

# EPILEPSY AWARENESS MONTH TOOL KIT

November 2016

Your Guide to Creating Epilepsy Awareness



**EPILEPSY  
FOUNDATION**

Eastern Pennsylvania

# EPILEPSY AWARENESS MONTH TOOL KIT

## YOUR GUIDE TO CREATING EPILEPSY AWARENESS

Epilepsy is the 4<sup>th</sup> most common neurological disease after migraine, stroke, and Alzheimer's disease.<sup>1</sup> In fact, **1 in 26 people will be diagnosed with epilepsy at some point in their lifetime.** Yet epilepsy remains misunderstood by the general public, discriminated against, and underfunded in research initiatives. **The fact is that anyone can have epilepsy, and everyone should know about the prevalence, impact and seizure first aid.**

That's why November Epilepsy Awareness Month (NEAM) is so important. **It's our chance to teach others what a seizure is, and is not. Let's dare to imagine a community free of stigma, fear and discrimination against epilepsy.** A community that's safe and supportive of those with seizures. This world—it doesn't have to be imaginary. Work with us to create it.

Throughout the month the EFEPa will work to educate Eastern Pennsylvania about epilepsy through educational conferences, events, lighting up purple, social media campaigns and reaching out to our 18 counties to declare November as Epilepsy Awareness Month. **You can be a part of this too!** Use this toolkit as a guide to **taking action in your community.** Included are ideas and resources that can be implemented anywhere you spend time: school, work, your neighborhood, social groups and places of worship. **By using this guide we can ensure our voice is clear and united.**

If you have questions or want more information, contact Josh Myers, [jmyers@efepa.org](mailto:jmyers@efepa.org) or call 215-629-5003.



<sup>1</sup> "Epilepsy Across the Spectrum: Promoting Health and Understanding." For More Information Visit [Www.iom.edu/epilepsy](http://www.iom.edu/epilepsy) Epilepsy Across the Spectrum (2012): n. pag. [Http://iom.nationalacademies.org/](http://iom.nationalacademies.org/). Institute of Medicine, 30 Mar. 2012. Web. 19 Oct. 2015.

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## EPILEPSY 101: THE FACTS TO SHARE AND KEY POINTS

As an epilepsy advocate, you're going to interact with tons of people—and that's great! But there are many sources of information and it's easy to get facts and statistics confused. Below are a list of talking points, facts and key messages to use when spreading awareness. Statistics are provided by the Center for Disease Control.

- **Epilepsy is a brain disease that causes seizures: abnormal activity in the brain.** These seizures aren't caused by a temporary underlying medical condition like a high fever. A person is diagnosed with epilepsy when they have had 2 or more seizures.
- In approximately **70%** of epilepsy diagnoses, the cause is unknown. Some common causes include; stroke, brain tumor, brain infections, traumatic brain injury and other genetic or neurological diseases.
- **2.9 million Americans have active epilepsy;** meaning they are currently diagnosed and taking medication/undergoing treatment to control it.
- **110,000 people in Eastern PA** are currently living with epilepsy.
- **1 in 26 people will have epilepsy** at some point in their lifetime, meaning they will be diagnosed, but may find medication or treatment to control it.
- **150,000 people are diagnosed with epilepsy each year.**
- **1 in 10 people will have a seizure.**
- Seizures look different for different people; some seizures look like staring spells, others can cause a person to mumble, be unaware of their surroundings, collapse or shake.
- Seizures may last a few seconds or a few minutes.
- **1/3 of people diagnosed with epilepsy live with uncontrolled seizures** because there are no available treatments or medications that work for them.
- **Treatments** for epilepsy vary from medicine, surgery, diets, special devices or electrical devices.

**Common Questions**

**Q: I've heard I should put something like a wallet in a person's mouth while their having a seizure because they might swallow their tongue! Is that true?**

A: No, a person having a seizure cannot swallow their tongue. Never put something in their mouth—it could actually cause them to choke.

**Q: Can someone with epilepsy drive?**

A: The rules vary from state to state, but generally someone needs to be seizure free for a certain amount of time in order to drive. In Pennsylvania you must be seizure free for 6 months. The EFEPA can help someone with epilepsy find transportation assistance if they can't drive.

**Q: Can someone with epilepsy work?**

A: Yes! People with epilepsy can work just the same as you and I. They may need accommodations in the workplace to help make sure they are safe, and that right is protected under the Americans with Disabilities Act.

**Q: Is epilepsy contagious?**

A: No, epilepsy is not contagious. You cannot "give" epilepsy to someone the way you can the common cold.

**Q: Can people with epilepsy play sports and exercise?**

A: Yes, but they may need to be careful. Exercise is rarely a trigger for a seizure, but it's always a good idea to be safe, like having a work-out buddy who knows what to do if you have a seizure and wearing a medic alert bracelet.

**Q: Can someone die from having a seizure?**

A: Sadly, although most people with epilepsy live full, healthy lives, others have died due to having a seizure. The risk of dying for a person with epilepsy is 1.6 to 3 times higher than that for the general population. During a seizure, a person could suffer a brain injury or other kind of injury with fatal consequences.

Another complication is SUDEP: Sudden Unexplained Death in Epilepsy, which is when someone with epilepsy dies unexpectedly and no other cause of death is found. **It occurs in every 1 out of 1,000 person with epilepsy.**

**Q: What can I do to help those with epilepsy?**

A: Having a conversation is a great start! If you hear someone make negative comments about epilepsy, share with them what you've learned. Knowledge is key in creating a safer community. You can go the next step by supporting organizations like the Epilepsy Foundation Eastern PA, who helps those with epilepsy. You can sign up for their e-newsletter or donate to their free programs and services.

**A special word on language:**

So many misconceptions surround epilepsy that someone may accidentally add to the negative image of the disorder merely making the wrong word choice. When talking about epilepsy, try not to use the following terms:

**"Epileptic"**

Like all individuals with disabilities, people with epilepsy dislike labels, such as in "He's an epileptic." This dislike can be summed up by the statement, "epilepsy is what I have, not what I am." The preferred terminology is person with epilepsy or child with epilepsy, rather than epileptic, which can be cumbersome for

headlines, something that is, in fact, rarely an issue. Use of epileptic as an adjective, as in “epileptic seizures” is appropriate.

**“Fit”**

Although the term fit is commonly used by the medical profession in the English-speaking world outside of the U.S., most individuals with epilepsy in the U.S. are particularly sensitive to the description of seizures as fits. The feeling is that this word connotes mental derangement or loss of emotional control. Some associate the word with the symptoms of rabies in animals. Seizures or, in some cases, convulsions, is preferred. Convulsion is a more specific term that more aptly describes a single type of seizure involving muscle contractions throughout the entire body. Not all epileptic seizures are convulsions. Some seizures may amount to only a momentary stare.

**“Control”**

Seizures are controlled with medication, persons with epilepsy are not. “Controlled epileptic” is particularly to be avoided as it often gives the impression that the person needs to be restrained from willful, aggressive behavior. The adjective violent as a description of a seizure is also unfortunate because the term implies a threat to others and a force out of control. Actually, there is no danger to anyone from the seizure.

## EPILEPSY FIRST AID

Because seizures are very common, chances are you will have to help someone experiencing a seizure at some point in your life. Below are key first aid steps:

1. Ease the person to the floor if they are shaking, or make sure they are in a safe place.
2. Turn the person gently onto one side. This will help the person breathe.
3. Clear the area around the person of anything hard or sharp. This can prevent injury.
4. Check to see if they are wearing a medical alert bracelet or identification.
5. Put something soft and flat, like a folded jacket, under his or her head.
6. Remove eyeglasses.
7. Loosen ties or anything around the neck that may make it hard to breathe.
8. Time the seizure. Call 911 if the seizure lasts longer than 5 minutes.

After the seizure, speak calmly to the person and stay with them until they are fully conscious.

### **Call 911 if any of these things happen.**

- The seizure lasts longer than 5 minutes.
- The person has another seizure soon after the first one.
- The person is hurt during the seizure.
- The seizure happens in water.
- The person has a health condition like diabetes, heart disease, or is pregnant.

## FLYERS & POSTERS

Flyers and posters are a great way to capture people's attention and teach them about epilepsy. You can click below to download some of our educational flyers to share in your community. If you don't have access to a printer, simply contact us and we can mail a package out to you!

### [What is Epilepsy?](#)

**What is Epilepsy?**

Epilepsy is a chronic disorder defined by recurrent, unprovoked seizures. Many people with epilepsy have more than one type of seizure & may have other symptoms of neurological problems as well.

Epilepsy affects an estimated **3 Million** Americans and over **110,000** residents of Eastern PA.

1/3 of people with epilepsy live with uncontrolled seizures because no medication or surgery will work for them.

300,000 Children under the age of 15 are diagnosed with epilepsy.

**There is no cure for this life altering condition**

Many people with epilepsy are subject to isolation and discrimination at school or in the workplace. Anxiety and depression are often the result.

In 60% of the cases, the cause of epilepsy is unknown.

Raise awareness about Epilepsy. Share that November is Epilepsy Awareness Month with someone you know.

Education is the first step towards a safer community, better treatments and ultimately, hope for a cure.

**EPILEPSY FOUNDATION**  
Epilepsy Foundation  
1400 Locust Walk  
Pittsburgh, PA 15206  
www.epilepsy.org  
1-800-431-0011  
www.epilepsy.org

### [First-Aid for Tonic Clonic \(Grand Mal\) Seizures](#)

**First Aid for Seizures**  
(Convulsive, generalized tonic-clonic, grand mal)

**DO NOT PUT ANYTHING IN MOUTH**

**LOOK FOR MEDICAL ALERT IDENTIFICATION**

**TIME THE SEIZURE WITH A WATCH**

**AS SEIZURE ENDS, OFFER HELP**

**DO NOT HOLD DOWN**

**CUSHION HEAD, REMOVE GLASSES**

**LOOSEN TIGHT CLOTHING**

**TURN ON SIDE**

Most seizures in people with epilepsy are not medical emergencies. They end after a minute or two without harm and usually do not require a trip to the emergency room. But sometimes there are good reasons to call for emergency help. A seizure in someone who does not have epilepsy could be a sign of a serious illness.

Other reasons to call an ambulance include:

- A seizure that lasts more than 5 minutes
- No "epilepsy" or "seizure disorder" identification
- Slow recovery, a second seizure, or difficulty breathing afterwards
- Pregnancy or other medical diagnosis
- Any signs of injury or sickness

**EPILEPSY FOUNDATION**  
www.epilepsy.org 215-629-5001 epilepsypa.org

EPA 341 Rev. 2/2010

### [First-Aid for Complex Partial Seizures](#)

**First Aid for Seizures**  
(Complex partial, psychomotor, temporal lobe)

**1. Recognize common symptoms**

BLANK STARRING, CHEWING, FUMBLING, HANDBERRING, SHAKING, CONFUSED SPEECH

**2. Follow first-aid steps**

TIME THE SEIZURE, SPEAK CALMLY, DON'T GRAB OR HOLD, EXPLAIN TO OTHERS, BLOCK HAZARDS

People who've had this type of seizure should be fully conscious and aware before being left on their own. Make sure they know the date, where they are, and where they're going next. Confusion may last longer than the seizure itself and may be hazardous. If full awareness does not return, call for medical assistance.

**EPILEPSY FOUNDATION**  
www.epilepsy.org 215-629-5000 epilepsypa.org

EPA 341 Rev. 2/2010

## LETTER TO THE EDITOR

A letter to your local newspaper editor is a great way to gain media exposure for NEAM! If you have a personal connection to epilepsy, meaning either you or a loved one has epilepsy, sharing your experiences in the letter is a great way to educate others about how seizures can impact someone's life. If you're stuck on ideas, use our simple template below to get started:

**Date:**

[Insert contact's address]  
 [Insert city, State]  
 [Insert zip code]

Dear [Insert name of editor]:

Even though 1 in 10 Americans will have a seizure at some point in their life the public is largely unaware how prevalent and serious the condition can be. Although it's a challenge to increase awareness, it's time to learn the facts. November is National Epilepsy Awareness Month and I am working with the Epilepsy Foundation Eastern PA to create a community that is safe and supportive of those with seizures.

Epilepsy is very common--in fact there are over 110,000 people with epilepsy in Eastern Pennsylvania. Yet many people cannot properly recognize a seizure or what to do when someone has a seizure. As a result individuals with epilepsy often feel socially isolated and are afraid to live their lives. This doesn't have to be the case if we all take the time to learn a little more. Here are a few simple facts that can go a long way to improving our community:

- Seizures are not always convulsive; there are many different types of seizures
- If you see someone having a convulsive seizure, you should turn them on their side and cushion their head, but **do not put anything in their mouth.**
- A seizure isn't always an emergency—*only call 911 if the seizure lasts longer than 5 minutes.*
- Epilepsy is not contagious and seizures are not dangerous to anyone witnessing one.
- **Purple is the official color for Epilepsy Awareness.** You can show your support by wearing purple in November!

Making a difference isn't hard—knowledge and understanding goes a long way. As someone affected by epilepsy, I strongly encourage everyone to get educated by visiting [www.efepa.org](http://www.efepa.org). The first steps towards change are often the smallest. Please take them with us.

[Insert your name]  
 [Insert your address]  
 [Insert daytime telephone number]

[Click here to download a PDF of this letter.](#)

You can easily find contact information for your local outlets at: <http://capwiz.com/efa/dbq/media/>.

## EMAIL SIGNATURE

Many of us send emails every day, either at work or just communicating personally. Updating your email signature to include information about Epilepsy Awareness Month is a simple and easy way to educate everyone you connect with. Below are several examples to use:

- I support Epilepsy Awareness Month because someone I love is battling epilepsy. Learn the facts about epilepsy at [www.efepa.org](http://www.efepa.org).
- Did you know that November is Epilepsy Awareness Month? Nearly 3 million Americans live with epilepsy. Learn more at [www.efepa.org](http://www.efepa.org).
- 1 in 26 will be diagnosed with Epilepsy in their lifetime. November is Epilepsy Awareness Month. Join me in spreading the word. Learn more at [www.efepa.org/neam](http://www.efepa.org/neam).

## SOCIAL MEDIA

### *Turning Facebook, Twitter and Instagram PURPLE for Epilepsy!*

Social Media is a great way to show your support of Epilepsy Awareness Month. All month long we'll be posting epilepsy facts, statistics and pictures to educate others. You can start up a conversation by adding comments and photos to the daily posts or share our posts on your own pages. This helps to create an active online community as well as spread our messages out to people we may not otherwise reach. Through this social media campaign, individuals and families who may have never heard of the EFEPa or its programs can be learn about epilepsy facts, community action, and the programs that the EFEPa offers!

Here's a quick overview of the three different major social media outlets.

### Facebook

Facebook is a commonly used social media platform where people or businesses can start a page and connect with others. It's a great place to share your thoughts, connect with the EFEPa and others in our community, and share educational posts. User names would just be your name, or the name of the business.



### Instagram



Instagram is an online mobile photo-sharing, video-sharing and social networking service that allows you to take pictures or videos and share them with your friends, or on other networks like Facebook and Twitter. User names are listed with an @ symbol before their name. Our Instagram name is @efepa. You can only add pictures and videos through the Instagram App on your phone or tablet.

### Twitter

Twitter is an online social networking service that enables users to send and read short 140-character messages called "tweets". You can also attach pictures to your "tweets." User names are listed with an @ symbol before their name. Our Twitter name is @efepa.



### Hashtags #



If you're not a social media wiz, you may not know what a "Hashtag" is or what the # symbol means. It's actually not so complicated! Hashtags are used in social media on Twitter and Instagram as a way for people to search for "Tweets" or picture with a common topics. It's similar to color coding—it organizes people's thoughts and photos under a category, marked by the "#Hashtag" to link people together. Great hashtags to use throughout the month are:

#Epilepsy #EpilepsyAwareness #NEAM. Another great idea is the use a Hashtag of the location you're in, like #Philadelphia.

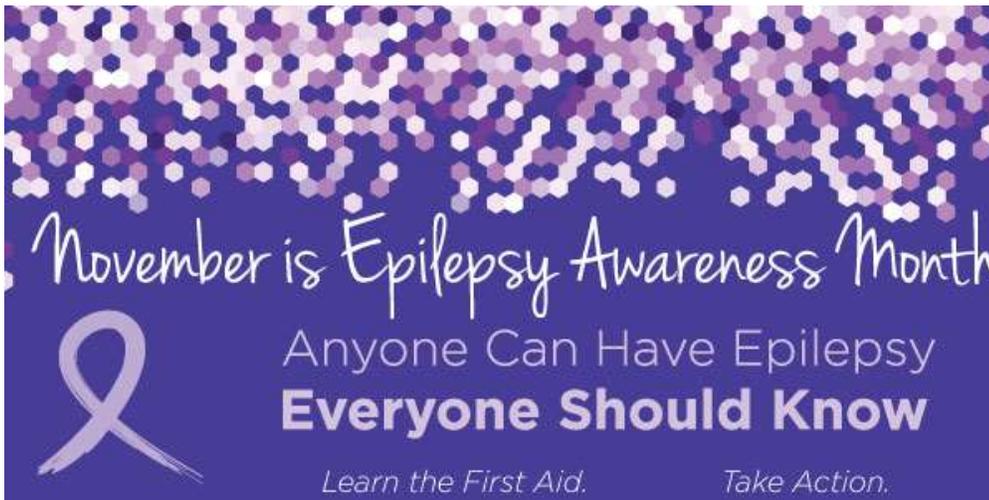
### Sample Tweets:

- November is #Epilepsy Awareness Month! Learn the facts and get involved at [www.efepa.org](http://www.efepa.org) #neam
- I support #EpilepsyAwareness Month because someone I love is battling epilepsy. Learn the facts about epilepsy at [www.efepa.org](http://www.efepa.org).
- Did you know that #November is #Epilepsy Awareness Month? Nearly 3 million #Americans live with epilepsy. Learn more at [www.efepa.org](http://www.efepa.org).
- 1 in 26 will be diagnosed with #Epilepsy in their lifetime. November is Epilepsy Awareness Month. Learn more at [www.efepa.org/neam](http://www.efepa.org/neam).
- Quick #epilepsy first-aid: Place them on their side, time the #seizure, don't put anything in their mouth. Learn more at [www.efepa.org](http://www.efepa.org)

An easy way to get involved is by changing your cover photo for the month! That means making your cover photo represent NEAM. The #AimForZero image promotes the shared campaign to raise awareness about SUDEP, seizure control and four key actions. This is a campaign led by the Epilepsy Foundation and SUDEP Institute. The Foundation recognizes that for 3 out of 10 people living with epilepsy, a life without seizures is not within reach YET. The #AimForZero campaign encourages people to adopt four key behaviors while working toward the best seizure control possible to reduce their risk of SUDEP and improve their quality of life. [Click here to download.](#)



Or use this general NEAM cover photo. [Click here to download.](#)



## AREA ACTIVITIES

### ***Getting out and Getting Involved!***

With you on our team, we're sure this November will be the best one to date. That's why we're hopeful you'll join us at some of our hosted events throughout the area this November. You can stay up to date with the full calendar of events on our website, [www.efepa.org/neam](http://www.efepa.org/neam).

We encourage you to share pictures of you and your friends, family and loved ones throughout the month. Encourage everyone to wear purple to show your solidarity and support.