

Caritas Malta Epilepsy Association
3rd Nov. 2001 Malta Seminar Report.

In June 2001, the committee of the Caritas Malta Epilepsy Association felt the need to hold a seminar as a way of increasing the campaign to spread knowledge and understanding of epilepsy. This in the hope of minimising the stigma that exists locally particularly with employers. A second issue was to target the education sector to encourage educators' understanding of the needs of children with epilepsy particularly those with Absence seizures. Our campaigning for the seminar as well as for epilepsy in general, which included talks at schools yielded information that teachers were not conversant with epilepsy least of all with the absence type. Children with epilepsy were not getting the same assistance as those with other disabilities particularly those, whose condition was not known, to the school.

It was also agreed that a seminar would also increase the awareness of the needs of people with epilepsy with policy makers and health authorities if the seminar were given the appropriate esteem and punch. It was important to target prominent people. To inaugurate the seminar we had the highest authority in the country, The president of Malta Profs. Guido de Marco.

Because we mostly wanted to target the educators and employers, the Minister for Education and the shadow minister for Education were invited and accepted. The Minister for Social Policy had other engagements as did the Minister of Health. For employment we asked the Employment and Training Corporation ETC, who kindly sent an employment adviser to address the seminar.

In our campaign for the seminar we targeted all schools sending covering letters together with registration forms. Similarly we targeted Social work Agencies, Local Councils, Police, all NGOs, dockyards, factories and others.

The total population in Malta is a little over 350,000. For the seminar the attendance exceeded 250 people including nurses, teachers, doctors, social workers and the general public. We feel that considering the strong stigma on people with epilepsy, this was an achievement. For the seminar organisation Dr. Janet Mifsud mustered the backing of the Malta University and together with the expertise of the New Dolmen Hotel, the seminar was a resounding success enjoyed and praised by all. Included in the portfolio that each person in the audience was given, was a well designed certificate of attendance kindly donated by the university. It is attached with this report.

For our success we must thank Maltacom, AirMalta, The British Council, for their generous donations. Paramount Garage for the free transport given and Caritas for its help with paperwork that included posters, registration forms, backdrop etc. A very big thank you goes to Mr. Philip Lee and Ms. Hilary Mounfield for their kind acceptance to come over to Malta and deliver their presentations.

The following is the gist of the presentations made by the various speakers. In nearly all the presentation, reference I made to the way epilepsy is discriminated against and the strong stigma attached to the condition. Everywhere reference is made to the way it is hidden and the fear and shame that people feel in revealing it. Most speakers urge people with epilepsy and their families to come out of the shadows and live a normal life. Let society see that there is nothing to fear from people with epilepsy. Let us come out in the open with it, treat it with normality and confidence so future children learn to accept it in the same way they have accepted and learnt to respect other disabilities

His Excellency Professor Guido de Marco, President of Malta kindly agreed to inaugurate the seminar. In his address the president said that his presence underlined the need of more awareness and education on epilepsy in order to bring it out in the open with an aim of a better quality of life for people with the condition. He went on to give a personal experience he had when still a boy at school. His fear and unpreparedness. He said this was the scope of this seminar. To learn more about epilepsy and what we can do about it. Epilepsy paralyses the social life of the person and also that of his/her family.

Monsignor Dun Victor Grech, Director of Caritas Malta followed the President's speech with his own, titled "The importance of creating awareness of the needs of PWE. The work of the Caritas Epilepsy Association". Mons. Victor Grech thanked the President for attending and for expressing his feelings. He said the world needed people with feelings who felt responsible for their brethren. Mons. Grech went on to mention an experience of his own when he was attending a wedding reception and a young woman had a fit. He said some wished to help but did not know what to do, so they called for a doctor and an ambulance. Others just looked and walked away. The atmosphere at the reception turned to one of tension while the parents of the young woman felt ashamed.

Mons Victor said that at that moment he felt sick because he suddenly realised the fear and the social stigma that pushed these people in the shadows of society. He realised how PWE must feel. How many of them were there? How much did their parents and the authorities know about it? What consideration was being given to them? At school? Above all, what can Caritas do about it? But Caritas had a policy not to create further services to the 17 already in existence. He went on to mention how the Association was created with the persuasion made by the present Committee and with Caritas help, in 1996. The Association now grew to more than 250 members. Mons. Grech gave an overview of the work done to date by the Association in its educational campaign on epilepsy and to improve the self image and acceptance of those with the condition. Work done includes the printing of thousands of flyers about different aspects of life with epilepsy, the production of a one hour video film in Maltese about epilepsy, radio talks and television appearances, interventions with policy makers and health authorities. The efforts of the Association were not fruitless. It has helped to improve the treatment and diagnosis at St. Luke's hospital (Malta's primary state hospital to date) by the acquisition of more modern equipment and more technical staff. Health authorities are now realising the need of keeping a register of people with epilepsy to make known the seriousness of the problem and meet the needs.

Mons. Victor Grech's delivery was followed by that of Mr. Philip lee.

Mr. Philip Lee, President of IBE and BEA delivered his address stressing on the social aspect and consequences of epilepsy, the work of IBE and the global campaign against epilepsy. He said epilepsy was once defined as being 4000 years of superstition and stigma followed by 100 years of knowledge, superstition and stigma. It sums up quite accurately what it is like to have epilepsy.

While referring to the OHP, he remarked that some of the social implications included employment, driving, relationships and the law. To these must be added the consequences of these aspects. People's economic well being and the effect on their mobility as well as the isolation and the exclusion that they feel. They miss opportunities and often experience discrimination and prejudice. The word stigma sums it all up. Research around the world has consistently shown that society's attitude towards PWE and towards epilepsy itself is based on lack of understanding and knowledge and this is what causes the stigma. In turn it

is stigma that results in those aspects (shown on OHP), PREJUDICE, DISCRIMINATION, LOSS OF OPPORTUNITY, DENIAL OF ACCESS, PERSONAL FRUSTRATION AND A POORER QUALITY OF LIFE that people would normally expect to have.

Mr. Lee then gave an overview of the birth of IBE as a not for profit organisation aiming to improve the social aspects caused by epilepsy; the work done by the different Commissions and working Groups, head offices, represented in 55 countries and 26 organisations. Some Commissions he mentioned included those for Driving regulations, employment, psychosocial approaches to seizure control, public education, research, and insurance risks. He went on to demonstrate how IBE goes about in its efforts to improve the quality of life for people with epilepsy. He also gave a view of the work done by IBE and also the work done by IBE in collaboration with ILAE and WHO. A copy of his speech is included.

Mr. Lee mentioned the European White Paper and the accompanying document, its call to action, a campaigning document for all Europeans with epilepsy. He mentioned that this Global Campaign was felt necessary because there are over 50 million people with epilepsy world wide and that 32 million of these receive no treatment or diagnosis. The objective is to reduce the treatment gap. His last words were “We are making real improvements to the lives of thousands of people and we are laying the foundations for lasting improvements for millions more. There is a tremendous amount of work still to be done. That’s why we have to keep working at it , remain committed and keep focused on our objectives to bring epilepsy out of the shadows and into the open”.

The Hon. Dr. Louis Galea, Minister for Education.

The Honourable Louis Galea started by saying that the stigma attached to this medial condition creates a negative attitude that induces the whole family to feel shameful and to try and hide the condition. Sometimes as in the case of Absence seizures it is difficult to recognise a seizure resulting in the child falling back in education and become prone to bullying. Treating epilepsy with normality and confidence inspires children to accept it also. This helps the child to concentrate more on life, childhood happiness and studies without the dark clouds accompanying the condition. He referred to the BBC home page http://news.bbc.co.uk/hi/english/health/newsid_536000/536686.stm to be used by students and teachers alike as an interactive quiz.

He spoke about psychological and emotional effects of stigma and the opportunities that are missed by PWE.

Local research shows 205 children under 15 have epilepsy and emphasised the need to study difficulties encountered by children with epilepsy. the educational system in Malta provides:

- a. School psychological services, assessing psycho-educational needs of students with an educational problem. Discussions are between psychologist, parents, student, teacher and health workers.
 - b. Special arrangements during exams.
 - c. A committee is being set up to study the issue of administration of medicines at school.
- Individualised educational programme.

The Hon Carmelo Abela MP MLP.

Honourable Mr. Abela talked about the need of educators to learn about epilepsy and be observant, making their observations to the needs of these children to authorities. The local situation shows a lack of knowledge on epilepsy and that this results in stigma and discrimination. From parliamentary questions he put, it emerged that no form of statistics is kept in either the Health Ministry or Education Ministry. He appealed to PWE to come out

in the open. The seminar should help society to be more conscious of epilepsy and the needs of people with the condition. He said the beautiful wording in the National Curriculum is not enough if barriers still exist or if some students are allowed to fall behind for lack of help. It is time to pass from words to action.

Teacher training should focus more on the student. He said he noticed that teachers did not feel well prepared and backed to address this challenge. There is also the problem of administration of medicine and inoculations at school. In the implementation of the National Curriculum School Medical Service is not even given a mention. He concluded by saying "When children have seizures.....understanding makes a difference".

Mario Dimech is the chairperson of the Caritas Malta Epilepsy Association. Mario has partial complex seizures and is 50% controlled. Mario concentrated on personal experiences. His full speech can be seen in the attachment if required. It includes an honest view of his condition of people with whom he had close contacts. The stories he says are worth a visit or a place in one of your columns.

Mr. Joe Camilleri is the chairman of the National Commission for People with a Disability (KNPD).

Mr. Camilleri is himself disabled by arthritis in childhood. He matched the discriminations that Mario experienced, with his own and explained the problems he had because of stigma and discrimination. His entire speech was very absorbing. He showed how stigma can be turned from a negative aspect to a positive one. How it was up to the person with epilepsy him/herself to prove him/herself. Not to be passive and accept it because there was a lot that s/he can do about it. If your feeling is that you have lost the battle before you have even begun it, you cannot blame others for your failure.

While showing OHPs he explained why his presentation was called "Citizen Cain" because Cain was the first person with a stigma – but he deserved it. He mentioned how some negative stains can be turned into positive ones. The stain on Martin Luther was that he was black. He did something about it and showed pride in the fact that his skin was black. He became a symbol of a negative mark becoming positive.

Mr. Camilleri made reference to an iceberg on OHP, the beauty and greatness of which could be seen below the surface of the water. He said people tend to look at the disability rather than the person as a whole. He admitted that this point of view was changing nowadays to one of respect. Stigmas change according to one's point of view. Some see a bottle half empty and others see the same bottle as still half full. Stigmas do change but you have to make it happen. Mr. Camilleri made reference to the book/film "Scarlet Letter" how the adulteress with a big letter A on her breast turned that stigma into one of honour.

Before trying to remove fear from a person, find out why he fears you. If you expect people to respect you, educate them about your condition. Do not hide epilepsy. Bring it out in the open. When you are upfront and sincere with a person, you are giving him a chance to adapt. We have capabilities to help others similar to the way the Association's committee is doing for you. Every effort on our part like the leaflets the Association circulates, the video film it made and this seminar, every bit counts in breaking up the Berlin wall. Show society there is nothing to fear, that we function and that we have a right to education, to employment and to living a full life. We are capable of relationships and we can live with others in friendship, marriage, parenthood and we are reliable.

Franklin D. Roosevelt said the first thing we should fear is fear itself. Let us not be afraid. Say to yourself, "yes I have epilepsy, but I am capable of functioning and doing things as much as anybody else". It is all a matter of picking up courage. Secondly, let us be visible not invisible. Let us be seen, go out more, go to the theatre, take our share of the services

offered by society. Let us make our voices heard, on radio, tv, papers. We must challenge prejudice even on other disabilities. Do not isolate your disability. Above all we must change our stigma from one of dishonour to one of honour. The only way is to be united.

Mr. Ch. Vella Employment Advisor / Employment Training Corporation (ETC).

The mission of ETC is to provide and ensure equal opportunities to all in its training programmes and job related services

Mr. Vella highlighted the difficulties ETC employment advisers find when trying to instigate employers to employ people with a disability especially people with epilepsy. He admitted that these people fall backwards in spite of their efforts. ETC offers various incentives to employers among which are the Bridging the Gap training programme where the employer does not pay N.I. (National Insurance stamps (1/10 of salary), or salary during the training programme and is not obliged to keep on the trainee. ETC gives the trainee Lm.35 pw during this time which is about 13 weeks. This gives the PWE a chance to show what s/he knows. A second scheme is the ETPS employment training placement scheme. ETC pays 50% of salary for one year. A third scheme is the Community work Scheme with Local Councils. ETC provides job coaches and subsidises

Sometimes employers requiring clerical personnel require applicants to drive to avoid employing PWE. I find it very difficult to find employment for people with epilepsy.

Mr. Frank Mallia. Special Education.

Mr. Mallia accentuated the right of all children to education where every student can maximise his/her potential. He gave an overview of special education and segregation of students from the early 50s to the present inclusion system into regular schools with facilitators to cater for each child for his/her individual needs. Inclusive education is the first step to inclusive and accepting community that lived shoulder to shoulder and offered help where needed. Today they cater for 700 students and schools are under obligation to have the necessary backing for every individual student, including changing rooms, resource rooms, special apparatus, special toilets, lifts etc. academic accessibility is part and parcel with physical accessibility and teachers have to see that their methods of teaching targets all children. Two year courses are offered at university for assistants to take care of children with an impairment. At the end of these courses there should be 400 facilitators. "Lastly, inclusive education makes sense. Segregation instils in children lack of courage, lack of tolerance and prejudice. They need to mix and socialise to prepare themselves for the future. It is only inclusive education that can obtain respect, tolerance and friendship. It is a vision with a future".

Dr. Ant. Galea Debono. Consultant Neurologist.

Dr. Galea Debono briefly explained epilepsy seizures, identified and unidentified causes, onset, and importance of blood tests for calcium levels to eliminate parathyroid gland problems. He talked about EEG, CT and MRI. The local excellent supply of all medicine no matter the cost. Dr Galea Debono went into problems met with pregnancy, the use of folic acid; driving problems and ethical problems. He said that there are 20% of people with epilepsy that they cannot control. He emphasised that in his experience the stigma he finds is in employment. Employers are afraid of being sued in case of accident at work.

Dr. Doriette Soler. Paediatrician.

Dr. Soler quoted a survey of two years where it was found that 2 – 3 children in every thousand between birth and 14 years have epilepsy in Malta. One third was due to some

form of brain damage mostly prenatal asphyxia. Trauma was also responsible, trauma like accidental injury as well as child abuse. Malformation was the third cause in Maltese children. 47% of seizures were of the Generalised type while 33% were Partial. Some 15% had a mixture of partial and secondary generalised. 6% of children had problems with the way they move and many had cerebral palsy, motor disability. Besides epilepsy, these had mental retardation and motor disability.

The rest of the recording was spoiled by a bad tape.

Mr. Martin Micallef. Psychologist. (same bad tape) the following is what could be extracted. Low self esteem is also found in Epilepsy because the person feels that there will be instances in life that s/he cannot foresee and feels cut off from normality resulting in low self esteem. Stigma does not help them in building enough confidence in themselves to tackle their problems. Together with the issue of low self esteem there is also the issue of locus of control where they feel that their control on their lives is insignificant

Epilepsy and learning. Seizure activity determines the level of attention and also memory negatively. Abnormal seizure activity can take place hundreds and even thousands of times a day and neither the teacher nor the people around the person will notice. This issue needs to be addressed by both teachers and clinicians.

Ms. Hilary Mounfield CEO Epilepsy Action Scotland.

Ms. Mounfield said that whereas previously they concentrated on providing services and information for people with epilepsy. Today it is realised that campaigning is an important additive. She quoted misdiagnosis in UK as being between 20 and 30% due to difficulty in acquiring the services of specialists, particularly in some parts of Scotland. Other reasons for campaigning is that PWE have reduced opportunities particularly because of the stigma attached to them.

Ms. Hilary mentioned 4 ways of campaigning – Lobbying, Influencing, general campaigning and Empowering. She outlined how these four ways could be done.

Lobbying. Power in numbers. Use of vote. Find support from people who matter, MPs , people in authority. Convince them of your cause.

She said **campaigning** is on specific issues and is a matter of finding an issue and targeting outcomes. Use of Radio, television daily papers. We must know what we want before we start campaigning for it. Find some support, convince people of the rightness of your cause.

Influencing is more personal, she said, sometimes Machiavellian. Use whatever skills you have. Use the media. Plan how to reach the people you wish to influence with the message you want to pass. Make sure you know what you want them to do.

Empowering people with epilepsy. Stop treating them as victims. They have a voice, the strongest because it is the one with the experience. They have votes.