

What can be done about epilepsy?

My true story..

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

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

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

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

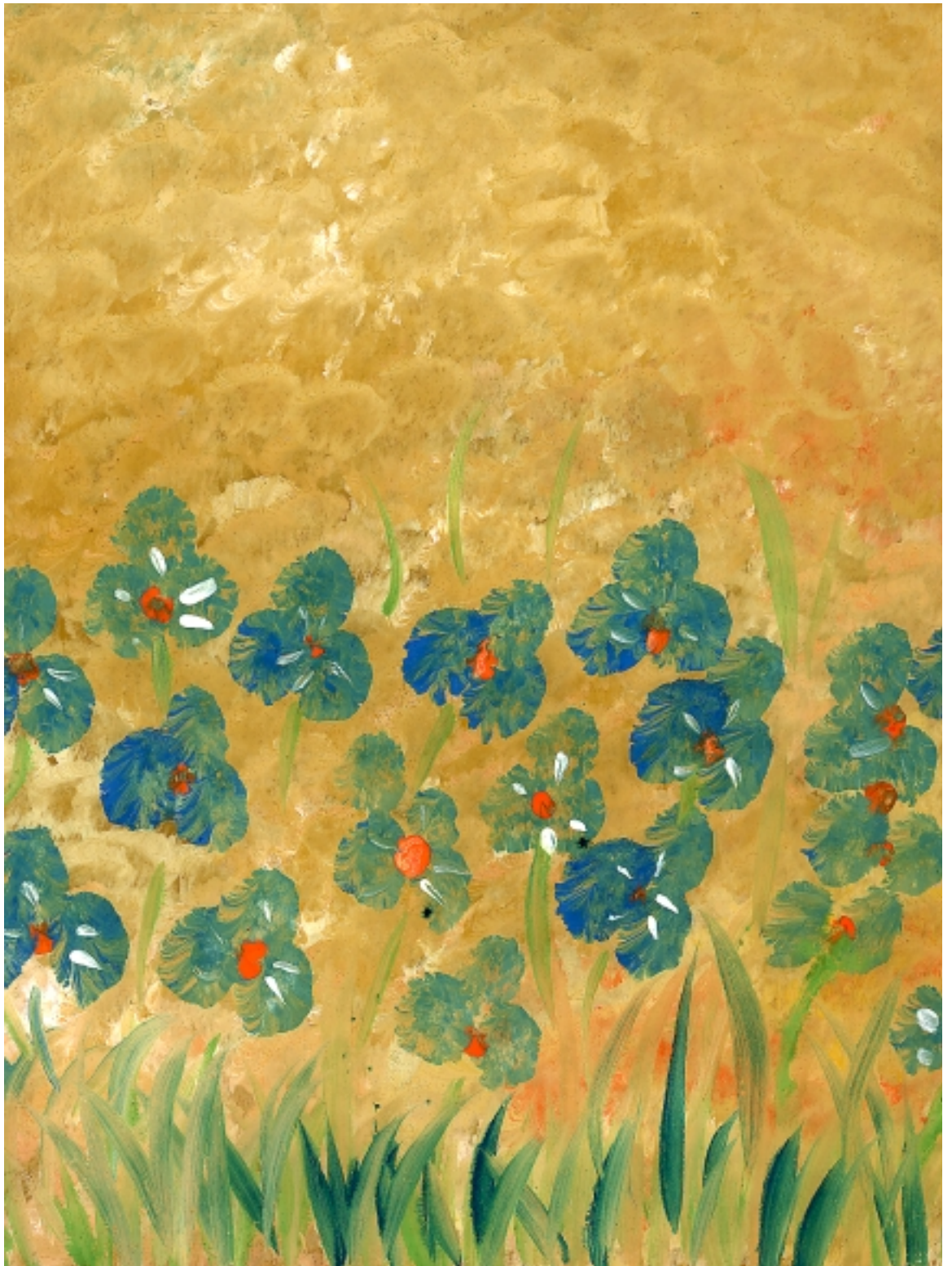
However, let's not go away from here thinking that all is well for people with epilepsy. There is a harsh reality outside. There are many people out there who will tell you they can deal with the seizures but not the stigma; who are suffering because of it. At medical congresses, it is apparent that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

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

Let us make it our mission.

Thank you.

Carol D'Souza



"Valley of Flowers"

Painting by Ms. Yogeeta of India

Some dos and don'ts for patients: Ten Commandments

(Adapted from Indian Epilepsy Association, Bangalore, India)

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

What the patients can do for themselves

Everyone can contribute...

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

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



“I Am Not Alone”

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

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

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

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

Some basic information for health professionals ...

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

A case history from an eyewitness should always be obtained.

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

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

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

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

Highlight the importance of stocking an appropriate amount of drugs.

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

lead to discontinuation.

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

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

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

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

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

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

Role of Health Professionals

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

Role of the pharmaceutical industry

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

Role of NGOs

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

Role of the Health Sector

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

Epilepsy and the education sector

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

The health sector can...

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

Teachers can help...

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