



# **Bereavement & SUDEP Family Resource Guide**

Information for Individuals Bereaved by Sudden  
Unexpected Death in Epilepsy (SUDEP) & Epilepsy Mortalities



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## Who We Are and What We Do

### Introduction

We understand hearing your loved one passed isn't easy. The Epilepsy Foundation SUDEP Program would like to express our deepest condolences to you and your family during this difficult time. As part of the SUDEP Program, you are not alone – we are here to help. Our services for families and individuals include:

- Individual or family support from trained grief facilitators, one who has personal experience with SUDEP. Call our 24/7 Helpline at 1-800-332-1000 or email us at [contactus@efa.org](mailto:contactus@efa.org) to speak with someone and learn more about our services.
- An online bereavement support group designed to help families connect with others who have lost someone to epilepsy in a safe and confidential environment. Email us at [sudep@efa.org](mailto:sudep@efa.org) to get connected to the support group.
- Accurate information regarding SUDEP and other causes of epilepsy-related deaths on [www.epilepsy.com/sudep](http://www.epilepsy.com/sudep).
- Remembrance pages where families can create a memorial or honorarium webpage to share their story and help raise awareness and understanding of SUDEP: <https://www.epilepsy.com/stories/ejourney>
- Advocacy, as needed on a case-by-case basis, which includes coordination and assistance with traversing the death investigation process.
- SUDEP-related research opportunities and assistance in enrolling and participating. Call our Helpline at 1-800-332-1000 for more information.
- Regular email communications with information on epilepsy and the latest news, research, and efforts focused on preventing epilepsy mortality: <https://www.epilepsy.com/forms/newsletter-subscriptions>

The SUDEP Program also leads education and awareness efforts targeted to people living with epilepsy, their caregivers, medical professionals, death investigators, first responders, and others who may benefit from learning about SUDEP. We drive and support research into the causes and prevention of SUDEP. Learn more about these programs and how you can become involved at [epilepsy.com/sudep](http://epilepsy.com/sudep) or email us at [sudep@efa.org](mailto:sudep@efa.org).

## Who Is Involved with the SUDEP program?

The Epilepsy Foundation SUDEP Program unites and collaborates with leading epilepsy organizations and experts to work together to end SUDEP. We thank our many volunteers and supporters, especially our SUDEP Institute Advisory Board members listed below.

### Staff Leadership Team

Laura Thrall  
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SUDEP Program Coordinator, Epilepsy Foundation

### Community Partners

Danny Did Foundation

Partners Against Mortality in Epilepsy

In addition to our dedicated staff and contractors, we have nationwide support through our affiliate and Regional Teams network. Find out about our local services and offerings by looking up your local office at: <http://www.epilepsy.com/local> or by calling the Epilepsy & Seizures 24/7 Helpline at 1-800 -332-1000.

We would like to thank the team at The Sudden Unexplained Death in Childhood (SUDC) Program for their support and guidance in making this resource guide possible. Learn more about their excellent program and services at: [www.sudc.org](http://www.sudc.org).

## Our Advocacy Work

### **Education and Awareness Advocacy**

The SUDEP Program carries out SUDEP education and awareness programs for people touched by epilepsy and medical professionals. These efforts include participating in and hosting conferences and webinars, as well as and distributing materials about SUDEP.

### **Case Advocacy**

Since death investigations vary widely across regions, the SUDEP Program offers its support to help families navigate this often confusing and stressful process. It is also a unique experience for each family, where the requests will vary based on the situation and their personal needs. We can explain the investigation process, work with the medical examiner/coroner on the family's behalf, and advocate for them when and how they need it.

### **Local/Regional & Legislative Advocacy**

The SUDEP Program works with the Foundation's advocacy team and regional and affiliate network to connect families to help promote and coordinate local advocacy efforts to improve awareness of SUDEP and the other serious risks associated with epilepsy among people living with epilepsy and their caregivers. This can take many forms including working to build awareness among medical professionals, including death investigators. The SUDEP Program can also support and promote state and federal legislative efforts that build upon the current system to ensure comprehensive and standardized investigations, fair treatment of families and thorough data collection, and to improve our understanding of these tragedies to aid in their prevention.

## What is SUDEP?

You may have never heard of SUDEP before your loved one passed. Sudden Unexpected Death in Epilepsy (SUDEP) is said to occur when a person with epilepsy dies unexpectedly and was previously in their usual state of health. The death is not known to be related to an accident or seizure emergency such as status epilepticus. When an autopsy is done, no other cause of death is found.



1 in 1,000 individuals  
with epilepsy die  
each year from  
SUDEP

## How Common Is SUDEP†?

- SUDEP occurs in 1 out of 1,000 people living with epilepsy per year.
- SUDEP rates are higher in studies of children with rare epilepsies and difficult-to-control epilepsy.
- SUDEP is the leading cause of death in young people with poorly controlled seizures.
- People with only absence or myoclonic seizures are not known to have an increased risk for sudden death.

†Cynthia Harden, Torbjörn Tomson, David Gloss, Jeffrey Buchhalter, J Helen Cross, Elizabeth Donner, Jacqueline A French, Anthony Gil-Nagel, Dale C Hesdorffer, W Henry Smithson 1, Mark C Spitz, Thaddeus S Walczak, Josemir W Sander, Philippe Ryvlin. Practice guideline summary: Sudden unexpected death in epilepsy incidence rates and risk factors: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology and the American Epilepsy Society. National Library of Medicine. 2017 Apr 25;88(17):1674-1680. Available at: <https://pubmed.ncbi.nlm.nih.gov/28438841/> Accessed July 25, 2022. [PubMed]

## What Causes SUDEP?

No one knows what causes SUDEP, but many areas are being researched. SUDEP occurs most often at night or during sleep and the death is not witnessed, leaving many questions unanswered. There may be evidence that a person had a seizure before dying, but this isn't always the case.

Current research on the possible causes of SUDEP focuses on problems with breathing, heart rhythm, and brain function that occur with a seizure.

- **Breathing:** A seizure typically may cause a person to briefly stop breathing (apnea). These brief pauses in breathing are not dangerous. Rarely, the brain signals that tell the body to breathe may be disrupted by a seizure. If this occurs, it may reduce the oxygen delivery to the heart and the brain, which can be life-threatening. In addition, a person's airway may sometimes become obstructed or blocked during a convulsive seizure, leading to suffocation (inability to breathe).
- **Heart Rhythm:** Rarely, a seizure may cause a dangerous heart rhythm or cardiac arrest.
- **Brain Function:** Seizures may suppress or interfere with the control centers in the brainstem for breathing and heart functions.

- **Others:** SUDEP may result from more than one cause, or from a combination of breathing difficulty, abnormal heart rhythm, changes in blood pressure regulation, and changes in brain function. Or, it may result from factors researchers have yet to discover.

## Who Is at Risk for SUDEP?

The greatest risk factor for SUDEP is frequent seizures, especially generalized tonic-clonic (grand mal) seizures. The SUDEP guidelines from the American Epilepsy Society and American Academy of Neurology found that people with 3 or more tonic-clonic seizures in a year had a 15-fold greater risk of SUDEP. Seizures occurring at night seem to increase SUDEP risk as well.

## Is It SUDEP If There Was No Sign of a Seizure?

Often, there are signs that a person had a seizure before dying, but this isn't always the case. While a seizure is not a requirement for SUDEP to be diagnosed, recent studies suggest most cases of SUDEP occur after a seizure.

## Is SUDEP Genetic?

There are some studies that suggest genetic factors may play a role, but no definite information is available now. We know that other causes of sudden death in otherwise healthy people are often caused by a genetic mutation that affects the heart. Several research efforts are considering genetics and SUDEP.

A few other identified risk factors include:

- Epilepsy begins at an early age
- Having epilepsy for a long time
- Not taking medicines as prescribed
- Stopping or changing medication suddenly
- Young adult age (20-40 years old)
- Intellectual disability (IQ<70)

## Navigating the Death Investigation Process

### What You Need to Know Immediately Following the Death

If you are experiencing the recent loss of a loved one, this is not only a time of extreme grief, but often a time of great confusion about why your loved one died and the health of remaining family members. If the death investigation is still active or the death is recent, please consider the following:

A seizure cannot be detected at autopsy, so the only way for a forensic pathologist to know to consider SUDEP is to tell the death investigator that your loved one had epilepsy.

- Assist the medical examiner or coroner in their investigation. The more information they have about your loved one, the more thorough an investigation they can conduct, which will them in attaining the most accurate diagnosis of the cause of death. A seizure cannot be detected at autopsy, so the only way for a forensic pathologist to know to consider SUDEP as playing a role in your loved one's death is to tell the death investigator that your loved one had epilepsy. Expect the investigator to ask questions about where epilepsy began, what caused it to begin, how often seizures occurred, what medications were used to control epilepsy, etc.
- Contact the primary care physician and any epilepsy specialists and notify them of your loved one's death. Your loved one's medical providers may be able to answer your questions about the circumstances surrounding their death and direct you towards bereavement and other resources.
- Consider participating in research. The autopsy report does not always provide clarity in cases of SUDEP or unclear causes of death. Often families want to pursue additional avenues to gain insight into their loved one's death, as well as contribute to medical research to prevent others from dying in the future. If you are interested in participating in research, it is important to notify the coroner or medical examiner of your wishes so they can assist in the process. (See SUDEP Research Opportunities section.)



## SUDEP Research Opportunities You Can Support

Below are research opportunities that may be of interest to you in being aware of or helping to support studies into the causes of SUDEP.

### North American SUDEP Registry

If you have recently lost a loved one to SUDEP, one option for research is to contact the North American SUDEP Registry (NASR) at [info@sudepregistry.org](mailto:info@sudepregistry.org) or by calling 1-855-432-8555 and participate in their study to help discover the causes of SUDEP.

#### **What is the purpose of the Registry?**

The SUDEP Registry seeks to help identify risk factors and mechanisms leading to a sudden unexpected death in people with epilepsy. Towards this end, they will try to collect DNA, brain tissue, and clinical data (e.g., medical records, EEGs) for scientific studies about the causes of SUDEP.

#### **Why participate?**

To make a difference and help other families. Your loved one's information will help researchers, clinicians, and other families better understand the causes of SUDEP and help prevent future cases. Through the registry, the hope is to improve surveillance and identification of SUDEP-related deaths and increase tissue and DNA donations that will help understand SU DEP. Ultimately, the goal is to understand its causes and use this information to prevent future cases of SUDEP.

#### **What is involved?**

This is a voluntary research study. Any information obtained from participants is vital to the success of the study. You will be able to withdraw from the study at any time if desired. Once consent is given, NASR will proceed with a telephone interview (~30-45 minutes) after helping you gather all the information required. They will also request a release of medical records from your loved one's medical providers. If you contact NASR within the first 48 hours after the death of your family member, and you are interested in donating the brain, NASR will work with you to facilitate this donation.

#### **Is my information kept confidential?**

Yes, NASR requires written consent to obtain any medical records or information. Confidentiality is honored and no individual information will be released to anyone that isn't connected to this research without written consent from next of kin. You can view the consent forms and medical release form at the NASR website.

#### **How can I participate?**

For an immediate response regarding tissue donations please call NASR's toll-free number at 1-855-432-8555, which is available 24hrs/7days. NASR can

also be reached at [info@sudepregistry.org](mailto:info@sudepregistry.org). Please visit the NASR website to learn more at [www.sudepregistry.org](http://www.sudepregistry.org).

## Sudden Death in Young Registry

The Sudden Death in the Young Case Registry (SDY) gathers information to learn more about children (up to age 20) who die suddenly and unexpectedly including the ability to track SUDEP-related deaths. The project is funded by the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). The SDY Data Coordinating Center is in Michigan, at the Michigan Public Health Institute (MPH) and is working to put the SDY Case Registry into action.

The SDY is collecting information regarding new cases of sudden death in the young in a few select jurisdictions. Unfortunately, the SDY cannot receive data directly from parents or other caregivers, data related to cases that occurred prior to 2015, or from jurisdictions outside of those specified. The SDY can only receive information through the participating grantees.

For more information on the SDY, and learn if your jurisdiction is participating, please visit [www.sdyregistry.org](http://www.sdyregistry.org).

## What to Expect During the Death Investigation Process

### **The Medical-Legal Investigation Process and SUDEP**

Tragically, when someone dies because of epilepsy, the death is often unexpected. Many of the common causes of premature death in people with epilepsy such as accidents, drowning, suicide and SUDEP, occur in people who were otherwise healthy. In these cases, the medical examiner or coroner becomes involved in determining the manner (for example, natural, homicide, suicide, accident) and cause of death (for example, epilepsy, heart disease, pneumonia, cancer).

### **Why is the death investigation important?**

This investigation is important to provide the surviving family and the deceased's physicians an understanding of why the person died but also may have legal consequences. For instance, if the deceased had post-traumatic epilepsy as a result of an assault and died of a seizure-related death, the manner of death would be homicide, which has certain implications in the criminal justice system.

### **Why does the death investigation take so long?**

While it may be frustrating to families who desperately want to know why their loved one died, this medico-legal investigation can take some time. The investigation around a death involves multiple steps and several professionals.

The process begins with investigation of the death scene by trained investigators (or, in some jurisdictions, police officers) to note the circumstances of death such as location, positioning, and environment, as these can provide clues to the cause of death. This often occurs before the body is moved. The investigators also interview family members and take note of medication bottles to get information about the deceased's medical history. Investigation into the medical history may continue through discussion with the treating physician and review of recent medical records.

At the same time, an autopsy may be performed. An autopsy is a systematic examination of the external and internal organs, which can give clues as to the cause of death. Often, sections of organs are also examined under the microscope. This can require special processing and handling of the tissue. Specially trained pathologists, called forensic pathologists, typically perform these examinations.

In smaller communities, consulting pathologists may perform the autopsies because the medical examiner/coroner's office does not have the resources to employ full-time pathologists. This resource limitation can lead to some delays. Blood and other bodily fluids are typically analyzed for levels of medications and illicit drugs and alcohol. If there is no obvious cause of death found on routine autopsy and toxicology tests, special tests may be needed to help determine the cause of death. These may include additional microscopic analyses, specialized laboratory tests, and genetic analyses.

### **How long does the death investigation take?**

Unlike the immediate results depicted on television shows, these tests may take weeks to months to come back. On average, the results of these tests are not available for 10 to 12 weeks, but there are jurisdictions in which it takes up to a year to receive toxicology results, delaying certification of the death. A determination of an epilepsy-related death like SUDEP may take some time because other causes of death must be excluded. In addition, it may be difficult to determine the cause of death with exact certainty because of the limits of our tools. In some cases, the cause of death may be unknown.

### **Can I contact my medical examiner/coroner?**

You may contact your medical examiner to give them information about your loved one and ask for results available now and about timelines on when you may have additional results of the autopsy. Death investigation agencies understand that family members are grieving, but the conversation will be most useful to both sides when you and the medical examiner are able to talk openly and without interruption. If grief overcomes you whenever you try to speak, try asking a trusted representative, such as a more distant relative or a friend, to relay your questions to the medical examiner.

You can also contact the medical examiner/coroner to ask them if they can collect tissues or organs that can be used in research and refer them to the available SUDEP research opportunities. Please be patient with the death

investigation team. They are dedicated to determining the cause of death and need time to make an accurate diagnosis.

### **Are there people who can support me through this process?**

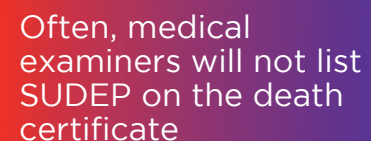
Please reach out to the SUDEP Program at [sudep@efa.org](mailto:sudep@efa.org) or contact the Epilepsy Foundation at [contactus@efa.org](mailto:contactus@efa.org) or 1-800-332-1000. We have dedicated staff who can support you through this difficult time and answer many of your questions. The North American SUDEP Registry team ([info@sudepregistry.org](mailto:info@sudepregistry.org)) is also available to help with any questions you may have about the medical examiner/coroner autopsy, medical-legal death investigation, and epilepsy-related mortality.

### **What You Need to Know When the Death Investigation is Complete**

When the autopsy report is finalized, whether a specific cause of death is revealed or not, many families feel that the finality of the report itself ushers in a wave of grief that brings them back to the early days after their loved one's death. The final cause of death, as determined by the medical examiner or coroner, also brings forth many new questions and sometimes confusion.

#### **Reading or not reading the autopsy report**

The autopsy report is graphic in ways that are often surprising to families. And unfortunately, once you have read it, there is no way to "unread" it and get those thoughts and visions out of your head. Consider not reading it alone at first but reviewing it with a medical professional who will be able to better answer your questions. Ask the medical examiner or coroner to sit down with you and explain their findings or request a phone call with them. If those options are not available or not preferable to you, consider having your primary care provider review the report and meet to discuss the findings with them.



Often, medical examiners will not list SUDEP on the death certificate

#### **Contact your primary care physician and epilepsy specialist with your loved one's final cause of death.**

Ask them if there is any medical testing you should consider and devise an appropriate screening plan for your entire family. There are some types of sudden deaths that have genetic predispositions and run-in families. These medical screenings can help more fully evaluate your family for the care and safety of all members, including the surviving siblings.

#### **What if the cause of death is not listed as SUDEP?**

When the medical examiner/coroner determines the cause of death, he or she weighs all the available evidence to determine the cause that was most

probable and there may be competing explanations. Often, medical examiners will not list SUDEP on the death certificate. Instead, you may see terms such as, but not limited to, "epilepsy, idiopathic epilepsy, post-traumatic epilepsy, asphyxia due to seizure, or seizure disorder." The SUDEP Program is actively working with the death investigation community to develop more consistent determination of SUDEP.

If you believe your loved one died of SUDEP and you would like "Sudden Unexpected Death in Epilepsy" (do not use the acronym on death certificates) listed on the death certificate, you can contact your medical examiner and discuss this as an option.

Understand that depending on the circumstances, they may or may not be able to modify the cause of death. However, to help with research efforts and ensure accurate statistics of SUDEP and other types of epilepsy-related mortality it is important to have epilepsy listed on the death certificate. Epilepsy can be listed as the direct or indirect cause of death or as an existing medical condition. If the medical examiner has questions about SUDEP or adding epilepsy to the death certificate, you can refer them to the North American SUDEP Registry (1-855-432-8555 or [info@sudepregistry.org](mailto:info@sudepregistry.org)).

### **Considering Research Opportunities**

While it may be too late to donate tissue to some of the research efforts, you still may be able to provide helpful information for research into the causes of SUDEP and possible strategies to prevent it. See the research section for research opportunities.

## [Understanding Grief: Support Services, Information, and Resources](#)

### Introduction and Overview of Our Services

If you or someone you know has been impacted by SUDEP, the SUDEP Program is here to offer help and guidance. The SUDEP Program provides comprehensive support services at no cost to meet the needs of those impacted by SUDEP.

#### **Services to our families Include:**

- Bereavement services provided by a trained grief support specialist: individual support, regular grief support follow up, and linkage to grief resources in a community.
- Assistance in navigating the death investigation process.
- Assistance with determining if participation in research efforts is appropriate for the family.
- Opportunities to support advocacy efforts and advance awareness about epilepsy-related mortality, if interested.

- Opportunities to raise funds and create your own event for awareness and/or fundraising, if interested.
- An online bereavement support group designed to help families connect with others who have lost someone to epilepsy in a safe and confidential environment.
- Remembrance pages where families can create a memorial or honorarium webpage to share their story and help raise awareness and understanding of SUDEP

To enroll in these services email: [sudep@efa.org](mailto:sudep@efa.org), [contactus@efa.org](mailto:contactus@efa.org), or call 1-800-332- 1000.

## Understanding Grief

There is no right or wrong way to grieve. When your loved one dies not only does the death destroy the dreams and hope you had but it also forces your family to face an event for which you are not prepared.

Grief is a natural process of emotions that occurs when someone dies. Grief integrates into normal routines at variable timeframes for each person. It can be an intense, lonely, and personal experience. No two people will experience the death of a loved one the same way.

A SUDEP death is different from any other death because the loved one was "not supposed to die" and in most cases the family did not even know the possibility of SUDEP existed. Death is incomprehensible. Often, the death causes confusion and shock: "How could this happen? No one told us this was possible."

When your loved one dies, not only does the death destroy the future you had, but it also forces your family to face an event for which you are not prepared. Many families wonder if they will be able to tolerate the pain, to survive it, and be able to feel that life has meaning again.

Grief can have its ups and downs. Intense reactions may return on specific dates (birthdays, holidays, anniversaries, etc.), or in connection with milestone events {like moving from the home where the loved one died, the growth of a subsequent sibling beyond the age of the child that died, etc.}. As times move on, the pain from grief becomes less sharp and more integrated into your life. Happiness does return, slowly at first. At some point, you begin to laugh and appreciate life again. Timing for this process. Is different for everyone. Death can change a person and you may never be the same. Family, friends, and your community at large will help you to slowly start your journey to healing.

## The Emotional Responses to Grief

Not everyone experiences each of these, but they are common in many people. These reactions are also not linear, starting with the first and then ending with the last.

These reactions are normal and allowing yourself to go through them helps you heal. Others, who are unacquainted with the grieving process, may incorrectly assume that you are strong and holding up well, or incapable of experiencing the loss. What they do not understand is that shock, disbelief, denial, and numbness allow you to begin to face the tragedy without losing control. These reactions may last from minutes to weeks. You will decide when you are better able to face the reality of your loved one's death.

Some of the emotions you may experience:

- Shock
- Regret and guilt
- Anger
- Fear
- Difficulty concentrating
- Depression
- Acceptance

**When your loved one's death becomes a reality, intense suffering and pain begin.**

Your spouse, children, family, and friends will all express grief differently. Crying, weeping, and incessant talking are all normal reactions. You may also feel very alone. Some may have trouble hearing your feelings, be uncomfortable talking about death, or unable to meet your need for comfort and support. Help is available through the SUDEP Institute or through clergy, counselors, or other bereaved parents.

[Some of the emotions you may experience:](#)

It is important for you to allow yourself full expression of the emotions that you feel when you feel them. There is no "correct time" to express emotions. If you have concerns about what you are feeling, contact a professional.

- **Shock:** You may feel numb and not be able to make decisions. Feeling faint or sick is common. You may not show the degree of sorrow you or others expect, or you may go about your daily routine as if nothing has happened. Shock diminishes as we are comforted and begin to accept that our lives must continue. Sharing how we feel about death and what is now missing moves us closer to healing.
- **Sadness:** Once the initial reaction of shock, numbness, and denial after the death lessens, especially if the death was sudden and unexpected, feelings of intense sadness, pain and suffering may begin. You and others may express this externally by crying or talking constantly, or internally by being withdrawn or quiet. There is no right way to grieve.

- **Regret and Guilt:** You may blame yourself or each other for something you did or did not do in the past or present. "If only" becomes a familiar saying or thought. Many times, you may feel guilty thinking of all the things that you wish you had done with or for your loved one. With time, you may begin to accept that you did the best you could with what you knew to do, or could do, at the time.
- **Anger:** You can feel angry with yourself, your spouse, the doctor, or even the loved one for having died. You may find yourself angry with others around you or even with a God who allows people to die. Many people are uncomfortable with the emotion of anger and may feel that it is inappropriate. These thoughts and feelings may cause great anxiety, even though they are normal. It is important to express your anger in healthy ways. Screaming in private, hitting a pillow, or regular exercise may help.
- **Fear:** After the death of your loved one, you may experience an overall sense of fear that something else horrible is going to happen. You may become extremely protective of your other loved ones. At the same time, you may find yourself struggling at times with the current responsibilities you have in life such as being a parent, spouse, or employee.
- **Difficulty Concentrating:** Your mind may wander, making it difficult to read, write, and make decisions. Sleep may be disrupted, leaving you edgy and overtired. Even with sleep, you may feel exhausted. You may find yourself thinking about what happened and how things could have been different. You may feel as if you are "going crazy."
- **Depression:** Depression may take different forms for different people. You may feel constantly "down," unhappy or sad, worthless, and that life has little meaning. You may have changes in appetite. Although people may invite you out and encourage you to do things, you may feel very alone. You may notice that you don't want to stay at home, but when you leave you are anxious to return. Thoughts of suicide may arise. Thoughts of your loved one are always on your mind. Aching arms, hearing your loved one cry, and finding yourself doing some familiar tasks to care for your loved one are all normal. As you begin to recover, depression will slowly ease and the "down" times or "waves of grief" will be less frequent. It can be a long, slow process so allow yourself to work through it. The sorrow, sadness, or what we call grief depression is different than clinical depression. You need to be patient with yourself and those around you. If you find you are unable to recover from depression, we suggest you speak to a professional counselor.
- **Acceptance:** Accepting your loss and going about your routine doesn't mean that you don't miss your loved one or that you care any less. Acceptance allows you to live with the loss. Sometimes, triggers such as



a song or a fragrance will cause you to feel your grief as if it were fresh. When this happens, it does not mean that you are not coping.

Interestingly, the feelings of grief are not linear, but come and go based on "triggers" (thoughts, memories, and experiences) that may provoke them. Sometimes, the triggers will cause you to feel your grief as if it were fresh. Sometimes, you may not even have an obvious trigger that causes emotions to surface. When this happens, it does not mean you are not coping, especially if the moment passes. It may simply be a reminder of your loss and the meaning it has.

Because your spouse, children, family and/or friends will all express grief differently and at different times, you may feel very alone. Some may have trouble sharing their feelings, be uncomfortable talking about the death, or unable to meet your need for comfort and support. You may find it helpful to seek help outside of your circle - other bereaved individuals, clergy, or a counselor.

### The Physical Responses to Grief

Along with emotional reactions, you may also notice you may have physical responses at different times, including:

You may notice differing physical responses at different times including:

- Trouble sleeping or sleeping too much
- Crying easily and often
- A change in appetite and/or digestive problems
- A hollow feeling in the stomach
- Lack of energy
- Confusion
- Sudden panic or trouble breathing

Emotional and physical responses to grief are normal and often go away with time as your ability to cope with your loss changes and improves. However, if they don't improve or last longer than expected, or if they are severe and interfere with your ability to function normally, it may be very helpful to speak with a mental health professional who can assist you. Counseling can help you explore your loss, your past and current relationship with your deceased loved one, find new skills to manage your grief journey and regain hope.

If you are thinking about suicide, please call the National Suicide Prevention Lifeline by dialing 988 or 1-800 -273-TALK (8255) to speak with a trained crisis counselor. They are available 24 hours a day, 7-days a week. You can also contact your local 9-1-1 center or visit your nearest emergency room.

## The Tasks of Grieving

There are many different theories about grief. You may be familiar with grief as a series of five phases as described by Dr. Elisabeth Kubler-Ross during the late 1960s. Another theory that was developed by Dr. J.W. Worden in the early 1980s identifies grief not as a succession of phases through which a person passes and over which she/he/they has little or no control but as a series of four tasks which a person must work hard to complete. Below is the series of four tasks he describes:

### Dr. J.W. Worden's Tasks of Grieving:

- Acknowledging the reality of the loss
- Experiencing the pain of grief
- Adjusting to a life without the loved one
- Moving forward

- **Acknowledge the Reality of the Loss:** After any death, grieving family members and friends usually express disbelief --"I can't believe this is happening to us." Grieving family members often experience strong feelings of wanting their loved one back at all costs or wanting to know, or assign, a certain cause to {or blame for} their loved one's death. Their first task is to acknowledge that their loved one has died. Ultimately, our hope is that they accept that there was no way to know their loved one was going to die and that they will not ever have their loved one back. This is an important step to beginning the journey of healing.
- **Experiencing the Pain of Grief:** While grieving family members begin feeling the pain of grief from the moment, they discover their loved one has died, the full extent of their pain may initially be "numbed" by the shock or disbelief surrounding the death. Many family members experience their most intense pain {both physical and emotional} after they have acknowledged their loss and are trying to resume "normal living." There isn't a way to avoid the pain of grief and working through the emotions and reactions is inevitable.

Unfortunately, it is also generally currently that the family ceases to receive comforting calls and notes from friends. They are expected to return to their usual productivity at work or home. Such sudden absence of attention and increased {often unrealistic} expectations from others lead family members to feel isolated and may cause them to suppress their pain. By allowing themselves to express and release their pain, family members are better able to move forward through grief.

- **Adjusting to a Life Without the Loved One:** As the pain of grief is released, family members begin finding ways to accommodate the changes in their lives brought on by the loved one's absence. They begin to weigh the options related to issues such as what to do with the loved one's room or things or returning to or taking on new projects at work. They decide how to answer questions like "how many children do

you have?", "Do you have any siblings?", or "Are you married?" They once again turn their full attention to managing their daily life and making plans for the future. Such adjustments may be difficult because they require the family members to develop a degree of detachment from their loved ones. Many families may take some time to make these adjustments and may struggle with their issues for a while before they make decisions.

- **Moving Forward:** This isn't about "moving on" but "moving forward" without your loved one. This involves keeping lasting emotional ties with the person who died while finding a way to re-engage in life and routines. Some describe this as a process that gets easier with time, still, others see it as a moment in time when they finally decide to live.

As they begin to move forward with their new decisions, family members will eventually begin enjoying the people and activities that brought them pleasure before the loved one died. However, their new sense of happiness may be interspersed with periods of guilt or regret because they fear that by enjoying themselves, they are forgetting the presence and devastating loss of their loved one. Many grieving family members will describe moving forward as a process, rather than a decision. It may take months, sometimes years, to acknowledge the changes. One indication that they have incorporated the grief into their lives may be demonstrated through their realization that other people want and need their love -- and loving those people does not mean they love the one they lost any less.

## Taking Care of Yourself During Grief

The stress of grief can be hard on your body as well as on your soul. Taking care of yourself and working toward a good daily routine can help keep you healthy. Begin with your physical needs.

### Healthy Eating

Changes in appetite may occur during grieving. You may prefer comfort food and snacks. Even though you may not be hungry or feel like eating, balanced meals provide the energy you need to manage and work through your grief.

Try to eat a variety of foods from each of the food groups - grains, fruits and vegetables, dairy, and meats or other sources of protein. It is best to eat small meals regularly throughout the day and not to skip meals. Try having small amounts of your favorite foods available.

Unless your doctor has directed you to restrict your fluids because of a health condition, drink at least eight glasses of water each day. This keeps your body working well. Although junk food and high-fat foods are easy and tempting,

limit them as much as you can. These foods are hard to digest and can leave you feeling as if you have less energy.

## Getting Rest

You may have trouble sleeping for a period after your loss. You may find that your pattern of rest and sleep changes. Your body will tell you when you need rest. Rest whenever you are able.

### **These tips may be helpful to get the rest your body may need:**

- Cut down on the amount of caffeine you consume (found in coffee, tea, chocolate, and many soft drinks).
- Limit the amount of alcohol you drink as it may prevent you from sleeping soundly.
- Set a bedtime routine such as walking the dog, reading, or listening to music.
- Stay active during the day but avoid exercising just before bedtime.
- Try finding spiritual comfort at bedtime. Inspirational reading, prayer, or meditation can help calm and relax you before going to bed.
- Try to maintain normal sleep patterns by sleeping longest at night.
- Your energy level may be low, so give yourself permission to rest when you need it.

If you still find that you are having trouble sleeping, talk with your doctor. Your doctor may prescribe medication to help you sleep. You may only need to use the medicine for a night or two to get your sleep pattern back to normal. Be sure to talk to your doctor before taking any over the counter or herbal sleep aids.

## Staying Physically Active

The last thing you might feel like doing is becoming or staying active. However, physical exercise helps to relieve tension during times of stress and raises your overall energy level. It can also improve your mood and your ability to sleep.

If you have a regular form of exercise, try to resume it as soon as you are able. You may feel better when you return to your normal activities.

If regular exercise is not a part of your lifestyle, you may want to try walking, even if for a short time. Walking alone provides time for reflection and walking with a friend allows you to share your feelings. Both offer excellent stress relief.

## Relaxation Ideas

Grieving is emotionally and physically draining and stressful. Taking time to relax will help your body cope with the stress in a healthy way. Find a soothing activity such as reading, listening to music, writing a journal, or visiting with friends.

You may want to experiment with some of these techniques to relax and ease tension. For best results, find a comfortable, quiet place for:

- **Deep Breathing:** Just stop wherever you are. Take a deep breath. Let the air out very slowly. Imagine that you are breathing in energy and breathing out tension. Let all the tension go. Repeat several times throughout the day.
- **Stretching:** Stand or sit and gently reach as high as you can with comfort. Stretch in that position for five seconds. Relax. Repeat.
- **Rag Doll:** Sit in a comfortable chair. Allow your whole body to relax and become limp. Imagine yourself loose and limp just like a floppy rag doll.
- **Meditation:** Watching a candle, a fire burning in a fireplace, or a fish swimming in a tank are all ways to focus as you meditate. Empty your mind of your thoughts as you sit comfortably and focus on the image. Take a couple of deep breaths and allow your body to feel more and more relaxed.

## Other Ways to Care for Yourself

It is normal to have low periods and to feel depressed while grieving. Be gentle with yourself as you find a good routine to get you through the dark days. Make taking care of yourself your priority each day. Resting or doing nothing is fine if you mix in some active times.

Don't let yourself become isolated from friends and family. Let them show you their love and support when you need it most. Ask for their help too. Seek out supportive family and friends who will listen to you talk about your loved one and help you during the grief journey. Accept or suggest support with concrete tasks (i.e., grocery shopping, laundry). As much as you don't want to bother people, they want to help.

**Below are some helpful activities during your journey:**

- Journaling
- Scrapbooking
- Exercising
- Making a book about your loved one
- Going back to work
- Creating a memorial website
- Speaking to others about your loved one

- Doing or creating rituals in your loved one's honor
- Writing yourself a letter and opening it a year later
- Giving a gift in memory of your loved one each year on their special day or on a holiday
- Writing a blog
- Creating a photo collage
- Spending time with friends
- Gardening
- Reading
- Getting a massage
- Resuming or finding a favorite sport or hobby
- Visiting a park
- Volunteering or doing something for someone else
- Attending grief support groups
- Seeing a counselor
- Listening to songs that your loved one liked
- Planting a tree or donate a bench at a park in honor of your loved one
- Having a favorite photo of your loved one made into a painting
- Trying something new that you've always wanted to do

These activities will help you keep your mind and body active as you heal. Set small, daily goals and don't get discouraged if you sometimes don't feel like doing anything. Your energy and interest will increase with time.

## **Twelve Suggestions for Coping with Your Grief**

1. Whatever you are feeling, it is normal. There is no right or wrong way to grieve.
2. Your body requires food and fluid even if you do not want it. It is important to eat small nutritious snacks and meals at regular times and drink plenty of fluids.
3. Sleeping is often difficult. If you cannot sleep, it is important to rest throughout the day. However, try to maintain normal sleep patterns by sleeping longest at night.
4. Your energy level will probably be low. Give yourself permission to rest when you need it.
5. Seek out supportive family and friends who will listen to you talk about your loved one. Accept and ask for support with concrete tasks (i.e., grocery shopping, laundry).
6. Be patient with yourself. It is alright to say no to things that are overwhelming. When you are stronger, then you can say yes.
7. You will not forget your loved one. They will always be part of your life. Choose personal ways to memorialize your loved one.
8. Keep a journal to write how you are feeling and what you are doing. Write as often as you need.
9. If you feel that you cannot cope on your own, consider a professional counselor who can give you support and insight.

10. Find the support of other bereaved people through local support groups, the SUDEP support specialists or a peer contact program. The SUDEP Program can assist with this.
11. Consider seeking out other formal and informal social supports through programs such as you're a church, a civic or social club, or crisis hotline.
12. Sharing your story to protect others living with epilepsy can often feel healing. The SUDEP Program can assist with sharing your story and building awareness for SUDEP through local and national media.

## When Professional Counseling May Be Helpful

Complicated grief occurs when the initial grief emotions continue and significantly impact functioning over the long term. It is different from normal grief where the emotions and physical reactions lessen over time. Complicated grief is debilitating grief that interferes with everyday life and sometimes gets worse rather than better.

Professional support is available at any time but should be sought around the six-month mark if symptoms of complicated grief are present. If the grief becomes too overwhelming and no longer manageable, it is time to seek professional counseling.

When grief becomes overwhelming and no longer manageable, professional counseling may be needed.

The American Academy of Bereavement suggests that intense grieving lasts 3 months to 1 year. However, some people continue to experience profound grief for up to 2 years.

### Signs that counseling would be helpful

- Inability to return to your activities you enjoyed before the death
- Chronic depression
- Desire to die and talk of suicide
- Frequent talk of reunion with the deceased
- Inability to eat or excessive eating
- Inability to sleep or excessive sleeping
- Increased use of alcohol, recreational, or prescription drugs
- Numbness, flatness or "no feeling at all"
- Isolation from family and friends
- Hopelessness, helplessness, or the inability to "see the light at the end of the tunnel"
- Extreme or unreasonable anger, or anger outbursts
- Constant irritability and moodiness

During the grieving process it is normal to occasionally express thoughts that may initially feel/ sound alarming, such as "I just want to be with my loved one" or "Life's not worth living anymore now that my loved one is gone." This

is part of normal grief. However, if you or a family member find yourselves unable to cope and begin to consider, or express, thoughts of suicide, you should seek immediate assistance.

Everyone who has experienced the death of a loved one has one, some, or all these feelings at some time during the grief process. Determining when to seek professional help is a very personal issue. Many people find that they are understood for the first time in the presence of an unbiased, trained counselor. Certainly, when grief becomes overwhelming and no longer manageable, professional counseling should be sought. With the assistance of a professional, your grief can become more manageable.

You can find a therapist through your local mental health agencies, primary care providers, insurance carrier, churches, and hospitals. Websites such as [www.psychologytoday.com](http://www.psychologytoday.com) list available therapists in your area, and their specialty. Just like with any professional, you may find that you must explore various options to find someone who can best meet your needs. Although all licensed mental health providers have met professional criteria to practice, their individual training, expertise and even personalities need to be considered to find the best match for you and/or your family.

If you or a loved one are experiencing thoughts of wanting to die or are having thoughts of hurting a loved one, call the National Suicide Prevention Lifeline right away by dialing 988 or 1-800 - 273-TALK (8255). You can speak with a trained crisis counselor. They are available 24 hours a day, 7-days a week. You can also contact your local 9-1-1 center or visit your nearest emergency room.

The SUDEP Program is here help you through this most difficult, lonely, and overwhelming time in your life. We have a complete program of support, advocacy, case management and a peer-based support network. Please call us with your needs or questions at (800) 332- 1000.

## Coping with Holidays and Special Anniversaries

Holidays and other special anniversaries can be very difficult after a loved one has died. Rather than being a time of family joy and sharing, holidays can bring feelings of sadness and loss. No simple guidelines exist that will take away the hurt or the renewed sense of grief that you might feel during these special days.

### **Here are some suggestions to help ease the pain:**

- Continue a tradition that was special to your loved one. Cooking some of your loved one's favorite foods or sharing recollections of things they



enjoyed during the holidays, and then doing them, may bring positive memories.

- Consider changing a tradition or creating a new one to honor your loved one on the holiday. Have a dinner or toast friends and family to celebrate your loved one's memory. Don't be afraid to cry or to laugh.
- Visit the cemetery or memorial site. Plant a tree or donate in your loved one's memory.
- Attend a prayer service or donate flowers to your place of worship in his or her memory.
- Do things because you want to, not because they are expected. Avoid things that cause you stress. Take time to care for your own needs.
- Forgive yourself in advance for enjoying parts of the holiday. This is not a betrayal of your loved one.
- Embrace your memories. They are one of the legacies that exist after the death of a loved one. Instead of ignoring the memories, share them with family and friends.

## Helping Someone Who is Grieving

It can be difficult to know how to help a loved one who has suffered a traumatic or distressing experience, but support from friends and family can be a crucial factor in your recovery process. Friends and family members may not know the best way to support you. They may even feel awkward around you because they are not sure how to comfort you.

You might share the following information below with your loved ones to help them understand your feelings.

- **Be patient and understanding.** Healing from emotional or psychological trauma takes time. Be patient with the pace of recovery and remember that everyone's response to trauma is different. Don't judge your loved one's reaction against your own response or anyone else's.
- **Expect a wide range of emotions.** A sense of unreality is common in the early stages of grief. There is no right or wrong way to feel, whether it is guilt, regret, relief, anger, sadness, or fear.
- **Your presence is more important than anything you say.** Don't assume you know how they feel or what you can say to make it better. A hug or the squeeze of your hand and "I'm sorry" are usually enough.

- **Listen attentively.** At first, your loved one's talk may be mostly about the death. Later, they may talk more about the deceased's life. Listen, even if they repeat their stories over and over.
- **Don't try to lessen the loss with easy answers.** Avoid using phrases such as "You are not given more than you can handle", "It's God's will," "You were given this challenge because you are strong enough to handle it," "you need to move on," "God needed a little angel in heaven," or "There must be a reason." Although these statements may be considered helpful, they don't often ease the pain someone is feeling. Try not to hurry the grief process.
- **Offer practical and specific support** to help your loved one get back into a normal routine. Make specific offers such as, "Let me pick up some groceries for you when I'm at the store," rather than, "If there's anything you need, give me a call." People don't want to be a burden and most often won't accept help if a specific offer isn't made.
- **Don't pressure your loved one into talking but be available when they want to talk.** Some trauma survivors find it difficult to talk about what happened. Don't force your loved ones to open up but let them know you are there to listen whenever they feel ready.
- **Help your loved one to socialize and relax.** Encourage them to participate in physical exercise, seek out friends, and pursue hobbies and other activities that bring them pleasure. Take a fitness class together or set a regular lunch date with friends.
- **Don't take the trauma symptoms personally.** Your loved one may become angry, irritable, withdrawn, or emotionally distant. Remember that this is a result of the trauma and may not have anything to do with you or your relationship. Try not to judge the emotional ups and downs they may encounter, instead, understand the pain they are struggling with.
- **Call often.** Your loved one may not have the energy to call you but may still want to talk. After the first few months your calls may even be more helpful. Your loved one may not wish to talk much, or even at all, but regular calls are a reminder that there are others who love and care for them.
- **Text or email.** If you know your loved one doesn't want to talk, try texting or emailing them. Some people find it easier to express themselves in writing and you may find they open up even more using these avenues.
- **Send them a card.** Mail might seem to be a thing of the past for some, but many still enjoy receiving mail, such as a card. Often a card lets someone know you are thinking of them, especially if they are not able to talk or you feel you don't have the right words.

- **Plan a date.** Evenings and weekends may feel especially lonely, so it might be good to spend some of that time with your loved one. Or drop by their home with dinner or just sit with them, even if they don't want to talk.
- **Share your positive memories of the deceased.** It helps your loved one to feel connected and relive past experiences. Most often, they just want to talk about them, say their name and help remember them.
- **Express you're caring.** If your loved one wants to laugh or cry when talking to you, it's okay. Sharing these feelings and emotions together can help ease the pain of their loss.
- **Let your loved one know what you appreciate about them.** Build them up and include them in your life and activities. Self-esteem and a sense of identity suffer after a major loss.
- **Remember special days.** Mark holidays, birthdays, and anniversaries on your calendar. These are likely to be difficult times for someone who is grieving.
- **Remember that there is no timetable for grief.** Keep your support ongoing, and don't rush your loved one to put away the deceased's belongings. They will do that when they're ready; then offer to help.

## Suggestions for Helping Bereaved Parents

A parent's grief is unique and often extremely difficult. If you know of someone who is dealing with the death of their child, the following suggestions may be helpful:

### **DO:**

- Acknowledge the child's death by telling the parents of your sadness for them and by expressing love and support; try to provide comfort.
- Visit and talk with the family about their child who died as to see pictures or mementos the family may have.
- Extend gestures of concern, such as bringing flowers, writing a personal note, sending a card, texting, or emailing and expressing your feelings; let the parents know of your sadness for them.
- Attend the child's funeral or memorial service.
- Remember to reach out to them on anniversaries, birthdays, holidays, or special days.
- Donate to a specific memorial in honor of the child. Offer to go with the parent(s) to the cemetery in the days and weeks after the funeral, or whenever they would like to go with support.

- Make practical and specific suggestions, such as offering to stop by at a convenient time, bringing a meal or purchasing a gift certificate to a local restaurant, purchasing a comforting book, offering to take their remaining children for a special outing, or treating the mother or father to something special.
- Respect the dynamics of each person's grief. Grief is an ongoing and demanding process.

**DO NOT:**

- Tell them you know just how they feel.
- Avoid the parents or the grief by not asking how they are doing.
- Refrain from talking about the child who died or referring to the child by name.
- Impose your views, feelings or set limits about what is right or appropriate behavior.
- Wait for the parents to ask for help or tell you what they need.

Your care and tangible expressions for support beyond the immediate days after the child's passing will be remembered and bring much comfort to them during this most difficult time.

### Mourner's Bill of Rights

As a bereaved person, you have certain rights that others must not take away from you. In fact, it is the very upholding of these rights that makes healing possible.

You have the right to experience your own unique grief. No one else will grieve in exactly the same way you do. Don't allow others to tell you what you should or should not be feeling.

1. You have the right to talk about your grief. Talking about your grief will help you heal. Seek out others who will allow you to talk as much as you want, as often as you want, about your grief.
2. You have the right to feel a multitude of emotions. Confusion, disorientation, anger, fear, guilt, and relief are just a few of the emotions you might feel as part of your grief journey. Know that there is no such thing as a "wrong" emotion. Accept all your feelings and find listeners who will do the same.

You have the right to:

- Experience your own grief.
- Talk about your grief.
- Feel a multitude of emotions.
- Be tolerant of your physical and emotional limits.
- Experience grief "attacks."
- Embrace your spirituality.
- Search for meaning.
- Move toward your grief and heal.

3. You have the right to be tolerant of your physical and emotional limits. Your feelings of loss, anger, and sadness will probably leave you feeling fatigued. Respect what your body and mind are telling you. Get daily rest. Eat balanced meals. And don't allow others to push you into doing things you don't feel ready to do.
4. You have the right to experience grief "attacks." Sometimes, out of nowhere, a powerful surge of grief may overcome you. This can be frightening, but it is normal and natural. Find someone who understands and will let you talk it out.
5. You have the right to embrace your spirituality. If faith is part of your life, express it in ways that seem appropriate to you. Allow yourself to be around people who understand and support your religious beliefs. If you feel angry at God, find someone to talk with who won't be critical of your feelings of hurt and abandonment.
6. You have the right to search for meaning. You may find yourself asking, "Why did he or she leave me?", "Why this way?", or "Why now?" Some of your questions may have answers but some may not. And you may hear some of the cliched responses people may give you. Comments like, "You will be OK," or think of what you have to be thankful for" or "you do have other children" are not helpful and you don't have to accept them.
7. You have the right to move toward your grief and heal. Reconciling your grief will not happen quickly. Remember, grief is a process, not an event. Be patient and tolerant with yourself and avoid people who are impatient and intolerant with you. Neither you nor those around you must forget that the loss of someone loved changes your life forever.

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## How Grief Can Vary by Relationship

The individuals lost to SUDEP and other mortalities in epilepsy cross a wide spectrum of ages and stages of life as do the relationships of the bereaved with the victim. The grief experience can vary depending on the relationship, and there are some specific characteristics to be aware of, as well as different types of support needed.

### **If You Have Lost a Child**

A child's death can be especially hard for his or her parents, no matter what the age of the child. As a parent, you may feel guilty that you outlived your child. You lost not only your child but also some of your future hopes and dreams. Each parent may react differently to a child's death. Because you

may not be able to support one another during this time, seek help from others.

For parents who have lost a child, the inability to accept pleasure is one of the biggest barriers to healing. Beginning to enjoy life again doesn't mean you have forgotten your child or no longer grieve for him or her. You will always love and remember your child.

### **If You Have Lost a Sibling**

Your unique relationship with your brother or sister may make your feelings of grief different from the reaction of your other siblings or your parents. You may also believe that you need to protect your parents from your grief.

It can be hard to talk to your parents about your feelings at any time, let alone when they have lost a loved one as well. Seek out someone you can talk to. Know that it is okay to forgive yourself for the fights and arguments you may have had with your brother or sister.

You may feel as if there is an empty place in your family, but you can go on living. Remember your sibling but know that it is okay to go on with your life. Be patient with your family members because each of you will mourn in a different way.

### **If You Have Lost a Spouse**

The relationship of a husband and wife may be one of the closest in life. The grief you feel after the death of your spouse may be one of the worst in life. The grief you feel after the death of your spouse may be more difficult and last longer than that surrounding other losses in your life.

You may feel torn between the past and the future. Though you know you must move forward, you may find yourself looking back. This is normal. You may have trouble making decisions. You may have been doing things jointly for so long that it is now difficult to make choices alone. It helps to find a trusted friend or family member to talk about decisions. Over time, making decisions will be easier. Becoming single again can be lonely and even frightening at times. Connecting with others, especially those who have also had a loss, may bring needed support.

If you were raising children together, it can also be a scary time. Raising children alone is also a big challenge. It takes courage to address family needs without a partner. Find resources such as support groups, books and articles, and family members to help you make the adjustment. Your children will also need to explore and share their feelings with you and other trusted adults.

### **If You Have Lost a Parent**

The death of a parent is one of the most important life events. The loss of your parent forces you to accept your own mortality. To lose someone who

was such a central part of your life is hard, no matter what age he or she may have been.

The loss of your parent may require some adjustments to your life. Some may see the death of an older parent as timely and appropriate and yet still feel a deep sense of grief. Share your feelings and thoughts with others who have lost a parent.

## How Children Experience Grief

Like adults, children and teens may feel intense sadness and loss, or grief, when a person close to them dies. And like adults, children and teens express their grief in how they behave, what they think and say, and how they feel emotionally and physically.

Each child grieves differently, and there is no right or wrong way or length of time to grieve. Some grief reactions cut across all age groups and developmental levels, and children may show their grief in many ways. However, because there are individual ways grief is expressed through emotions and/or behaviors, and the timing of these can be unexpected, it is easy to confuse their grief reactions or be surprised by them.

Helping a child recover from a loss or trauma:

- Communicate openly
- Maintain routines
- Reinforce safety
- Provide comfort
- Validate feelings
- Professional support

Bereaved children may also act in ways that those around them may not recognize as grief reactions. Whatever a child's age; they may feel guilty about having caused the death. Sometimes bereaved children take on adult responsibilities and worry about surviving family members and who would care for them if something happened to their caregivers. Professional support or counseling is recommended if grief reactions seem to continue without any relief and significantly impact the ability to function. At this point, the child may be suffering from trauma associated with grief.

## How Children React to Emotional and Psychological Trauma

- **Regression.** Many children return to an earlier stage when they felt safer and more cared for. Younger children may wet the bed or want a bottle; older children may fear being alone or lose confidence. Being patient and providing reassurance and support will help them regain their skills.
- **Feeling helpless.** It is easy for a child to feel overwhelmed and confused. They can gain a sense of hope and control by maintaining their normal routines, participating in rituals and ceremonies for their deceased loved one, engaging in family activities to commemorate their loved one such as planting a family tree, collecting photos for a special album, doing their best in school or activities, and writing thank you

letters to those who have helped. Being actively engaged relieves their helpless feelings.

- **Thinking the event is their fault.** Children younger than 7 or 8 tend to think that if something goes wrong, it must be their fault, no matter how irrational this may sound to an adult. Be sure your child understands that he did not cause the event or is to blame. Answer their questions honestly.
- **Sleep disorders.** After a trauma or a loss of someone close, some children have difficulty falling to sleep; others wake frequently or have troubling dreams. A stuffed animal, soft blanket, or flashlight in bed can help. Quiet activities in the evening can also soothe. Gently reinforcing bedtime routines can be calming and reassuring.
- **Health Issues.** Complaints about aches and pains may occur. Addressing each and offering simple solutions can ease their anxiety.
- **School and Relationship issues.** Difficulty concentrating in school, not wanting to do normal activities, more anger and irritability about schoolwork, withdrawal and isolating themselves from family and friends may occur. Providing them with additional support, attention, and mentoring can help them return to their normal activities, along with working with their teacher and school counselor.

## How to Tell a Child Someone Died

When death happens, have a close relative, preferably a parent, tell the child about it immediately. Understand that children do indeed grieve, can comprehend loss, and experience grief processes.

Stay close to the child, giving them appropriate affection and attention to manage their grief. They will need extra love, care, and attention during this difficult time.

Let the child see you grieve; it gives them permission to grieve with you or on their own. It will also help the child to see the remaining parents, friends, and relatives grieve. If those around the child behave as if nothing is wrong, or act overly "strong", then the child will think they must meet this standard rather than react naturally and express their feelings. This is a shared loss for family and friends, so it reassures the child to see that everyone is dealing with grief in mourning in some way.

Very young children may not understand the permanence of grief and may need very concrete explanations. Avoid euphemisms such as, "passed on," "gone away," or "departed." In-and-of-itself, the concept of death is difficult enough for a child to understand; using euphemisms may only add to the difficulty. These phrases may lead to questions such as, "when will they come back?" or "when will they come down from heaven?"



Gently help the child grasp the concept of death. Avoid vague explanations to the child's questions but answer each question as honestly as possible. It is more helpful to speak of death and dying in very clear language, with simple explanations.

Discuss the funeral with the child. Forcing him or her to go may not be the best decision. Decide what is right for your family based on the child's development and personality. If they decide to go, explain in detail what they will see, hear, and your expectation of them.

Most children will appreciate being included in this experience, even if they need your support to feel comfortable.

Keep other stressing situations, such as moving or changing schools, to a minimum; after the ceremonies, continue the child's regular routines.

Be honest with the child about the depth of the pain he or she will feel. You may say, "This is the most awful thing that could happen to us or to you." Contrary to popular belief, minimizing the grief does not help.

### **How Siblings Experience Grief**

The sibling relationship is unique. The death of a sibling therefore presents a unique experience that has been left virtually unexplored in the literature. While parents are grieving the death of their child, they may not be available to attend to the grief of their living children. This can lead to a feeling of isolation, leaving a brother or sister to work through their grief alone.

More recently, parents of grieving siblings and grief counselors have begun to address this issue. The impact is immense. The legacy that a grieving sibling carries forward is immeasurable. If allowed to be explored, it may provide insight for future generations about family grieving. The living sibling also plays a role in educating society about the conditions that a brother or sister succumbed to.

Most of the information that is available regarding sibling bereavement is anecdotal. Parental attitude determines how a deceased sibling is incorporated into the family. As parents and families have been allowed to openly grieve so have siblings.

It is important to recognize that children grieve. The way they grieve is determined by their age. However, children, even infants and toddlers, experience sadness especially if their caretaker is sad, distant, or distraught. Therefore, acknowledging sibling's feelings is vital. Allowing them to express an array of emotions will help them cope during a very stressful time.

It is difficult to accept the expression of feelings such as crying, stubbornness, playfulness, and periods of withdrawal. However, like adults, it is unavoidable.

Encouraging siblings to talk about their brother or sister, draw pictures, write poetry, attend memorial services is helpful. This process helps a child work through their grief and decreases isolation. Siblings want to be part of the grieving family.

Allowing children to talk and ask questions can be painful for adults. However, children learn and obtain control through this process.

The bereavement community is beginning to see the results of a decade of "open grieving" related to infant and child death. Sisters and brothers, including the subsequent sibling, seem to be well-adjusted and consequently comfortable with issues of death and dying. They are loving and compassionate people. Parents and their children can grieve together and receive comfort and support from one another. A sibling who is allowed to integrate a deceased brother or sister into their lives seems to feel more complete. After all, the sibling relationship is unique and needs to be nurtured in life and death.

#### Help children honor their siblings

- Create a memory book
- Plant a tree
- Light a candle
- Write a poem
- Draw a picture
- Acknowledge anniversaries of the sibling's birth and death

## Ways to Commemorate

Although with time the pain of grief will become more manageable, you will never forget your loved one and what they meant to you. They will always be a part of your life. Having personal ways to memorialize your loved one can help you begin to let go of your grief and give you positive memories of your time together.

During your grief journey, you will find ways to cope with the shock, denial, sadness, and longing. You will regain hope and find new energy to reinvest in your daily activities and in the people who are still a meaningful part of your life.

Activities that may help commemorate your loved one can provide you with comfort, a way to remember them, and the peace you seek. These can include:

- Looking at photos and/or videos of your loved one
- Making a book about your loved one
- Creating a memorial website
- Speaking to others about your loved one
- Doing rituals in your loved one's honor
- Writing yourself a letter and opening it a year later
- Donating in memory of your loved one
- Writing a blog
- Creating a photo collage or special album
- Listening to songs that your loved one liked

- Planting a tree or donating a bench to a park
- Having a favorite photo of your loved one made into a painting
- Inviting family and friends to a memorial event on the one-year anniversary or creating another type of ritual on the anniversary
- Creating a "memory box" to hold special keepsakes and photos of your loved one
- Planting a memorial tree in a special place
- Taking a trip to visit a place that holds special memories
- Volunteering for a cause or an organization
- Participating in community events that your loved one cared about
- Creating a special memento with your loved one's clothes or belongings

Embrace your memories. They are one of the legacies that exist after the death of a loved one. Keep pictures of your loved one around the house. Instead of ignoring the memories, share them with family and friends.

## Suggested Resources

### Websites

#### **SUDEP and Epilepsy Mortalities Information and Services:**

- Epilepsy Foundation SUDEP Program: [epilepsy.com/sudep](http://epilepsy.com/sudep)
- American Epilepsy Society: [www.aesnet.org/about/about-aes/position-statements/position-statement-on-sudep-counseling](http://www.aesnet.org/about/about-aes/position-statements/position-statement-on-sudep-counseling)
- American Academy of Neurology: [www.aan.com/practice/guidelines](http://www.aan.com/practice/guidelines)
- Center for Disease Control: [www.cdc.gov/epilepsy/about/sudep/index.htm](http://www.cdc.gov/epilepsy/about/sudep/index.htm)
- Chelsea Hutchison Foundation: [www.chelseahutchisonfoundation.org](http://www.chelseahutchisonfoundation.org)
- CURE Epilepsy: [www.cureepilepsy.org](http://www.cureepilepsy.org)
- Danny Did Foundation: [www.dannydid.org](http://www.dannydid.org)
- North American SUDEP Registry: [www.sudepregistry.org](http://www.sudepregistry.org)
- Partners Against Mortality in Epilepsy: [www.pameonline.org](http://www.pameonline.org)
- SUDEP Action: [www.sudep.org](http://www.sudep.org)
- SUDEP Aware: [www.sudepaware.org](http://www.sudepaware.org)

#### **General Grief Support:**

- National Center for Post-Traumatic Stress Disorder: [www.ptsd.va.gov](http://www.ptsd.va.gov)
- The Complicated Grief Program at Columbia University: [www.complicatedgrief.org](http://www.complicatedgrief.org)
- American Psychiatric Association: [www.psychiatry.org](http://www.psychiatry.org)
- Association for Death Educators and Counselors: [www.adec.org](http://www.adec.org)
- Resources for Grief: [www.resourcesforgrief.org](http://www.resourcesforgrief.org)

#### **Specific Support for Children:**

- The National Child Traumatic Stress Network: [www.nctsnet.org](http://www.nctsnet.org)
- American Academy of Child and Adolescent Psychiatry: [www.aacap.org](http://www.aacap.org)

- Parents Trauma Resource Center: [starr.org/resources](http://starr.org/resources)

### **Specific Support for Siblings:**

- Dougy Center: The National Center for Grieving Children and Families: [www.dougy.org](http://www.dougy.org)
- Fernside: A Center for Grieving Children: [www.fernside.org](http://www.fernside.org)
- Solace House: [www.fernside.org/grief-resources](http://www.fernside.org/grief-resources)
- The Compassionate Friends: [www.compassionatefriends.org](http://www.compassionatefriends.org)
- Comfort Zone Camps: [www.comfortzonecamp.org](http://www.comfortzonecamp.org)
- Seasons Centre for Grieving Children: [www.grievingchildren.com](http://www.grievingchildren.com)

## Books

Below is a list of books some families have found helpful.

- 35 Ways to Help a Grieving Child (also available in Spanish) – The Dougy Center
- A Grief Observed – C.S. Lewis
- A Tiny Boat at Sea – The Dougy Center
- After a Death: An Activity Book for Children (also available in Spanish) – The Dougy Center
- Beyond Grief: A guide for Recovering from the Death of a Loved One – Carol Staudacher
- Children Helping Children with Grief – The Dougy Center
- Does Anybody Else Hurt This Bad and Live? – Carlene Vester Eneroth
- Don't Take My Grief Away from Me – Doug Manning
- Explaining Death to Children – Earl A. Grollman
- Gifts from the Sea – Ann Morrow Lindberg
- Grieving: How to Go On Living When Someone You Loves Dies – Therese A. Rando
- Healing After Loss: Daily Meditations for Working Through Grief – Martha Whitmore Hickman
- Helping Children Cope with Death (also available in Spanish) – The Dougy Center
- Helping Children Cope with Separation and Loss – Claudia L. Jewett
- Helping Children Grieve When Someone They Love Dies – Theresa Huntley
- Helping Teens Cope with Death (also available in Spanish) – The Dougy Center
- How It Feels When a Parent Dies – Jill Krementz
- How to go on Living When Someone You Love Dies – Therese Rando
- In an Instant: A Family's Journey of Love and Healing – Lee & Bob Woodruff
- It's OK that You're not OK – Megan Divin e
- Jessie: A Mothers Story – Marianne Leone
- Lament for a Son – Nicholas Wolterstorff

- Living When a Loved One Has Died – Earl Grollman
- Living with Death and Dying – Elisabeth Kubler-Ross
- Making Toast: A Family Story – Roger Rosenblatt
- Memories Matter: Activities for Grieving Children & Teens – The Dougy Center
- Men and Grief – Carol Staudacher
- Modern Loss: Candid Conversation about Grief – Rebecca Soffer
- Motherless Daughters – Hope Edlemen
- Never the Same: Coming to Terms with the Death of a Parent – The Dougy Center
- On Children and Death: How Children and Their Parents Can and Do Cope with Death – Elisabeth Kubler-Ross
- On Death and Dying – Elisabeth Kubler-Ross
- Only Spring: On Mourning the Death of my Son – Gordon Livingston, MD
- Parental Grief – Dennis Klass, PhD
- Parental Loss of a Child – Therese Rando, PhD
- Poems of Mourning – Emily Dickenson
- Standing at the Edge, A year of Days After Sudden Death – Meg Tipper
- Sudden Unexpected Death in Epilepsy; A Global Conversation – Denise Chapman, Rosemary Panelli and Jane Hanna
- Sudden Unexpected Death in Epilepsy; Continuing the Global Conversation – Denise Chapman, Rosemary Panelli, Jane Hanna and Tamzin Jeffs
- Talking About Death: A Dialogue Between Parent and Child – Earl Grollman
- The Bereaved Parent – Harriett S. Schiff
- The Courage to Grieve – Judy Tattlebaum
- The Empty Room: Understanding Sibling Loss – Elizabeth DeVita-Raeburn
- The Fall of Freddie the Leaf – Leo Buscaglia
- The Road Less Traveled – Scot F. Peck, MD
- The Tenth Good Thing About Barney – Judith Viorst
- The Worst Loss: How Families Heal from the Death of a Child – Barbara D. Rosof
- The Year of Magical Thinking – Joan Didion
- To Live Until We Say Goodbye – Elisabeth Kubler-Ross
- Understanding Grief; Helping Yourself Heal – Alan D. Wolfelt
- When Bad Things Happen to Good People – Rabbi Harold Kushner
- When the Bough Breaks: Forever After the Death of a Son or Daughter – Judith R. Bernstein

## SUDEP and Epilepsy Mortalities Articles

SUDEP: Assessing the Public Health Burden, Review Article by David Thurman, Dale Hesdorffer, and Jacqueline French in *Epilepsia* (2014)  
<https://onlinelibrary.wiley.com/doi/10.1111/epi.12666>

The Definition of SUDEP, Epilepsia (2012)

<https://onlinelibrary.wiley.com/doi/full/10.1111/j.1528-1167.2011.03358.x/full>

Sudden unexpected death in epilepsy: epidemiology, mechanisms, and prevention., The Lancet neural. 2016;15(10):1075-88.

<https://www.sciencedirect.com/science/article/abs/pii/S1474442216301582>

Practice guideline summary: Sudden unexpected death in epilepsy incidence rates and risk factors: Report of the Guideline Development, Dissemination, and Implementation, Subcommittee of the American Academy of Neurology and the American Epilepsy Society. Neurology. 2017;88(17):1674-80.

[www.neurology.org/content/88/17/1674.full](http://www.neurology.org/content/88/17/1674.full)

Do antiepileptic drugs or generalized tonic-clonic seizure frequency increase SUDEP risk? A combined analysis., Epilepsia. 2012;53(2):249-52.

<https://onlinelibrary.wiley.com/doi/full/10.1111/j.1528-1167.2011.03354.x>

The 2009 SUDEP Task Force Report, Report of the American Epilepsy Society and the Epilepsy Foundation joint task force on sudden unexplained death in epilepsy in Epilepsia (2009)

<https://www.dannydid.org/assets/1/6/SoEL-SUDEPTaskForceReportEpilepsia.pdf>

Institute of Medicine SUDEP Report

Highlights from Institute of Medicine Report: Epilepsy Across the Spectrum: Promoting Health and Understanding, National Academies Press, Washington, D.C. (2012)

<https://nap.nationalacademies.org/catalog/13379/epilepsy-across-the-spectrum-promoting-health-and-understanding>

National Association of Medical Examiners position paper

Recommendations for the investigation and certification of deaths in people with epilepsy, 2018.

<http://files.constantcontact.com/cf103203601/9554e5be-81bf-45ec-9387-1c3035e216c0.pdf>

Sudden death can occur even in well-controlled epilepsy

U.S. News & World Report, U.S. News & World Report, 2019

<https://www.usnews.com/news/health-news/articles/2019-06-19/sudden-death-can-occur-even-in-well-controlled-epilepsy>

SUDEP and Grief: Overview and Current Issues, Psychiatric Quarterly, 2018

[https://www.dannydid.org/assets/1/6/PhychiatricQuarterly.SUDEP\\_Grief.Oct.2018.pdf](https://www.dannydid.org/assets/1/6/PhychiatricQuarterly.SUDEP_Grief.Oct.2018.pdf)

## **Other Information & Resources:**

**Partners Against Mortality in Epilepsy:** The Partners Against Mortality in Epilepsy (PAME) Conference is designed to increase the sense of urgency and accelerate action around an overlooked and underfunded public health issue - mortality in epilepsy. This conference brings together clinicians and scientists at the forefront of treatment and research with those most deeply aware of and impacted by these issues - families and individuals directly touched by epilepsy and its consequences. This extraordinary convergence of commitment, energy, knowledge, and action is what makes PAME such a special experience.

Link to PAME: [www.pameonline.org](http://www.pameonline.org)

Past PAME Conference Summaries

- 2018 Conference Summary:  
<https://journals.sagepub.com/doi/full/10.5698/1535-7597.18.6.398>
- 2016 Conference Summary:  
<https://journals.sagepub.com/doi/pdf/10.5698/1535-7511-16.6s1.1>
- 2014 Conference Summary:  
<https://journals.sagepub.com/doi/pdf/10.5698/1535-7597-14.s6.14>
- 2012 Conference Summary:  
<https://journals.sagepub.com/doi/pdf/10.5698/1535-7511-13.s2.1>