

Workshop B: Finding Help: Adults

Moderators: Dr Josanne Aquilina, Mr Matthew Attard

Rapporteur: Ms Claudine Aitkens

First Aid in epilepsy

- The workshop started with a discussion on first aid treatment for persons having an epileptic seizure. A general summary of the treatment was outlined. However it importance to the issue of safety for both the rescuer and in particular to the person having the seizure was given. This is because of the long term consequences that an injury during a seizure especially caused by the fall can have on the person with epilepsy. It was also highlighted that the use of mouth gags during the seizure is contraindicated. The importance of positioning a person in a left lateral recovery position was also highlighted. Persons queries regarding when one should call for an ambulance. It was stressed that seizures of 5 minutes or more in duration necessitate emergency care however complications arising during a shorter seizure would also warrant calling for an ambulance.
- At this point the issue of monitoring and recording the seizure was discussed. The role of the witness taking notes of the duration albeit difficult at times and nature of seizure was highlighted. The issue of videoing of seizures was questioned in particular when bystanders might be agitated, take time to access camera or fail to record the seizure.
- The use of drugs by family and carers during a seizure was brought up. The use of buccal midazolam was mentioned but its use in this particular situation is off license and it is highly sedative and thus one has to be careful when prescribing it. With this in mind one should place more importance on providing good quality first aid.
- Here it was evident that first aid education is of utmost importance. It was pointed out that Caritas Malta provides such information to those requesting it. Persons attending the workshop voiced their concern re. lack of first aid knowledge on the workplace. It was stressed that local Occupational Health and Safety Legislation calls for mandatory First Aid training on the workplace and that all major local first aid training providers include first aid for the main two types of epilepsy in their curricula.

Stigma in epilepsy

- There was general concern that the stigma of epilepsy might stem from the fact that there seems to be a lack of education re the condition especially at schools and at the workplace. This lack of education might also lead to educators failing to provide the support necessary. Here it was made clear that Caritas Malta Epilepsy Association does provide education to various entities free of charge on request. One of the CMEA educational endeavors is that of the inservice training for teachers, which unfortunately is poorly frequented. The Department of Health has also its Information department that can provide such information. Once again it was stressed that the Role of a Clinical Epilepsy Nurse Specialist would definitely be of valuable help. CMEA also has various educational pamphlets which can be given to family, teachers friends etc. the use of media was suggested as a potential means of education. However, this would involve the need of funds which is not always readily available for a NGO such as CMEA and epilepsy education through the media might be less difficult to achieve by governmental entities.

Safety in epilepsy

- The issue of safety was once again brought up and the perceived lack of protective and safety medical equipment. Locally, the services of Occupational therapy department which are free of charge can be sought and home visits for assessments can be made and

evidence based suggestions are made. Also, one can have alterations done to the home and at times even order safety helmets done free of charge. The use of the local OT department was highly encouraged.

- Adulthood brings with it different challenges for a person with epilepsy. Firstly there is the issue of independence that might be effected by the need to be supervised. This is particularly true when one for example goes to swim which regardless of the fact that one might be seizure free a certain level of supervision is needed. One might feel that the independence is threatened and at times still feel like a child. Although sports is highly encouraged it was highlighted that at times this needs to be discussed with professionals and some sports might not be as safe as others.

Work and Epilepsy

- Adulthood also brings with it the issue of work. One should discuss this issue with employment agency and the best solution for all parties especially the person with epilepsy is found. Driving is another issue that was highlighted. It was pointed out that legislation calls for one to be certified by the Consultant neurologist as being seizure free (regardless of the type of seizure) on antiepileptic drugs for one year. However there are cases where people continued to drive despite not supposed to. In these cases, people were reported to the local transport authority. When heavy vehicles such as trailers are involved one has to be seizure free for 10 years.

SUDEP and dental care

- The issue of sudden death in epilepsy was brought up. However one has to bear in mind that warning signs exist and this is highly attributed to pts who fail to comply its treatment or stop taking treatment abruptly.
- A concern of an amount of people present was that of dental care. The concerns were twofold: Damage to the teeth due to seizures and Damage to gums and teeth due to antiepileptic drugs. Unfortunately there are no dentists who specialize in caring for people which present with dental and oral problems secondary to epilepsy and it's treatment. The use of bridges, retainers and splitters during sleep were mentioned, however it is important that one's dentist discusses things with the caring neurologist. It is important to note that not all antiepileptic drugs affect teeth and gums. Phenytoin is the main culprit and thus oral hygiene and checkups is encouraged if persons are taking phenytoin.

Antiepileptic drugs

- This discussion led to that of antiepileptic drugs, especially there was a general concern on the long term effects. First line drugs such phenytoin. Second line antiepileptic drugs such as vigabatrin. The neurologist takes an evidence based and educated decision in deciding which antiepileptic drug/s to start. This depends on the sort of epilepsy. People were reassured that the treatment given is that most beneficial and that which causes less harm. Each drug has its pros and cons one sees the risks and benefits and a calculated decision is made. Persons were concerned re the interaction with other drugs (polypharmia) and other conditions such as mental health or (co-morbidities) issues are involved. They were reassured that the various specialists discuss things between them for the best course of treatment and here the importance of a multidisciplinary team was key.
- Another issue in adulthood is the use of certain drugs in female of childbearing age. It was highlighted that sodium valproate (epilim) is contraindicated in females of childbearing age and thus seldom used. However it is important that pregnant women with epilepsy discuss their treatment with the neurologist. The use of folic acid is highly encouraged. Also due

to the disastrous effects that stopping AED's might have on both the baby and mother outweighs the potential risk of continuing AED's in pregnancy and lactation and continuing Antiepileptic treatment is strongly encouraged.

Triggers in epilepsy

- The discussion then proceeded to discussing the various triggers. Flashing lights, particular smells, withdrawal and low compliance, alcohol and use of recreational drugs and other stimuli were all mentioned as potential triggers. Of particular importance to those present was the use of information technology devices such as computers. It was suggested that epilepsy which is of photosensitive origin can be minimized with the use of screen glare guards. A major trigger that might not come to mind is that of sleep deprivation, in fact a minimum of eight hours of sleep are suggested. Another trigger was that of stress and heightened anxiety, here the roles of the psychiatrist who prescribed treatment and the psychologist who listens to the patient and can suggest coping skills were highlighted.

Psycho-developmental aspects

- Those present for the workshop were concerned about the psycho-developmental implications of epilepsy in particular in late adolescence and early adulthood. They stated that there was lack of support network for the younger adults and youths especially during postsecondary and university life. It was here that it was brought to their attention that CMEA has a youth sub-committee. The role of a Nurse specialist was highlighted and the valuable work that can be done to ease the difficulties this age group could encounter especially when educating friends and teachers and lecturers. Counseling services provided by educational institutes can help a lot however one has to keep in mind that a great challenge is that at times people hide their diagnoses from fear of being isolated or being bullied due to the stigma. Hiding the condition for instance might lead the young adult to uptake activities with friends which might trigger a seizure. It is not unknown that friends willingly take an active part in helping a friend to live with epilepsy and for this reason, parents should be the ones to encourage their children not to hide their condition.

Stigma and other issues

- The issue of hiding the condition due to stigma might was mentioned as one of the reasons for a substantial amount of people not wearing medical alert bracelets or carrying the Epilepsy identification cards which are issued by CMEA. It is difficult to find persons carrying medical alert bracelets locally. Such aids would help medical personnel to reach a diagnosis earlier.
- The next topic of discussion was that of nomenclature. It was made clear that seizures and convulsions are used interchangeably. One has to point out that the term "tal-qamar" is highly degrading and such term stems from an old wife's tale which is completely untrue and thus unacceptable.
- The last topic covered was that of various warning devices that exist on the market. One has to pay attention to the fact that the efficiency such devices need to be backed by a sane, rigorous and vast high level of body of evidence. The use of therapy/guide dogs for persons with epilepsy has saw a recent increase. Although these dogs are being used locally one has to point out that the training of these dogs is expensive.
- The take home message for this workshop was that despite of the various actual and perceived hurdles, help is available and one should never give up.