

New Dolmen Hotel

Saturday 22 February 2003

Caritas Malta Epilepsy Association

Seminar

Epilepsy:

impact on educational attainment and challenges

Today's Conference is another landmark for both families of persons affected by epilepsy, the persons themselves, as well as for practitioners from the health, education and social welfare sectors who are responsible for a range of personalized services provision.

We all appreciate that families and family support organizations have a dynamic role to play in shaping policies at national level. For many years now, families and family support organizations have lobbied for better, more professional and more equitable service provision. In the special needs field alone, a large number of support and self help groups and organizations have been established both to inform and to support the individuals and their family as well as to engage in social planning by submitting policy recommendations and putting pressure on policy makers to implement recommended measures.

Epilepsy and its impact on educational performance

The majority of children affected by epilepsy in Malta attend mainstream school. For some, the condition in itself may not be critical. Irrespective of how serious the condition is, children with epilepsy are prone to experience emotional and learning difficulties possibly as a result of the negative attitudes of their peers. Such attitudes may provoke anxiety while they may inhibit children from coming to terms with their condition. Other effects include:

- 1. Excessive lack of self-confidence, little belief in one's own abilities and potential, unrealistic self-assessment;**
- 2. Awkwardness in social situations, low decision-making ability, and immaturity;**
- 3. Overestimation of the seriousness of the illness, psychosomatic disorders, and sometimes symptoms of depression;**
- 4. Rebellion against the illness, trivialisation of the risks involved, and lack of proper knowledge about the illness itself;**
- 5. Mood changes, and little affective control which may impact the individual's relations with his peers and relatives.**

The parents themselves may experience feelings that are very similar to the process of grieving: denial, attempts to challenge the veracity of the diagnosis, anger, and depression.

Siblings sometimes experience teasing from their peers because of their brother or sister's condition. Their educational attainment may also suffer since parents may refrain from praising them so as not hurt the feelings of their suffering siblings.

Fortunately, there now exists a body of knowledge and guidance regarding epilepsy itself, and the assessment and treatment of epilepsy in children. Such knowledge now extends to an understanding of the nature of the links between the effects of epilepsy, the medication used for seizure control and the intellectual or educational impact and performance.

Some educational implications of epilepsy

Some of the widely acknowledged educational implications of this condition and its treatment have only recently become evident. I would like to mention five of these implications:

1. **Epilepsy may affect children of any ability level.**
2. **The immediate impact of the epileptic seizure is upon attention, concentration and, as a result, memory.**
3. **Individual "absences" may not be readily noticed, but their cumulative effect may be significant on the person's educational progress.**
4. **The impact of medication to control epilepsy may itself inhibit concentration and memory.**
5. **The resultant stress may trigger seizures.**

Challenges

Knowledge of these educational implications poses a number of challenges on the educator. I would like to highlight nine key challenges:

1. We need to make a concerted effort to ensure early identification modalities across key sectors - education, health, and social welfare.

2. Schools need to develop in-house capability in early and accurate identification of epileptic children who are most at risk of developing both learning as well as behavioural problems. In combination, known biological and psycho-social factors appear to be linked with a greater probability of learning and behaviour problems. It appears that children with a combination of anxiety, low self-confidence and immature motor development during the early school years are the ones who are most at risk for continuing and increasing disorders at later development stages. Teacher training should therefore include the development of the required competence in early identification and the related intervention work. Such competence needs to extend to an awareness of those epileptic attacks of a non-convulsive type, such as petit mal, that risk remaining unidentified and undiagnosed. These symptoms are often interpreted by teachers as episodes of day-dreaming or simply misbehaviour. Moreover, some practitioners may even mistake them for symptoms of ADHD.

3. Schools need to be flexible enough to develop a range of stress reducing strategies for such pupils. For example, whereas other children may respond well to intensive remedial provision, the same provision may lead to more pressure on the child with epilepsy and to a worsening of the condition.

4. Schools may need to develop an in-house referral capability that ensures access to appropriate treatment and management.

5. Comparative research needs to be undertaken on the impact of medication on ability. For example, research on reading progress among children with epilepsy suggests an average retardation of one year in the 10 to 11 age group. Research has also demonstrated that the IQ measures of at least 10% of children with complicated epilepsy declined by more than 20 points during their schooling years.

6. Early childhood education needs to become a more specialized field of practice. Those entrusted with pre-primary education may need further training and qualifications in a number of conditions. This is a key development phase where crucial, careful and ongoing observation and assessment of children can and should take place and where children should access a range of early teaching methodologies that tap particular strengths and compensate for certain weaknesses. I am saying this because even among children with severe impairments, the focus of the impairment may be specific (e.g. short-term memory) rather than broader scale.

7. Practitioners from different fields of specialization should avoid reaching decisions based on single assessments, however overloaded their schedule may be. As you know, particular forms of epilepsy are associated with different patterns of skills and disabilities. Practitioners should therefore collaborate to undertake systematic and ongoing assessments.

8. Schools should benefit from the provision of interactive tools that would help remove the stigma that still surrounds this condition. All too often, epileptic children, especially those with multiple impairments, are viewed with great sympathy, but sometimes judged

as hardly capable of meeting the demands that the curriculum places on them. Such an experience can lead the young person to a completely false assessment of his or her own capabilities and to develop additional learning difficulties and lack of enthusiasm to learn. School staff and students in primary and secondary education are often unaware of the causes and effects of epilepsy, and do not always know what to do if a student has a seizure during school hours. Such interactive tools should stimulate users to behave in more appropriate ways with persons within the school community who suffer from epilepsy.

9. Students with epilepsy should be assisted to make effective career choices. In the process of assisting students with epilepsy to make a career choice, sufficient consideration should be given both to their personal inclinations, their abilities as well as to their suitability. Should we try to dictate a career to young epileptics because of the supposed risks associated with their career preference, we risk damaging rather than nurturing the process of vocational and social integration. Experience abroad has shown that a number of measures could be provided so as to reduce or eliminate restrictions to career choice for young people with epilepsy. Persons impacted by epilepsy need to make up for gaps in schooling, and to gain an insight into a variety of professions or jobs, and need to learn to make a better assessment of their own abilities. Other responses need to be explored depending on whether the epilepsy is combined with other disabilities.

Allow me to briefly highlight some of the measures my Ministry has introduced to further safeguard equitable access of students with

special educational needs to the national curriculum. Five months ago, my Ministry published two key documents:

- i) *Creating Inclusive Schools – guidelines for the implementation of the National Curriculum Policy on Inclusive Education.*
- ii) *Guidelines for Special Examination Arrangements for Candidates with Particular Requirements.*

These two documents are the latest in a series of key guidelines provided to schools by my Ministry. Other documents in the series include:

- *Creating our Future Together – National Curriculum, 2000.*
- *Strategic Plan on the Implementation of the National Curriculum, 2001.*
- *Inclusive Education - policy regarding students with a disability; 2000.*
- *Good Behaviour and Discipline Policy for Schools, February 2002.*
- *National Policy and Plan on Bullying in Schools, 2000.*
- *Child Protection Procedures for Schools, September 1999.*
- *Tackling Substance Abuse – procedures for schools, September 2001.*

The process leading to the issuing of these guidelines has been a participatory one. Stakeholders have contributed their share in their formulation. In order to monitor their implementation, we have set up a National Curriculum Council. This Council, in turn, has established 15 specialist Focus Groups to provide technical and practical support to schools in such key areas as Inclusive Education, Parental Involvement, and Early Childhood Education.

Moreover, we have established a number of structures and units and increased substantially the number of complementary and peripatetic teachers in order to implement the various aspects of the National Curriculum and to cater for the specific needs of pupils.

As you can imagine, this is truly an exciting but also a challenging time for educators and the education system. For the first time in the history of our educational system, educators are guided by important and wide-ranging policies, guidelines and plans and are provided with the required expert support. However, there are still many educational aspects in the field of special needs that we need to cover. Unfortunately, this is not an area that is attracting the right number and quality of practitioners. Indeed, we are facing serious shortages in particular areas that are not attractive to applicants.

Since 1997, educators have been engaged in school-based planning processes leading to the annual revision of their School Development Plan. Professional development opportunities abound. At the school level, access to specialised information is readily available through the Internet. Through the Internet, teachers can even access materials developed by other teachers. They can dialogue around issues of concern through professional networks over the web.

A few days ago, a new course for facilitators leading to a diploma has started at the Faculty of Education at the University. The course intends to build on other courses already undertaken by participants and to provide in depth insights in a variety of disabilities and the approaches and methodologies a professional needs to cater for them so that pupils can develop their full potential. We are determined to make facilitation of educational needs more professional.

Before I conclude, I truly augur that educators in Malta feel enthused to seek meaningful ways of understanding pupils with epilepsy and of using all available resources, specialists and services to respond effectively to their particular learning needs. Commitment to do so will free our children with epilepsy from needless inconvenience and suffering – thus enabling them and to trod the path of self-directed autonomous learning.

Moreover, I sincerely hope that parents will continue their relentless advocacy for the right of their children to benefit from their entitlements in the national curriculum, while offering their generous support to their children’s educators and schools.

Active membership of the CARITAS Malta Epilepsy Association should ensure that the children having epilepsy enjoy the satisfying and rewarding life they deserve.

Thank you.