

Workshop C Living with epilepsy and the family.

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Although the session tended to focus more on the younger persons with epilepsy, other age groups were also discussed. The group attending this workshop was quite mixed as it consisted of persons with epilepsy, family members, healthcare professionals, Learning support assistants, support workers, people from employment agencies and other agencies. This could enable a more holistic understanding of the issues being discussed.

Clearly, a sense of fear as in, what to in an emergency, was evident in both family members and healthcare professionals alike. The first episode in particular is very traumatic for both those experiencing the seizure and those witnessing it. Of common consensus was the need to know what to do in this emergency. Living with epilepsy or living with someone who has epilepsy is a learning curve. Having a formal plan was suggested, but this a bit problematic due to the various types of epilepsy. The use of videos in epilepsy education demonstrating the various forms of epilepsies were deemed as necessary. It is obvious that a very important aspect of tackling epilepsy is that of the medical management. Nevertheless, nowadays we are moving away from the medical model towards a more holistic approach which in this case is person and family - centered approach to care. The aim is to promote a sense of being in it together where there is mutual support. The information provided by the family in particular observations of seizure episodes, the keeping of diaries of seizures and videoing of seizures together information progress at school or at work with are vital in providing the medical care plan. However, healthcare professionals care also be there to help families in other ways and it is important that the need for this help sought, identified and provided. Persons with epilepsy and significant others pass through a grieving process and fears, guilts, hopes and questions such as "Why me?" are not uncommon. A person and family centered approach is important here with provision of psychological help ideally through timely counseling for early identification/ prevention of any problems.

The main goal of all parties is to aim for as normal quality of life as possible even when the condition is severe. Central to increasing the quality of life is accepting the condition and thus aiming at normalising the condition. A main goal is to try and reduce the chance of isolation of all parties involved as much as possible. People need to be aware that they are not the only ones and this is especially true for the younger generations. Networking, peer support which increase motivation and informal chats which decrease the stigma of the condition were all seen as means of decreasing the sense of isolation that might arise. The use of humour and having a positive outlook was suggested as a means of maintaining a good quality of life despite things might not always be well

The valuable help of support workers and carers provided through agencies such as Agenzja Appogg was mentioned. Regrettably these are not always present. The fact that no rehabilitation schools that can also act as respites are present locally was also highlighted. There were some mixed feeling regarding epilepsy and schools. Children spend a lot time at school. Some mentioned that some schools do try hard to help the child with epilepsy and in cases the provision of a learning support assistant helps a lot. However, it is important that the teachers are aware of

the condition. Also, teachers need to be knowledgeable and need to know what to do in an emergency. It is evident that some schools and teachers still fail to have enough knowledge on the condition and how to give first aid in an emergency and panic when a student has a seizure. Additionally, the witnessing of an epileptic seizure is a traumatic in particular for other fellow students and both embarrassing and traumatic for the child. Some suggestions to minimize these included age appropriate talks for students, educational programmes for schools and the use of visual aids especially video teaching and first aid teaching. Of particular interest was the mentioning of an award scheme introduced in the UK where schools who demonstrate positive supportive and learning environment for students with epilepsy especially by involving other students are rewarded for their efforts. Such a scheme acts as an incentive to increase awareness regarding epilepsy.

It was also mentioned that siblings of persons with epilepsy (younger people) need to be included and motivated. This is enhanced through age appropriate explanation of the condition and motivating the sibling. All this is done to try to decrease the chance of sibling rivalry escalating due to the other sibling feeling left out. Adolescents with epilepsy were also discussed. Person with epilepsy and parents of persons with epilepsy recalled how adolescents have a better understanding and awareness of the condition. One issue highlighted was that of the social life of youths. They stressed that one has to create a balance between giving independence and protecting the youngster with epilepsy.

All in all this fruitful workshop had very positive outcomes. Living with epilepsy is far more than tackling the medical aspect of it. One has to aim for a good quality of life. The need of support both formal and informal and education were highlighted as being important aspects of daily living of a person with epilepsy and the family and others who play an important part in their lives.