

## WHAT IS SUDEP?

SUDEP stands for Sudden Unexpected Death in Epilepsy. When a person receives a diagnosis of epilepsy they are told that having a seizure while performing activities like swimming and driving can lead to accidents. However most people, even those who live with seizures every day, have never heard of one of the most devastating epilepsy-related causes of death, SUDEP.

SUDEP is the sudden, unexpected death of someone with epilepsy who was otherwise healthy. A seizure may or may not have occurred around the time of death. In SUDEP cases, no other cause of death is found when an autopsy is done. The death certificate may list epilepsy or seizures as the cause of death or it may refer to other factors, such as respiratory or cardiac issues, that are believed to cause SUDEP.

Tragically, many families never hear this word until they have lost a loved one to SUDEP. The EAWCP and the Mason Langford Center for Support and Learning on SUDEP is here to help.

## DID YOU KNOW:

- ▶ Each year, SUDEP occurs in 1 in 1,000 adults and 1 in 4,500 children with epilepsy.
- ▶ The exact cause of SUDEP is unknown, but the factors that tend to lead to death are breathing, heart rhythm, or a combination of both.
- ▶ Many SUDEP deaths occur during or right after a seizure, during normal activity or during sleep.



REACH OUT. WE ARE HERE TO HELP!

[www.eawcp.org](http://www.eawcp.org)

### PITTSBURGH OFFICE

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Pittsburgh, PA 15233  
1-800-361-5885  
412-322-5880

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WE ARE PROUD TO BE A MEMBER  
OF EPILEPSY ALLIANCE AMERICA.



CREATING A CONVERSATION:

# SUDEP

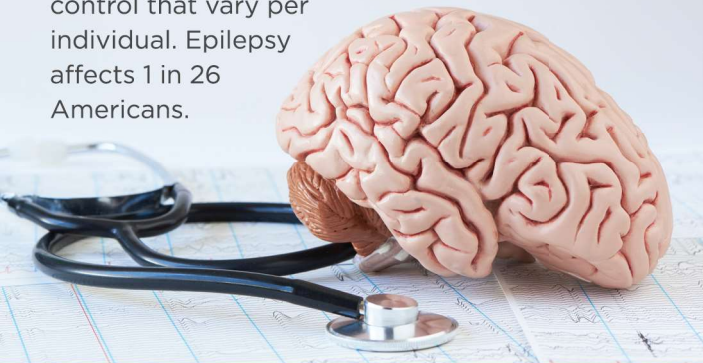
and Supporting Families

INFORMATION FOR FUNERAL HOME  
DIRECTORS AND STAFF



## WHAT IS EPILEPSY?

Epilepsy (often called a seizure disorder) is a neurological condition that causes changes in the brain's electrical balance, resulting in recurring seizures. Epilepsy is a spectrum condition, meaning it affects each person differently, and there is a wide range of seizure types, frequency of seizures, and seizure control that vary per individual. Epilepsy affects 1 in 26 Americans.



## WHAT IS A SEIZURE?

A seizure is a sudden surge of electrical activity in the brain that can alter a person's body, awareness, movement, and emotion.

If you and your staff would like to learn more about seizure recognition and first aid, visit [www.eawcp.org](http://www.eawcp.org) or call 1-800-361-5885.

## ABOUT THE EAWCP

The Epilepsy Association of Western and Central PA (EAWCP) is a private, non-profit service organization providing public education and supportive services to individuals and families affected by epilepsy/seizure disorders.

Support is available to any family who has experienced loss to SUDEP or other epilepsy-related causes.

### Mason Langford Center for Support and Learning on SUDEP



Mason Langford died from complications related to SUDEP in 2015. The Mason Langford Center for Support and Learning on SUDEP was created by the Epilepsy Association of Western and Central PA in partnership with the Langford family, to honor Mason and provide support and resources to other families impacted by SUDEP.

The family's mission is to help provide emotional support by increasing awareness of SUDEP for families to learn, listen, share, and connect to one another and resources.

Like the Langford family, the EAWCP is here to help provide programs, services, and to create a conversation with families who have lost their loved one to SUDEP or other epilepsy-related causes.

The EAWCP can connect families to a network of western and central Pennsylvania families who have sadly experienced the tragedy of SUDEP. This network is willing to help others experiencing the loss of a loved one to SUDEP.

For more information about the Mason Langford Center for Support and Learning on SUDEP and other SUDEP-related information, families can visit the Mason SUDEP Center on the EAWCP's website at:

[www.eawcp.org/Langford](http://www.eawcp.org/Langford)  
1-800-361-5885 or 412-322-5880

## How to support families who have lost their loved one to SUDEP or other epilepsy-related causes

The EAWCP has a network of families who have lost their loved ones and want to support others experiencing this loss.

### Encourage. Help. Support.

**Encourage** families who have lost a loved one to SUDEP or another epilepsy-related cause to reach out to the EAWCP for resources like the Mason SUDEP Center, programs, and events for support.

**Help** anyone supporting a family impacted by SUDEP to realize that SUDEP is traumatic, unexpected, and shocking.

**Support** entire communities impacted by SUDEP by getting them the resources and knowledge they need to educate themselves about SUDEP .

EAWCP is here to help. Refer families now and later for help.



**EPILEPSY**  
ASSOCIATION®  
OF WESTERN AND CENTRAL PA