Psychosocial Aspects of Epilepsy

Epilepsy has been known throughout history. It observes no cultural, geographical, racial or economical boundaries. It can happen to anybody at any age. Approximately 1 in every 100 have epilepsy. Most of them either have their first seizure in childhood or in old age. If not treated properly at the right time, epileptic attacks recur and hamper the growth and development of children. Epilepsy thus poses a widespread, major problem.

Most people with epilepsy can lead an essentially normal life. Better control of attacks leading to better quality of life for patients and their near ones depends on three key factors.
- Early recognition of the attacks whether they be the major or minor types.
- Early initiation and regular continuation of proper management.
- Social acceptance of the patients.

In cities and towns there has been a significant improvement in the first and second factor but social acceptance is still a problem.

Generations of neurologists have done their best to remove misconceptions associated with epilepsy amongst lay people. The scenario, at least in major cities, is showing improvement. More and more people now come forward for the medical management of epilepsy and overall the attitude is positive. Compliance i.e. regular intake of medicines and a healthy lifestyle is definitely better and even availability of antiepileptic drugs is better. On the diagnostic front doctors are better equipped as well.

However, people with epilepsy and caretakers still have to learn how to deal with associated problems especially with regard to EDUCATION, EMPLOYMENT and MARRIAGE. It is often said that the social attitude towards the disorder often causes more distress to the person with epilepsy and the near ones than the disease itself.

Broadly there are 4 categories of people suffering from epilepsy

**Group I** – People whose epilepsy is well controlled with medication, where the epilepsy has been of a shorter duration and the concerned individuals function adequately at all levels.

**Group II** – People who have suffered from uncontrolled seizures for a long duration (most of whom have had early onset of seizures) but who in the recent years, because of advances in treatment and medication, have achieved some degree of seizure control but are still dependent on others.

**Group III** – People who have suffered from uncontrolled seizures for a long duration and continue to do so. The chronic nature of their illness has impacted all major domains of life and because of the unpredictability of seizures they require constant care and attention.

**Group IV** – People who have epilepsy with associated neurological disorders e.g. mental retardation. They are dependent on a caregiver for looking after all their needs.

Depending on which category the person with epilepsy belongs, difficulties regarding education, employment and marriage will vary.

**Education:** This is affected because of misunderstanding, ignorance and fear among parents and teachers. In our country most of the parents are overprotective and fearful which make them reluctant to send their children to school, especially when the distance from home is long. This is supported by teachers too as it reduces their burden. An epileptic attack in the
classroom is a nuisance and disturbance, especially if the way to handle the person during a seizure is not known. If the teacher has negative reactions to the person with epilepsy, the reactions of students are bound to be negative as well. They also tend to be looked down upon by the family members and neighbours and this gives them an inferiority complex. Whilst education of most people with epilepsy does not pose a problem, those with continuing seizures face this difficulty.

**Employment** – Once the education of the child remains incomplete the future of the child tends to be bleak, even if later full seizure control or cure is obtained. Again it is worth pointing out that most people with epilepsy do get employment or do something on their own. Those with continuing seizures have to exploit their talents (which all of us have) and become contributing members in society.

**Marriage** – Without proper education and employment, marriage prospects go down. The stigma of epilepsy also contributes to poor marriage prospects. People with epilepsy are however advised to reveal the disorder to their partner before the marriage takes place.

What people with epilepsy need most are confidence building exercises/activities. They need to be as independent as possible. Like every one else they need goals and the knowledge and skill on how to achieve their goals. The Ten Commandments which people with epilepsy and caretakers need to follow are given below:

**Ten commandments**
- Awareness and education at all levels (caretakers need to contribute).
- Boosting of morale by support group activities.
- Compliance of all thumb roles for a healthy and regular life style.
- Doctor’s advice should be followed rigorously.
- Empathy and encouragement by family members and friends.
- Family should give optimal support and not be overprotective.
- God helps those who help themselves – message to all people with epilepsy.
- Honesty, hardwork and sincerity on the job.
- Independence – physical, financial and emotional, the ultimate goal.
- Joyful and useful living – the outcome.

– Contributed by Dr. Pravina Shah