When a Child Dies

Surviving the Tragic Death of a Child
Dedicated to all the beautiful children who died before their time and the parents, siblings, grandparents and others who will always miss them...

This information is an outreach provided by:

MISS Foundation
602-279-MISS (6477)
888.455.MISS (6477)
www.missfoundation.org

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Grief After Child Death

The word, bereavement, literally means “to be deprived by death.” The experience of the death of a child is, indeed, life’s most stressful event.

Death is the most common human experience, traversing socio-economic groups, race, religion, language, and culture. Yet, there is something unique, and inexplicably painful, about the experience of a child’s death.

Grief is a normal response after the death of a loved one. It is particularly difficult after the death of a child. Family members may experience many overwhelming emotions such as severe sadness, disbelief, anger, guilt, shame, regret, and confusion. Usually, early grief resembles a ‘fog-like’ state. Memory and focus are compromised, and people find themselves easily overcome with emotions. As the denial fades and the reality of the tragedy sets in, life can be difficult to manage. You may find yourself experiencing extreme emotional outbursts throughout the day. Perhaps, you don’t want to get out of bed. Some may feel angry at God, or the Creator, for the injustice, questioning their own values, beliefs, and faith. For others, spirituality may play an important role in the healing process. Often, individuals report physical symptoms such as headaches, stomach aches, aching arms, forgetfulness, and changes in appetite and sleep. It can be difficult to communicate your needs to friends and family, who may desperately want to help. Practical aid such as assistance with housekeeping, childcare, home cooked meals, and allowing you to talk openly about your feelings for weeks, months, and years following your child’s death may be most helpful. Openly expressing emotions in a safe environment can be helpful for many people.

There are no linear stages to the grief experience. Rather, it is a moment-by-moment journey through one of life’s most perilous landscapes. We are here to provide support and resources to you and your family.
The Death of a Child

“There is no greater tragedy, no more devastating human experience, than the death of a child.”
Joanne Cacciatore, Founder, MISS Foundation

More than 120,000 children die every year in the United States. After the death of a child, families experience significant trauma and grief that can affect family and individual functioning and an entire community. The MISS Foundation is committed to helping families through local support groups, camps for grieving kids, bilingual books and resources, indigent funeral funds and funeral planning assistance, counseling, newsletters, web sites, and opportunities for volunteerism that allow people affected by the death of a child family member to begin to heal.

Children can die suddenly, in the hospital, after an accident, sudden illness, or during the perinatal period. Children can also die from a terminal illness or disease. Whether the death was unexpected or anticipated, suffering the death of a child is one of life’s most difficult experiences. It is often challenging to make even simple decisions, and family members may not realize how the choices they make today can affect them in months and years to come. Here are some important things to know if your child has just died:

- You can request to see and touch your child both at the hospital and at the funeral home or mortuary;
- You may ask questions about hospital protocol and what will happen to your child’s body once you leave the facility;
• You may ask for private time alone with your child, in the hospital and at the funeral home. In most cases this is possible;

• You can request to keep mementos such as blankets, identification bands, or other things. You may take photographs and you may videotape the funeral services;

• When a physician is certain of a cause of death, an autopsy is not usually required, although you may request a private autopsy if you so desire;

• If a physician is not certain of the cause of death, the Office of the Medical Examiner will perform a full, postmortem evaluation to determine the cause. Once the evaluation is completed, the funeral home of your choice will pick up your loved one and transport them to the mortuary for the memorial services (see the section on page 28 regarding the autopsy);

• There is no rush to decide on final arrangements. You can wait days or even weeks to bury or cremate. If you choose cremation, you may keep, scatter, or bury all or part of the ashes. Again, there is no rush in making your decision;

• If you need help planning your child’s funeral services, you can visit our online website: missfoundation.org, where you can download a funeral planning sheet at no cost. You can also call us and one of our volunteers can contact you directly to provide aid and guidance;

• If there are siblings at home, they should be offered an opportunity to say goodbye to their brother or sister who died. The hospital social worker or pastoral care can facilitate this process for the family.

“Children who die young are our greatest teachers.”

Elisabeth Kubler-Ross
“There is a sacredness in tears. They are not the mark of weakness but of power…they are messengers of unspeakable love.”

Washington Irving

After the death of a child, many people learn to wear an, “I am fine mask.” Of course, life resumes and the responsibilities of daily life do not stop. Some bereaved parents feel like no one understands their pain. How can life go on when your child has died? It is incredibly painful and unjust.

Because of the overwhelming nature of a child’s death, some bereaved parents find self-care difficult. Grief not only causes emotional responses but it also affects the physical body.

It is important to try to take care of yourself. It is also important to get help if you have surviving children in the family (see page 20 on how to help grieving children). Here are some ideas to help you navigate the journey of grief:

**Sleep**

Give yourself plenty of time to rest. Grief is emotionally draining and you will need to recharge more often.

**Exercise**

Take walks, work out, spring clean, try yoga, or learn a new sport. Physical exertion is a great stress reliever and may afford you some time alone to gather your thoughts in the process. *Note: Consult with your physician before beginning any rigorous exercise.*
Be patient with yourself
Your emotions may be unpredictable and unstable for months after the death of your child. You may also be more irritable than normal and concentration may be difficult.

Attend support groups
Those affected by death may seek out like others, through support groups, church groups, or family connections. Support groups may reduce feelings of isolation and connect you to a community of others with shared experiences. Ensure that grieving children in the family have access to counseling opportunities as well as children’s grief support groups.

Keep a journal
This is a highly effective, self-help technique for bereaved individuals. Write every night, even if it is just a few lines.

Cry, cry, cry
Tears can be very healing. Allow yourself alone time everyday to cry.

Meditate
Quiet, deep thinking and meditation may help you reestablish emotional clarity. Couples can even do this together. Take five or ten minutes each morning and evening to sit quietly and “feel” or think through your expectations and experiences of the day.

Don’t rush yourself
Give yourself permission to feel the many emotions you will face after your child’s death. Don’t expect to get over it: You do live on, and will be happy again and you will survive, but you probably will never get over it. It is a gentle and gradual acceptance that happens over many months and years.

Read
Be proactive. Read about others’ experiences with child death and consider new ideas for coping with grief.
Avoid major changes
Try to avoid major decisions that will dramatically change your life now. Wait a few months before making life-altering decisions.

Ask for help
Grief is a long and tiring process. Don’t be afraid to ask friends and family for specific things they can do to help you, even months later. Some ways in which others can help:

• Provide childcare for surviving children
• Make and deliver meals
• Arrange to clean your home
• Run errands

Be prepared for reoccurring grief
Holidays, birthdays, anniversaries, and other special occasions can cause a resurfacing of very strong feelings of sadness for many who have lost a child to death. Some ways you can cope may include:

• Participate in the Kindness Project™ (See page 36 on the Kindness Project)
• Establish new ways to celebrate holidays
• Do something special in memory of your child
• Visit the cemetery or “special place” of remembrance
• Attend a support group
• Develop a special ritual to honor your child

“There is one way to live without grief and that is to exist without love.”

Carol Staudacher
How a support group may help
Agencies in your area may offer self-help support groups for grief. MISS Foundation support groups are attended by other families who have also experienced the death of a child in their lives. It is a safe haven to share feelings and emotions which you may not feel comfortable sharing elsewhere.

“Who better to softly bind up the wound of one then he who has suffered the wound himself?”
Thomas Jefferson

What if I don’t want to talk about it?
You won’t ever be pressured to discuss any matter which you are not ready to share. Many people attend several meetings, merely listening to and learning from others. When, and if, you are ever ready, you may share any aspect of your experiences.

What if I don’t like it?
No one “likes” or “wants” to become a member of this group. However painful the group experience may seem at first, try to attend at least three meetings. Social support has been proven to aid in the management of the very harsh effects of grief, particularly after a child’s death. It is important to remember that you don’t have to go through this alone. When you are ready, others who have been through it want to help.

Should I still go if I feel I don’t need group any longer?
Yes! Many continue to attend group for years after their child has died. Why? Because you can give the gift of hope, peace, and encouragement to another parent who has more recently
endured the death of their child. Helping others is a wonderful way to honor and cherish your child’s memory.

What about our surviving children?

There are also support groups and programs for grieving children. Grief is a family experience.

“The support group provides the opportunity to meet with other parents who have experienced the death ...and who extend their friendship and understanding to newly bereaved parents. In the group setting, parents are encouraged to talk about their (child) and express feelings about death in a safe environment. Gradually, parents begin to cope with their loss and are supported in the process.”

Mandell, in Culbertson, Krous, and Bendell-1988

Perinatal and Infant Death

Perinatal death can occur through stillbirth or neonatal death. Babies can die just before, during, or after labor. They can also die shortly after birth. About one in 100 pregnancies ends in stillbirth, or about 30,000 per year. There are about four million stillbirths around the world every year. There are slightly fewer neonatal deaths. Babies can also die from unexplained causes such as sudden infant death syndrome (SIDS) or crib death. About 2500 babies a year die as a result of SIDS.
Stillbirth

In about half of stillbirth cases, the cause of death is undeterminable. However, the autopsy rate for stillbirth is very low and there is no current uniform process for postmortem evaluation. Because so little is known about stillbirth, even healthy women may be at risk.

Stillbirth is the death of an infant in-utero and past 20 completed gestational weeks. It can happen before or during the onset of labor and can happen to any woman. Many full-term stillbirths occur to low risk mothers and approximately 40% of stillbirths occur with no diagnosable cause of death. These deaths are called Sudden Antenatal Death Syndrome, or SADS. This means that a baby has died at or near term for no explainable reason.

The most common diagnosable causes for stillbirth include:

- **Placental problems**: Pregnant women who smoke cigarettes have a greater risk of placental abruption. High blood pressure (preeclampsia) also increases the risk of abruption. Other problems with the placenta, which prevent it from supplying the infant with enough oxygen and nutrients, may also increase the risk of stillbirth.

- **Birth defects**: Between five and ten percent of stillborn babies have chromosomal anomalies. Others may have structural anomalies which can result from genetic, environmental, or unknown causes.

- **Intra-Uterine Growth Restriction (IUGR)**: Infants who are not growing at an appropriate rate for their gestational age are at an increased risk of stillbirth due to hypoxia (lack of oxygen) both before and during birth.
• **Infections:** Bacterial infections often cause no symptoms in the pregnant woman and may go undiagnosed. These infections increase the likelihood of stillbirth or premature birth.

Scientists and physicians do not fully understand the causes of many stillbirths. We do know that at this time, stillbirth cannot be prevented or predicted.

_NOTE:_ This information is not intended to replace your doctor’s advice. This is for informational purposes only. Please call your physician if you have any other questions.

“You cannot measure or limit a parent’s love by the age of their child at death.”

Joanne Cacciatore

The Difficult Questions after Perinatal Death

• **What if I have a stillbirth or if it happens to someone I know?** Though the chances of having a stillborn baby are decreasing in most states, it is helpful to know who to call for help. The MISS Foundation has volunteers who can help you or someone that you know who may be going through this tragedy.

• **Will I still have to go through labor if my baby dies?** Most often, yes. Even if a baby is stillborn before the onset of labor, most women will experience labor and childbirth in the same way as a “live” birth. Having adequate pain control options, supportive family members, and birth assistants or doulas can help ease the overwhelming emotional and physical pain of stillbirth.

• **Will I get to see my baby?** Yes. We encourage women and their families to see, hold, and touch their baby. You may be able to participate in bathing and caring for your baby after his or her birth. Although it may be difficult, most families are very grateful that they had those special moments with their baby.
• **Will my baby get a birth certificate?** Several states recently began offering this to parents. Call the Office of Vital Records in your state and tell them you’d like to obtain a “Certificate of Birth resulting in Stillbirth.” For more information, please contact info@missfoundation.org or 623.979.1000 or visit www.missingangelsbill.org.

• **Is the grief process after a baby’s death different than the death of an older child?** There are different features about every child’s death. In the case of stillbirth, neonatal death, and SIDS, most parents report the same degree of unconditional love and attachment to their new baby as they feel with older siblings. Thus, their grief and emotional responses are often indistinguishable from any situation where an older child has died. It is important to remember that love and attachment, and the resultant grief, are not contingent on a child’s age, genetic perfection, or cause of death. Each child’s death represents a tragic loss for those who loved him or her.

• **What happens after my baby is delivered?** You will be presented with many options that can seem overwhelming. Generally, you will be asked if you want to see and hold your baby, if you want photographs, if you want an autopsy, and if you want genetic studies. In our experiences with grieving families after a perinatal death, we know that most mothers and fathers never regret seeing and holding their child. As painful as it to imagine doing this, it may be an important step in the healing process and to minimize regret. Parents often want mementos of their child, such as a lock of hair, hand and footprints and molds, blankets, and other artifacts. Also, the autopsy may be the only way to truly determine the cause of death and to determine if your future children are at an increased risk for genetic anomalies.

“I have found the paradox that if I love until I hurt, then there is no more hurt; only love.”

Mother Teresa
The deaths of toddlers, young children, and teenagers are also very painful experiences for families. The memories that once comforted can evoke sadness and grief for everyone sharing in the loss. Siblings, parents, and grandparents will have to adjust to the physical absence, day-to-day, of the child who died.

There are many causes for death in this age range. Some deaths are considered unpreventable, while others may have been preventable. Sometimes, the cause of death is not determinable, meaning a medical examiner could not identify the biological mechanism for death. In these cases, the death certificate will read “unknown” or “undetermined”. Whether a family knows the cause of death or not, the loss of a child family member at this age can trigger many emotions in family members. Friends of the child who died may be a comfort or a painful reminder. Their clothes, toys, and remnants scattered throughout the house may also incite deeper grief or for others may provide solace in remembering. Take your time putting your child’s things away as you struggle with their physical absence. You may feel reassured by collective mourning, that is, friends, neighbors, and family members’ expression of shared sorrow. Discovering a ritual can be helpful to some. For example, if your child was killed in a car accident, you can light a candle at the accident sight. Siblings may struggle to normalize life after the death. The special relationship between siblings is irreplaceable. It is important to seek help for your surviving children from a professional trained in death and grief issues.
What about the burial or cremation?
Bereaved parents, siblings, and grandparents often report a sense of peace when visiting the place where their child is buried. Other parents cremate their child’s body and keep the cremains with them at home. These funeral rituals may provide comfort to remember your child in a special way on anniversaries, holidays, and other significant days. With either cremation or burial, you may have a memorial service and invite loved ones to say goodbye. Some choose a more elaborate funeral service.

Our thoughts/questions:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Should we see and/or hold our child who died?
This can be a very difficult decision to make. Some family members experience a strong urge to see and hold their child who died. This is an option for you. Take your time in making this decision, and ask for support and help from others if you feel too overwhelmed to face this ritual alone. Sometimes, fear drives the decision not to see a child who died. Other options would include seeing/touching your child’s foot or hand.

Our thoughts/questions:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
What do I do when my child has just died?
You have the right to see, touch, and hold your child who just died at the hospital and again at the funeral home. No one should pressure you to “hurry along” and say goodbye. You can request extra time even after you’ve said your ‘final’ goodbye should you change your mind. You may also engage in a ritual called *memento mori*, that is, memorial photographs. You may request a professional photographer or may take your own photographs of your child who died. Spend as much time saying goodbye to your child as you need. Do not be timid in taking care of your own emotional and physical needs. Caregivers should facilitate culturally competent care, religious practices, and rituals. You should feel comfortable and respected by others during this process. You may request private time alone with your child. And you should ask any questions you may have about postmortem care, autopsy and other procedural tests, and any forthcoming reports.

Can we have our child blessed?
Some parents choose to have a blessing ceremony for their child after he or she has died. You may wish to invite your family to participate in the ceremony. If you belong to a local church, you can ask caregivers to contact your spiritual leader. If you do not, some local churches will offer this in the event of a child’s death, recognizing the enormity of the loss.

Our thoughts/requests:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
What do we do with our child’s nursery or room?
Some parents find comfort spending time in their child’s room. Others find it painful. Sometimes well-meaning family members will put everything away before the parents get home from the hospital. It is important that you let your family know your feelings on this. It may be best to not make this decision at this time because you don’t know how you will feel when you get home. Many parents find it helpful to do this task at a later date as part of the process of saying goodbye. Still others decide to leave the child’s nursery/room intact for a period of time, until they are ready to put their personal items away.

Our thoughts/requests:

__________________________________________________________________________

We have other children. Should we let them see their sibling who died? What should we tell them?
There are many factors to consider such as the age of the child, the cause and manner of death, and the condition of their siblings body. Most children, despite their age, do grieve whether they see their sibling after death or not. They also know that their parents are very sad and it may be helpful to involve them as much as possible to help them understand the tremendous sense of loss in the family. It is important to let them know it was nothing they did, said, or thought which caused the death of their brother or sister.

Our thoughts/questions:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitivity and an understanding of life that fills them with compassions, gentleness, and a deep loving concern. Beautiful people do not just happen.

Elisabeth Kubler-Ross

The grief of grandparents is a unique grief – they mourn not only for the grandchild, but also for their child who has suffered this unspeakable loss. The Grandparent HOPE Mentors is a MISS Foundation program organized to provide support, education, resources, and peer contacts throughout the world. Staffed entirely by volunteer grandparents, Mentors responds to newly bereaved grandparents with information packets, personal contact, and remembrance cards. For more information on the MISS grandparent program, please call 602-279-MISS (6477).
The Grieving Sibling

For children, the death of a sibling, parent, grandparent, or friend can affect their sense of security, self-esteem, and it can de-center them. The family and the community can help children who are grieving. This type of support will enable the children to resume their lives more fully at home and at school. Parents, teachers, medical professionals, and community leaders all play an important role in the life of the grieving child.

Avoid telling them that ‘God’ took their loved one. Avoid associating death with sleep or something ‘lost.’ Remember children are very literal. Allow them to participate in rituals such as funerals, memorial services, and candle lightings. Children at all ages should be offered the opportunity to say goodbye to their loved one. Adults should encourage children to ask questions. Do not discourage them from talking about their pain and be patient and very gentle. Try not to yell at, hit, or isolate children after the death. Children may appear to be “misbehaving” but they may actually be manifesting grief symptoms through such behavioral changes. Here are some common ways in which children may respond to a death:

• Sadness
• Denial, shock, and confusion
• Anger, rage, or ‘bad’ behavior
• Inability to sleep
• Nightmares or fear of sleep
• Loss of appetite
• Fear of being alone
• Somatic/physical complaints such as stomach aches and headaches
• Inability to concentrate or focus
• Guilt over failure to prevent the loss
• Depression or a loss of interest in daily activities
• Regressive behavior—acting much younger or reverting to earlier behaviors
• Withdrawal from friends
• Sharp drop in school performance
• Talking frequently and asking repeated questions about the death, or making repeated statements of wanting to join the deceased.
• Profound emotional reactions

“They that love beyond this world cannot be separated by it. Death cannot kill that which never dies.”

William Penn
Quick Tips for Adults

- Children need comfort and frequent reassurance that they’re safe, loved, and taken care of.
- Be honest, simple, and direct when talking to them about death.
- Encourage them to express their feelings through talking, drawing, and playing.
- Try to maintain a normal routine.
- Find local children’s support groups to help.

How to Help a Grieving Child

Children are physical in their grief process. Interact with children through gentle play, and support their special ‘language’ of grief expression. Art and writing are particularly helpful.

Young children are concrete thinkers. Avoid expressions such as “passed on,” “at rest,” or “we lost” when talking about the person who died. Be direct and honest. Offer only what they can absorb and keep it simple. Be patient when trying to help them understand.

Children can be fearful about death and feel insecurity about their future. Give them a chance to discuss those fears and validate their feelings. Offer the support of another adult whom you both trust as some children may resist talking to their parents about their true grief feelings.

Be patient with the child. Children may not be able to express overwhelming sadness into words, so try to interpret perceived behavior problems as manifestations of grief. Be
more flexible in punishment, and we suggest positive reinforcement rather than harsh discipline. Yelling, hitting, or isolating a grieving child can exacerbate the symptoms and create a cycle of negativity.

Keep routines as much as possible. Try not to make any major decisions for 18 months. Children need to be assured that they have security, stability, and love.

Adults can provide a good grief “model” for the grieving child. Share an ‘open emotion’ policy and allow yourself, and your child, to cry when needed. Your openness will validate their feelings.

Children are intermittent grievers. Just because they don’t cry everyday doesn’t mean they aren’t hurting. Some children cry for one minute and jump right back into normal play.

Expect their grief to revisit during their childhood and through adolescence. Triggers awaken old grief. Make yourself available.

Shower them with affection and attention. If you are feeling too overwhelmed with your own grief, call a friend, a support group, your church, or someone else who can help!

Because death brings many complications for a family, we recommend a therapist evaluation, when possible, to determine how the child is coping with their grief. Particular symptoms to look for include:

- Extended periods of depression in which he or she loses interest in daily activities and events.
- Inability to sleep, loss of appetite, prolonged fear of being alone.
- Acting much younger for extended period of time
• Withdraws from friends at school.

• Sharp drop in performance or refusal to attend school.

Children are often deeply affected by the death of a brother or sister. At the same time, parents may be too overwhelmed with their own grief to provide the emotional and physical care that children so desperately need. In an effort to help children and parents dealing with death, the MISS Foundation has created the “Kids in Sympathy & Support” (or K.I.S.S.) program. This very special outreach offers monthly support groups, art, music and writing therapy, ‘Kids Kamps’, books, counseling, and resources for grieving children.

We help parents and grandparents better understand the grief process for children so they can be more patient and understanding during critical periods after a death. We also help grieving mothers, so vulnerable to depression during subsequent pregnancies after a child’s death, cope with emotions in a healthy way so that she can develop a positive and nurturing attachment with future children.

“We are healed of a suffering only by experiencing it in full.”

Marcel Proust
PTSD is a cluster of symptoms that can occur when a very traumatic incident occurs in a person’s life. Trauma often initially leaves a person feeling powerless, victimized, and emotionally, physically, and mentally paralyzed. Types of trauma that increase a person’s chance of experiencing PTSD include the death of a child, hurricanes and other natural disasters, fires, severe transportation accidents (auto, plane), victimization by criminal activity (rape, burglary, assault), witnessing violence, rape, prolonged trauma such as war, child sexual abuse, cult involvement, and verbal/emotional familial abuse. PTSD can also frequently occur months after the death of a child.

PTSD symptoms can include:

- Sadness and depression
- Denial, shock, and confusion
- Anger and irritability
- Inability to sleep
- Nightmares or fear of sleep
- Loss of appetite
- Fear of being alone
- Somatic/physical complaints such as stomach aches & headaches
- Inability to concentrate or focus
- Guilt over failure to prevent the loss
- Depression or a loss of interest in daily activities
- Regressive behavior (acting much younger or reverting to earlier behaviors)
- Forgetfulness
- Apathy
- Extreme emotional outbursts
What can be done about PTSD?

Each situation is unique, however, someone suffering from symptoms should consider seeking counseling or psychotherapy. In addition, the person may want to evaluate what they are doing to help themselves through the resultant post-trauma grief.

Support groups are another way to help a person establish a safe place to express difficult emotions and cope with feelings and symptoms associated with the trauma.

Other things that may help:

- Eating well and taking good multiple vitamins and minerals
- Daily exercise
- Establishing new routines or hobbies
- Daily journaling

“Unless we remember, we cannot understand.”

E.M. Forster

What are the effects?

The effects of PTSD can be subtle or they can be apparent. They can include extreme mood swings, uncontrollable outbursts, irrational long-term fears, physiological symptoms (somatic) such as headaches, lethargy, digestive troubles, repetitive disturbing nightmares, and a change in appetite. Self destructive behaviors can also appear in some such as drug and alcohol abuse or self-mutilation.

According to the Post Traumatic Stress Disorder Alliance, recognizing PTSD includes identifying clusters of symptoms that have been present for one month or longer which cause “severe problems or distress.” Some of the indicators include:

- Hyper-sensitivity
• Reliving the event through nightmares or other uncontrollable and “intrusive” thoughts. Often this replay causes physical stressors such as heart palpitations, headaches, or sweating.

• Avoidance of reminders of the event or death which includes a person going out of their way to avoid places, people, or activities associated with the trauma.

• Hyper-arousal and sensitivity at all times making it difficult to concentrate, work, sleep, and increasing irritability, aggression, withdrawal, or isolation.

Can Children Experience PTSD?

Yes. But as with adults, often it can be dismissed or misdiagnosed, according to the PTSD Alliance. It is important that children are well-supported during times of high-stress and trauma. We recommend that grieving children who are struggling with their emotions have an opportunity to be evaluated by a children’s grief therapist, either a clinical social worker or a psychologist.

Books, resources, sharing or support groups, and open family discussions may also help the child. When children are involved, ensuring that the other family members are part of any therapy plan, when appropriate, is critical to assist the child in more expedient resolution of the PTSD symptoms. Also, remember that children may not manifest the same symptoms as adults. They may experience social, emotional, and behavioral based on their stage of development. They may also experience changes in appetite and sleep patterns.

Please call your doctor if you believe that you or someone you love is suffering from PTSD.

“Death ends a life, not a relationship.”

Jack Lemmon
Facing the option or in some cases, mandate of an autopsy is very difficult. However, it can be very important at the time of the sudden death of a baby or child.

The autopsy may determine the nature of an illness, reveal genetic abnormalities, uncover the cause of death, and provide answers to the questions about the appropriateness of the health care provided. A forensic pathologist should consult with all involved parties, such as family members, private physicians, funeral directors, and attorneys to ensure clear understanding and alleviate the additional burden that the process of an autopsy may create.

In some cases, autopsies are compulsory by law. In stillbirth, neonatal death, some terminal illnesses or if a physician has signed the death certificate, the autopsy may be an option. It is important that you are offered a full explanation of the procedure and the option to choose the autopsy.

**Why the Autopsy?**

Some causes of death are diagnoses of exclusion or are unknown until further examination. It is imperative that a thorough death scene investigation and a complete autopsy be conducted in order to correctly determine the cause of death. The autopsy is important both in terms of its use in accurately determining the cause of death and its emotional value to many families. Here are some facts about autopsies:

- It is like a surgical procedure performed to examine internal organs.
- It is performed by a physician trained in forensic science in a professional manner so that the dignity of the deceased child is maintained at all times.
• Small amounts of tissues will be removed for detailed examination under a microscope.

• The procedure will not prevent families from having an open casket at the funeral.

• In cases of compulsory autopsies, there is no charge to families. There may be charges involved for stillbirth cases or for second opinions.

**Key Points About the Autopsy:**

A presumed diagnosis of “unknown” or “undetermined” may not prevent tissue, heart valve, or organ donation even in some stillbirth cases.

The most common question of parents “Why did our child die?” can really only be answered by performing an autopsy.

Some parents who initially objected to an autopsy were later relieved that it was done.

The autopsy may help reduce the guilt that families experience and the suspicion that often accompanies the sudden death of children.

The autopsy may be the only way to rule out illness that could affect other family members or genetic problems that may affect future children.

The child’s body will be treated with respect and dignity. There will be some noticeable incisions as a result of the autopsy.

The final autopsy report and death certificate may not be available immediately. Toxicology and microscopic examinations may take several months to complete.

Parents have a right to communicate with their local coroner or medical examiner about the status of the evaluation.

If you have specific questions about the autopsy, please contact your local office of the medical examiner in your county.
Because Grief is as Real as Love

To be a compassionate caregiver and friend, be gentle, kind, and patient.

Give them permission to feel their sadness and to experience the depth of their loss for weeks, months, and even years after their child’s death. Be present. Offer practical aid such as help with younger family members or children, meal making, and day-to-day tasks. Be sincere and listen. Don’t rush their grief experience. If you feel they will benefit from services, encourage them to attend support groups and one-on-one counseling.

The best gift you can give a grieving parent or child is your unconditional love and support. Don’t use clichés to comfort them. No words can heal a mourner’s grief. Just be present and show you truly care.

“An event has happened upon which it is difficult to speak and impossible to remain silent.”

Edmund Burke

Grief brings on a wide range of emotional responses. Many people feel an initial stage of numbness after first learning of the death. There is no real order to the grieving process, however, emotions that some may feel include: denial or disbelief, confusion, shock,
anger or rage, sadness and depression, yearning, desperation and despair, guilt and shame, as well as physical symptoms such as headaches, appetite changes, and tiredness or lethargy. Individuals may withdraw from social settings and friends after the death experience. They may have frequent emotional outbursts. They may feel unable to normalize their day-to-day routine and it is likely that you will see many changes in the person over the coming months and years. Holidays, or trigger-events such as the anniversary of the death, may cause setbacks even years later. Providing long-term, compassionate and empathic support is crucial to help facilitate healing.

It is important to allow as much time as the person needs to heal. Rushing their journey will make them feel lonely and afraid. Note: If you are concerned about someone you know who is mourning, contact your local crisis hotline.

“Feelings of grief are commensurate with the depth of love.”

Joanne Cacciatore

Death Affects Us All; Ripples Move Outward and Touch Many

Death affects individuals and families, communities and organizations, institutions and societies. It is the one, most common human experience, traversing socio-economic groups, race, religion, language, and culture. The death of a loved one is not something to ‘get over,’ but rather, it is a long-lasting anguish that, if treated with loving compassion, becomes a part of a new sense of self and offers meaning. It isn’t something that
Our MISSION
Founded in Phoenix, Arizona in 1996, the MISS Foundation is a volunteer-based, nonprofit, 501(c)3 corporation that provides immediate and ongoing services, support, and resources to grieving parents, children, and families when a child has died or is facing death; risk management programs to decrease infant mortality and improve maternal health; empowerment through community volunteerism; economic assistance; public policy analyses and legislative call-to-actions; and educational opportunities for professional disciplines in the field.

Our Board of Directors
Our Board of Directors is a merging of professionals in the field, including physicians, nurses, mental health professionals, and public service officials, with family members from diverse religious, socio-economic, ethnic, and racial backgrounds who have all experienced child death.

The Ripple Effect
The death of a child may seem like an isolated family tragedy. However, it is a break in the chain of life and anecdotal evidence suggests that the effects of child death are far-reaching. Like a pebble tossed into a still lake, an infant or child’s death profoundly affects entire neighborhoods and communities.
“There is no greater imperative for community responsiveness as when a child dies... compassion is a duty, not an option.”

Joanne Cacciatore

Strong Individuals, Strong Families, and Strong Communities

The death of a child is a tragedy. Without proper support and services, this tragic human experience may affect the well being of family members. Grieving parents may fall victim to high levels of stress, which can be devastating to the surviving children and the parents’ health, careers, and marriage. Especially in cases of limited services and support, the death of a child may affect an individual’s ability to nurture and provide care to surviving children (McGoldrick & Walsh, 1991).

Without the MISS Foundation, these children and families have limited resources for education and support, which are critical to developing healthy and congruent responses in their grief. Through continuing and expanding our family support services, the MISS Foundation helps to keep grieving families connected, not only to one another, but also to a larger community. This, in turn, helps to buffer the effects of negative coping. Eventually, our members not only return to a level of functioning in which they existed before their child died, but many transcend their place in the world to accomplish amazing things as a legacy to their child. Ultimately, this transformation, if well-supported, builds strong individuals, strong families, and strong communities.
Our Programs

Family Outreach

Since 1996, the MISS Foundation has come to the aid of families upon the death of a child family member. Free services we provide to grieving children and adults include:

- Crisis intervention and counseling services
- Mentoring program: parent and grandparent HOPE Mentor Support Program
- Emergency packets
- Kindness Project™
- Books, brochures, and resources
- Support groups for adults and children
- Kid’s in Sympathy and Support Camp
- Annual gatherings and conferences
- Economic aid for low income families
- Interactive website providing online support group forums
- Weekly, monthly, quarterly eNews and newsletter
- Volunteer opportunities
- Perinatal/Pediatric Hospice Support
- Every second Sunday in December, the MISS Foundation hosts a candlelight remembrance ceremony for National Children’s Memorial Day

More information on our programs is available on our website: www.missfoundation.org or call our office at 602-279-MISS (6477) or 888.455.MISS (6477).
Risk Management and Maternal Health
While many infant and child deaths are not preventable, research indicates that certain behavioral changes can significantly modify the risk of death in the first year of life. At highest risk are certain minority populations with limited access to information or healthcare. The MISS Foundation provides crucial knowledge to families and to pregnant women in an effort to reduce stillbirth and premature birth, and improve a newborn’s chance of survival during the first twelve months of life.

“Motherhood is an eternal place within your heart...a sacred place that belongs only to you.”
Joanne Cacciatore

The Circle of Compassion: Professional Education
The MISS Foundation provides educational opportunities for professionals, community leaders, and academicians, covering topics such as psychosocial crisis intervention, grieving children and families, and the “circle of compassion.” During the course of one year, approximately 150 training sessions are completed by more than 2500 police officers, fire fighters, doctors, nurses, social workers, teachers, administrators, and other professionals. Continuing education credits are provided as a learning incentive for many disciplines. For more information on our professional seminars and workshops, please call 602-279-MISS (6477) or 888.455.MISS (6477) or contact info@missfoundation.org.

Advocacy and Volunteer Opportunities
One of the basic tenets of the MISS Foundation is the idea of giving back. Volunteers get involved in public health advocacy
at the legislature. We have successfully passed dozens of bills into law, helping to transform the way our communities respond to child death. By fostering an increased sense of volunteerism, and then by providing opportunities for community activism, the MISS Foundation encourages growth, empowerment, and positive focus. Many of our members remain involved for years as volunteers in order to help other newly affected children and families. No other group in the world does what the MISS Foundation does!

The Kindness Project™ began by the MISS Foundation in October of 1997 as a way for families to honor their child and to help themselves heal. By 2007, more than 750,000 Kindness Project cards have been used around the globe to perform random acts of kindness in memory of a child, parent, friend, or spouse who died before their time.

The idea is to perform random acts of, usually anonymous, kindness in the community. A little card is left behind so that the person who benefits from the kindness knows that someone’s life and death continues to matter.

How can I participate in the project?
You can participate by ordering Kindness Project cards or just doing nice deeds in your community with your child’s loving memory at heart.

What is the Kindness Project card?
The Kindness Project Card is a business sized card that reads:
The card can be left anonymously or given when you have done a ‘kindness act’ for someone else as a legacy to your child.

Can others participate in the Kindness Project?
Yes! This card can be used by siblings, grandparents, friends, aunts, uncles—by any person who wants to honor and remember the life of a very special child.

The MISS Foundation is available to help you and your family. Our website has 25 online support groups in the section called “Forums.” There are also many support groups for grieving parents and children around the country. To find out more information, visit our website: missfoundation.org or call the home office at 623.979.1000 or 1.888.455.MISS.

In Mourning Bands™

Changing the way our Culture Mourns
The In Mourning Band™ and One Who Soars Band™ Campaign is intended to increase awareness about the ways in which death affects individuals, families, and communities.
The In Mourning Band is an outward display of active grief, often worn by bereaved when wanting to express their sorrow in a public, yet discrete, manner. The One Who Soars Band is intended to honor the deceased child, and to remind bereaved families that they indeed have “One Who Soars.” Death does not end a relationship. Love is stronger than death.

The bands are a great way to educate others because “grief is as real as love” (Cacciatore, 2005).

For more information, please visit: www.inmourningband.org.
“Without the help of the MISS Foundation, I don’t think I would have survived.” Linda Schmidt — Ten-week-old son died unexpectedly

“I am really happy about the MISS Foundation. I really miss my brother and sometimes I cry. But I know it’s okay to be sad when I miss him.” Timmy, 9 years old — Older brother died in a bicycle accident

“…To simply say ‘thank you’ seems inadequate.” Heidi Ohms Cass — Infant son died as a result of Hypoplastic Left Heart Syndrome

“I’m forever grateful…that the MISS Foundation exists to help so many families through the staggering grief and sadness.” Annette Alvarez — Niece was stillborn at fullterm

“…Your brochures and information help us to deal with grieving families after the loss of a child…Thank you so much.” Panthea Baker, Victim’s Advocate, Pinal County Attorney’s Office

“I know of no other organization that offers the quality and variety of support that the MISS Foundation does…a community like no other.” Sgt. Randy Force, Phoenix Police Department

“Our community is a better place because of your good work…” Richard Slager, Vista Care Hospice

“…The MISS Foundation’s training “Compassionate Intervention With Families” provides the information to extend the natural compassion brought to the job to the next level. I would recommend this training to all first responder organizations.” Fire Chief Alan V. Brunacini, Phoenix Fire Department

“Thank you…Our grief support program is forever changed.” Sarah James, Phoenix Children’s Hospital

“I am deeply moved by the spirit of the MISS Foundation.” Dr. John DeFrain
Contact information

The MISS Foundation
602-279-MISS (6477)
888.455.MISS (6477)

Tax deductible donations to help us continue our good work may be sent to:

Memorial Donations
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Phoenix, AZ 85012

www.missfoundation.org
www.ekrfoundation.org

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If you are interested in participating in ongoing research projects sponsored by the MISS Foundation, please email us at: info@missfoundation.org.

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