

Workshop A: Finding help: for children

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Major challenges bringing up children with epilepsy

- Lack of openness from schools to receive information. At times schools receive information with fear rather than to empower and know what to do. Teacher over reacting towards child
- Recently, it is understood that Diazepam can be left at the school and administered only by first aiders if on site. Difficulties arise when a school does not have a first aider or first aider is off duty.
- Concerns with administering rectal valium in schools. Issues of lack of privacy and difficulties with administration. The current oral midazolam is reconstituted from intravenous midazolam and thus has a short shelf life of one month.
- Lack of advice given to parents from hospital emergency.
- Memory issues caused by epilepsy or med

Suggestions

- Pick out key people from the school, such as assistant head, inclusion co-ordinator and first aider. This contact person would receive information about what to do in event of a seizure.
- Bring school council on board with regards to diazepam / oral midazolam storage and administration. Speak with class children to help them understand when child has seizure in class Student services department offer support, guidance, specialised teachers and provide additional help in a classroom setting.
- Insist that child goes to a school with a first aider and Advocate for availability of buccal midazolam or nasal midazolam.
- Algorithm with details to read quickly to ambulance in emergency; Technological devices; Seizure monitoring mattress; Embrace watch is not supported in Malta; SAMI Camera in range of wifi; Pulse guard monitors a change in heart rate
- Psychological support and Psychological help not just medical treatment.
- Living with anxiety of not knowing when the next seizure will be.
- Communicating with children: Importance of information giving to the child and How to speak to a child and Allay fear of death; Never underestimate the psychological and emotional impact on the child. Counselling child psychologist could help in this process. A child may be puzzled by the news. Children do not want to be different from other kids.
- Family camps. Already being organised by nurse specialist for children with diabetes.
- Telecare for families and Parent facebook groups that share epilepsy experiences
- Exercise improves learning ability; Different methods of learning; Reassurance

Cannabis?

- Complex substance – 400 different chemicals
- Cancer treatment and neurological treatments; Small studies undertaken; Used as a medicine for compassionate use; Long term use may give paranoia; More research is required. Keep scientific approach; Not panacea