# EPILEPSY

## MEDICAL & SOCIAL ASPECTS

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## FOREWORD

This revised edition of a booklet on "Medical and Social Aspects of Epilepsy" is meant primarily for the general public, especially patients and their relatives. The best way to handle a disease is to try and know as much about it as possible. Enough information has been given so that either the patient or the relative should be able to know the type of epilepsy which the patient has, the drug treatment required along with it's duration and potential for side effects. The reader will also get to know about the probability of full control, the risks of a relapse when drug treatment is withdrawn and the role of surgery in epilepsy. Emergency treatment at home for continuing seizures is also emphasized. The understanding of information given may not be easy but going through it more than once is worth the effort.

The Indian Epilepsy Association consists mainly of non-medical people, patients, parents and those interested in our objectives viz. **to dispel the myths about epilepsy and make life worth living for these pateints.** Chapters of this association are in existence in most state capitals in our country. Do join them and strengthen our hands.

Our thanks are due to Dr. K.S.Mani, retired Professor and Head of Departmnet of Neurology, National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore for writing of this booklet. We are indebted to Vijayam Bharani Trust for their continuing support in publishing this booklet.

We earnestly hope you will find it useful.

Bangalore - 560 004.
1st October, 1991

N.Nagendra,Hon. Secretary
Indian Epilepsy Association
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## MEDICAL ASPECTS

### 1. GENERAL

1.1 Epilepsy is an extremely common illness occurring in about 1 in 200 of the general population in Western countries and as per studies in the sixties perhaps 1 in 100 in our country. This higher figure in India may be because of a combination of poverty, poor nutrition, large families and infections, particularly during childhood. However, recent epidemiological studies in the eighties in India have challenged the previously held view of a greater prevalance of epilepsy in our country. Figures ranging from 4 to 6 per thousand (approximately 1 in 200) of the general population have been obtained. An epidemiological study on the prevalence of epilepsy carried out in Yelandur Taluk, Mysore District by us, with help from the Indian Epilepsy Association (Bangalore Chapter) and Karuna Trust, Yelandur through a door-to-door survey of a population of 61,801 has given a figure of 4.3 per thousand in addition to one of 1.93 per thousand for Hot Water epilepsy. This drop in the figures could well be due to improved maternal and child welfare, childhood nutrition and universal immunization measures in the country.

1.2 Epilepsy is not caused by devils or evil spirits. **It is due to a mild disturbance in the working of the brain and no more.** Provided it is treated early/and properly it hardly interferes with the activities of the individual. Famous people in history like Alexander, Julius Caeser and Napoleon were all epileptics, yet they were brilliant. There are very prominent, active and intelligent people in present day society who have epilepsy, eg. Tony Greig, the Test Cricketer and Richard Burton, the actor. It is very unfair to think that these patients are cursed by evil influences or punished for sins in their previous births.

### 2. MEDICAL

2.1 Ordinarily epilepsy is considered as a condition wherein there are violent convulsions in the body. **This is not always so.** All movements are not epileptic and in certain types of epielpsy there may be no movement at all.

2.2 If a patient develops an attack, **observe the details.** Do not get panicky. What are the types of movements ? Where do they start ? How do they spread ? What happens to the eyes ? Are they rolled up or are the eyelids closed ? Is there froth ? Did the patient pass urine or stools during an attack ? Pinch the nose tight for full 30 - 40 seconds and observe the reaction. How long do the convulsions or unconsciousness last ? How is he ( or she) on recovering consciousness ?

There are extremely important data which help the doctor to diagnose not only whether it is epilepsy at all but also, if it is so, its type. The single most important aid in the diagnosis of epilepsy and its type is an accurate description. **Nearly 15% of cases diagnosed as epilepsy do not suffer from it and this state of affairs is because of poor history.** Imitate the attack if you can, but do it accurately.

2.3 It is completely wrong to say that epilepsy is a mental illness. It is almost always due to a structural disease in the brain. The commonest such structursal abnormality is a scar formed at or after birth or during childhood with resultant epileptic attacks years later. Other causes include tumours, head injury, infections, diseases of blood vesseis etc. In 85% of patients the intellect remains normal. However, when the underlying structural disease is very extensive, generally starting at or after birth during childhood, there may be associated mental retardation (MR). This is seen in 15% of all epilepsies. Thus both epilepsy and mental backwardness are due to some other common cause and it is seldom epilepsy by itself which leads to mental dulling. **Excessive doses of drugs and too many restrictions can cause mental and emotional dulling and these should be avoided.** Likewise unrecognized small attacks, especially absence or complex partial seizures, can be mistaken for mental dullness.

**Epilepsy is thus a symptom like headache, stomachache or fever.**

2.4 To repeat epilepsy is just a symptom, like fever and associated with an electrical disturbance in the brain. There are different types of fever and from different causes - e.g., malaria, pneumonia, typhoid,

tuberculosis, etc; so also in epilepsy. Epilepsy consists of recurrent episodic phenomena known as seizures. These are of different types and for any one patient they are stereotyped - i.e. they have a constancy of pattern, which repeats itself in the seizures and this is of great practical significance with respect to the choice of drug treatment.

How to recognize the seizure types or patterns ? This is where we need help, help from the family, friend, teacher, colleague, etc. One cannot diagnose epilepsy much less its type, by examining the patient even for hours at a stretch. It is seldom that a doctor has an opportunity to witness an attack and in between attacks most patients are absolutely normal. **Hence, the need for an accurate history,** description of an attack and if possible, an actual imitation or demonstration of an attack as accurately as possible.

Broadly speaking epilepsy can be divided into 2 groups - focal or partial and generalized. In partial seizures, the electrical disturbance arises from the outer aspect of the brain known as the cerebral cortex. This disturbance is strictly localized, limited to a small area of the brain, on the outer surface. Partial seizures are subdivided into simple and complex partial seizures, depending on whether consciousness or alertness is retained (simple partial seizures - SPS) or disturbed (complex partial seizures - CPS).

2.5 In SPS, the patient is fully alert. He knows what is happening or what he is experiencing. An onlooker may not be able to make out an SPS unless the patient were to tell him. There is one exception to this rule - the so called partial or focal motor seizures. Here both the patient and the onlooker know about it and the patient is fully alert. The angle of the mouth can get pulled to one side with rhythmic twitchings of that corner of the mouth, eye lids, thumb, or other fingers or toes - all on the same side. The head and eyes may also jerk to the same side. The patient is fully alert.

Other types of SPS are only experiential phenomena, obvious to the patient only and not to the onlooker. He may feel repetitive numbness or tingling on one side of the face, fingers or toes. He may find that objects tend to appear bigger or smaller or come forwards or recede backwards. External sounds may appear loud or faint. Or

he may have a funny smell - smell of rotten vegetables or fish when no such thing is nearby. Or it may be a pleasant smell. There may be peculiar sensations of taste - bitter or sweet with nothing in the mouth to provoke it. A common manifestation is a funny, churning feeling in the pit of the stomach and an ascending sensation like a ball of gas coming up from the stomach. During these the patient is fully alert and is puzzled, if not disturbed, by these strange experiences. By and large SPS phenomena last for few seconds or 2 or 3 minutes only. Any consistent symptom which warns a patient that he is going to get a big attack **within the next few minutes,** can be taken as an SPS. SPS alone occurs in about 3% and SPS $\pm$ generalized tonic clonic seizures (GTCS) in 17% of all epilepsies.

2.6 When the limited electrical disturbance has a **limited** speed to the same or opposite side of the brain, consciousness or alertness is impared, but not totally lost. This resuls in the phenomenon or seizure type known as complex partial seizures (CPS). Here the subject is not fully alert. He may not be fully aware of the content of an attack, but an onlooker is. There is an initial vacant, unblinking stare, then the eyes move hither and thither in a puzzling manner. This is often associated with what is known as automatism or automatic behaviour. The patient may champ or chew his lips or mouth, make swallowing movements or make purposeless coordinated movements of the hands and / or legs - e.g., repetitive tapping, rubbing, moving the legs on the ground to and fro and so on. In fact one of my patients removed her saree during an attack in a church and she was totally unaware of it. Generally, there is no loss of posture or fall; no injury or tongue bite. The limbs move but are not stiff nor do they shake rhythmically. If you talk to the patient during this attack, either he won't respond at all or at best, it is a delayed and only a partial or fragmentary response. These episodes last from a few seconds to 2 or 3 minutes and in the latter followed by sleep, tiredness, headache, etc., but seldom severe. The patient has no or only a fragmentary recollection of what happened during an episode.

CPS can arise on its own or may follow a SPS. Both SPS and CPS can be followed by a secondary generalized tonic clonic seizures (GTCS) - the so called major epilepsy but of the secondary type. In these cases the electrical discharge spreads rapidly to all over the

brain with resultant total unconsciousness, fall, stiffness, convulsions, froth, tongue bite, passage of urine and/or motion, followed by **severe** headache, bodyache, tiredness, etc. Thus focal or partial seizures can either remain purely focal, partial or restricted OR, as is more common, result in secondary generalization. CPS alone is seen in 11% and CPS $\pm$ GTCS in 26% of all epilepsies. Thus 37% of all epilepsies are CPS with or without GTCS. This is the commonest of all seizure types and difficult to control fully. Secondary GTCS (SPS $\pm$ GTCS and CPS $\pm$ GTCS) is more common 43% than primary GTCS - 28%. It is important to recognize the partial seizure component in these patients, failing which if the GTCS has ceased the drugs may be stopped without realizing that partial seizures continue leading to a high risk of relapse. SPS and CPS with or without secondary GTCS respond best to phenytoin (PHT) or carbamazepine (CBZ) and perhaps less to phenobarbitone (PB). These should be given preferably as monotherapy (single drug) and not in combination.

In primary generalized seizures, the electrical disturbance starts from the depths of the brain and spreads very quickly to cover the entire brain. Hence there is no warning. There are 3 subtypes - primary generalised tonic-clonic seizures (or major epilepsy), absence seizures and myoclonic seizures. There are also difficult and rarer types - so called astatic or atonic seizures and atypical absence seizures..

2.7 Primary generalized tonic clonic seizure (GTCS) is the same in its expression as secondary GTCS, except that there is no preceding SPS or CPS. There is no warning. The first symptom is loss of consciousness and loss of posture which is gradual taking seconds and never sudden. There is first a shrill cry - common, but not constant. The limbs become stiff - so called tonic phase and they rise slowly. Repetitive rhythmic, twitches or convulsions - clonic phase - follow with the eyes rolled up and froth coming out. They have a sequence or a pattern. The limbs on the two sides have a synchronous rhythmic and in-phase jerky move ments - ie, the movement on one side is the mirror image of the other. These last about 1 - 2 or at best 3 minutes and seldom beyond. Time is a relative phenomenon. To the worried relatives it may appear very prolonged. Every minute

consists of 60 seconds. Towards the end of the seizure, the rhythmic jerks - clonic phase - subside slowly and the patient breathes heavily and noisily gurgling as it were, because of the saliva in the mouth. After the seizure the patient goes to sleep for few minutes or hours and wakes up with a whacking headache, bodyache, tiredness, etc. Primary generalized tonic clonic seizure (GTCS) is less common than secondarily GTCS (28% as against 43%) - a point of importance when we try to reduce or withdraw antiepileptic drugs. This highlights the necessity for specific enquiry for partial seizures - SPS from the patient and CPS from the relatives. Primary GTCS responds best to PHT, PB, CBZ or Sodium Valproate (SV).

2.8 Another type of primary generalized epilepsy is what is known as absence seizures. (old term petit mal). This generally starts in school-going children. There is no warning. The duration is brief, measured in seconds - 5, 10, occasionally 15 and exceptionally beyond. The central theme of the attack is unconsciousness, seldom associated with a fall. The child then does not see, hear, or feel, nor can he talk. The eyes look dull and vacant. All ongoing activities come to a stop or freeze as it were. Immediately after an attack the child is back to normal, resuming whatever he was doing. He was unconscious - absent from the world, temporarily, during those five seconds. There are often accompaniments to this unconsciousness - complex absence seizures – eg., eyelid flutter, stiffness or drooping of neck on chest, stiffness of limbs or mild twitchings of fingers, lip smacking, swallowing or even automatism. In that respect absence may mimic CPS, but unlike in the latter the patient becomes normal and resumes whatever he was doing before **immediately** after an attack. Abrupt onset and an equally abrupt termination is the rule. Moreover absence attacks tend to occur daily and several times a day - even 30 - 50 per day, a very rare occurence in CPS. **Absence attacks are often missed and the children are labeled as absent minded or backward at school.** Because of repeated periods of unconsciousness, the attention span of the child is interfered with and naturally he cannot take in what the teacher says. Absence seizures must really be demonstrated to and discussed repeatedly with school teachers and parents for more cases to come to light. It is very common for brief CPS to be misdiagnosed as absence seizures. The latter respond very well to SV.

2.9 A third type of primary generalized epilepsy is known as myoclonic seizures. Myo means muscle and clonus is movement. This can involve a limb or part of a limb or, as is far more common, both upper limbs or lower limbs or even the neck or trunk. It is a single brief momentary jerk which may be mild or explosive, something like a startle reaction. It is all over in a flash. Sometimes in infants they are **spasms** lasting 2 or 3 seconds rather then jerks. **Bodily jerks are very common during sleep or as one goes to sleep and are then a normal phenomenon.** They do not connote epilepsy and should not be treated as such. Hence, myoclonic jerks occuring while awake are the things to worry about. Objects may be dropped - a coffee cup, tooth brush, or a new born child in the case of a young mother. Consciousness is probably retained. If this involves the trunk or lower limbs, the child will fall down and there may be scars from injury on his forehead or knee-caps. These occur repetitively and may go up to even 50 - 100 per day. Myoclonic epilepsy is more frequent in children and generally associated with tell-tale signs of brain damage like mental retardation and / or extreme restlessness. They are difficult to abolish totally. The best drug(s) for myoclonic epilepsy is SV with or without clonzepam.

2.10 To sum up **there are several seizure types; learn to recognise them, describe (or imitate) them accurately. Maintain a diary of the daily attacks - the time, type and duration. Share this vital information with your doctor. Please help him to help you.**

## 3. Epileptic Syndromes

A collection of symptoms constitute a syndrome and these have been described recently in epilepsy as well. It is important to recognize them since the age group involved, seizure type, associated brain damage, type of drug required, response to treatment and long-term outlook vary from one to the other.

### 3.1 West Syndrome

The age at onset is 3 months to 1 year. The seizure type is a myoclonic **spasm** rather than a jerk, occuring soon after waking up and several times - even hundreds - a day. The neck bends forwards, eyes roll up, the arms bend upwards and inwards at the

shoulder and the legs bend at the hips. Associated developmental delay is very common but often missed in the early stages. Treatment with ACTH or steroids **early in the course of the illness** is the only hope, failing which the child remains mentally retarded throughout its life. This accounts for 1% of all epilepsies.

### 3.2. Lennox- Gastaut Syndrome

The age at onset is 1 year to 7 or 8 years. Associated mental retardation and overactivity is almost always present and indicate brain damage. The seizure type(s) consist of (i) myoclonic jerks, (ii) atypical absence - stiffness of limbs, with eyelids elevated and non-responsiveness for 15 or 20 seconds, (iii) astatic seizures - sudden loss of tone with the result the head may sag at the neck, sudden slumping of trunk or fall lasting hardly a second; and (iv) GTCS, especially at night. Because of myoclonic jerks or astatic seizures the children fall down frequently with injury and resultant scars on forehead and / or knee-caps. LG Syndrome is an extremely difficult condition to treat, full control of all seizure types occuring hardly in 10% of subjects. The best drug is sodium valproate (SV) with or without clonazepam or carbamazepine. Mothers of these patients deserve to be worshipped for their patience and forbearance. LG syndrome has been seen by us in 2.4% of all epilepsies.

### 3.3. Benign Rolandic Epilepsy

Occuring in 1.9% of all epilepsies, the age at onset is 3 - 5 years. The seizure type consists of SPS - focal motor or focal sensory involving sometimes both sides of the face or tongue. These occur especially during sleep waking up the child, who may just point to his mouth or tongue indicating his inability to talk. Rare GTCS occur, again mostly during sleep. There is no associated mental retardation or neurological handicap. The outlook is excellent, the seizures showing a spontaneous tendency to clear up by the time the child reaches puberty - ie. around 12 - 14 years. PHT or CBZ as monotherapy is useful.

### 3.4. Childhood Absence Epilepsy

Accounting for 2.5% of all epilepsies, the age at onset is 4 - 10 years. The seizure type consists of typical complex absence attacks occur-

ing generally soon after waking up and may be several times daily. Associated GTCS may occur, but is rare. There is no brain damage. Response to sodium valproate as a single drug is excellent, full control being met with in 90 - 95% of patients.

### 3.5. Juvenile Absence Epilepsy

This is the same as childhood absence epilepsy, except that the age at onset is around 12 - 16 years and it accounts for 1% of all epilepsies. The absence seizures are much less frequent - once or twice a week and associated GTCS more common. There is no brain damage and response to SV monotherapy excellent.

### 3.6. Juvenile Myoclonic Epilepsy (JME)

This accounted for 5.2% of all epilepsies in our experience. It is also known as Impulsive petit mal or Benign Myoclonic Epilepsy of childhood and adolescence. This was described nearly 40 years ago in German literature by Prof. Janz. But the English speaking fraternity have learnt to recognize it only recently. This is eminently treatable. The patient's intelligence is normal and there is no brain damage or neurological handicap. The jerks are more common soon after waking up. Tooth brush or coffee cup may fall down. The jerks occur usually in clusters of 4 or 5, even once or twice a week. One day the jerks increase to 15 or 20 over a period of half - 2 hours and these lead to a GTCS. Unless specificallyy asked for, the story of the jerks do not come out. Many think it is a normal phenomenon. "Oh, I thought everybody got it !" We make it a practice to ask for a history of jerks in all patients with epilepsy. Both the jerks and the tonic clonic seizures can be completely abolished in 75 - 80% of these patients with sodium valproate. Treatment should be continued beyond the usual 5 years because relapses are common - occuring in nearly 70% of patients. Attacks tend to be precipitated by lack of and/or disturbed sleep as during an overnight bus journey which, therefore is better avoided.

## 4. INVESTIGATIONS IN EPILEPSY

4.1. Certain minimum number of tests are required in every patient with epilepsy. A detailed examination is necessary not for a diagnosis of epilepsy, but to try and find out whether there is gross brain disease,

for eg. tumour. Depending on several factors, certain blood tests and the recently introduced CT or MRI scan of the brain (which show the underlying brain - not bones only as in x-rays - taken in the form of sections at different levels) may be necessary to determine the cause.

4.2 Epilepsy has to be diagnosed primarily from an accurate description of the attack. **Recording the electrical activity of the brain known as EEG** (just like ECG for the heart) **is the only objective way available for a diagnosis of epilepsy and its type.** Unfortunately **in the tropics,** if a single EEG is taken, it is likely to give positive confirmation for epilepsy in only 30% of all cases, though in certain types like absence and myoclonic epilepsy this may go up to even 80%, if not more.

More the number of EEGs, greater the chances of getting a confirmation, which in some instances may help in determining the type of epilepsy and the type of drug required.

4.3 It should be emphasized time and again that a **normal EEG does not mean the patient is not having epilepsy.** Like all tests, EEG is part of a total picture and must be interpreted along with all other available data.

## 5. DRUG TREATMENT

5.1 Not infrequently individuals with epileptic attacks are prescribed antiepileptic drugs for a few days only. **This is of absolutely no use and in fact can be dangerous.** Epilepsy cannot be controlled by giving drugs for short periods unlike in common cold, cough or fever. Drug treatment has to be a prolonged affair not for days or weeks but months, or years.

The attacks are due to an increased excitability of groups of nerve cells. Most of the drugs used in this disease do not act on the abnormal nerve cell itself. They only prevent the abnormality from spreading, hence the need for prolonged drug treatment. During this period when the abnormality is prevented from spreading, the abnormal cells tend to become quiet and it is this which takes a very long time. Unfortunately, the type of drugs and the dosage vary considerably from patient to patient and thus **it may take several**

**weeks or months before complete control is achieved in a patient.**

5.2 Many people are afraid that these drugs make the patient dull or lose his memory. Time and again it has been shown that provided a proper dosage is given, such is not the case. The effects of uncontrolled seizures are far more serious than the so called side effects of drugs. In the control of attacks, drugs alone are not the only answer. The attitude of the patient, the family and society with special reference to ridicule, taboos and unnecessary restrictions are far more important. God can only help those who are willing to help themselves.

## 6.0 ANTIEPILEPIC DRUGS (AEDs)

6.1 There are several drugs available, but none of them are of benefit in all types of epilepsy. The choice of the drug depends on the seizure type and /'or syndrome which in turn means an accurate diagnosis.

6.2 In olden days the practice was to give the antiepileptic drugs in gradually increasing dosage till the desired response (control of attacks) was obtained OR undesirable side effects made their appearance. However, in the last 20 years considerable knowledge has accumulated on the rate of absorption of the drugs from the stomach and intestines, their distribution in various parts of the body including the brain and the rate of their elimination. Accurate methods are available in Western countries and in few places in India, for determining the blood levels of antiepileptic drugs.

It is based on this knowledge and studies on several patients that the so called effective or therapeutic levels in the blood of anticonvulsant drugs have been determined. Likewise knowledge has also accumulated on the duration of action of a single dose of these drugs which varies from one to the other.

6.3 Though absorption of a drug from the stomach and/or intestine may be rapid it takes time for effective levels to be built up in the blood from which the drug has to build up its own steady level in the brain which is the ultimate site of action. When drug treatment is by mouth, effective blood levels could be achieved in very many cases over a period not less than 3 - 4 days and effective levels in the brain

are reached over a period of 2 - 4 weeks. **Hence addition of an extra dose by mouth after one seizure is going to be of no use. Likewise when drug treatment is started one must give sufficient time for steady levels to build up in the brain which may take even 2 or 4 weeks. Failure to understand this leads to frequent change of drugs or doctors or both, by which time more attacks may occur.**

6.4 Table 1 gives a list of currently available antiepileptic drugs with some of the brand names in the market. The list of brand names is by no means complete. However, it is always better, as far as possible to stick to one brand. Change over to another brand from an equally reputable firm can be resorted to only if the previous one is not available in the market. It is always a sound practice in medicine to opt for quality rather than go by cost factor alone.

TABLE 1

| Sl.No. | Drugs | Some brand names in alphabetical order |
|---|---|---|
| 1. | Phenobarbitone | Emgard; Gardenal ; Luminal; Phenobarbitone |
| 2. | Phenytoin | Dilantin;Epsolin;Eptoin;M-toin |
| 3. | Primidone | Mysoline |
| 4. | Carbamazepine | Carbatol; Carmaz; Mazetol; Tegretol |
| 5. | Ethosuximide | Zarontin |
| 6. | Nitrazepam | Hypnotex; Nitravert; Sedamon |
| 7. | Clonazepam | Clonopin; Rivotril |
| 8. | Sodium Valproate | Epilex;Epival;Valparin |

6.5 Most anticonvulsant drugs, eg: phenobarbitone, phenytoin, primidone and carbamazepine make the liver cells work very fast. On the other hand ethosuximide, nitrazepam, clonazepam, and lastly sodium valproate do not have this action. The liver by working very fast causes a rapid elimination of other drugs including other antiepileptic drugs with the result that effective blood levels in respect

of dosage given by mouth fall short of what they ought to be. Oral contraceptives, for example, get eliminated fast and become ineffective and a lady on such of those antiepileptic drugs which make the liver cells work very fast has a high risk of pregnancy in spite of taking oral contraceptive drugs. This type of drug interaction resulting in reduced effectiveness is giving rise to treatment of epilepsy as far as possible with one drug at a time, rather than two or three as used to be done in the past - in other words **monotherapy rather than polytherapy**. Ultimately what we want is effective concentration in the brain and this is unlikely to be achieved if more than one drug is given. With two or more drugs which make the liver cells work fast, it is as good as the drugs fighting amongst themselves in the blood and not reaching the brain in adequate amounts. However, as pointed out by Porter, monotherapy is like motherhood; it is not for everyone. In 10 - 15% of patients with epilepsy, if adequate trial with monotherapy has failed, one may have to resort to polytherapy, but seldom with more than 2 or at best 3 drugs. Response to this polytherapy is often poor, but a lucky few may get away with it and hence it is worth a trial.

6.6 **Phenobarbitone (PB)** available as 30, 60 and 100 mg. tablets, has been one of the earliest antiepileptic drugs. It is of benefit in primary and secondary GTCS and possibly certain types of partial seizures. **Once taken, the blood levels are maintained well beyond 24 hours even when the drug is taken once a day.** There is no point in giving this drug 2 or 3 times daily. This is totally unnecessary, cumbersome and often leads to missing a dose. Though generally free from side effects it can certainly cause learning difficulties, particularly in children, who, if already brain damaged, can become more restless. Moreover in high doses patients feel dull and drowsy and hence it is generally not advisable to give more than 45 - 60 mg for a child and 90 - 120 mg for an adult. The usual dose is 30 mg for a child and 60 mg for an adult. The cost of PB per day works out about 10 - 20 paise.

6.7 **Phenytoin (PHT)** This is available as 50 mg and 100 mg. tablets, capsules or syrup. It is generally given in primary and secondary GTCS and partial seizures. As in the case of phenobarbitone the blood levels are maintained beyond 24 hours and **it is enough if the**

**whole dose is taken once or at best twice in 24 hours.** This drug is excreted through saliva and can cause swelling of the gum margins. Unusually this can also cause excessive growth of hair on the face and limbs - not acceptable in women. As mentioned earlier, phenytoin like phenobarbitons is a drug which makes the liver work faster than normal and thus causes a rapid elimination of any other drug given concurrently. One peculiari ty about phenytoin is the fact that as the daily dose is slowly increased, at a particular stage which varies from one individual to another, the blood levels shoot up beyond the expected range resulting in overdosage and toxic symptoms. Overdosage produces instability while walking (like a drunken person), double vision or drowsiness. Long term side effects, some of them serious are known to occur but are **extremely rare** and include glandular enlargement, liver damage and softening of bones. The usual daily dose for a child is 100 - 200 mg and for an adult 300 - 400 mg. The daily cost of treatment with PHT comes approximately to 20 - 30 paise.

6.8 **Primidone (PHT)** is available as 250mg. tablets. This is a powerful antiepileptic drug used in primary and secondary GTCS and partial seizures. Blood levels are maintained for only 4 to 6 hours and **hence the drug has to be given 3 or 4 times a day which is a great disadvantage.** Moreover it makes patients extremely sleepy or giddy and increasing or reducing the dosage must be done very very slowly - over a period of weeks. The use of this drug has come down considerably.

6.9 **Carbamazepine (CBZ)** available in the form of 100 mg, 200 mg. and 400 mg.tablets, is a very powerful antiepileptic drug and is perhaps the drug of choice in CPS. It is also used in GTCS as a second line drug. Blood levels after a single dose by mouth are maintained for 10 - 12 hours and hence **this drug must be taken atleast twice a day. Generally** it is remarkably free from minor or major side effects, though liver damage can occur exceptional ly. The usual daily dose for a child is 400 mg and for an adult 800 - 1200 mg. CBZ is a very expensive drug, the cost per day coming to about Rs.7/-.

6.10 **Ethosuximide (ETHO)** is available as a syrup and contains 250 mg. per teaspoonful. Effective blood levels are maintained beyond 24 hours and **a single daily dose will suffice, but a high single dose**

**can cause vomiting and hence two doses in 24 hours may be required.** It is useful in absence seizures but can make associated GTCS worse. Its use has come down considerably with the introduction of sodium valproate.

6.11 **Nitrazepam (NZP)** marketed in 5 mg, 10 mg tablets or capsules, is given mainly in myoclonic epilepsy. Unfortunately, after an initial period of cessation of attacks it tends to lose its potency and epileptic seizures tend to recur. It also has a disadvantage that it can make any associated GTCS worse. The most common side effect is drowsiness. Blood levels are maintained beyond 24 hours and **once daily dose is enough.**

6.12 **Clonazepam (CLZ)** marketed in 0.5 mg, 1.0 mg. and 2.0 mg tablets is not yet available in India. This is said to be helpful in certain types of myoclonic epilepsy and possibly in some cases of absence attacks. It is chemically related to nitrazepam mentioned above and likewise can make any associated GTCS worse. Side effects include drowsiness especially in high doses. Blood levels are maintained beyond 24 hours and **once daily dose is enough**.

6.13 **Sodium Valproate (SV)** is a remarkable anticonvulsant drug which has revolutionised the management of absence seizures and to lesser extent myoclonic epilepsy. It also has a great advantage in that it does not make any associated GTCS worse (unlike etho suximide, nitrazepam or clonazepam). Indeed it is also useful to control primary GTCS.

It is marketed as 200 mg tablets. Blood levels are maintained for about 10-12 hours and **it is generally given in two doses in 24 hours.** This drug is an irritant of the stomach and hence is better given immediately after a meal. Though extremnely rare (1 in 2000 or 3000) serious and potentially fatal side effects can occur, especially in children with brain damage and that too usually in the first six months. As a warning signal the patient may have **persistent** vomiting or is acutely ill or has severe abdominal pain or develops jaundice. If any of these complications were to arise the doctor must be contacted immediately without delay and possibly he may advise stoppage of the drug. If this simple precaution is not taken the result can be fatal. The daily dose of SV works out to 400 - 600 mg for a

child and 800 - 1200 mg for an adult, though exceptionally much higher doses are given in children. SV is not an inexpensive drug. The cost of daily treatment works out to about Rs.3/-.

6.14 Allergic reactions though rare can occur with any drug and cannot be predicted before hand. If present, the drug must be with drawn.

6.15 While side and/or toxic effects do occur, one should not be blind to the fact that **no drug in the world can be free from side effects.** In fact any drug without side effects can be questioned about its efficacy. It is for the doctor to assess the beneficial effects of any drug against the frequency and/or severity of the side effects which must be discussed frankly with the patient. If any of the side effects mentioned above were to occur, do not stop the drugs but report to your doctor immediately. Do not stop the drugs on your own because of side effects. Inform the doctor and he will help you. Have faith in him.

## 7. GENERAL PRINCIPLES OF DRUG TREATMENT

7.1 The trend now-a-days, is to give a single anticonvulsant drug at a time and not multiple drugs. Multiple drugs do not, in general, produce any better response and only give rise to undesirable side effects. The dosage required varies from one patient to another and **it takes considerable time, sometimes even months, before effective dose in a patient can be achieved.** Far too often, anxious parents change their doctors each time the patient gets another attack or has a side effect: this only results in more expense and frustration. Stick to one doctor and help him to help you.

7.2 **It is the duty of every patient to maintain a daily chart of the attacks with the date, time, the type** - SPS, CPS, GTCS, MJ, absence - and the duration of the attacks. The doctor must be contacted at frequent intervals (to be determined by mutual understanding) to arrive at the correct dosage for the patient without serious side effects. If one drug is adequate dosage is not effective, the doctor will slowly replace it with another, and if that is also ineffective he will try a third drug. Polytherapy will be only as a last resort. All these take time. The doctor will naturally try simple drugs first before going to more expensive ones. Remember all cases need not and cannot go to the

Supreme Court straight away. Describe fully the type of attacks which helps the doctor to choose the correct drug.

**Even if a patient is free from attacks of fits the doctor must be kept informed about the patient's condition. Unfortunately, most people neglect this very important aspect, which is, indeed a tragedy.** Remember he takes the responsibility for long term administration of drugs.

7.3 It must be noted that it is not very difficult to control epilepsy. Injections of gardenal four times a day would stop all attacks but the patient will be sleeping all the time. This is not what one wants.

7.4 The habit of prescribing drugs which have combined two or more anticonvulsant preparations in one tablet must be condemned in no uncertain manner. Such drug combinations are not more effective and because of interaction of their components they may indeed be less effective. Moreover side effects increase and of course they are more expensive. Unnecessary waste of money with less response and more side effects !

7.5 **Whatever the drugs, they should be taken at a fixed time,** at best one or one and a half hours either way. In general they are best taken immediately after breakfast and/or dinner in the night. **Have the tablets next to the plate so that at the end of the meal the patient will take these tablets with a gulp of water in the presence of others.** This is much better than trying to take the tablets before going to sleep. One may feel lazy to get up from bed or forget all about it - human nature. Another method is to have a transparent box with the day's dosage packed in. Anyone looking at the box will know whether the tablets have been taken or not.

7.6 A common mistake is to stop the drug whenever the patient has fever or becomes pregnant. This is precisely the time when the drugs should not be stopped. One does not stop breathing because of some other illness, nor does a lady who is pregnant or is nursing a child. These drugs are like breathing. **They should not be stopped on any account**. If a patient vomits the drug within an hour or so of taking it an extra dose must be given, since the drug has mostly been thrown out. Likewise if a patient is having diarrhoea, absorption of the drug will be interfered with and it is as good as not taking

the drug. Please contact your doctor immediately. The aim must be to maintain adequate levels in the blood and thus in the brain. The site of action of these drugs is in the brain and not in the stomach or in the bottle !

7.7 Many parents become anxious when a lady with epilepsy becomes pregnant. The question in their minds is whether antiepileptic drugs can affect the developing child in the womb in any way. In general it has been worked out that congenital abnormalities in children can occur in about 1 in 100 of all pregnancies. When a pregnant mother takes antiepileptic drugs (AEDs), particularly phenytoin, phenobrbitone or sodium valproate, **especially in the first 6 - 8 weeks of pregnancy** the risk of congenital malforma tion in the new born child becomnes roughly double - ie - 2 in 100 or 1 in 50. Generally the type of abnormality is splitting of the upper lip or the roof of the mouth (known as hare-lip or cleft palate). These are diagnosed very easily and are amenable to surgical correction. On the other hand, by stopping antiepi leptic drugs the risk of epilepsy is increased and epileptic attacks during pregnancy can damage the unborn child much more than drugs. It can even result in abortion or miscarriage. Hence the risk from epilepsy is much more compared to that from drugs. Sodium valproate can result in serious defects in the brain or spinal cord of the developing child. These are seen mainly with polytherapy. If a lady on sodium valproate becomes pregnant, there is no point in stopping the drug once pregnancy is confirmed. Whatever damage the drug can cause to the fetus is already done. Repeated ultrasound examinations and estimation of alpha feto-proteins in the fluid surrounding the fetus will unearth cases with congenital defects of the brain / spinal cord referred to earlier. If positive, therapeutic abortion has to be advised. If negative, pregnancy is to be continued.

7.8 Another common doubt is whether a baby breast fed by a mother on these drugs, can be affected. Studies have shown that while these drugs do occur in breast milk it is so in extremely small amounts and hardly pose a danger to the child. Drowsiness may occur in infants breast-fed by a mother who is receiving more than 90 mg. of phenobarbitone per day.

7.9 **Under no circumstances should antiepileptic drugs be stopped suddenly.** Any change from one drug to another must be done slowly - over a period of weeks or months. Sudden stoppage of these drugs, even if it be for a day, causes an abrupt fall in the blood and brain levels of the drug, whose controlling influence is no longer present. This leads to continuous epileptic attacks - a condition called status epilepticus which has a very high mortality and often leaves behind severe brain damage in those that survive, especially in children. Sodium Valproate, however, can be stopped suddenly if potentially life-threatening symptoms mentioned earlier, were to occur.

7.10 The traditional belief that epilepsy is a condition with frequent recurrences requiring AEDs for several years is based on chronic patients who attend hospitals or specialist clinics and is no longer valid. Studies based on general population attending a family doctor give a much more rosy picture. There are several patients with epilepsy who need AEDs only for 2 - 3 years with the correct drug as monotherapy taken regularly without even a single missed dose. **If epilepsy is treated early and properly, the cure rate is quite high.** If the life time total of GTCS exceeds 20 or 30, the chances of a full control become less.

7.11 Drug treatment will have to be continued may be for life - in those with long standing epilepsy, associated brain damage, as with MR, CPS, as the seizure type and those with a mixed pattern of attacks as for eg: GTCS and absence, or GTCS and myoclonic epilepsy. In such cases two drugs may be required, but not before trying sodium valproate as the sole medication.

7.12 Very often anticonvulsant drugs go out of stock in the market. Hence it is always advisable to keep a sufficient stock of these drugs at home. Get a new prescription atleast once in six months. Strict regulations are being enforced to prevent sale of drugs without a valid prescription. **Please do not wait until the last minute and search frantically for the drug.** One does not wait to purchase provisions for the house till the last grain of rice or wheat is over. The same principle should be followed here as well.

7.13 **The drugs which are prescribed for the patient must always be kept under lock and key.** Like all other drugs these also should be beyond the reach of children. Looking at others taking the drugs, children have a curious habit of imitating their elders and swallowing drugs. This can result in serious complications if not death and hence this note of caution.

7.14 One question frequently asked is why a patient should get an attack at a particular time, may be inspite of regular drug intake or after a long fit-free interval. This is an extremely difficult question to answer. Often it is due to a combination of several factors - a physical illness, fatigue, lack of sleep, skipped meals, emotional upset, lowering of blood level of the drug due to may be change in brand name, quality of the drug, defective absorption from the stomach or interaction with other drugs used for some other illness or taken regularly for some other purpose. Why do these factors not combine to produce attacks more often ? One wishes the answers were known !

## 8. FIRST AID DURING A GTCS

8.1 Whenever a patient has an attack, particularly a GTCS it tends to frighten the relatives, bystanders and other interested persons. Convulsions can be dreadful to watch with froth in the mouth, loud breathing and unconsciousness. It is not sufficiently realised that the convulsive movements would last only for 2 - 3 minutes namely 120 to 180 seconds. The natural history is such that the convulsions stop on their own though patients may be unconscious for minutes or hours later. This panic has given rise to a plethora of the so-called first- aid measures.

8.2 One popular belief in South India is that giving an iron piece in the hands would stop the attacks. In Western india, particularly in Maharashtra, the belief is to place an old shoe near the patient's nose. By the time one searches for an iron piece or an old shoe the convulsions have stopped on their own and unnecessarily the credit goes to the false belief.

8.3 What is more dangerous, however, is to insert some objects-soft or hard-between the teeth in an attempt to stop tongue bite. Even if by chance the tongue gets bitten it will heal beautifully within a few

days. Monstrous attempts at trying to introduce something between the teeth have resulted in broken teeth. A broken tooth can get into the lungs and result in immediate death or serious complications. Likewise attempts to hold the patient tight during the vigorous convulsive movements are dangerous. They can result in fracture of the limbs or dislocation of the joints. A common habit is to pour something down the throat of an unconscious patient thinking that it will revive him. **In an unconscious patient the swallowing reflex is considerably reduced and any fluid will find its way into the lungs choking the patient to death.** Turning the neck of the patient to one side to prevent the tongue from falling backwards is another dangerous myth which can result in fracture or dislocation of the neck and consequent total paralysis of all the 4 limbs, if not death.

8.4 **The best first aid one can give a patient is to leave him severely alone.**

God will look after him. The so called first aid measures can be extremely dangerous and may result in death or serious incapacity to the patient. **The habit of giving an extra dose of the drugs which the patient is accustomed to, has already been condemned.** Likewise there is no need for the patient to be given any injec tion for one attack or admitted in a hospital for one attack. He may sleep for two or three hours, wake up with a headache for which any simple pain killer would suffice and he would be normal the same evening or the next morning.

8.5 But if the patient gets recurrent GTCS in quick succession (3 or above in 24 hours), with or without recovering consciousness in between, or one GTCS lasts not the usual just 2 - 3 minutes but is prolonged - continuous convulsions beyond 10 minutes by the watch - **this is an emergency.** The commonest cause for such recurrent attacks in a patient who is on drugs is failure to observe the golden rule - viz. **'do not miss even a single dose, come what may'.**

This can be handled at home in its **early stages** and is known as Home treatment of status epilepticus or cluster attacks. **It should not be used for single isolated seizures, however frightening it may be.** The drug to be used is diazepam solution meant for in-

travenous use. Diazepam is available in our country as calmpose or valium, 2 ml. ampoule containing 10 mg. of the drug ie. 5 mg. per ml. In children upto 5 years of age, the usual dose is 0.5 mg per kilogram of body weight. In children aged 6 - 12 years, the usual dose is 0.3 mg per kilogram and above 12 years 0.2 mg / kg. The ampoule is first checked for date of expiry, broken at the neck and the contents placed into a spoon which is then pourned into the mouth taking care not to spill it. Adequate levels are reached in the blood in 2 - 4 minutes, peak levels in 7 minutes and they stay in the blood for about 7 hours. A second dose may be needed 3 - 10 hours later. Diazepam by mouth is much more convenient and easy to administer than by rectum. However it must be resorted to with considerable caution in an unconscious patient, for whom rectal diazepam would be preferable. **Intramuscular calmpose, the most commonly resorted to emergency treatment in general practice is useless because of erratic absorption.** It appears to work because the seizure would have stopped even without it. If this home treatment fails the patient should be rushed to the nearest hospital.

## 9. RESULTS OF DRUG TREATMENT

9.1 In general, GTCS, primary or secondary is easier to control fully than partial seizures - 70% - 80% of patients. **Full** (100%) control - zero attacks of any type - in SPS is seen in 65% of subjects, but in CPS, the commonest seizure type, the figure is only 40% all over the world. If there is an associated mental retardation full control is seen in hardly 15 - 20%, often due to the associated brain damage, high frequency of partial seizures, especially CPS, and sometimes because of mixed or atypical seizure patterns as in LG syndrome. In childhood and juvenile absence epilepsy full control is seen in 90% and in JME in 75%. In LG syndrome the figure drops to a depressingly low 10%. It is, however, heartening to note that more than 50% reduction in the seizure count can be seen in about half of the remaining subjects with epilepsy - a modest gain. Uncontrollable or intractable epilepsy is seen in 15 - 20% of all patients.

9.2 **Once full or 100% control of all seizure types has been achieved, one may consider reducing the drug dosage and stopping it completely after a seizure-free interval of 2 - 5 years.** Life time total of

GTCS of less than 20, absence of associated mental retardation or neurological handicap, seizure type mainly a primary GTCS and quick control of seizures after starting AED - these are good features encouraging drug withdrawal after 2 - 3 years. Absence seizures as in childhood and juvenile absence epilepsy may require a seizure-free interval of 5 years. CPS is difficult to control fully anyway, and in such an event, drug withdrawal may be contemplated after 5 - 7 years. **JME is easy to control, but unfortunately has a very high relapse rate of 70% even after a seizure-free period of 5 years and possibly may require treatment for life.** The risks of drug withdrawal are more when there is an associated brain damage as in MR or neurological handicap, possibly necessitating treatment for life. This may also be necessary in CPS.

9.3 **Drug withdrawal should never be sudden.** It should be carried out very slowly spread out over a period of 6 - 18 months.

9.4 The risk of relapse is there in all seizure types and one cannot give a 100% guarantee against a relapse. In general, the risk of relapse is low, may be 5 - 10% in primary GTCS, childhood and juvenile absence epilepsy; higher - may be 15 - 20% in partial seizures, especially CPS; and very high - 70% in JME. In case of a relapse, the unfortunate patient has to go back to his AED for a longer period, may be for life.

## 10. INTRACTABLE OR CHRONIC EPILEPSY

10.1 As mentioned earlier, response to treatment is poor in 15 - 20% of all epilepsies. This is more so in long standing epilepsy (lifetime total of GTCS more than 20) associated brain damage as in MR, LG syndrome, etc, multiple seizure patterns and CPS. The epilepsy is said to have entered the chronic phase. To some extent this can be prevented by early treatment of seizures with the appropriate AED as monotherapy to be taken regularly without even a single missed dose and attention to life-style compliance especially with regard to adequate sleep.

## 11. SURGERY FOR EPILEPSY

11.1 Patients with intractable epilepsy which has failed to respond to adequate medical treatment can be considered as potential candidates

for surgical treatment. This cannot be resorted to without repeated and proper pre-operative evaluation and investigations. It is the latter for which facilities do not exist in India today. The patient is generally admitted to a hospital, and AEDs withdrawn slowly. The habitual seizures which get precipitated are recorded simultaneously on a video and an EEG recording of the seizure obtained repeatedly. Preliminary EEG recordings with special electrodes and in between seizures are also obtained. CT scan with special views for the temporal tobes - (unfortunately this is practically never resorted to in CT studies of the brain in India !) and MRI scan of the brain are obtained to detect small tumors, blood vessel abnormalities or areas of atrophy of the brain with scar - provided they are large, which can then be removed. If CT and MRI are normal and EEG recording during a seizure shows consistently an area of the brain from where the seizure activity originates, it is so identified and removed provided it is feasible and does not lead to post-operative neurological / psychological deficit.

11.2 Provided cases are studied intensely preoperatively and chosen with care, the results of surgery are rewarding. Seizure control or reduction occurs in 60 - 70% of patients and maintained for 5 - 10 years. The AEDs must be continued for at least 2 - 3 years after surgery before being tapered off.

11.3 Video - EEG monitoring of the seizures in the pre-operative period sometimes shows that the so-called intractable or chronic epilepsy is really due to hysterical and not genuine seizures ! Treatment is then psychological.

## 12. CERTAIN SPECIAL SITUATIONS

12.1 Patients with a single or first seizure - though not diagnosed as having epilepsy, seek medical aid. Generally they are not pre scribed AEDs, but are kept under observation. As time goes on, over a period of 6 months to one year, an increasing proportion develop a second seizure. Whether this can be prevented by starting AED is not clear. However, more number of patients opt for AED therapy even after the first seizure to enable them to drive a vehicle.

12.2 Some subjects get seizures at very rare intervals of time - once an year or two. Do they require AEDs? Probably not, provided they do

not have any additional seizure phenomena in the form of partial seizures, absence or myoclonic seizures which should be specifically asked for. This same rule also applies to the previous category - seizure 1 or first seizure. If the seizures become more frequent, AEDs cannot be withheld any longer.

## 13. FEBRILE CONVULSIONS IN CHILDREN.

13.1 Children in the age group of 6 months to 6 years, especially 6 months to 2 years, are likely to get convulsions whenever they have fever, whatever its cause. Unlike in older children and adults, these convulsive movements may last far beyond the usual 2 or 3 minutes. Known as febrile convulsions, when they occur frequently and/or are prolonged, beyond 10 minutes by the clock, there is a 10 - 15% risk of developing CPS in such instances, 15 or 20 years later. **The overall risk of future epilepsy is still small.**

13.2 Whenever such children develop fever keep Crocin syrup ready. You may have to give it to bring the temperature down and repeat it every 6 hours. If the fever is high - 101 degree or 38.3 degree C (at the arm pit), take a thin sari or any other cloth, dip it in cold water, remove the excess water and cover the child from neck downwards. These measures will bring the temperature down rapidly and can be used as a first aid measure before the arrival of the family doctor. **Please do not give a dose of gardenal** by mouth. It will take days to reach the brain.

13.3 Do children with febrile seizures require any prolonged drug treatment ? The general concensus is no drugs. The risk of subsequent CPS has been over emphasized in the past and drugs advised. The only two drugs likely to be effective are phenobar bitone and sodium valproate. The former can interfere with the learning capacity of the child and make him restless, while the latter is not free from serious toxic effects. It is held that febrile seizures are generally innocuous and need not cause any panic. If the seizures are prolonged or recurrent, home treat ment for status / cluster attacks referred to earlier in 8.5 can be resorted to. Some trials are being conducted on oral diazepam tablets at the onset of fever for preventing febrile seizures, but nothing clearcut has emerged as yet.

## SOCIAL ASPECTS.

### 14. RESTRICTIONS ON A PATIENT.

14.1 These are surprisingly very little. An epileptic patient should not fast for prolonged periods and must avoid as far as possible going to bed late **so that his normal quota of sleep is not disturbed.** Over night travel in a bus is a very common precipitating factor for an attack and must be avoided as far as possible. Other common causes are reading late in the night for examinations, watching video late in the night, New Year parties, wedding at home, etc.

### 15. EPILEPSY AND SCHOOLING.

15.1 There is an erroneous belief that children with epilepsy should not go to school or college lest the other children be affected. **Epilepsy is not an infective or a contagious illness.** Several teachers prevent epileptic children from attending classes and the parents are told that the illness has to be **cured** first before the child could be permitted to continue schooling. This is a fallacious belief and requires a change in orientation on the part of the teacher. It has been shown clearly that epilep tic children can continue and do well in studies as well as other children. To bar schooling for these children is as unfair as following such a policy for a child with recurrent headache or stomachache.

### 16. EPILEPSY AND WORK.

16.1 Epileptic subjects can take up any desk job or an intellectual occupation like any other person. They can even work in factories. Experience all over the world is that the accident rate of epileptics, even while working with moving machinery, is much less compared to their non-epileptic counterparts. This is due to several factors - firstly, about 40% of patients with epilepsy get a warning signal seconds or minutes before the attack which enables them to move away from the machinery. Secondly, of the remainder, nearly 40% get their attacks only during sleep and are not in danger at the workspot. It has also been shown that during an attack of fits, patients very often tend to fall back wards rather than forwards, thus minimising their getting caught up with the machinery. **The commonest cause of accidents is the human factor of carelessness**

which is perhaps manifest to a greater extent in a non-epileptic than in an epileptic.

16.2 Lastly, an epileptic because of difficulty in getting a new job has a greater motivation to work harder and many turn out to be a better worker in the long run.

## 17. EPILEPSY AND MARRIAGE.

17.1 Epileptics can certainly marry like any other person. Unfortunately because of societal attitudes, many parents hide the information from the prospective partner. But this short-sighted policy back-fires when the other people come to know about the drug treatment or the illness itself. One cannot fool all people all the time. Tragedy ensues in that the girl, as often is the case, is sent back to her parents and a petition filed for divorce. Thus the parents owing to their short-sightedness have ruined the life of the patient for ever. It is essential that the prospective in-laws be told about the illness and the doctor incharge of the case has a moral right to discuss this factor with the other party. It is really heartening that following such a frank discussion most people accept the alliance and the marriage is successful, since neither party feels cheated or guilty.

17.2 According to Indian Law, a person with epilepsy cannot marry at all and if he (she) gets married, especially without disclosing the information, the marriage can result in a divorce. Parents and relatives beware ! Your Association is trying to amend this law by appealing to those that matter; but nothing tangible has come out so far.

## 18. EPILEPSY AND SEX

18.1 Epilepsy does not in any way come in the way of a normal sexual life. Many anxious relatives debar sex thinking that it will weaken the individual and lead to fits. This is far from the truth. If sex were to be prohibited after marriage the very purpose of marriage will get defeated leading to frustration and more attacks.

18.2 Epilepsy may interfere with sex drive in certain individuals more from psychological inhibitions than from epilepsy itself. It does not interfere with the fertility of the individual. Antiepileptic drugs are unnecessarily blamed for infertility in certain situations. This is a myth.

## 19. EPILEPSY AND CHILDREN.

19.1 While there are undoubtedly some hereditary influences these are probably extremely small. **What we inherit is not epilepsy itself, but a tendency to convulse.** The hereditary factor in epilepsy is much less compared to other illness like diabetes, asthma, or headache of a particular variety. If one parent is an epileptic the chance of a child developing an attack is around 3 - 4%. If both parents are epileptics the risk goes upto around 10 - 12%. Hence it is always advisable that no epileptic should marry a person related to him or her. As regards having children an epileptic lady has a perfect liberty to give birth to a child 9 months after conception - i.e. at any time.

## 20. 'TONICS' IN EPILEPSY.

20.1 Many anxious relatives erroneously believe that the patient with epilepsy has "nervous weakness" and want a "tonic." This is a fallacy which has been handed down from generation to generation. Most "tonics" contain vitamins and the so called essential minerals in high doses and they have become extremely popular because of high pressure salesmanship. The body needs very small doses of vitamins and essential minerals which are adequately covered in a **balanced diet**. Any extra dose given by mouth is excreted in the stools; or if given by injection is thrown out in the urine.

They are a sheer waste of money and nothing else. **Adequate nutrious diet is all that is required not only for patients with epilepsy but for all human beings.** Generally the so called tonics are consumed by people who can afford a good diet and who indeed take them. In the section of under-privileged and very poor people, what they need is not tonics but good nutritious diet. So either way this is totally unnecesary except in very rare instances.

20.2 There are no dietary restrictions for an epileptic patient. If he is capable of digesting a stone he can have it.

## 21. EPILEPSY AND SPORTS.

21.1 Children and adults with epilepsy can certainly participate in active games and sports as any other individual. A living, retired, Test

Cricket Captain - Tony Greig was one. Chances of such participation leading to attacks are very remote

21.2 One note of caution about swimming. In general it is better to avoid swimming for atleast two to three years after the last seizure. Swimming alone or in a crowded place where an epileptic patient cannot be watched every minute is potentially dangerous. If an expert were by the side of the patient, and if he can observe the patient every minute, then perhaps there is no harm. Even then the expert swimmer being human cannot be expected to concentrate on the patient all the time. Hence it is advisable to avoid swimming for 2 - 3 years. Common sense would tell us that if a seizure were to occur while in water and the patient becomes unconscious he will drown to death. However, if the patient were free from seizure for 2 or 3 years, the chances of a recurrence are very remote and swimming need not be prohibited then.

22. **TELEVISION AND EPILEPSY.**

22.1 **In some patients** with epilepsy viewing television in certain situations can bring an attack of epilepsy. This is known as Photosensitive epilepsy. This does not occur because one views television but attacks can be provoked in a **small** proportion of epileptics probably due to rapid slipping of the image on the screen. This intermittent stimulation of the eyes is likely to produce epilepsy, particularly when the susceptible individuals sit very close to the TV screen. Hence it is always a good advice that epileptic subjects particularly children, while watching television observe certain precautions.

22.2 Television must be viewed from a distance of greater than 8 feet.

22.3 The room must be well illuminated with a small table lamp on the TV set. In other words avoid watching the TV in a totally dark room.

22.4 Patients must avoid approaching the TV set to switch it off or adjust it. If such an action is absolutely essential, **one eye must be covered with the palm of the hand.** If these simple precautions are observed the risk of getting epilepsy because of viewing television is considerably reduced.

22.5 **It is essential to repeat that viewing of television need not and should not be banned for epileptic subjects**. Please do not take away a simple pleasure from these patients.

## 23. EPILEPSY AND HOT WATER BATH.

23.1 It is true that in certain individuals hot water bath, especial ly on the head, can provoke an epileptic seizure, often a CPS. This has been described from Karnataka State for the first time in the world. But it does not mean that **all** epileptic patients should deny themselves the luxury of a hot water bath. Only those who get an attack during a hot water bath need to be cautioned against it. The temperature of the water used for bath should not exceed 28 degrees celsius. Rapid pouring of the water on the head should be avoided.

## 24. EPILEPSY AND ALCOHOL / TOBACCO

24.1 The belief that epilepsy and alcohol do not go together is not true. Recent studies have shown that in general alcohol does not make epilepsy worse, provided the intake is limited to one or two pegs twice or thrice a week. This does not mean that one advocates the use of alcohol in epilepsy. Social intake of alcohol is not harmful, but addiction should be avoided.

Smoking has no relationship with epilepsy. **But it is a definite life hazard and hence better avoided.**

## 25. EPILEPSY AND DRIVING.

25.1 According to the regulations existing in our country, an epileptic is totally barred for life from driving a two wheeler (not a cycle), three wheeler or a car or any public transport vehicle. This rule is observed more in the breach with family members often in tow !

25.2 In Western countries studies have shown that the risk of epilepsy while driving a car is very small. Hence in general if a patient is free from attacks for atleast two years, he/she is allowed to possess a driving licence but **not** as a **professional driver**. Some countries give a driving licence even if the patient continues to take his antiepileptic drugs, whereas in some others licence is given only if the patient is free from attacks after stopping the drugs. Epileptics can certainly ride a bicycle.

25.3 **Nowhere in the world is an epileptic permitted to be a profes sional driver** - whether three wheeler, car, bus, lorry, railway engine or an aircraft, unless the seizure had occured several years earlier.

26. **EPILEPSY AND EMOTIONS.**

26.1 Emotional factors have a tremendous role to play in causing the attacks to persist inspite of absolutely regular drug treatment. **It is here that the family and society have an important role to play.**

26.2 At one end are patients who are pampered and get whatever they want because of the relatives' fear that emotional upset would result in a fit. This is the worst thing to do - to give into fear. **Once fear comes in common sense flies away**. Some patients even learn to fake an attack if they don't get what they want. Don't be afraid to say NO to a person. **Treat the patient as you would if he (or she) did not have epilepsy**. Societal responsibility is neither to treat them as out castes nor pamper them. They are perfectly normal people except during a seizure and require no more or less attention than any other individual.

26.3 Far too often, rich or indulgent parents choke completely the social and emotional contacts of these individuals by keeping them at home and not allowing them to go out. Their schooling is stopped as also their music classes, because the patient had a fit in the bus stand ! The patient cannot go out and meet friends or go and see pictures. They ask - "Is it not a great calamity to the family if she gets a fit in a public place ?" Thus the patient is virtually made a prisoner, which she naturally resents. Recriminations, and fights or silent suffering build up tension and the attacks continue as merrily as before inspite of drugs. The patient goes out sometimes to an understanding relative and the attacks stop completely only to recur on returning home. The parents place restrictions out of a genuine but mistaken notion, with disastrous consequences. It is not a crime to have a fit, just as it is not a crime to suffer from fever, headache, asthma or stomach ache. Such a short sighted policy denies long term benefits. To this can be added the jibes and taunts of "well-meaning" relatives, friends, teachers and what not. What then is the motivation for this unfortunate patient to survive in "civilised society" ? **What they need is not pity or sympathy, but understanding.**

They have as much pride as any one else but let us show them understanding and this benefits not only the patient but also society.

## 27. SUMMARY & CONCLUSIONS.

27.1 Epilepsy is a symptom of a disease in the brain and can be of several types. In a vast majority it is not associated with mental retardation. It can be due to a simple cause like a scar in the brain or rarely part of a disease like brain tumour.

27.2 A diagnosis can be made only from a detailed description of the attack. Detailed examination and investigations help to determine the cause, as far as possible.

27.3 Epilepsy can be controlled in most patients by proper administra tion of the correct drug. The present trend is to use a single rather than multiple drugs.

27.4 The prescribed drugs must be taken at the correct time and with out even a single missed dose, come what may.

27.5 Maintain an accurate chart of the attacks and keep in touch with your doctor at frequent intervals, even if the patient is free from attacks. This help on your part is of extreme value to the doctor in determining the drug and its dosage to control the attacks and help you in return.

27.6 The attacks can be controlled by continuous, regular drug intake for months or years - not days or weeks.

27.7 Epileptics can go to school, college, work, marry and have chil dren. They are quite capable of leading a perfectly normal life. Help them towards this goal by treating them like any other person. Do not be over-protective and restrict their life nor be too lenient and allow them to get away with whatever they like.

27.8 Spread this message amongst your friends and relatives. This will be a small step towards strides to remove misconceptions, superstitions and fear about this extremely common illness.