

Inclusive education for children with epilepsy. Dr Paul Bartolo

Dr. Bartolo thanked the Association for the opportunity to talk at the Conference. Reference was made to an overhead projection showing mother and her child having a seizure. Two problems are evident. One, the child's excessive electricity in the brain that needs to be controlled, the other problem is the anxiety of the mother which in turn will effect the quality of life of the child. We need to address both. Research shows that the greater impact on the child is not the epilepsy but the way with which s/he is treated by family and the community. Priority must be addressed to the condition in the brain. When this is controlled, the quality of life of the child becomes better and his/her capacity of learning will also improve. Latest technologies such as MRI help in obtaining a more precise investigation with the result that the medication can be better targeted and monitored. It is also important that all those involved with the child are knowledgeable about epilepsy in order to catch it early.

Two points present themselves. We have heard about the learning effect on the child, and how others look at it. If epilepsy is treated you can live a normal life and you can develop your abilities to the full. We need to address the impact that might keep the child from having the same experiences as other children. Once epilepsy is diagnosed, we need to focus on the development of the abilities in the different aspects of their lives.

We all know the effects of stigma, how the child is considered different. This has a great impact on the social and psychological life of the child. It is natural for the parent in particular to be anxious about the condition of the child. We need to address their anxiety in order for them to help the child lead as normal a life as possible.

We have heard on the impact of epilepsy on the child, how the child may have learning difficulties and how they may not meet their full potential. We have children with difficulties in learning but we also have children with epilepsy who have a normal IQ. Most of the ill effects are due to negative attitude, lack of expectations, lowering of expected learning standards and their experience of relationships with other children. Epilepsy will have its own effect on the child, worries and fears and other anxieties about fits in public, loss of hair etc. the secret the child is keeping will have an effect on the development of the psycho-social life of the child and his/her relationships in society. This in turn may lead to low self-esteem, depression and sometimes isolation. The child needs to be told of the condition. It is very important for the professional who make the diagnosis to explain well to the carers and also to the child. The impact to the child depends also on our approach. There is a tendency for over protectiveness. Care should be taken, yes but indications are that the child can take part in all activities including swimming, so long as someone is watching over him/her. Parents need to be counselled to relate in a positive manner to the child and accept the condition. It is a challenge that parents must overcome with our help. This must be done in the interest of the quality of life of the child. Teachers too have their problems. Lack of knowledge on epilepsy brings with it anxiety. They need to know about epilepsy and how to handle it.

Should one tell ? To have such a secret will effect your self-identity, your self-esteem and your relationships with others. It is better to tell, but we know that parents are often in a dilemma and the answer is not always clear particularly because epilepsy has many forms.

The other problem is the worry of teachers to accept the child in mainstream school on grounds of medical issues. Medical interventions need to be made by a medic and information and collaboration must be shared by all. In my experience, where the parent has not met the facilitator/teacher or other school staff, there cannot be understanding of the needs and actions to be taken. Parents can be of great help in teaching tutors on how to handle the situation and on how to accept it.

To conclude, while recognising the medical aspect we must also spread information on epilepsy, that it is a condition not a disease. The more we understand it the less the chance of the child being isolated and less the chance of them not reaching their full potential and learning. In this sense I auger that the Association keeps up its good work and that a research will be made in Malta on how epilepsy is effecting the life of children, including from the psycho-social point of view. My second recommendation is for the way diagnosis is presented, how it is explained to the parents and the child in a way that they look upon it positively without too much alarm and in order for them to approach their child holistically as before. While facilitators are being trained, there is still a lack of in-service training for teachers in schools. Understanding of epilepsy will result in the child developing his/her skills and receive the necessary experiences for a fulfilled and contented life regardless of epilepsy. Support to children is mandatory. Not all children accept epilepsy in the same way and it is up to us to understand them in order to help them without overprotection but with safety in mind.

To close I wish to accentuate that different people involved must work hand in hand. The system in schools must be effective, continuous communication between parents and teachers; daily problems should be shared. From the medical side, a thorough explanation of the condition should be given. Feelings should be shared, even children with the same problems need to get together as a self help group. For those wishing more information, I refer them to the internet websites on the subject. Thank you