SPECIAL CARE**

### *5.1 Fit with high fever*

These are fits seen in children between the age group of six months to six years and are always associated with high fever. The convulsion is usually brief and lasts for a few seconds to about a minute.

In general, fits with high fever:

- Occur in children aged 6 months to 6 years
- Consist of jerky movements of the entire body
- Episode of fit does not recur within the same episode of fever
- Usually have no adverse effect on the child after the fit is over.

Most cases of fit with high fever do not need long-term treatment for fits. Acute care of fits is required. We need to treat the cause of fever. Efforts should be made to bring down the temperature by use of medicines like paracetamol or nimesulide and cool water sponging. If the child recovers completely in 4-6 hours after the fit, there is no need to refer the child for special evaluation. However, if the child does not recover, he/she should be referred to a hospital for special evaluation.

### *5.2 First fit in select age groups*

- Children less than three years old, having a major fit for the first time.
- First fit in persons over 20 years old.

Patients in these age groups need special attention which can be provided adequately only in a hospital.

### *5.3 Fits during pregnancy*

Fits during pregnancy could be due to very high blood pressure. As the life of the baby is also in danger, such patients will need special care and should be referred, if available, to the nearest hospital. It is important and urgent to refer a pregnant woman who has a major fit to a hospital for specialized care.

#### *5.4 Fits associated with paralysis of limbs*

This is also an indication that there is some damage to the brain and may need special tests in a hospital. If the paralysis is of one side of the body (even if it lasts for a short time), it is of even greater significance.

#### *5.5 Fits associated with high fever AND confusion in the mind*

If fits occur together with high fever and confusion in the mind, the possibility of brain infection or brain malaria has to be considered. Also, if the person develops other symptoms such as change in personality or is progressively getting worse, there is a possibility of a serious underlying illness which has caused the major fit. Such persons should be sent to a hospital for detailed tests and treatment of their illness in addition to treatment of major fits.

## **6. EXERCISES**

Given below are two case histories. Based on this, decide whether the patient can be classified as having major fits or not. Give reasons for your answer.

### *6.1 Case History – 1*

Usha, an 18-year-old girl has been brought to you with complaints of falling unconscious frequently for the last three months. When you enquire about the details of the episode of unconsciousness, you are told the following:

“During such episodes, she suddenly lies down and twists her hands and feet. Clenching of teeth is present. No frothing from mouth is seen. These episodes have always happened in the house during day time. After this she lies still for some time and stares vacantly and does not respond to any command. These last from 30 minutes to 2 hours. After recovering, she can recall some of the talks that were held during this period.”

Question: What additional questions would you like to ask to clarify the situation? Do you think Usha suffers from major fits? Give reasons.

### *6.2 Case History – 2*

Seven-year-old Shyam was brought to your clinic from the school, where he suddenly fell down. You ask the teacher who was present during the episode to describe it. He says:

“While attending the morning prayers, he suddenly fell down and started having jerky movements in his hands and feet. He got a small cut on his head which was bleeding due to the fall. His eye balls went up and there was blood-tinged frothing from his mouth. The teacher tried to hold the limbs but failed. They even tried to put keys into his hand but failed. By the time they

arranged for transport, the movements had stopped and Shyam went off to sleep. They also noted that Shyam had passed urine in his pants.

You ask the parents of the child to come next day. They tell you that he had a similar episode a week ago, while he was asleep. When asked, Shyam says he does not remember anything that happened the day before.

Question: Do you think that Shyam is suffering from major fits? Give reasons.

## **7. CARE, COMPLIANCE WITH TREATMENT, COMMUNITY EDUCATION AND SOCIAL ISSUES**

### *7.1 Care during an acute episode of major fit*

**When the person starts to have a fit, you should DO the following:**

- Be calm and tell other people who are around not to be afraid.
- Make the person lie down in a safe place. Move the person away from any danger, such as traffic, fire or sharp objects.
- Fold a cloth or piece of clothing and put it under the person's head.
- Loosen any tight clothing that the person is wearing.
- Turn the person onto his or her side so that the tongue falls to the front of the mouth. Then any saliva will flow out of the mouth making it easier for the person to breathe.
- Stay near the person until the fit is over and the person knows what is happening around him or her. Comfort the person. Explain what has happened as the person may not know what has happened.
- Let the person rest.
- The person may be injured after the fit. If so, wash and dress any small cuts and scratches.

**It is also important to know what should NOT be done if someone is having a fit:**

- **DO NOT** attempt to force anything between the teeth, like cloth, spoon or wooden piece. They can break the teeth or cause choking. Even if the tongue gets bitten, it usually heals in the next few days.
- **DO NOT** attempt to stop the convulsion by catching hold of the limbs as it may injure the person.
- **DO NOT** allow people to crowd around the person.
- **DO NOT** put a shoe, onion or any other thing in front of the patient's nose. They are of no use.
- **DO NOT** give the person any thing to eat or drink including medicines.

- **DO NOT** put anything on the person's skin, like hot iron rods etc.

### *7.2 Instructions to the patient and family regarding treatment*

It is important to give the following instructions to the patient and family, taking care to see that they are fully understood by the patient and family members.

1. Take the medicine at bed time, regularly, not missing even a single dose,
2. The patient can feel drowsy in the beginning of the treatment. This should not lead to any change in the drug dosage.
3. Missing of the dose can result in an attack. Keep stock of the medicine for at least two weeks at any time.
4. Keep the medicine in a safe container to avoid misuse or accidental use by other children.
5. Regular follow-up is essential for the adjustment of the dosage and assessment of any side effects.
6. Follow-up visits to the doctor should be once a fortnight in the beginning and later, once a month.
7. Till the attacks are under control, do not work near fire, water, moving wheels, do not climb trees and do not drive vehicles.
8. There are no food restrictions during treatment.
9. The patient can continue all routine work (going to school, work etc.)
10. Drugs take a minimum of two weeks to show results. Do not worry if there is an attack during this period.

### *7.3 Side effects of phenobarbital*

Some patients may develop side-effects when taking phenobarbital to control their major fits. Usually, these side effects are present only at the beginning of the treatment and disappear within 2-3 weeks. After this, the patient can go on taking the medication without any untoward effects. You should encourage the patient to keep taking the medication until his body adapts to it. Make sure the patient is taking the medicine only at bed time.

Phenobarbital is a safe medication when administered appropriately. However, you should be aware of some untoward reactions. The common side effects of phenobarbital are:

- increased sleepiness,
- trouble in walking,
- problems in controlling hand movements,
- hyperactivity and restlessness especially in children;
- digestive problems such as nausea, vomiting, diarrhoea, loss of appetite;

- behaviour and neurological problems such as headache, dizziness, anxiety, nervousness and difficulty in concentrating; and
- impotence, which is particularly bothersome to young men.

If these side effects are severe enough to interfere with the patients day-to-day functioning, refer the patient to the physician.

Rarely, phenobarbital can induce other problems which require urgent medical assistance

Some of these are:

(1) Blood and liver problems, characterized by persistent infections, sores in the mouth, bleeding, jaundice, dark yellow urine, and light-coloured stools. If any of these are reported to you by the patient, there is an urgent need for the patient to be referred to a physician as it may be necessary to stop the medication.

(2) Skin rash: Rash all over the skin can be seen with phenobarbital use. The patient feels itchy and scratches his/her skin. Rarely, a serious reaction which consists of large blisters all over the body occurs. This requires immediate discontinuation of medication. Patients with skin reactions, therefore, should be referred to a physician immediately.

#### *7.4 Compliance with treatment*

Phenobarbital 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. Patients should be made aware of “withdrawal seizures”, i.e. an abrupt discontinuation of phenobarbital may cause an increasing number of seizures. Patients should also be informed about the necessity of good compliance with treatment. The patient’s adherence to any prescribed treatment will increase if the patient is informed in a clear and understandable way to bear in mind the following points:

- a. the patient needs to accept his clinical condition (in this case, seizures) and not view it as a problem;
- b. the patient should be convinced that the proposed treatment has a reasonable probability of improving his clinical condition (i.e., decreasing the magnitude of the problem);
- c. that disappearance of seizures does not mean that treatment is no longer necessary;
- d. some of the side-effects have to be tolerated;
- e. the goal of the treatment is the reduction of seizures to a minimum possible, not necessarily “guaranteed”. For some patients this could represent no more seizures, but for others only a less number of seizures;

- f. the treatment may not have immediate effect; it can take upto one-two weeks before the drug reaches a protective blood level;
- g. the prescribed dose should not be altered by the patient and his/her family, regardless of the degree of seizure control. Only the physician can modify the prescribed dose;
- h. abrupt interruption of drug intake should be avoided at all costs as this may precipitate continuous seizures (status epilepticus). Provisions should be made for timely procurement of the drug.

The following procedures can promote compliance with treatment:

1. The treatment instructions are easy to follow (eg. take the medicine at bed time).
2. Family members assist in reminding the patient to take the medicine, particularly children.
3. Linking drug intake to specific daily activities (eg. just before going to bed).
4. Periodic home visits by the health worker to reinforce regular intake of medicine.
5. Ensuring continuous supply of the medicine.

#### *7.5 Educating the community on myths and facts about major fits*

The communities of South-East Asia continue to perpetuate many myths and misconceptions about epilepsy. These have been passed on from generation to generation and deprive patients of bona fide treatment and prove extremely detrimental not only to the patients but also to the family and community.

**Myth:** Fits are due to incarceration with evil spirits. Therefore, driving away these spirits can cure them.

**Fact:** Fits are a medical disease. It is now easy to treat with modern medication. Other therapies that are not injurious to the patient may also be tried. But, if drug therapy has been started, it should be continued.

**Myth:** These patients are possessed by God. They should be worshipped.

**Fact:** Patients behave in an uncontrollable manner during a 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 immediate and appropriate care. Please do not hesitate to do so. Fits cannot be passed on to others by touching the patient.

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

**Fact:** Having fits is like having any other disease. Every effort should be made to remove this stigma through education. Parents and relatives should be encouraged to seek early treatment.

**Myth:** Fits are a sign of madness, so it should be treated in a lunatic asylum.

**Fact:** While fits are a disease of the brain, it has nothing to do with madness. Not only medically, but also legally, fits are not considered to be a part of lunacy/madness. People with fits can live normally in the community with treatment and should NEVER be isolated.

**Myth:** Children with fits are dull and cannot learn, so they should not be sent to school.

**Fact:** Most children with fits have normal intelligence. Some children with fits do have co-existent mental retardation, but they have some underlying identifiable brain defect. However, it is also true that some children with fits are extremely intelligent. Therefore, parents should be encouraged to enroll their children in schools along with other normal children. This way, they can regain their self – esteem and achieve their full potential

**Myth:** Women with fits can never have children, so they should never be married.

**Fact:** Most women with fits can safely have children, with no adverse effects on the baby. Thus, there is certainly no bar against women with fits getting married or having babies.

**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 aware of first-aid measures required during a seizure.

**Myth:** Marriage will cure fits.

**Fact:** Marriage is not a cure for any disease including fits. Medical treatment should be sought for fits rather than trying non-medical, ineffective social methods based on myths perpetuated by the community.

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.

#### *7.6 Issues of importance to persons with major fits*

A child who has major fits needs to be treated like other children of the same age. An adult who has fits needs to be treated like other adults. A child or an adult who has fits should be able to

live a normal life. A person who has fits needs to be able to do the same things that other people of the same age do. Thus, they should live through the different phases of life in a normal manner. Outlined below are some important points that, if kept in mind, will enable them to do so.

### **Major fits and childhood**

Parents, naturally, are quite anxious about their child with fits. This often leads to over-protection, sometimes to the extent that the child is almost made invalid. It is absolutely essential that the child is made to feel normal like other children. Except for certain precautions, like avoiding swimming, playing alone etc., the child can live a normal childhood. An adult who has fits needs to be able to do household activities, to work, and to join in family and community activities.

A baby who has fits needs to be breast-fed and to play like other babies. A child who has fits needs to play. The child needs to be able to feed himself or herself, to drink and to dress. The child needs to be able to wash and keep clean, and to go to school like other children. These children should be provided stimulus and encouragement for their proper development.

### **Major fits and schooling**

Good and decent education is a fundamental requirement of any child. In fact, it is widely recognized as a basic right of the child. It is indeed sad that children with fits are often deprived of this basic right. Children with fits are not sent to school because of parental fears. In school, teachers may display a biased attitude such as separating these children from routine school activities. The major problems encountered by school-going children with fits are coping with studies, difficulty in making friends, fear of a fit occurring at school, disliking of school, fear of the teachers, drowsiness due to medication, decreased attention and low performance. It should be noted that fits by themselves do not impair the intellectual performance of the child. Usually, the impairment is due to the side-effect of the medication or the social stigma faced by the patient. Therefore, we should encourage parents to send their children to school. Explain and counsel them about the likely problems that the child is likely to face so that they can confront them positively.

### **Major fits and job/career**

Usually, employers do not want to employ a person with fits. It should be clarified that having fits is not a disqualification for most jobs. It is preferable to avoid having such patients work near heavy machinery and to avoid jobs like driving etc. However, giving them routine jobs should be encouraged. Working at home or in farming is perfectly acceptable.

### **Major fits and marriage**

Marriage is neither a cure for fits nor is it true that people with fits should not get married. Marriage is a social contract between two individuals and, in our context, between two families. It is desirable that the proposed marital partner of a person with epilepsy is told about the condition and has complete understanding of the condition prior to marriage. However, since revealing the fact about the boy or the girl having epilepsy usually results in the person (usually the girl) not getting married, families choose to suppress this fact prior to the marriage. Thus, this is a delicate and sensitive issue and should be handled appropriately as per social norms.

### **Major fits and pregnancy**

Women with fits can safely become pregnant. However, they may need an adjustment in their dose of drugs during this period. Therefore, they need to regularly consult their doctors while pregnant. Also, they should be advised to deliver in the hospital and not at home. A small percentage (less than 5%) of children born to mothers with epilepsy on treatment can have minor or major birth defects. However, most such women have normal babies.

Mother with fits should be encouraged to breast feed like other normal women. Though, some of the drugs used for treatment of fits pass through the breast milk to the child, these are in small amounts and usually do not pose any danger to the child. The children could be slightly irritable, drowsy and some times overactive due to the medicine which they get in the breast milk.

### **Major fits and treatment with rituals**

Some people believe that major fits are due to incarceration with evil spirits. Thus, they are taken to faith healers and treated with rituals, some of which can be harmful. It must be emphasized that major fits are due to a disease which affects the brain and so must be treated with medications.

## **8. INSTRUCTIONS FOR ADMINISTERING THE QUESTIONNAIRE**

Please remember that there is a substantial amount of misunderstanding and stigma about major fits. Thus, the parents may not give reliable and detailed information. Do try to make them comfortable and reassure them that everything will be fine. Sometimes, the respondent will give vague responses such as “not sure”, “I think so”. Such vague responses which are not clearly “yes” or “no” should be entered as “do not know”. If the respondent gives too many (50% or more) vague or “do not know” responses, change the respondent if possible. If not then, exclude the patient. Many of the events about which we are inquiring would have happened in one episode, but not in others and almost never in all episodes. It will be taken as “yes” if the event

happened even in one episode. Patients/relatives may think only about the most recent episode. Remind them about all past episodes.

### **Information about episodes:**

It is very important that you follow the instructions for administration of the questionnaire exactly as described in this manual.

#### **Question 1**

Being completely unconscious is defined as:

a) The patient being totally unaware of what happened during the episode. (Sometimes relatives tell the patient what happened during the episode and thus the patient is informed of what happened. THIS DOES NOT QUALIFY AS BEING AWARE OF WHAT HAPPENED).

#### **AND**

b) The patient cannot hear, understand or respond meaningfully to what is being said to him or her during the episode.

#### **Question 2**

This question inquires if the patient has passed urine or stool in his or her clothes during ANY of the episodes. Passing urine or stools is sometimes a very sensitive issue and the observers may be reluctant to reveal this. This information should be acquired very discretely.

#### **Question 3**

The patient may sustain injury in two ways. One, due to the major fits itself, and the other due to the consequence of major fits occurring in a dangerous situation like near a fire. This questions include both these types of injuries.

This question inquires about any sort of injury during an episode, including tongue or cheek bite. Tongue/cheek bite happens due to the cheek or tongue getting caught between the teeth. This may lead to bleeding and pain/discomfort to the patient for several days. Sometimes very serious injury such as breaking of a bone, dislocation of a shoulder, or burns due to falling into a fire can occur. Many times the respondent will say, "we caught hold of him/her so that there is no injury: However, the question clearly asks whether or not an injury actually occurred. Sometimes, the patient just falls down, but, no injury has actually occurred.

#### **Question 4**

This question inquires about foam or froth coming from the mouth during and after the episode. It may be blood stained. Sometimes, saliva can drool from the angle of the mouth, but this does

not equate to actual frothing from the mouth and should not be considered as positive for this question.

**Question 5**

This inquires if the episode has ever occurred while the patient was asleep. The emphasis here is on the word ever, and even one episode during sleep qualifies as positive for this question. Sleep can be day time sleep or during the night. Somebody may have gone to bed without actually being asleep. This is not to be included.

**Question 6**

This question inquires if the episodes have occurred without any preceding mental/emotionally stressful events. The emphasis here is on the words without and on mental/emotionally stressful. If the respondent asks for a clarification of mental/emotionally stressful events, depending on the age of the patient, explanation of mental/emotionally stressful events include examinations, quarrels, deaths, conflict with mother-in-law etc. Sometimes major fits are precipitated by factors such as fever, lack of sleep, loose motions etc. Although, these are precipitating factors for major fits, these are not considered as mental/emotionally stressful factors. If these are specified, the response should be coded as “Yes, have occurred without mental/emotionally stressful events”.

**Appendix - 2**

**TRAINING MANUAL  
FOR  
COMMUNITY-BASED HEALTH CARE PROVIDERS  
ON  
TREATMENT  
OF  
GENERALIZED TONIC-CLONIC SEIZURES (MAJOR FITS)**

## 1. DRUG TREATMENT OF “MAJOR FITS” WITH PHENOBARBITAL

This manual recommends the use of phenobarbital as the drug of choice for the treatment of major fits.

***Please remember...***

Treatment is to be started only if there have been two or more episodes of major fits on different days and the patient does not have indications for referral.

The following regimen is to be followed for the treatment of “major fits”.

### 1.1 Drug dosage

Age	< 5 years	6-10 years	11-15 years	> 15 years
Weight	<15 kg	15-20 kg	21-30 kg	> 31 kg
Starting dose (per day)	15 mg	30 mg	60 mg	60 mg
Average maintenance dose (per day)	30 mg	60 mg	75 mg	90 mg
Maximum dose (per day)	60 mg	75 mg	90 mg	120 mg

**Note:**

- It is advisable to weigh the patient before starting treatment and base the dosage on weight rather than on age.
- Please check the strength of phenobarbital tablet (30 mg or 60 mg) before deciding on the number of tablets to be taken by the patient.
- Compliance should be checked and the need for regular treatment re-iterated during each visit.
- The starting dose should be maintained for at least two months to check its effectiveness. If the person is still having fits, increase the dose by 15 mg and observe for at least two weeks. Continue increasing the dose in this manner till the fits are completely controlled or there are indications for referring the patient to a specialist.
- The dose on which fits are controlled is called the “maintenance dose”. This should be maintained till it is time to stop the treatment.

- When you make dose changes, it is best to make small changes gradually (the 30 mg tablets can be broken in half. For example, if the patient has no fits but is experiencing sleepiness on 90 mg per day (3 tablets), the dose could be reduced to 75 mg (2 ½ tablets). It is important to remember that any dose change may take 1-2 weeks to show its effect.

### *1.2 Instructions during treatment*

It is important to give the following instructions to the patient and family, taking care to see that they are fully understood by the patient and family members.

11. Take the medicine at bed time, regularly, not missing even a single dose.
12. The patient can feel drowsy in the beginning of the treatment. This should not lead to any change in the drug dosage.
13. Missing of the dose can result in an attack. Keep stock of the medicine for at least two weeks at any time.
14. Keep medicine in a safe container to avoid misuse or accidental use by other children.
15. Regular follow-up is essential for the adjustment of the dosage and assessment of any side effects.
16. Follow-up visits to the doctor should be once a fortnight in the beginning and later, once a month.
17. Till the attacks are under control, do not work near fire, water, moving wheels, do not climb trees and do not drive vehicles.
18. There are no food restrictions during treatment.
19. The patient can continue all routine work (going to school, work etc.)
20. Drugs take a minimum of two weeks to show results. Do not worry, if there is an attack during this period.

### *1.3 When to stop treatment with phenobarbital?*

Usually, drugs have to be taken for a minimum period of three years after the last attack of a major fit. Phenobarbital may be stopped if the patient is free of fits for at least three years. To stop the treatment, the dose should be decreased gradually, preferably by 15 mg every month.

Phenobarbital should never be stopped suddenly as it can lead to continuous fits.

#### *1.4 Side Effects of phenobarbital and its management*

Some patients may develop side-effects when taking phenobarbital, usually at the beginning of the treatment. These side effects usually disappear within 2-3 weeks and the patient can continue taking the medication without any untoward effects. This is why you should not stop the medication if initially an individual complains of some uncomfortable reaction. You should encourage the patient to keep taking the medication for a few more weeks until his body adapts to it. Make sure the patient is taking the medicine only at bed time.

Phenobarbital is a safe medication when administered appropriately. However, you should be aware of some untoward reactions in order to be able to handle this situation. Since all individuals do not react in the same way, you should learn to grade these reactions:

##### ***Sleepiness***

Phenobarbital can produce increased sleepiness. That is why it is useful to know before starting treatment how many hours the patient used to sleep and whether he/she used to take a nap in mid afternoon or if he/she usually felt sleepy on awakening in the morning. This way, you can better assess if phenobarbital has changed the patient's sleep habits. Sleepiness due to phenobarbital can be graded as:

*Mild.* The patient wakes up sleepy, but, as the day continues, he does not feel sleepy at work. This situation does not bother him during his activities.

*Moderate.* The patient is forced to take a nap in the afternoon. At times he/she has problems in keeping awake during working hours.

*Severe.* The patient has difficulty in keeping awake during the day. He/she goes to sleep while working. This situation interferes with his/her working schedule.

##### ***Trouble in walking***

Phenobarbital can induce trouble in walking. To evaluate the intensity of his/her present situation, ask the patient to walk in front of you and to turn around as fast as possible. Then ask the patient to walk along a line, touching heel-to-toe. Trouble in walking due to phenobarbital can be graded as:

*Mild.* The patient is able to walk heel-to-toe but has some difficulty in turning around.

*Moderate.* The patient is very unstable, can fall when doing the heel-to-toe test. The patient walks slowly and with a wide-based gait.

*Severe.* The patient is unable to walk following a line; he/she even needs help to walk straight. If he/she walks alone he/she could fall.

### ***Problems in controlling hand movements***

To assess this problem, ask the patient to extend his/her arms and to touch his/her nose with the index finger. Also watch the patient carefully while he/she is drinking a glass of water.

Problems in controlling hand movements can be graded as:

*Mild.* The patient can touch his/her nose with the index finger. There is some trembling while drinking water.

*Moderate.* The patient has difficulty in touching his/her nose with the index finger. A clear-cut tremor is seen while drinking water. He/she needs to hold the glass with both hands.

*Severe.* The patient fails most of the attempts to touch the nose with the index finger. A severe tremor is evident on drinking water. The contents of the glass are spilled.

### ***Hyperactivity***

Phenobarbital can produce restlessness, specially in children. They appear to be constantly moving. You should ask the parents how the child's behaviour is in different situations, at home, in the school, while playing or eating: Hyperactivity due to phenobarbital can be graded as:

*Mild.* The child is definitively more active than children his/her age. He/she stays quiet only for a few moments. He/she does obey when asked to stay quiet.

*Moderate.* The child is seen running, climbing up furniture and grabbing everything within his/her reach. The child has problems in finishing school tasks and obeys with difficulty.

*Severe.* The child is unable to concentrate in a given activity. He/she acts without thinking of the consequences of his/her actions. The child does not obey any commands at all.

### ***Other side effects***

Rarely, phenobarbital can induce other problems. Some of these are:

(1) Blood and liver problems, characterized by persistent infections, sores in the mouth, bleeding, jaundice, dark yellow urine, and light-colored stools. If any of these are reported to you by the patient, there is urgent need for the patient to be seen by the local technical supervisor (neurologist), as it may be necessary to stop the medication

(2) Skin rash: Rash all over the skin can be seen with phenobarbital use. The patient feels itchy and scratches his/her skin. Rarely, a serious reaction which consists of large blisters all over the body occurs. This requires immediate discontinuation of medication. Patients with skin reactions, therefore, should consult a physician or local technical supervisor (neurologist) immediately.

(3) Digestive problems: Nausea, vomiting, diarrhoea, loss of appetite.

(4) Behaviour and neurological problems: Headache, dizziness, anxiety, nervousness and difficulty in concentrating.

(5) Impotence is another side effect. This can be particularly bothersome to young men and you should be aware about it.

Based on the patients' feeling and interference with his/her work, these can be divided into *mild*, *moderate* or *severe* by asking the question "Do the side effects of phenobarbital bother you a little (mild), a lot (severe) or in between the two (moderate)."

### **Grading of side effects**

Based on the side effects of phenobarbital listed above, one can form an objective evaluation of the patient's side effects due to phenobarbital:

*No problems.* There are no side effects.

*Mild.* When all side effects are mild.

*Moderate.* Some side effects are mild, at least two are moderate, but none is severe.

*Severe.* Some side effects are mild, some moderate and at least one is severe.

### **Management of side effects**

If any of the side effects due to phenobarbital are severe even after three weeks of continuous treatment, reduce the dose of phenobarbital to one level previous to the current dose. However, if this results in inadequate control of major fits, the patient qualifies for the category of severe side effects and should be referred to the local technical supervisor (neurologist) for further management.

### **1.5 Compliance with treatment**

One of the common causes of failure to control major fits with phenobarbital is that the patient is not taking medication as prescribed on a daily basis. In medical terms, this is called non-compliance with medical treatment. Thus, you must enquire about adherence to treatment at each visit. Very frequently this non-compliance is because the patient and the family have not understood the importance of taking medication daily and also the consequences of non-adherence to treatment. You, as the community-based health care provider, must spend time with the patient and the family to explain to them the need to take the medication exactly as prescribed.

The patient and family must understand that 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. Patients should be made aware of "withdrawal seizures", i.e. an abrupt discontinuation of phenobarbital may cause an increasing number of seizures. The patient's adherence to any prescribed treatment will increase if the patient is informed in a clear and understandable way to bear in mind the points:

- a. the patient needs to accept his clinical condition (in this case, seizures) and not view it as a problem;
- b. the patient should be convinced that the proposed treatment has a reasonable probability of improving his clinical condition (i.e., decreasing the magnitude of the problem);
- c. that disappearance of seizures does not mean that treatment is no longer necessary;
- d. some of the side-effects have to be tolerated;
- e. the goal of the treatment is the reduction of seizures to a minimum possible not necessarily “guaranteed”. For some patients this could represent no more seizures, but for others only a less number of seizures;
- f. the treatment may not have immediate effect; it can take upto one-two weeks before the drug reaches a protective blood level;
- g. the prescribed dose should not be altered by the patient and his/her family, regardless of the degree of seizure control. Only the physician can modify the prescribed dose;
- h. abrupt interruption of drug intake should be avoided at all costs as this may precipitate continuous seizures (status epilepticus). Provisions should be made for timely procurement of the drug.

The following procedures can promote compliance with treatment:

1. The treatment instructions are easy to follow (eg. take the medicine at bed time);
2. Family members assist in reminding the patient to take the medicine, particularly children;
3. Linking drug intake to specific daily activities (eg. just before going to bed);
4. Periodic home visits by the health worker to reinforce regular intake of medicine;
5. Ensuring continuous supply of the medicine

Compliance can be graded as:

*Good compliance* : Takes medication as prescribed every day

*Not fully compliant*: Misses medication on 1, 2 or 3 days per week

*Severe non-compliance*: Misses medications on 4 or more days per week

### *1.6 Health care providers' assessment regarding patient's condition*

The success of any public health programme should be judged on the health care providers' assessment of the patient's condition as well as satisfaction with the treatment by the patient and his family. Your assessment regarding the patient's condition can be graded as:

*Excellent*. Seizures fully controlled on maintenance dose and no side effects of medication.

*Good*. Seizures fully controlled or no more than one seizure every three months on maintenance dose but mild side effects of medication.

*No Change.* Seizures as before or seizures less than before but with moderate side effects of medication.

*Worse.* Seizures worse than before or severe side effects of medication.

### 1.7 Patient/Family assessment regarding patient's condition

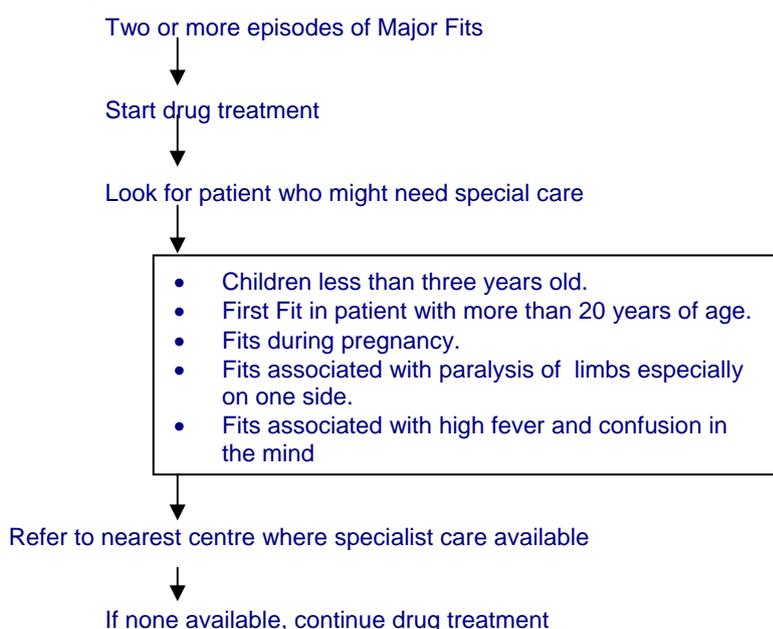
It is very hard to be completely objective in grading the patient's/family's opinion on the patients' condition. One simple way of assessing this is to ask the patient/family to give their opinion on the patient's condition by asking, "How do you assess the patient's condition on the current treatment for major fits: excellent, good, no change or worse." This is a subjective opinion. However, if they want descriptions of each category, use the definitions as for your assessment.

### 1.8 What to do if treatment fails?

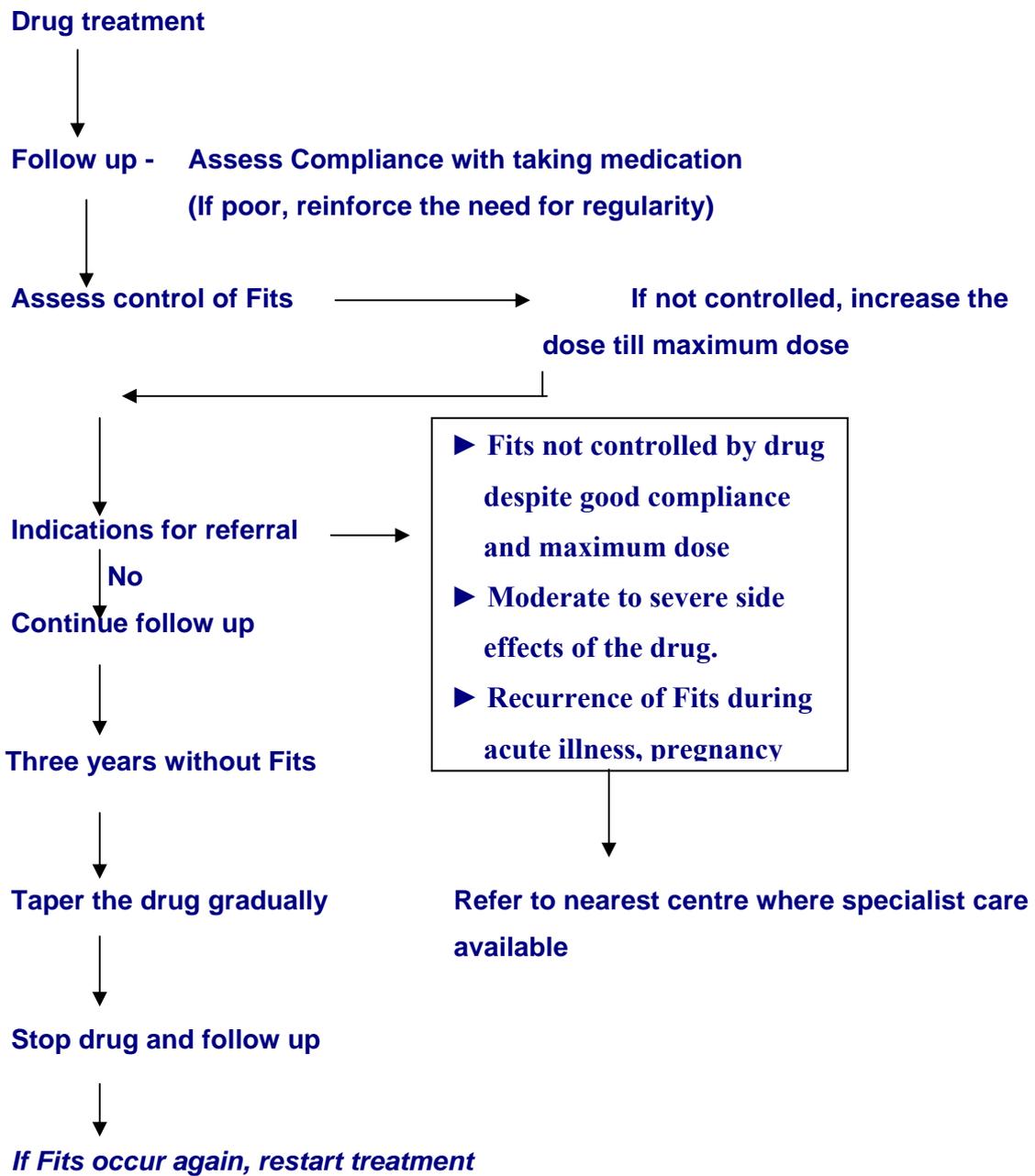
#### Refer the patient to a specialist if:-

1. Fits are not controlled by phenobarbital - If attacks are not controlled in spite of the above treatment for six months (last two months with the maximum dose).
2. Side effects of phenobarbital – If the side effects are severe as discussed above, and reduction of dose results in inadequate control of fits.
3. Recurrence of fits while on treatment during any acute illness, pregnancy, stress or while stopping treatment or soon after stopping treatment.

#### Management Steps



## FOLLOW UP OF PATIENTS WITH FITS



## EXERCISE

(Please use the flow chart given above to answer this exercise.)

Given below is a case history of Arun a nine year old child.

One day when he was about to go off to sleep, he suddenly made a loud cry and started having jerky movements of the right hand and right side of the face. This then went on to involve the whole body. The mother also noticed that the bed was wet. The next day morning, Arun had no memory of the episode. He however noted an injury on the elbow sustained during the fall. He had passed urine during this episode.

**Question 1.** Do you think Arun suffers from Major Fits. Give reason.

When the next week again , he suffered a similar episode, the parents decided to seek treatment. They consulted Doctor X for this. The doctor started Arun on phenobarbital 30 mg. at night. He asked them to take the drug regularly. On the eighth day of treatment, Arun had another seizure. Parents were worried and brought the child back to the doctor.

**Question 2.** What should the doctor advice to the parents?

The parents followed the advice and continued the treatment. The child suffered another seizure on the third month of treatment.

**Question 3.** What should Doctor X do ?

The boy came regularly for follow up for the next two years. He did not have any seizures. Subsequently, he shifted to a middle school in the next village. The follow up became irregular. He was brought to you again after five months as he had suffered a seizure. He had a burn mark in the abdomen. The parents said that they had taken him to a faith healer for treatment. The faith healer had also given some powder to be given on a regular basis to the child.

**Question 4.** What questions should Doctor X ask to assess the possible reasons for recurrence of seizures?

**Question 5.** What advice should he give to the parents?

The boy continued treatment for the next three years without any seizures. His parents were planning to shift to a nearby town. They wanted to know the treatment needs to be continued any more.

**Question 6.** What should Doctor X advice.

### 13. Further information

Further information on the Global Campaign Against Epilepsy can be obtained from:

#### **The International Bureau for Epilepsy**

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#### **The World Health Organization**

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Anyone interested in following the progress of the Campaign will be able to do so from the regular updates on the relevant web sites:

[www.who.int/mental\\_health/resources/publications/en/#epilepsy](http://www.who.int/mental_health/resources/publications/en/#epilepsy)

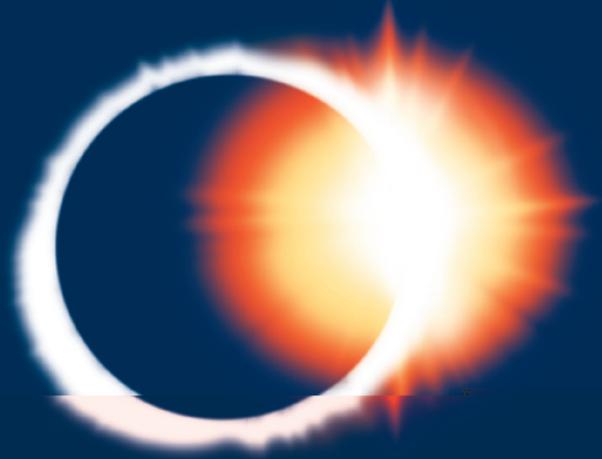
[www.globalcampaign-epilepsy.org](http://www.globalcampaign-epilepsy.org) (*joint IBE/ILAE Campaign site*)

[www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)

[www.ilae-epilepsy.org](http://www.ilae-epilepsy.org)

# EPILEPSY

out of the shadows



A Global Campaign  
Against Epilepsy