

## **Workshop C - Psychological aspects in children with Epilepsy**

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Facilitator Mr. John Chaplin, report by Victoria Dimech

The work shop started with Mr. Chaplin introducing a profile of a young man, given the age of 16 who has myoclonic seizures, a couple of tonic clonic seizures during the year and absence seizures off and on during the week.

First the group was asked to give possible characteristics for this young man, how his character could be, the problems he might be encountering and how he was coping with his every day life/problems.

Some characteristics identified:

loner, aggressive, moody, strange, defiant, bored, angry etc.

Some problems he encountered:

no friends or difficulty to make friends, no girlfriend, difficulty in keeping up with his friends, feels that he is not like others, teachers/parents over protect him, feels restricted in what he wants to do etc.

Then we were introduced to the 'parents' who were described as 'good parents'

Here again we tried to identify how they felt and what they experienced as from when the mother was pregnant up to the present. This section of the discussion was taken into stages of the child's life i.e. from 0 years, 2 years, 6 years, and teenage.

It was mentioned how the high expectations of when the mother was pregnant were "crushed" when the child was diagnosed as epileptic at the age of two. How the 'bereavement process' takes place and the possibility of the parents never accepting the child as being epileptic.

Shock, frustration, guilt, fishing around for reasons and other diagnoses, family disharmony, pain, sibling rivalry, difficulty to obtain support, lack of information, the dilemma whether to keep the fact a secret from family, friends and school staff and much more were mentioned.

At the end of the workshop we were asked to suggest what could have been done to prevent the child from becoming the 'person' he was today and what help/support was needed for the 'whole family'

The following was suggested:

Proper training in the treatment and handling of patients with epilepsy should be included in the medical training course (when studying to become doctors).

There should be a nurse specialising in Epilepsy so as to act as a medium between families and doctors and who should always be accessible in times of need for all types of information. She could also be instrumental to explain to teaching staff about a child and how to cope with epilepsy in the school (with the parent's consent)

Patients need to have more indepth information regarding medication and their side effects.

More information regarding the condition in the form of leaflets, books, media is needed to make everyone more aware of epilepsy, its effects and how to handle it.

A support group which can be contacted for help when needed (here it was mentioned that such a group already existed through Caritas)

Self help group where families could meet and discuss each other's problems.

Help line

Buddy system where epileptic sufferers are paired and they contact each other for friendship and support. This was felt important because these people can empathise with each other.

Baby sitting which could be arranged between families in order to offer respite of an evening or an afternoon.

Most importantly a transdisciplinary team was deemed of the utmost importance to co-ordinate help, services, support and information to enhance the life of the child and the whole family.