

# Out of the Shadows: Services for Persons with Epilepsy in Malta

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**Epilepsy is the most common neurological disorder in clinical practice and it is a generic term used to define a variety of seizure disorders. A seizure is a disturbance in the electrical activity of the brain. There are more than 20 different epilepsies and syndromes, according to recent international reclassification of symptoms by the International League Against Epilepsy. These seizures affect awareness, produce brief loss of muscle control and may involve sensory distortions. Early diagnosis is crucial. Children and adults with undiagnosed seizures risk developing a more severe, more difficult to treat condition with consequent poor prognosis and increased medical costs.**

before the age of five and 50 % develop before the age of 25. It is also increasingly associated with the elderly. In about 70% of cases there is no known cause. Of the remaining 30%, the most frequent causes include head trauma, brain tumour and stroke, poisoning, alcoholism and following infections such as meningitis or viral encephalitis. All people inherit varying degrees of susceptibility to seizures. The genetic factor is assumed to be greater when no specific cause can be identified. Modern treatment with drugs can achieve full or partial control of seizures in about 85% of cases. Yet social, educational and employment stigmas persist world-wide, even here in Malta.

The World Health Organisation estimates there are 40 to 50 million people with epilepsy throughout the world and, in many countries, remains a stigmatising condition surrounded by mystical beliefs and social taboos. In addition, there are a number of social and economic factors which will influence the outcome of seizure control in persons with epilepsy and lack of data relating to the number of persons with this disability will hinder progress in allocating medical, support, educational and employment resources for persons with epilepsy and their careers.

## **Local associations**

Over the last three years the Epilepsy Society of Malta and Malta Caritas Epilepsy Association have been

set up to serve as local chapters of the International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE). These are respectively the associations for health care professionals involved in the care of people with epilepsy and the group for patients and their families. These two groups are working together, with the Departments of Clinical Pharmacology and Therapeutics, Medicine and Paediatrics at the University of Malta and St Luke's Hospital as well as Kummissjoni Persuni b'Dizabilità to promote professional and lay knowledge of epilepsy in Malta especially since it is estimated that there are more than 2000 people suffering from epilepsy in Malta.

### Out of the Shadows

These two groups are also working to propagate the initiative of the International League Against Epilepsy / International Bureau Against Epilepsy and World Health Organisation ILAE/ IBE/WHO global campaign in epilepsy, "Out of the Shadows", which aims to seek to enlighten society about epilepsy as a medical and social problem and disability that can be treated. In this respect, the Epilepsy Society of Malta and Malta Caritas Epilepsy Associations are, respectively, affiliated members of the two organisations, and are participating

actively in this campaign. Over the last three years they have mounted promotional and educational campaigns, in line with WHO recommendations and using expertise from American Epilepsy Foundation and the National Epilepsy Association of Australia. These campaigns were held on local TV, radio and print media in order to make Maltese society more aware of the true condition, signs and symptoms of epilepsy and of the rights and duties of people with epilepsy and their families. These two groups also address issues such as developmental, educational and employment questions as well as legal matters. These discussions are held against a background of obviously increased medical needs e.g. seizure type, availability of treatment, investigations, prognosis and ability to have a family. In addition to providing support services, as a team of health professionals working in the field, i.e. neurologists, paediatricians, nurses, pharmacologists and pharmacists, they are promoting professional knowledge of epilepsy in Malta by undertaking coordinated scientific research in this area.

### Epilepsy Diaries

The two groups have also issued several educational publications in Maltese such as identity cards and

information about epilepsy in children. Recently, diaries were launched by the Hon. Minister of Health, Dr Louis Deguara. One of the key factors in epilepsy is the accurate recording in a diary of when the seizures occur and what form they take. The completed diary pages will then help physicians to plan their treatment to achieve the best possible control of the epilepsy. These diaries help one to keep track of the date and time of seizures, type of seizures and any possible triggering factors that may have caused the seizures, such as missed medication, stress, tiredness and any other items that affect mood or health, as well as space to record hospital or doctor appointments. The information thus recorded will help the persons with epilepsy to obtain some type of control on the factors that may induce the seizures, and thus may help remove some of the problems for daily life associated with the unpredictability of epilepsy.

**These diaries were kindly sponsored in Malta by Janssen-Cilag, a subsidiary of Johnson and Johnson, represented in Malta by AM Mangion Ltd. These diaries may be obtained from Neurology Outpatients' Clinics and Paediatric Clinics, St Luke's Hospital or by contacting the Caritas Malta Epilepsy Association on 233933 or 32902845.**

Month	<i>January</i>				
Date	Awake	Asleep	Time	Triggers	Notes
1					
2					
3	<i>2A</i>				<i>Very tired, grumpy</i>
4					
5					
6					
7	<i>2B</i>			<i>Period</i>	<i>Took paracetamol 2x500mg x 3</i>
8					