

Epilepsy ToolKit



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DISCLAIMER

The purpose of this toolkit is to initiate a discussion on how to find help on epilepsy. It is not intended to provide people with instructions on how to manage epilepsy on their own.

The information contained on this toolkit is for information purposes only, and you assume full responsibility and risk for the appropriate use of medical information contained herein. Do not make changes in your treatment, including medication or lifestyle, as a result of any information you read in this toolkit, and be sure to consult with your doctor before changing any medical treatment.

While CMEA takes pride in providing accurate and up-to-date information about epilepsy and its consequences, there may be omissions or inaccuracies in such information and on this toolkit.

CMEA does not guarantee the accuracy or completeness of its information or services, and specifically disclaims any liability thereof. It is always important to consult a doctor.

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Introduction about the toolkit

There are more than 4000 reasons for this booklet. That is the approximate number of Maltese who have epilepsy. Indeed, epilepsy is one of the most common neurological conditions affecting more than 50 million people globally.

You may see people with epilepsy every day and not even know it. People with epilepsy look just like everyone else ... except when they have a seizure.

This toolkit has two main purposes. If you are someone who frequently deals with the public, this should help you recognize a seizure and give basic first aid if it is needed. Secondly, the toolkit is designed to provide basic information to equip people with epilepsy to have a better quality of life.

Epilepsy, being a hidden disability, can create challenges. For many people with epilepsy, the stigma related to the condition is more difficult to deal with than seizures.

However, with education and proper adjustments, considerations and understanding, people with epilepsy can lead a normal life. In fact, many

famous people had or have epilepsy like Julius Caesar, Alexander the Great, Vincent Van Gogh, Ludwig van Beethoven, Agatha Christie, Danny Glover, Rap Superstar Lil Wayne, Olympic Athlete Dai Greene, former professional football player Jason Snelling, legendary singer Neil Young, Britain's Got Talent singer Susan Boyle and many others. If you have more questions or want more information, please do not hesitate to contact Caritas Malta Epilepsy Association or refer to our website to attend one of our bi-monthly meetings.

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Frequently Asked Questions

What is epilepsy?

According to the Epilepsy Society (www.epilepsysociety.org.uk), epilepsy is a neurological condition where there is a tendency to have seizures.

A seizure is caused by a burst of abnormal electrical activity in the brain. This means that having one seizure does not necessarily indicate epilepsy. In fact, many times people will have a single seizure and never have another one again.

How many people have epilepsy?

Epilepsy is a common neurological disorder affecting 1% of the population. In Malta there are over 4,000 people with epilepsy. Anyone can develop epilepsy, but it often begins in children or in seniors over the age of 65.

What are the types of seizures?

There are over forty types of seizures depending on the part of the brain affected by the extra discharge of electrical activity and what that area of your brain controls. The most widely recognized seizure is called a generalized tonic-clonic seizure and this affects the entire brain from the start. The person will lose consciousness, fall and their arms and legs will begin to shake. Other types of seizures known as absence seizures may involve staring blankly for a few seconds. In focal seizures the person involved may become confused and behave in an unusual way.



How is it diagnosed?

Epilepsy is a clinical diagnosis. Descriptions of the event by an eyewitness can be very helpful if the person has lost awareness or consciousness. Investigations such as an EEG (electroencephalogram) may be performed. An EEG tracks and records brain wave patterns. It is a painless procedure and can last anywhere from 20 minutes to a full week. An MRI (Magnetic Resonance Imaging) or a Computerized Topography Scan (CT) might also be recommended by the clinician.



What causes epilepsy?

There are several conditions that may lead to the development of epilepsy including a genetic tendency, stroke, head injury or infections. In certain cases no cause is found. About 70% of people with epilepsy will be controlled with Anti-Epileptic Drugs (AEDs). Others are candidates for surgery depending on the assessment of neurologists and neurosurgeons.

What triggers seizures?

Sometimes there are no known causes, but certain situations such as stress, sleep deprivation and alcohol abuse or withdrawal can increase the likelihood of a seizure.

What first aid procedures are recommended during a seizure?

If a person is having a focal seizure, stay with them and guide them away from danger whilst reassuring them. In some situations where seizures are prolonged, the doctor may also suggest “rescue medications”. However, this depends on the case and the advice given by the caring physician.



If the person is unresponsive:

- It is important to keep calm.
- Time the seizure.
- Cushion the person's head.
- Put the person into the recovery position (on their side) after the shaking stops.
- Stay with them until breathing returns to normal.

When is urgent assessment by a doctor recommended?

If the person:

- Is having a seizure for the first time.
- Is injured.
- Is diabetic.
- Is pregnant.
- Has a seizure in water.
- Has a seizure a short while after the first.
- Is not breathing properly.
- Has a seizure that lasts longer than 5 minutes.

If in doubt, seek medical advice.



Is there anything that one should not do during a seizure?

- Do not hold them down. Let the seizure happen.
- Do not put anything in their mouth.
- Do not move them unless they are in danger.

Can a person with epilepsy live a normal life?

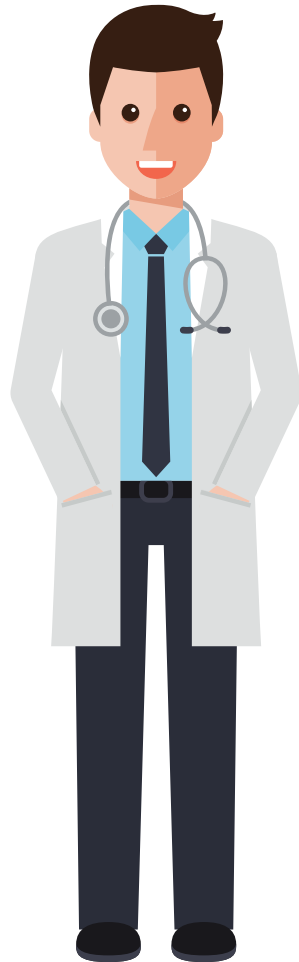
Yes, a person with epilepsy can live a normal life with some small adjustments. Almost 80% of people with epilepsy are able to have long periods in life where their seizures are controlled by medications. Some even go into remission. Unfortunately there are still some whose epilepsy is resistant to anti-epileptic drug treatments. However, this is improving thanks to continuous research and breakthroughs in technology.

Newly Diagnosed?

What should you ask your neurologist?

Preparing for your appointment: (Adapted from www.epilepsy.org.uk)

- If possible, take someone who witnessed your seizures and can fully explain what they saw with you.
- Keep a seizure diary - a record of when you have a seizure, what happened, how long it lasted, and the surrounding circumstances.
- You may prepare notes or a set of questions to ask.
- While talking with the neurologist, make sure your questions are answered. If you do not understand, ask the question in a different way.
- It would be a good idea to ask for written instructions regarding medication and first aid.



Some questions to ask: (Adapted from www.epilepsy.org.uk)

- Why do you think I have developed epilepsy now?
- What type of epilepsy do I have?
- What is the prognosis for my type of epilepsy?
- What are the side effects of the medication I will be taking?
- Which side effects are important to seek medical attention about?
- When should I take my medication?
- What do I do if I miss a dose or in the case of vomiting or diarrhoea?
- What happens if this medicine does not work?
- Can you explain how driving regulations will affect me?



Information for Parents/Caregivers

(Respite Centres and Homes for the Elderly)

Epilepsy is a serious yet treatable brain disorder. When a person is first diagnosed with epilepsy there will often be more questions than answers. It is good to know that some seizures are easily controlled with medicine and can eventually be outgrown, while other types can create difficult challenges.

How Caregivers Can Help

- Researching about epilepsy is important.
- Know seizure first aid.
- Do not say things that could make the person feel like a problem or burden.
- Be positive!
- Encourage them to take up sports, hobbies and other interests.
- Work with him or her to explain epilepsy to friends, relatives, teachers and others.
- Continue family activities and traditions as normal.
- Keep a clear record of the seizures in a diary.
- Medical appointments should not be missed.
- Encourage the person to lead a normal and independent life.



Tips for a Safe Environment for a Person with Epilepsy:

- Keep all medications in a safe location.
- Encourage showers instead of baths.
- Advise the person with epilepsy to avoid heights.
- Swimming alone should be avoided.

It is crucial as a parent or caregiver that you find the support you need and that you take time for yourself to rest.

At **Caritas Malta Epilepsy Association**, you can meet others who will understand, help, and support you. We promote education and local awareness about epilepsy, especially given the stigma suffered by people with this condition in society. Our campaign is aimed at improving health care services, treatments, social acceptance, and improving the quality of life for people with epilepsy and their families.

Joining our association can help you build a support network and keep you informed of any ongoing research and new developments.

Note for Respite Centres and Homes for the Elderly:

Epilepsy often begins in seniors aged 65+ due to strokes or other health reasons. In fact, the prevalence of epilepsy in the elderly is around 10% compared to 1% in the general population. It is important that seniors find help and support when they are diagnosed with epilepsy.

If you are a caregiver at a respite centre or home for the elderly, it is important to note the need for accurate timing of medications. It would also be helpful to record the time and duration of seizures to let the relatives and doctors know the person's medical history. If possible, take a short video of the event to help the doctor during assessment.

If you would like **Caritas Malta Epilepsy Association** to give training sessions at your respite centre, please do not hesitate to contact us for more information at:
maltaepilepsy@gmail.com

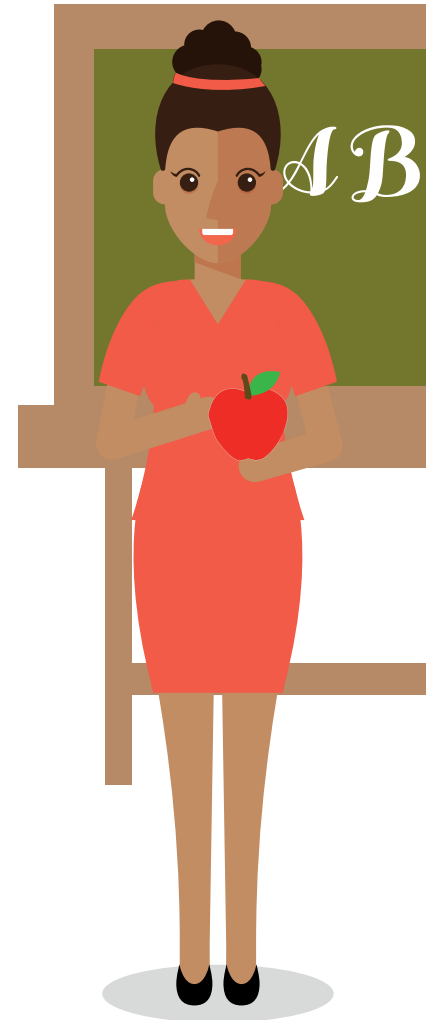


Information for Teachers/ LSEs

Teachers and Learning Support Educators (LSEs) will many times be the first to recognize that something is amiss when seizures start in childhood. It is important that they know the different types of seizures and what to do if they happen. If not, they may think the child is daydreaming. It is also critical that teachers and LSEs refer to the First Aid information so that they will be prepared if needed.

Absence seizures are easy to miss. The student may have very short moments, even just seconds, when they blink and lose awareness. Another sign to pay attention for is a sudden regression in the student's education and attention span.

Many children with epilepsy have no problems in school, particularly those whose seizures are controlled with medication. A diagnosis of epilepsy does not mean that a child is intellectually challenged. However, certain obstacles may be encountered. While there have been many improvements in medications, certain anti-epileptic drugs can affect concentration and cognitive function. There may also be behavioural problems or mood swings when there are changes in medication. Seizures may disrupt sleep leading to memory problems. Sometimes the student may be experiencing seizures in the classroom that are not visible to the teacher or LSE. Some people with epilepsy experience anxiety or stress induced seizures as well.

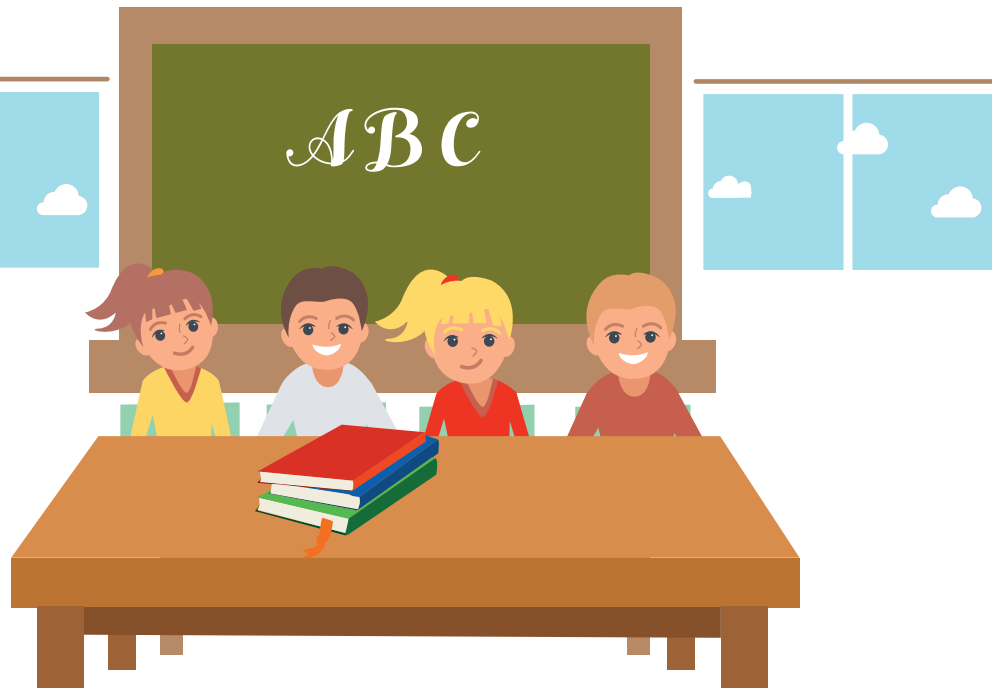


Information with respect to Employment

Proper attitudes and expectations are key to the success of the child. If a teacher or LSE can communicate with the child's family and doctor and understand the best way to help him or her, then great progress can be made.

Where a child who has epilepsy is thought to be underachieving educationally, or is experiencing learning or behavioural problems, the situation should be investigated fully. The child's medical treatment may need to be reviewed to establish if the problems are related to the seizure disorder or its treatment and, ideally, the child should have a full psychological assessment.

If you would like more information or for volunteers from **Caritas Malta Epilepsy Association** to give a session at your school, contact us at: maltaepilepsy@gmail.com



With patience, perseverance, and a positive outlook, most people with epilepsy are able to find work that they enjoy and that allows them to successfully use their skills and talents.

In certain situations it would be wise and safer for the person with epilepsy to let their employer know about the condition. One may opt to prepare a care plan. This can include what typically happens during seizures, how often they occur, and how others can help during and after a seizure if it happens on the job. It would also be good to indicate if there is an aura before a seizure and the normal duration. The more people learn about seizures and first aid, the more they will be able to help if seizures happen at work. Increased education reduces stigma.

When it comes to seeking employment, people with epilepsy can apply with Jobsplus to have their name in the appropriate register as per LN 156 of 1995. They will then be referred to a Placement Medical Officer who will assess their employability within the context of their abilities and once confirmed they will be referred to an occupational therapist. Following the OT assessment, they will be referred to the Lino Spiteri Foundation (LSF) who will support them through initial registration, advisory assistance, job search, job matching and on-the-job support.



Information for Police

It is vital that police realise how common epilepsy is particularly when dealing with crowds given that one in every hundred people has the condition. The more police can learn about the various types of seizures and how to give proper first aid, the more they will be able to respond efficiently and responsibly.

Odd behaviour displayed by a person having some types of seizures may mimic someone under the influence of alcohol or drugs. It would be helpful to look out for epilepsy identity cards, medic alert bracelets or dog tags that people with epilepsy carry to describe their condition.

Police should also follow the first aid procedure indicated in this toolkit, including dispersing the crowd that may gather.

Caritas Malta Epilepsy Association has regularly provided a 90-minute lecture to new recruits of the police force and plans to continue to do so.

Contact us at maltaepilepsy@gmail.com if you would like more information or training.



Conclusion

A journey of a thousand miles starts with a single step. By reading this, you have taken that step that will allow you to help people with epilepsy and their families. After all, education is power and that is what we need to fight the stigma associated with this condition.

The Caritas Malta Epilepsy Association wants to be a source of information and support in this journey so please contact us with any questions or concerns.

We also need your help! If you would like to become an advocate or trainer and help with our free educational campaigns through your personal experience let us know.

The more persons with epilepsy speak out and share their stories, the less the stigma will be. Raising public and professional awareness and dispelling myths about epilepsy is one of our key objectives.

Over the past years our promotional and educational campaigns of the various aspects of epilepsy have included talks on T.V. and radio; lectures at schools and parishes; articles in the local papers; a production of a video/DVD on epilepsy in Maltese and distribution of flyers translated into Maltese. Patient diaries and patient identity cards are also available. Membership is FREE. Bimonthly meetings for members are held on the second Friday of the month.

Whatever is discussed during these meetings is kept strictly confidential. To find out when the next meeting is, check our Facebook page or website at www.caritasmalta.org/epilepsy.

Donation to support our educational campaigns and conferences can be made to:

Bank: **Bank of Valletta**

Beneficiary: **Caritas Malta Epilepsy Association**

Account number : **40012251483**

IBAN: **MT44VALL22013000000040012251483**

SWIFT Code: **VALLMTMT**

Glossary of terms

A&E - Accident and Emergency

AED - Anti-Epileptic drugs

CMEA - Caritas Malta Epilepsy Association

CT Scan - Computerized Topography Scan

EEG - Electroencephalogram

MRI - Magnetic Resonance Imaging

PWE - Person(s) with Epilepsy

LSE - Learning Support Educators

OT - Occupational Therapist

List of useful contacts

Caritas Malta Epilepsy Association

www.caritasmalta.org/epilepsy

5, Lion Street

Valletta

Tel: +356 25906600

Email: maltaepilepsy@gmail.com

Commissioner for the Rights for Persons with Disability

<http://crpd.org.mt/>

Salvu Psaila Street, Birkirkara.

Tel: +356 22267600

Dar il-Kaptan Respite Services

<http://www.darilkaptan.org/>

Rotary Drive,

Triq il-Kaptan,

Mtarfa MTF 1155

Tel: +356 2145 0103/4 +356 7939 7265

Email: info@darilkaptan.org

Dar tal-Providenza

Id-Dar tal-Providenza

Lapsi Road,

Is-Siġġiewi, SGW 2822

Tel: (+356) 21462844

E-Mail: info@dartalprovidenza.org

Jobs Plus Head Office

Birzebbuga Road

Hal Far BBG 3000

<https://jobsplus.gov.mt/>

Tel: 22201403

Email: jobsplus@gov.mt

JobsPlus Sheltered Employment Training

Email address of person responsible:
maria.cacciatore@gov.mt
Tel: 22201722
Email: set.jobsplus@gov.mt

The Lino Spiteri Foundation,

LSF Centre,
St. Louis Street,
Msida
MSD 1464
www.linospiterifoundation.org
22201761 or 22201762
info@lsf.org.mt

Malta Employers Association

<http://www.maltaemployers.com>
35/1, South Street, Valletta VLT 1100
Tel: (+356) 21 237 585 (+356) 21 222 992 24/7 Helpline: (+356) 21 222 006
Email: admin@maltaemployers.com

Mater Dei Hospital

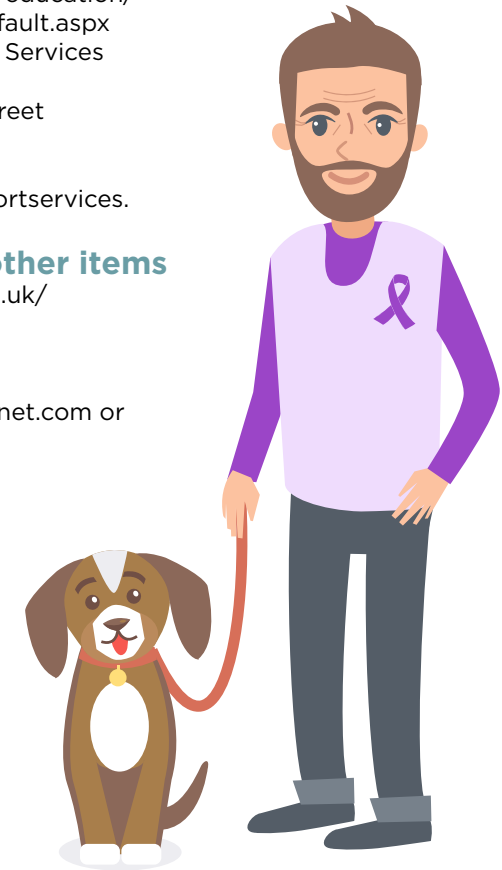
<https://deputyprimeminister.gov.mt/en/MDH/Pages/MDH-Phone-Numbers.aspx>
Msida, MSD 2090,
General Tel: 2545 0000
Tel: Emergency Ambulance 112
Tel: Accident & Emergency Department 2545 4030
Tel: Customer Care Office 2545 4184
Tel: Main Reception 2545 4182
Tel: Neuro Medical Ward 2545 6220
Tel: Neuro Surgical Ward 2545 6210
Tel: Paediatric Day Care 2545 4940
Email: mdh@gov.mt

Ministry for Education and Employment Support Services

<http://education.gov.mt/en/education/student-services/Pages/default.aspx>
Directorate for Educational Services (DES)
Fra Gaetano Pace Forno Street
Hamrun
Tel: 25983494
Email : nationalschoolsupportservices.mede@gov.mt

SOS bracelets and other items

<https://www.sostalisman.co.uk/>
21 Grays Corner, Ley Street,
Ilford, Essex IG2 7RQ UK
Tel: 00442085545579
Email: sostalisman@btinternet.com or maria@sostalisman.co.uk



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**Your condition does not define you.
Your strength and courage does.**

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