

## **Workshop B How can an Epilepsy Nurse help?**

**Moderators: Ms Christine Bennett and Ms Caroline Attard**

**Rapporteur: Ms Victoria Dimech**

During this workshop those present discussed what could be done to get a quicker, fairer and more efficient health service for people with epilepsy. At present there is inequality in the services given since in other areas such as in diabetes and multiple sclerosis and others there already exist a nurse specialised in the area and considering that epilepsy is the most common neurological disorder and it afflicts 1% of the population, nurses specialising in this area would go a long way to make the service more efficient.

One important factor which an epilepsy nurse/s could cover is to liaise between health care professionals mainly neurologists and patients. She would be an important link because she could spend more time with the patients, listen to their stories, build a rapport and look deeper into what the person needs and not just his immediate medical need. She could also give advice as to what other service could be used, enquire about why in some instances there is no compliance with doctors orders and medications and also look into the social requirements that particular person would need. A more holistic view of the needs of the person can be taken since the nurse could afford more time.

The Epilepsy nurse can also be a tool for dissemination of information. She can carry out courses to educate all people from all walks of life on what epilepsy is and how to manage it including first aid management and also produce material on the subject which can be used by anyone.

Train the trainer courses could also be organised to enable other professionals especially those in the voluntary sector and in turn these could train other people.

**Five main objectives were identified by the end of the session namely:**

### **1 Adult Epilepsy Nurse**

What would be the best option for our health system at the moment?

An analysis is needed to see whether having one full time nurse or two part time nurses would be better suited to have a continuity of service. It was also important to identify whether this would be a nurse for the paediatric unit or for adults. Those present expressed the opinion that since the paediatric unit was very satisfactory and well handled, at the moment it would be best to have epilepsy nurses for adults to start with. It was also suggested that the nurse could be one who already worked in the neurology dept so that she would already have a sound knowledge of what the job would entail however specialised training would be needed in order for her to carry out the role of an epilepsy nurse. We could also liaise with the services given abroad so as to know what the role is all about and what type of training is needed. Having said that, any nurse from other departments and interested in this role could apply for the training.

### **2 Patient User Group Involvement**

One thing which was quite evident was that patients often complain that they are not actually listened to when they are seen by their physicians. It was felt that they were undermined and told that the doctors know best and that their opinion was not very well accepted.

It is important that the patient's opinion is given priority in discussing the type of treatment he is given. Many often we believe that professionals know best however the PWE knows what he wants and feels and has a right in the decision making of his/her treatment. Sometimes they opt to have the risk of more seizures vis a vis a better quality of life. All medications have their side effects and the patient has a right to agree or disagree with the treatment given. Patient user groups aid in listening and guiding their members and share information. Discussion and dialogue are paramount to respect the rights of the patient.

### **3 Education**

Education across the board is needed. Lack of it results in fear, misconceptions and lack of service. The more people know about the condition the more they can help. Unfortunately stigma still persists and this causes a lot of pain to PWE and their families during all the phases of their life. Parents tend to overprotect, schools are not well informed and are not equipped to deal with seizure situations, children are not handled properly and are at times withheld from certain activities for fear of a seizure, during adolescence and adulthood they are discriminated against especially when they want to find a job not to mention other areas such as relationships. Education is the solution to many problems that PWE face. The condition itself is a challenge however the lack of knowledge and education about it can cause havoc in a person's life

### **4 Better communication**

It was felt there is lack of communication between stakeholders. Educators who were present said that very often they are not informed about what they are dealing with and because of the data protection act they said that they are not told that a child has epilepsy (or other disabilities for that matter). This is a very dangerous and unfair situation both for the teacher and the student. This is putting the life of the student at risk and the teacher's position compromised. Train the trainer courses would be very helpful not only for teachers but for everyone. There should also be a person responsible at workplaces who is educated enough to be able to manage seizures should one of the employees have them.

### **5 Mandatory training updates**

It is important that professionals are kept abreast of developments in their areas of expertise. Not only health care professionals but all professionals need to have mandatory training courses in order to always be more proficient in what they do. Graduating in whatever area is only the first step and professionals need to keep on learning and refreshing their knowledge in order to give the best service to their clients.