Caritas Malta Epilepsy Association

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When your child faces health problems, whether they are short- or long-term, you face many different feelings and challenges as a parent. When our son was three years old, he had his first seizure. Soon after he had a second seizure, and we began learning about parenting a child with epilepsy. It was two years later before we learned about the Caritas Malta Epilepsy Association (CMEA). What a blessing it is to find people who understood firsthand what it is like to deal with the challenges of epilepsy.

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Epilepsy is diagnosed when a person has two unprovoked seizures. There are over 40 different types of seizures, affecting people in various ways according to where in the brain the problem is occurring. Recently, with the help of the Ministry for Inclusion, Voluntary Organisations and Consumer Rights and the Freedom to Live Grant 2022, CMEA was able to produce some new material for training and educational purposes. The Malta Health Network helps smaller organisations such as CMEA to work together and have a stronger voice. We partner together at school fairs and on nationwide issues too. Another partnership that has been fruitful is collaborating with MCAST and their Community and Social Responsibility volunteers. Graphic Arts student Matthew Theuma helped produce CMEA's newsletter and designed the t-shirt logo. On 13 February we joined people around the world for International Epilepsy Day and officially launched the material, including our #1in100CMEA campaign. Did you know that 1 in 100 people suffer from epilepsy? If you are not around someone when they are having a seizure, and sometimes even when you are there during a seizure, you may not even realize that it is occurring.

CMEA is currently working on two different challenges. The first is rescue medication, which is given to adults and children if their seizures do not stop within five minutes. Presently the only one available in Malta is rectal Diazepam. Since 2006 CMEA has been campaigning to bring an alternative rescue medication such as buccal or nasal Midazolam to Malta, meaning that instead of administering the medication rectally, it would be given in the mouth or nose. This would reduce the stigma and embarrassment of the person with epilepsy and ease the burden of caregivers of clients in wheelchairs. Midazolam has been used for years in the UK and has an effective track record. This would also increase the possibility of having rescue medications available in schools. My son is now 15 and in another school system, but when he was attending government schools, I always felt the need to be nearby in case he had a seizure. Due to school policy and the delivery mode, his rescue meds (again, supposedly delivered after five minutes) could not even be kept on the school grounds. This MUST be addressed. His school administration did their very best to work with us and when he had some seizures at school, he always received excellent care, but it usually involved an ambulance ride and an overnight hospital stay too.

Secondly, CMEA would love to see the availability of an epilepsy or neurological nurse. Due to the very individual nature of a person with epilepsy seizures, many times they need to have someone to ask as they go on and off different medications and experience variations in their seizures. Again, I will be quick to point out that we have found help and support every time we needed it but having a specialist nurse would provide more support for the neurologists and give people with epilepsy and their caregivers someone to contact and perhaps even provide proactive care.

Over 70% of people with epilepsy eventually find complete control of their seizures with daily medications, but there are some that still experience seizures. If you would like to know more about the bi-monthly meetings at the Caritas Community Centre send an email to: *maltaepilepsy@gmail.com* or *https://www.caritasmalta.org/cmea/*

Reach out if you or someone you know has epilepsy or if you would like to receive information about free training. Our committee is 100% volunteers, but we are happy to work with you for "a better life for people with epilepsy in Malta".

Robin Pinkston is secretary of Caritas Malta Epilepsy Association

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