

Carpe Diem – Seize the Day Blog

Editor's Note: Content presented in the Carpe Diem – Seize the Day Blog is for awareness and informational purposes only, and it is not meant to be a diagnostic tool.

There are many myths that surround epilepsy. If your child has been diagnosed with epilepsy, it is important to separate fact from myth. What will it take to deconstruct the myths that are out there about epilepsy? Everybody has to re-double their current efforts to get awareness and education information out to the public. If you are involved with a club, church group, athletic team, etc., please let them know that Epilepsy Alliance Ohio can provide the needed education information and awareness training about epilepsy that they need.

Let's take a look at the common epilepsy myths listed below and clear up any false or misconceptions about epilepsy.

Myth: If you have met one person with epilepsy, you have met them all.

Fact: If you have met one person with epilepsy, you have met one person with epilepsy. No two people with epilepsy are the same. They take different medications and different doses. Not all medications work to control seizures. Epilepsy impacts each person differently.

Myth: Epilepsy is contagious

Fact: Epilepsy is not a contagious disease. It is a neurological disease or disorder that is characterized by recurrent seizures. Seizures happen when there is an interruption in the normal operation of the brain.

Myth: All seizures involve convulsions

Fact: Not all seizures involve convulsions – even a brief lapse of attention, muscle jerks, rapid eye movements, blinking, and staring could also be signs of seizure. After a seizure, the person may feel dazed and confused and have trouble remembering what happened. They may also suffer from a headache or feel unusually sleepy or fatigued. People with epilepsy do not get over a seizure, they have to recover from a seizure. Recovery time is different for each person who experiences a seizure.

Seizures can vary in frequency, from as little as one per year to several per day. These seizures can be highly distressing for both the person with epilepsy and for those witnessing them. For many people with epilepsy, a seizure can be preceded by a sense of impending disaster or a sense of euphoria. During a seizure, a person may lose consciousness, their muscles may relax and cause them to fall down unexpectedly, or they may jerk and move about uncontrollably and lose control over their bowels or bladder. A seizure can also cause what sounds like screaming, as a result of muscles tightening around the vocal cords.

Myth: All symptoms of epilepsy are the same

Fact: The difficulty with epilepsy in children is that symptoms are not always the same. Some children will not be aware of epilepsy signs, called “auras”, or if they are aware of them, they will not be able to report them to an adult. Auras can take the form of:

- “pins and needles”
- a jerking of one limb
- a strange sensation in the stomach

The signs will vary according to the area of the brain affected. A child’s seizures may seem generalized to the family, but under closer analysis by a doctor, they can turn out to be partial seizures, which is significant when it comes to the diagnosis and treatment of epilepsy. The other very important factor with epilepsy in children is that kids are still growing and often the manifestation of their seizures is related to how mature their brains are. In an adult, seizures will not change over time. However, in children, the way a seizure manifests can change as their brains mature,” explains Dr Nirupa Shah, formerly a neurologist at the Netcare Milpark Hospital in Johannesburg.

Myth: Epilepsy only affects older children

Fact: Epilepsy can be diagnosed at any age. In the data, there are spikes of diagnoses in ages 0-2 and 65 and older. Epilepsy can affect babies and preschool children, too. With preschool children, the most common seizure is the absence or “petit mal” seizure, in which the child will stare blankly, twitching, blinking, or chewing, but will not respond to a voice or hand movement. “The greatest difficulty with diagnosing absence seizures is that they’re often mistaken for daydreaming. Absence seizures only take a few seconds but can affect a child’s development if they go undetected for too long,” explains Noeline de Goede, a former director of Epilepsy South Africa in a 2011 Living and Loving article, titled ‘Epilepsy in Children’. Epilepsy in babies is often difficult for parents to cope with, as they cannot easily tell whether their baby is upset or frightened and therefore do not always know how to respond when their baby has a seizure. “Because seizures in infants are subtly expressed, it’s extremely difficult to know when a baby is having one. If parents notice something as unusual as a baby’s eyes moving over to one side or jerkiness in his body, they must consult a doctor immediately,” stresses Dr Shah. One of the most critical factors in dealing with babies, toddlers, and small children who have epilepsy is that parents have to be active participants in the treatment process. “Parents must keep a diary card of their child’s weight, the type, and quantity of medication he takes, and when and what type of seizures their child experiences. It is only with this information that doctors can make an informed diagnosis and prognosis. It’s also important that a child’s medication is monitored on an ongoing basis in order to keep his blood levels stable.” The positive aspect of children with epilepsy is that many of them outgrow it and are able to live a seizure-free life.

Myth: All epilepsy is totally treatable

Fact: It is believed that in 66% of cases, medication will control the seizures, provided the diagnosis is correct and the child’s growth and seizures are monitored regularly.

“According to the World Health Organization, in low- and middle-income countries, about three-fourths of people with epilepsy may not receive the treatment they need,” says Dr Chris Nathaniel, Medical Head – Specialty Care at Novartis Southern Africa. “This unfortunate

‘treatment gap’ exists despite the fact that inexpensive medication is available to control epileptic seizures. In fact, studies in both low- and middle-income countries have shown that up to 70% of children and adults with epilepsy can be successfully treated with anti-epileptic drugs (AEDs). Furthermore, after 2 to 5 years of successful treatment and being seizure-free, drugs can be withdrawn in about 70% of children and 60% of adults without subsequent relapse.”

However, there is low availability of AEDs in many countries. In addition, in many communities, fear, misunderstanding, discrimination, and social stigma still surrounded epilepsy for centuries, sometimes making people reluctant to seek treatment. Besides the obvious types of anti-epileptic medication given to children, parents also need to be aware of their child’s diet, which is another factor that affects a child’s tendency to seizures. For instance, children with epilepsy should not eat foods containing a high sugar content or colorants. Some parents put their children on a ketogenic diet, in which the child only eats a diet high in protein and fat, but this is not easy to achieve as the child has to eat exact quantities of fat and protein to make sure he is getting exactly what he needs. Parents must consult an expert in order to get the best possible advice on managing seizures in a small child,” explains Dr Shah.

Myth: It is always possible to find the underlying cause of epilepsy

Fact: Unfortunately, it is not always possible to find the underlying cause of epilepsy. However, the following have been identified as causes:

- Head injury
- Birth injury/trauma, such as a lack of oxygen during birth
- Infections such as meningitis or encephalitis
- Prenatal alcohol and drug abuse
- Metabolic or biochemical disturbances or imbalances

Triggers: Understand that not all seizures have a trigger. When the trigger of a seizure is not known that epilepsy is called intractable epilepsy. It is important to be aware of the trigger factors that may bring on a seizure. These include:

- Forgotten, too little or incorrect medication
- A fever
- Lack of sleep
- Photosensitivity (flickering lights, e.g., a TV screen)
- A startle response
- Illness
- Heat and humidity

Please know that Epilepsy Alliance Ohio is ready to provide epilepsy awareness training along with seizure recognition and seizure first aid training.

Editor’s Note: The Carpe Diem – Seize the Day Blog will be distributed and posted weekly.
Always remember – **CARPE DIEM – SEIZE THE DAY!**

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