



VON VOIGTLANDER
WOMEN'S HOSPITAL
UNIVERSITY OF MICHIGAN
HEALTH SYSTEM

Upon the Death of Your Child





This book is provided to Mott families by
the Family Hope Fund

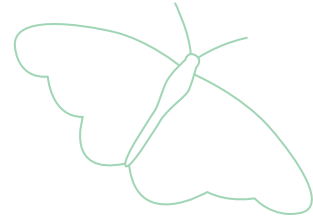
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A message of peace

Surviving the death of your child will probably be the most difficult thing you will ever have to do in your lifetime. I know, I buried my 16-year-old son six years ago; so it is with a very heavy heart that I sit here and write this introduction. There is no way possible to prepare for the pain which you are now experiencing. The pain is real, it is emotional, and it is physical. The staff of C.S. Mott Children's Hospital and Von Voigtlander Women's Hospital and parents who have also experienced the loss of a child want to help you navigate through this pain by answering some tough questions and helping you to feel a little less alone. Sometimes talking to parents who are in the midst of the death of their child can be a very delicate thing for health professionals to do, which is why we created this booklet. Nobody knows the "right" thing to say at a time like this. You are most likely in a state of shock and probably not thinking very clearly; take this booklet home, you can always refer to it in the future. You have a difficult journey ahead, but rest assured, time will be your friend. Then one day — and it may be a very long way away, you will smile again.

*I honor your loss,
Nancy, mother of Louie*



WE ARE HERE FOR YOU

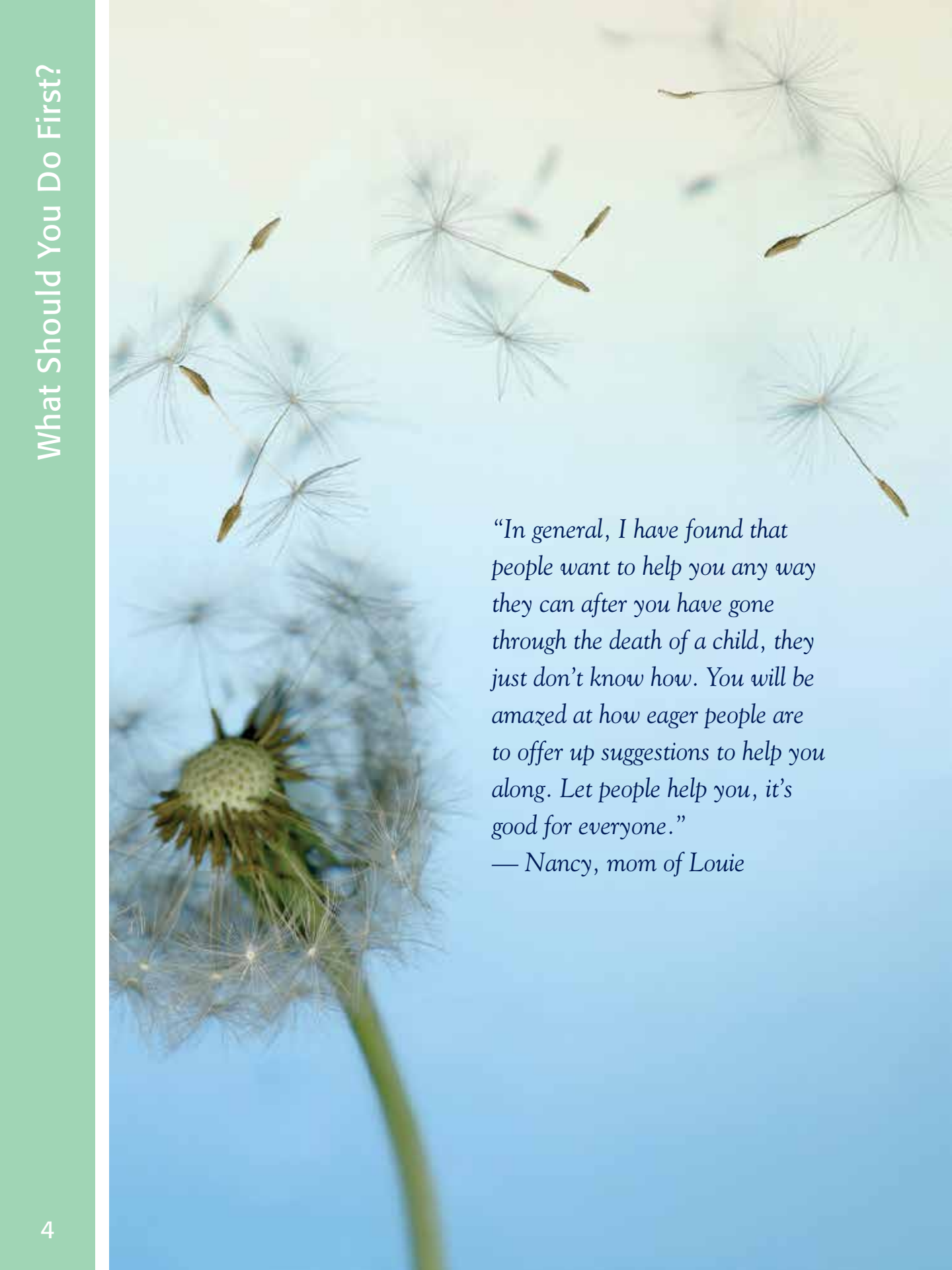
The staff of C.S. Mott Children's Hospital and Von Voigtlander Women's Hospital wish to express our deepest sympathy. We know that you had many hopes and dreams for your child. Now the unimaginable has happened, and there is no way for you to have been fully prepared. It is traumatic to lose a child. Your grief is individual and without expectations...no one grieves the same. We hope that this guide will help you to put one foot in front of the other as you begin this journey.

There are many staff members at Mott and Women's who can be helpful to you. You may already know one or more of our doctors, nurses, social workers, child life staff, or spiritual care providers. We realize that this is a very stressful time and you may not remember what you were told over the phone or at your child's bedside. We encourage you to read and re-read this booklet and to contact us with any questions you may have. A list of helpful telephone numbers is provided in this booklet (page 39) to put you in touch with the staff person who may be most helpful to you.

We are very grateful to the many courageous moms, dads, grandparents, and siblings who have also suffered a great loss and are willing to share with you their personal stories and wisdom surrounding their grief journeys. They all remember how you are feeling today and they want to share hope...hope that someday the sun will shine through your grief and you will smile again. We hope that you find their words helpful, from one broken heart to another—and hopeful, from their place of peace today.

May you find peace now and always,
C.S. Mott and Von Voigtlander Bereavement Committee





“In general, I have found that people want to help you any way they can after you have gone through the death of a child, they just don’t know how. You will be amazed at how eager people are to offer up suggestions to help you along. Let people help you, it’s good for everyone.”


— Nancy, mom of Louie

WHAT SHOULD YOU DO FIRST?

There are many people who need to know that your child has passed away. At this difficult time, you may wish to ask a person to help you make these important calls. Family and friends want to help you, and this is a need they can fill.

You may wish to call:

- Your relatives and friends
- The funeral home director to make funeral arrangements
- The spiritual or religious leader of your choice
- Your attorney, should you need to discuss legal issues
- Your child's pediatrician and other healthcare providers
- Your child's school and/or other programs in which your child was enrolled
- The Department of Human Services, should you require financial assistance with funeral arrangements



“My mother contacted family members, friends, and Kayla’s elementary school principal and teachers. She also contacted her brother’s teachers and coaches to let them know what had happened. She ordered flowers on behalf of the family. I’m grateful for my mother doing those things because they were the furthest things from my mind.”

— Kelly, mother of Kayla

“Your friends will want to help out. When you have a particular task you do not want to do or just cannot do, ask a friend to do it.”

— Shannan, mother of Maddie

Funeral and Memorial Service

Funerals and memorial services are the rituals we use to provide the chance for family and friends to help us say good-bye. Rituals help to guide us when we don't know what to say or do. This process helps us acknowledge that the death is real and provides an opportunity for family and friends to share memories so that healing can begin. If you find the process too difficult or overwhelming, enlist the help of friends or other family members who can help you with the arrangements and can help you decide how much or how little you and your family want to participate in the actual funeral or memorial service.

- A **funeral** generally takes place with the body present and prior to the burial or cremation.
- A **memorial service** takes place usually after the burial or cremation. Some families choose a special date, such as a birthday or holiday, while others plan the memorial service at a later time “when they feel ready.”

“We had a very short funeral service with only immediate family as that was what felt right to us. We did choose several things — a blanket, a stuffed animal as well as several pictures to be buried with our daughter. Four years later, I think about those items and I am so glad that we did that.”

— Michelle, mother of Lauren

“There is nothing more scary, heartbreaking and traumatic than preparing the funeral for your child. We were fortunate to have caring people at the funeral home who guided us through the process. We met with our pastor who had ideas of how to conduct the service and he incorporated our ideas as well...who was to speak, songs to be played, etc.”

— Paula, mother of John

Cremation and Burial

A difficult but important first step is to decide whether you want your child to have a burial or a cremation. This often, but not always, takes place at the same time as a funeral.

- A **burial** places the body in a shroud (a wrapping) or casket and then into a gravesite, which is customarily in a cemetery.
- A **cremation** is the burning of the remains after which the ashes are returned to the family in a container provided by the family, funeral home or crematory. Some families choose to keep the remains while other prefer to bury or release them at a favorite place or spiritual location.
- A **mausoleum** is an above ground structure constructed as a monument to hold a deceased person or persons.

Costs

By law, funeral directors must give prices by phone if asked, and to produce a price list that shows the cost of every service and item they offer. It is not unloving to compare prices or to limit services provided by the funeral home if cost is a concern. It is often easier to start with funeral homes in your community that people you know have used and recommended to you. Funeral homes often reduce their fees for the funeral of a small child. Although it may seem difficult, try to remember that you are in control when making final arrangements that are right for your family.


The least expensive option is to have a **direct cremation** where the body goes directly to the crematory bypassing the funeral home. In Michigan, a funeral director is still required for this arrangement since the body has to be transported from the place where the death occurred and the death certificate filed with the state. Direct cremation eliminates the cost of visitation, embalming, casket and cemetery plots. But it also eliminates the chance for one last viewing if that is something you or your family might need. You do not have to do anything with the ashes immediately—you can take time to decide.

A **cremation** may also take place after there has been a viewing by family and friends at the funeral home. Ask the funeral home staff whether they offer cremation caskets or caskets on loan. (A metal casket is not cremated with the body.) The funeral director will talk with you about these options, assist with arrangements, and provide advice about which of these costs and fees you will be paying.

There are many costs associated with burials. Casket options can range from a simple coffin or plain pine box that can be ordered or made by yourself to high-end caskets that cost thousands of dollars. There are also costs involved with opening and closing a gravesite, a concrete vault if required by the cemetery, and headstone if desired. The funeral director may have additional fees and costs as well, including transporting and embalming if desired. Embalming is not a requirement in the state of Michigan.

Additionally, there are fees for filing and obtaining death certificates, publishing death notices in the newspaper or online, paying the clergy who conducts the service, and using additional vehicles for out-of-town transportation of the body.

Minimal financial assistance may be available through the Michigan Department of Human Services (DHS) to help with costs if financial hardship exists and you meet their income guidelines. If you are from outside Michigan, contact your home state's DHS as this is a state-based program and varies widely. Medicare provides a fixed amount if your child was disabled and receiving Medicare benefits. Since Medicare is a federal program, eligibility is not based on home residency.



“Something we did which was very special was to incorporate Allie’s artwork and signature into her headstone. We used her adorable self portrait. We also had her sisters draw butterflies to add to the stone artwork. It turned out beautifully, and makes it more special for all of us.”
— Sandy, mother of Allie

Death Certificates

Death certificates must be signed by a doctor within 48 hours of death. Funeral directors then complete the form and submit it to the state within 72 hours. Funeral homes generally provide families with several copies of the death certificate, which are important to have for legal and financial purposes. For a small fee, you may also request copies of the death certificate from the County Clerk’s Office in the county where your child passed away. All University of Michigan Hospital deaths are recorded in the Washtenaw County Clerk’s Office (734) 222-6720 or www.ewashtenaw.org/government. You may also contact UM’s Office of Decedent Affairs at (734) 232-4919 for additional help or information.

Commonly Asked Questions

Who would I like to lead the service?

This may be a clergy person, but it can also be family member or friend who will listen to your wishes. While some families choose a traditional service, other families plan their own service.

Where should I hold the service?

Although funerals generally take place in a funeral home or place of worship, you may discuss more non-traditional options with the funeral director. A memorial service may take place anywhere and with whomever you are comfortable.

“Do whatever makes you feel comfortable. Don’t worry about what anyone outside of the immediate family thinks. Honor your child as you think they would want to be honored.”
— Kelly, mother of Kayla

What clothing should I dress my child in?

Selecting clothing is a very personal choice. This is a choice that you should make based on how you want to remember your child and/or how the spirit of your child can be best honored. There is no right or wrong choice of clothing.

“Hockey played an important role in our son’s life. Burying him in his Red Wings jersey made me feel I had clothed him in what he would have chosen himself. His friends commented this was the ultimate way to be buried.”
— Stacey, mother of Kodey

“I put soft, light blue, fuzzy footies on her. Only the funeral home staff and I knew they were there; it was like the last little secret between Kayla and me.”
— Kelly, mother of Kayla

“I had a hard time choosing something for John to wear. I actually went out and purchased a new outfit for him as I did not want to part with any of his own clothes.”
— Paula, mother of John

Who can participate in the service and how can we include them?

Your child’s funeral may be personalized as you wish. You may have special religious or cultural customs and traditions that are meaningful to you. Don’t worry about pleasing others.

Families can participate in many ways. Special music, meaningful readings, pictures and video are all special ways to include people in the service and remember your child. The urn or casket, as well as the space where the service will be held, can be decorated by family and friends. Some families have carried their loved one’s body to the burial site or to the crematory, while others have participated in opening or closing a grave or singing or reading a special verse at the burial site. Memorial tributes to a worthy cause may be arranged as well. No one need be excluded because they are too young or too old.

“It is okay not to have a plan, it will all fall into place as it should. Jen loved Barney and the service ended with everyone singing the Barney song: ‘I love you.’ The message was a perfect ending to the funeral of a little girl filled with love and who was so greatly loved by those who knew her.”

— Lynda, mother of Jen

If there are surviving siblings, should they be involved in the planning?

Any child old enough to love is old enough to mourn. If a sibling wishes to participate in some way, it would be good to include them. Perhaps they would like to color a picture, read a story, tell an anecdote, or write a letter. Or maybe they would just like to be a part of what the adults are doing. If siblings do not feel they can participate in the planning of the service or in the service directly, they may find it comforting to participate in some other way, such as writing a letter that can be read at the service on their behalf. For younger or special needs siblings, designate a special person to be a buddy in the event that they are not able to sit through a funeral or memorial service.

“Our older daughter had always been included in Jen’s life, so it made sense to include her in planning the funeral as well. She actually did the eulogy of her sister. Our pastor was prepared to read it, if she wasn’t able to. It is always good to have backup plans in place whether you need them or not.”

— Lynda, mother of Jen

“We gave Noah the choice to be included. He wrote a letter to Evan and he had a friend from Mott read it. At the cemetery the funeral director gave Noah the white balloon that was tied on to the back door of the hearse. Noah let the last balloon go.”

— Scott, father of Evan

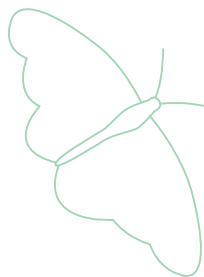
What about an obituary in the newspaper or online?

When you meet with the funeral director, he/she may ask you about publishing an obituary. This is something you and your family may write or something that the funeral director will write from the information that you share about your child. There are also countless online memorial websites where friends and family from near and far can pay their respects and send messages of love and support. You need not decide if you want to publish an obituary either in the newspaper or online immediately. You can decide this at your own pace.

Charitable Donations in memory of your child

Charitable donations made in your child’s memory is one way to honor your child and may encourage others to contribute to a cause that is close to your family.

To learn more, please refer to page 27.



“I thought life would never end until my child died. Now I must never quit living even though it’s hard at times. If I stop living his memories will die and that is something I can control.”

— Scott, father of Evan



LIVING WITH GRIEF

Adjusting to the death of your child will not simply come with time. It will take a lot of hard work which will leave you feeling physically, emotionally, and socially exhausted. The work of grief demands that you deal with all the feelings that come with loss including the losses of happiness, security, routine, and identity. Everyone in your family will grieve differently, and you must be understanding and patient with each other.

“Grief is so tricky — ever shifting and changing.”

— Michelle, mother of Lauren

“I never tried to tell my wife what was right (to feel) and what was not. Likewise, she never tried to say what or how I should feel. What we both knew was that we hurt in ways that were unimaginable. We were there for each other...to help each other and our other kids in any way that we could.”

— Mike, father of Eric

A Note to Grieving Families

Mourning the loss of your child will likely be the hardest thing you will ever face. Your emotions are raw. Your heart aches. You are lost. You are shaken to the core. You have spent endless hours loving, worrying, comforting, and nurturing. You have wiped noses, kissed boo-boo’s, and mended hearts. For many, taking care of your child was your “job,” your world, possibly even your identity...and now you find yourself feeling so empty and so alone. It does not seem that you will ever smile or feel like yourself again. Yet many of you will put on “the mask” and go about your daily duties hiding your pain and grief.

“Just because I don’t look weak, doesn’t mean I am strong. Just because I am functioning, doesn’t mean I am functioning well.”

— Jill, mother of Lucas

When your child dies, traditional expectations of how you are “supposed to” act are hard to maintain because your sense of order, hope, and plan for the future has been shaken. You were “supposed” to be able to “fix” anything and protect your child. Your desire to take care of and “fix” your family may cause you to immerse yourself in tasks to stay busy. This may result in avoiding your own sorrow surrounding the loss of your child. This can present unexpected stress on you and your relationships with other family members. It is important to find a balance of caring for yourself while you care for others.

“Being told I was strong isolated me. I felt a pressure to live up to the expectation of others. Strength is being able to say you’re weak”

— Stacey, mother of Kodey

Trust your instincts and listen to your body's demands. You must be gentle with yourself and listen to your inner voice that tells you to slow down, speed up, or get some extra TLC. You will find that some books will help. Some won't. Some people will help. Some won't. Surround yourself with people who listen, who do not try to make it better, who are willing to cry with you, who let you grieve how you want to grieve. Relying on others is not a sign of weakness; it is a sign of openness. Say yes to anything that will help to lighten your load. If you find yourself sinking into a dark hole, you must find someone who understands grief and loss, for instance mental health professional, a clergy member, or support group. Even if you don't talk right away, being in that person's presence may help you through the fog.

You will never "get over" the loss of your child, but you can learn to continue to be your child's mom, dad, grandparent without his or her physical presence. Finding peace is a long, slow, painful walk. You will miss your child every day, but you will always be your child's family. That can never be taken away.

"As grandparents, our son and daughter-in-law were experiencing Lucas' condition and treatment daily. We also knew that they were shielding us from the daily care they had to provide. We were grief stricken not only for ourselves but also our children as we watched them suffer. Alone at home we cried in each other's arms. We felt impotent; grandparents are supposed to make things better."

— Joe and Karen, grandparents of Lucas

"I used to say I can't put words to this emotion, only a sound — the sound of a train whistle at night, calling and calling, with no answer. Since then, I think that I have read every grief book printed, trying to find the words, because I thought once I could put words to it, once I could name this loss that had taken over every cell of my body, I could start to have some control over it."

— Julie, mother of Lauren

"For years I thought what I did would be enough, now that my child is gone I pray it was. My job was to protect and provide; now I must continue on because there are still three other important people in my life that I love."

— Scott, father of Evan

"It is critical that you allow yourself to be fully present with the very deep pain of losing your child. Breathe deeply. Write in a journal. Strive to talk about your child, favorite moments, and the story surrounding your child's passing."

— Jeff, father of Brandon

A Note to Grieving Families with Surviving Children

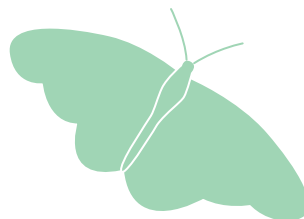
It is extremely challenging to be there for your surviving children when you are lost in your own grief. While much of helping your children through their grief will fall to you, also use the offers of friends and families to help you through. Accept offers for playdates, carpool, trips to the store as you find your footing. No one expects you to be the perfect parent at this difficult and confusing time. Allow yourself the help that you need so that you may continue to parent your surviving children as best as you can.

Remember that no matter the age, children are never too young to grieve, and they do grieve differently. A child's age, emotional maturity, perceived role within the family, and relationship with their sibling who died may affect what their grief will look like. Encourage your surviving child to talk about their brother or sister. Simply telling them that it is ok to talk about him/her will open the door for discussions. You will need to lead by example when you mention your child at different times. There may be questions or feelings from your child that are hard to answer or hear. It is important to remember that you do not have to have all of the answers. Listening and being open to discussion is what is most important to your child. Additionally, preparing them for insensitive comments that they might hear upon their return to school is very helpful. If it is too difficult for you to lead these discussions, solicit the help of a trusted family member or friend to engage your children in conversations about the loss of their sibling. Never assume they are done grieving or not grieving,

Often siblings will wonder if the death was a result of something they did. Some children may believe that their anger can kill; and therefore, it was their fault. Such "magical thinking" is a normal reaction to stress and anxiety particularly among younger children. Pre-teens and teens may feel guilty about feelings they have had towards the deceased sibling, and normal sibling rivalry or arguments may cause them to feel that they are somehow responsible for the accident or illness. Acknowledging that it is difficult to lose someone that you love and assuring them that their actions had no connection to their brother or sister's death are very important. Finding time to spend with your other children is also very important in the healing process. Finally, seeking counseling for you and your children, and giving them the space to grieve will help them to move through their grief in positive ways.

"When my two surviving children and I visit my son's grave and a special chapel that was named after him, I try to lighten the mood by letting them choose the flowers we place on his grave. We also take time to sit and throw stones into a nearby little river...all part of our ritual."

— Jill, mother of Lucas



A Note to Grieving Children and Teens (Please read this with your surviving children.)

Losing your brother or sister is probably the most difficult thing that you have ever faced. You will likely feel every emotion running through your body, sometimes one right after the other. Sometimes, you may feel sad, lonely, or scared, and other times you may feel angry or guilty that your sibling has died. Guilt may come from believing that in some way the death was your fault or that you should have been the one to die instead of your sister or brother. You may have not always gotten along with your sibling, and you may have said or thought something that you did not mean and now worry that you can't make it right. Forgive yourself. All siblings argue; all siblings fight. The death of your brother or sister was *not* your fault.

You may be angry that your brother or sister left you, or you might resent all of the attention that they got, especially if they were sick for awhile. You may also feel very scared and alone, especially if you have to figure out new daily routines and habits as you adjust to life without your brother or sister. It is also very common to feel less secure, to feel that the ground that you are walking on is not solid, or to worry about losing another family member or close friend. It is even possible to feel nothing at all and to worry that something is wrong with you for feeling nothing. You must remember that even though you feel really bad, *all of these feelings are normal*. You must allow yourself to feel whatever it is that you are feeling. Do not try to hide or push your feelings away. Sometimes the best thing to do is to talk about your feelings with your parents, a teacher, or a friend.

After the loss of your brother or sister, your parents may not seem like the same people that they used to be. Like you, they are experiencing deep pain and sadness, and they may not be able to do the things they used to do, like make dinner or help you with homework. It may seem odd to see them act differently. It may make you feel really angry with them or simply sad that they are not the same. It is important to remember that your parents are working through their own feelings about death.

After awhile, you and your parents will start to do the things that you used to do and feel happy again. Some siblings feel guilty for wanting to laugh and be happy. Just as it's normal to feel badly, it is also normal to feel good again. You do not need to feel guilty about being happy. Smiling, laughing, and having fun will come again—welcome it when it does.

“I don't have any regrets; however looking back, I did make a decision that changed the course of my life significantly. I made a decision to stay closer to home. I'm not sure that it would be fair to say that it was all because of Louie's death, but I certainly wasn't thinking clearly. If I could go back in time, I would tell myself that I can't change what happened and to keep moving forward with my life.”

— Rick, brother of Louie

“Siblings are the forgotten grievers. People will ask, ‘How's your mother/father?’ before they ask how you are.”

— Jackie, sister of Lauren

Developmental Reactions to Childhood Grief

Creative outlets can help you cope and begin to heal. Often it is something that you enjoyed before the death (i.e. listening to or making music, creating artwork, playing sports, taking walks, running or writing).

Children typically respond differently to grief than adults. Usually, grief causes some form of regression, meaning that the child may exhibit behavior patterns associated with an earlier age. This chart provides some common developmental responses to grief based on age.

Developmental Level	Common Reactions	Ways You Can Help
Infant	<ul style="list-style-type: none"> • Increased separation anxiety • Changes in sleep pattern and appetite • Increase in crying/irritability 	<ul style="list-style-type: none"> • Regular routine • Familiar caregivers/environment as much as possible • Parental self-care
Toddler	<p>In addition to the above reactions...</p> <ul style="list-style-type: none"> • Changes in personality • Increase/decrease in physical activity • Regression of newly learned skills 	<p>In addition to the above supports...</p> <ul style="list-style-type: none"> • "One on one" time with child • Creative outlets • Providing favorite comfort items • Establishing/continuing limit setting and parenting
Preschool	<p>In addition to the above reactions...</p> <ul style="list-style-type: none"> • New or increased fears (may increase at bedtime) • Misconceptions/Magical thinking about death • Behavioral issues 	<p>In addition to the above supports...</p> <ul style="list-style-type: none"> • Utilizing grief resources • Involving the child in the memory building
School-age	<p>In addition to the above reactions...</p> <ul style="list-style-type: none"> • Drop in school grades/behavior • Lost interest in previously enjoyed activities/ withdrawal from friends • Angry outbursts • Detailed questions 	<ul style="list-style-type: none"> • Allowing/encouraging child an opportunity to ask questions, answering honestly • Encouraging regular activities • Creative outlets
Adolescents	<p>In addition to the above reactions...</p> <ul style="list-style-type: none"> • Angry/withdrawn from family and friends • Possible suicidal thoughts • Questioning one's mortality • Guilty feelings • Putting future plans on hold • Need to complete unfinished business • Experimentation with drugs and alcohol • Exploration of sexuality, possibly through promiscuity 	<ul style="list-style-type: none"> • Allowing privacy and alone time • Journaling • Support groups • Joining volunteer organizations or becoming involved with awareness projects • Include in decision making • Encouraging relationships with peers and adults • Planning/participating in memorial service

What Grief May Look Like

Grief is a deep wound that goes through many phases of healing. The layers of grief can be like peeling back an onion. It may look the same after you have peeled away several layers but it is different. In other words, even though you may have successfully moved through stages of grief you may still feel like you are in the same place. Yet although it looks the same it may actually be at a deeper level of emotional healing than you realize.

There are many factors that may impact what your grief will look like, including previous loss, a sudden or traumatic death, a prolonged illness, the presence of other children, the availability of family, friends and/or professionals to support and other life stressors. It is important to realize that grief reactions do not necessarily come in order, nor are they boxes that one can “check off” after experiencing them. Sometimes healing goes one step forward, two steps back. You may revisit different feelings multiple times even in a single day. In time, your emotions will even out, but you will never completely let go of these questions and feelings. It may be helpful to find a support group, talk to your spiritual leader, or seek professional grief counseling or therapy to help you sort through the wide range of emotions that you are experiencing.

Grief is very complex, therefore this impossible to address every single emotion in this booklet. The following is meant to serve as a general guideline to help you identify some of the steps in your journey ahead.

“The stages of grief are fluid. You won’t go through a period of disbelief and then cross it off your list and move on to anger. You will go through the stages at different times and then return to them again. Your return to the stages may lessen in frequency or the depth at which you feel the anger or pain may lessen but you will go through these stages again and again. You will find that there are sounds, sights, or symbols that trigger the pain as if you were experiencing the loss anew and then there are times when you are able to feel joy and may be surprised at how well you coped with a certain event or date.”

— Michelle, mother of Lauren



Disbelief

When your loved one dies, at first nothing feels real. Everything you do will be hard. Even eating and sleeping may be a chore. Some days you might feel like you are in a fog. Other days you will feel on edge. The slightest thing may set you to crying. You may dream about your child or think that you hear your child's voice. There may be days when your feelings are mixed up. One minute you may feel angry and the next guilty. Sometimes even when you are with other people, even loved ones, you may feel lonely. All of this is completely normal. It may feel like you are going crazy. Remember that there are friends and professionals there to help you. Let them.

“Disbelief lasts a very long time. Did this really happen to us???”

— Paula, mother of John

Anger and Guilt

Some bereaved adults will experience guilt: guilt that you cannot make everyone happy; guilt that you could not prevent the death of your child; guilt that you survived your child. You may also experience anger: anger that other children will grow up; anger that others will see their child grow up; anger that “God” or “science” would not or could not save your child; and possibly even anger at your child for leaving you. You may question your faith and grapple with questions that have no answers such as “why did my child die before me?” “how could a just world allow this to happen?” “why couldn’t I have stopped this from happening?” The “Why’s and How’s” can be endless.

While sadness, guilt and anger are normal reactions in this horrendous world of loss, they also have potential to be destructive. Talking about your feelings with a trusted friend, someone who has experienced similar loss, or a professional may help.

“It is also important to have someone with whom you could talk out your grief — whether it is a pastor, a counselor, or a therapist. Negative feelings can fester, filling your life with constant sadness and anger. Our pastor, a compassionate and solid person, helped us through our sorrow and gave us a new insight on life and death, which tempered our grief.”

— Joe and Karen, grandparents of Lucas

“The emotions of our children, the parents of our granddaughter, were ever-changing. At times, they would lash out with anger, and at other times they would retreat into their private world silently fighting the pain of watching their child die.”

— Grandparents

The Pain of Grief

Slowly the reality sinks in. The pain can feel as real as a knife stabbing your heart. Cruel as it seems, this may be the first step towards healing. Sometimes, grieving parents try to block these feelings. The pain is so deep they pretend it is not there. Well-meaning friends, family and co-workers may say things that feel insensitive. Some may give open or hidden messages to “pick yourself up and go on” as if nothing has happened. Allow yourself the time to cry.

Give yourself the time to feel the pain. Remember this work is very important in the grieving process. Just getting through each day will be tough. Know that these experiences, though very difficult, are normal and okay.

“I have stopped putting pressure on myself to cry less, to hide my feelings, to spare others. I exhausted myself doing that during the first year. Don’t be rushed or shushed in grieving for your child.”

— Jill, mother of Lucas

Emptiness

Your child has a special place in your heart and in your family. No one will ever fill that place. Your memories will remain with you forever. Missing your child is normal. The hours and days may feel empty. The memories of day-to-day events with your child become precious—putting her to bed, feeding him a bottle, reading a story together, taking her to school. Still, life goes on whether we’re ready or not: eating, sleeping and working. Filling the empty hours will take time. This is another time where sharing with others who have experienced a similar loss may be helpful. They can tell you about the choices they made, how they filled the empty hours and how long it took to start feeling better. Most of all they can listen. Feeling better will take time.

“A couple of months after I lost my son, I realized I had also lost one of my best buddies.”

— Scott, father of Evan

“Offers for help and support may dwindle as the months and years go by. People start assuming that you are doing better because time has passed, but this is not usually the case in grieving for your child.”

— Jill, mother of Lucas

Adjustment

Adjustment does not mean you have to forget your child or dishonor your child's memory. It simply means that over time, you will adjust to your "new" life and to the loss of your child. You will learn to find joy in life again. It does not mean that you love your child any less or that you will not keep your special memories. It means that you adjust to the changes and challenges of your new life and that you honor your child every day by living. Most parents can, after several years, recall their child with a smile. There still will be sadness, though it does not come as often and is not as hard. Adjusting to living without your child is a final step along the path to healing.

It is not uncommon for grief to appear even when the loss is far behind you. These reactions may occur when an event such as a graduation, the start of school or the marriage of other children triggers a reminder of all that was lost. Sometimes it may even be a smell or sound that triggers more intense grief. Terese Rando, PhD termed these "subsequent temporary upturns of grief" or STUG, which captures the idea that intense grief may come back suddenly and then just as quickly go away. This does not mean that you have not adjusted. This is a very common part of the grief journey.

*"You never let go. While I know that John is no longer with us, he will always be part of our family."
— Paula, mother of John*

*"There are times when we feel his presence and things have happened that let us know that he is with all of us. It's a mystery of life and faith; we don't fully understand it, but we accept that mystery."
— Joe and Karen, grandparents of Lucas*

Seeking Professional Help

Accepting the fact that you and your family's lives have changed forever can be overwhelming. You may feel that you will never be able to accept your loss and you will never adjust to your new life. It is not only okay to ask for help, it is sometimes the best thing that you can do to take care of yourself and those around you. Although your friends and family members may want to help, having a trained grief counselor work with you and your family can help you understand how grief works as well as provide you with ways to help you cope. Counseling helps people work through difficult issues and problems. It is not a sign of weakness and it doesn't mean that you are not coping. What it means is that your loss is great and you need help overcoming your grief. Don't be afraid to reach out for assistance...and remember, it is okay to seek another counselor if the first one is not a good fit for you.

*"My husband and I found grief counseling very helpful. While our family and friends wanted to be helpful, they were not always comfortable talking about our loss. Our regular appointments with the grief counselor were a safe and comforting time to share our feelings."
— Robyn, mother of Isaac*

“Just talking about John and what he meant to our family was therapeutic in itself.”
— Paula, mother of John

“I needed to make it through each day and therapy was the one place I could let it all out and not be afraid of how hard or long I cried or what words came out of my mouth. Therapy also allowed me to see that even though my husband and I were expressing our grief in such different ways we were both grieving.”
— Michelle, mother of Lauren

Returning to a Routine

After the loss of a child, life will never be “normal” again. The definition of your life has changed forever. However, there will come a time when you will have to return to a routine not unlike the one you had before. There is no “right way” to return to the “functioning world” but preparing for when and how you and your surviving children will re-enter will help.

The first consideration is when to return. Some people wait several months before returning to routines, while others return after a few days or weeks. When making your decision, keep in mind that most people will be very accommodating during this difficult time. Talk to your supervisor or school principal. There may be flexibility that enables you to ease back to work and school.

“Louie was my routine, so the first Monday after the funeral when all of our out-of-town family returned to their lives, my husband left for work and my other son left for school, I found myself at a complete loss for what to do next. It was the loneliest feeling I had ever felt... Eventually, I realized that I needed to find a way where I could take all the experiences I had with my son and use them somehow to create my new identity. It was important to me to always keep my son present in my life, so what better way than to create a new routine, whether it be a career, volunteer work or a project that was inspired by him. Personally, I chose to become a volunteer at the hospital that had become our home-away-from for so many years.”
— Nancy, mother of Louie

“Have a ‘back up’ plan. You can plan to go to an event, but know that if it doesn’t feel right at the time, you can cancel. You have options and you don’t have to do everything just because you said you would. Give yourself permission to make plans and get back into your life, but know you can ‘opt out’ if need be.”
— Lynda, mother of Jen

Returning to Work

After you have determined when you will return to work or other scheduled commitments, decide how you wish to be received and treated by others with whom you will be interacting.

Some find it comforting to have friends, colleagues or co-workers acknowledge their loss, while others wish to be treated just as they did before. You may wish to contact not only your direct supervisor but some friends and co-workers as well. You may want to ask if they will come in with you on the day you wish to return to help ease the transition. If you wish to be left alone, they can help field questions and remind the other co-workers of your desires.

Preparing yourself mentally to return to work may be the most challenging aspect. Be prepared for difficult comments. Most people mean well but may say hurtful or disrespectful things. Comments such as, "You're so strong, I'd never be able to handle this," or "You seem better" may intend to comfort but may only make you feel worse. Sometimes the best thing to do is to speak to friends and co-workers about what would be comforting to hear. You can find more advice on how to do this in the "Do's and Don'ts for Family and Friends" section at the back of this booklet.

"I went back to work about two weeks after my daughter died. Looking back I do feel like this was too early, but I did that because my son was going back to school and my fiancé was going back to work. I didn't know what to do in the house by myself all day and I felt like the walls were closing in on me. When I did go back to work, I worked part time for about five months, which was very helpful. I have a friend who lost her son and she went back to work six months later. She still felt like it wasn't enough time off. There is no appropriate amount of time to be off work. Do what works best for you."

— Kelly, mother of Kayla

"Returning to work was quite significant because it symbolized another 'moving forward' milestone. I was conflicted though because I didn't want my return to work to symbolize to others that I was 'fine' and that the loss I had experienced was somehow over because I was 'back' to doing the things I had done before the loss of our daughter. It took some time but it felt really good to be busy doing something I loved again. I ultimately realized that returning to work for me was healing and it in no way symbolized that I 'was over' what happened."

— Michelle, mother of Lauren

Returning to School

Discuss with your children how they wish to be treated and then contact the school principal, counselor, social worker, or teacher to discuss the return plan. Sometimes teachers or social workers prefer to discuss the return with the child directly which may help ease your burden. Remember to respect your child's wishes about returning to school, even if his/her approach differs from your own.

To help a child prepare to return to school, explain to them that they might be told or overhear difficult comments. Let them know that people mean well but might not understand how to express their feelings. Remind them that they do not have to answer questions they do not wish to and that if someone says anything that makes them feel upset, he/she should talk to their teacher, school counselor or social worker.

Remember that the planned day to return to school can be changed if it does not feel right. Your child may try again another day.

“I let my son go back when he said he was ready, which was two weeks after Kayla died. After that, there were many times when he wanted to stay home or he would come home from school early and I let him.”

— Kelly, mother of Kayla

“My friends helped me a lot, and it was really special when I stood next to the post of Evan’s funeral arrangement in our classroom...and when all the crossing guards sent messages down the line to tell me they were sorry for my loss. I guess everyone knew Evan was sick and that he would probably die one day, but that didn’t scare them... they were not afraid to talk to me when it did happen.”

— Noah, brother of Evan

Taking Care of Yourself

After the loss of your child, you may feel disoriented and overwhelmed. When disbelief and grief take hold of you, it is difficult to get out of bed much less eat a balanced diet or exercise. However, it is important to try to take care of yourself. Things like eating well, taking time for yourself, and taking brief walks may help you process both day-to-day life and your grief. Be patient and kind to yourself. Surround yourself with supportive people. Be true to your inner voice and respectful of your feelings.

If you are in a relationship, remember to take care of that relationship, too. The loss of a child may bring you closer to your partner or it may push you apart. You may be so exhausted by your own grief and/or helping your surviving children through their grief that you have no energy left to support your partner. Take time to be with each other and hold each other. Talk together about your past and recall how you fell in love. Remember that taking care of your relationships is part of taking care of yourself and your other children.

“The world will not wait — go slow anyway.”

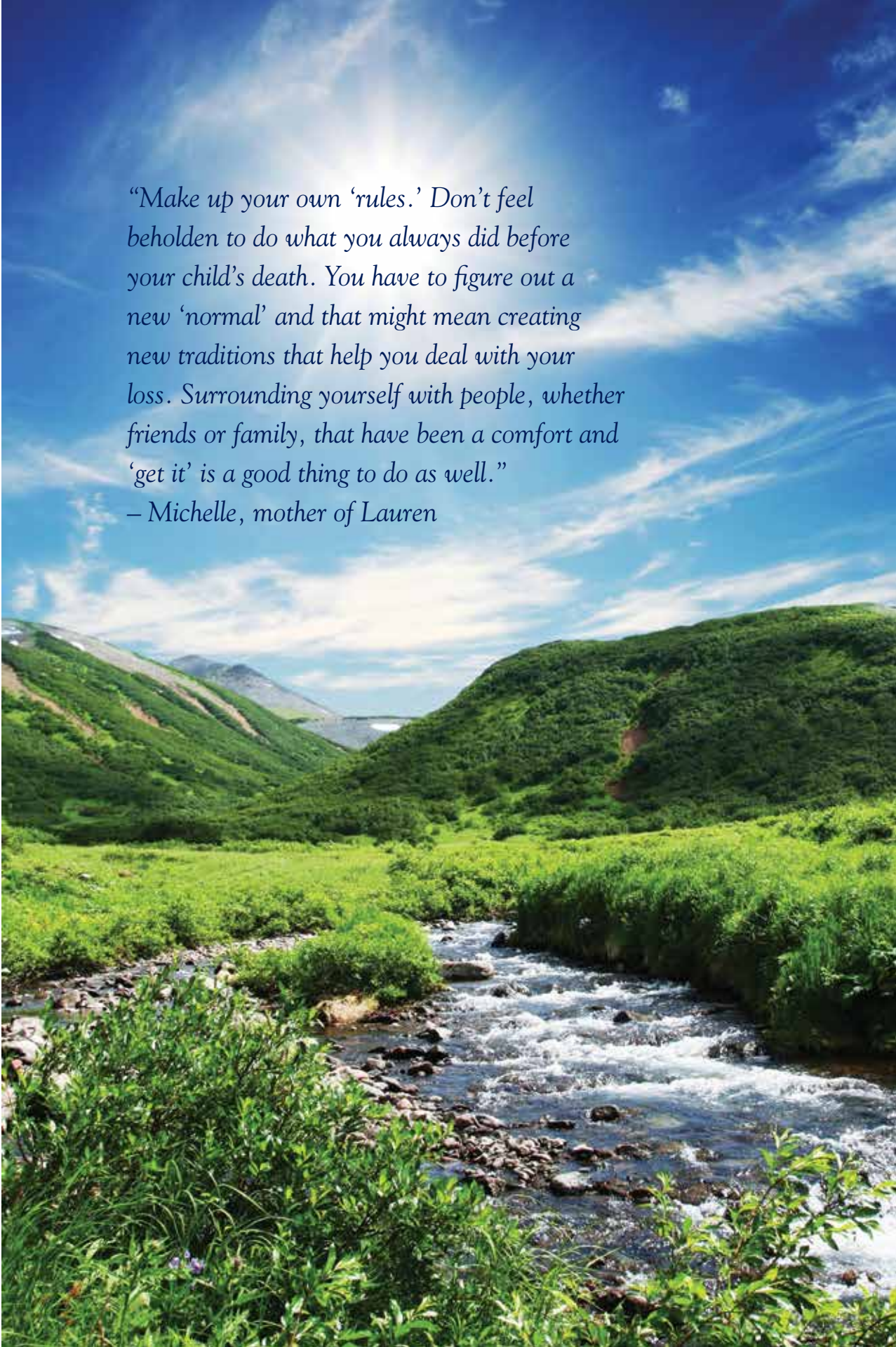
— Mary Ann, mother of Michael

“I knew the key to my survival was going to be in establishing a new routine. So the new routine began with a brisk power walk every morning. I had never been one much for exercise, but getting out in nature, feeling the fresh air, always clears my mind. I just feel better when I force myself to get up and get moving.”

— Nancy, mother of Louie

“Make up your own ‘rules.’ Don’t feel beholden to do what you always did before your child’s death. You have to figure out a new ‘normal’ and that might mean creating new traditions that help you deal with your loss. Surrounding yourself with people, whether friends or family, that have been a comfort and ‘get it’ is a good thing to do as well.”

– Michelle, mother of Lauren



REMEMBERING YOUR CHILD

Getting Through Special Days and Holidays

Holiday and birthday celebrations are traditionally known for joy and laughter; however for those who are grieving, they may be particularly painful and they may even feel inappropriate. The demands of grief require extra physical and emotional energy, which may leave you unable to deal with the excessive demands that holidays bring. These days will come and you will need to prepare yourself. Here are some things to think about:

- Be honest about what you can expect to be able to do. Realize that as a grieving person you have definite limits. You may not be able to or even want to do the things you used to do. Decide what is really meaningful for you and your family and feel free to do just that.
- Find new holiday traditions. It might be helpful to find a tradition that honors your child.
- It is helpful to talk and share memories of your child.
- Don't be afraid to make changes. Change the time or place of certain traditions. Change responsibility for various tasks. Change the number of people and remember what you choose to do this year may be different than what you want to do next year.
- If you have other children, remember that holidays are very important for them. Your other children have lost their sibling but they may not react to holidays in the same way as you do. They may still express excitement and joy during this time. This is okay.
- Talk over your fears and share your feelings about the upcoming holiday with your friends and family. This helps prepare them as well as helping you find the support you need

“We had shirts made with Kayla’s face airbrushed on them. Family members attended the Compassionate Friends Walk to Remember and wore the shirts. We took a big group picture; it was a beautiful sight to see. As a family we wear the shirts on her birthday and on her remembrance date.”
— Kelly, mother of Kayla

“I will never forget the first Christmas following the loss of our son and how sad we were without him. My husband and I started a tradition of hanging an ornament and stocking for our son. We also visit the cemetery on many holidays. On our son’s birthday, we send balloons up to heaven. We try to talk about our son openly and include our other children in these special remembrances. I think it helps all of us heal and at the same time keep our son as part of our lives.”
— Robyn, mother of Isaac

“Our first family vacation without John was very difficult. However, we chose to do something different, traveling with other families, and chose to go to a destination we had never been to before.”
— Paula, mother of John

“When my little brother died, it took time for thoughts of his well-being to overcome my personal grief. Looking back, most of the pain is forgotten, but the wonderful memories will never die. When my brother comes up in conversation, I do everything I can to convey that I have no problem talking about him, and I would prefer to relive the good times that we had rather than sweep him under the rug because everyone feels so badly for me.”

— Rick, brother of Louie

Celebrating Your Child

Many families who have lost a child choose to celebrate their child’s life in distinct ways. While many families choose a more public venue—such as starting a foundation in their child’s name, creating an annual fundraising event to raise awareness or seek a cure for what may have caused death, planting a garden in his/her memory, or writing a book about their child—to remember their child, other families choose to honor their child in a private way. There is no rule that says that you have to recognize your child publically. Your love for him/her speaks volumes. All of these tributes can help heal the mind and spirit.

“I had her friends each place a stone at her gravesite. We use these as a border for the small flower garden.”

— Sandy, mother of Allie

“I decided the most fitting tribute included something that was important to Lucas and me so I threw myself into writing a book about children that must spend time in hospitals, which was Lucas’ idea. It has been therapeutic for me and something positive that I can share with my two young daughters.”

— Jill, mother of Lucas

“John’s classmates and school planted a tree on his school’s grounds shortly after he died. When his 5th grade class graduated, a bench was presented near the tree in his memory from his class.”

— Paula, mother of John

“We take part in an organization that gave our grandson joy before he passed away.”

— Joe and Karen, grandparents of Lucas

“One thing that we knew we wanted to do despite John’s death was to give back to those who had helped us through John’s short illness and death. We started a foundation to continue the good work of many of the programs that were so helpful to us and our children, and to help change some of the programs that were in need of assistance to better serve patients and their families.”

— Paula, mother of John

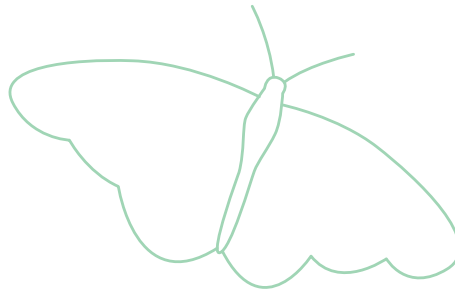
Charitable Donations in Memory of Your Child

After a death, friends, families and others in the community may wish to make a charitable donation to honor your child's memory. This may be something to decide early so it can be published in the obituary or mentioned at the funeral service. You might want donations instead of flowers. It is customary to direct donations to non-profit organizations that represent the values or interests of your family or those of your child. For example, donations can be directed to medical research through national or local organizations (such as American Cancer Society, American Lung Association) social service agencies (such as Hospice, Make A Wish) or even set up college or scholarship funds.

You can also direct donations to a specific department or program of your choosing at the University of Michigan Health System. The staff at the Office of Medical Development (734-998-6893) would be honored to help you choose an appropriate memorial fund. Donations can be made to provide services to other families struggling with illness or loss, support nursing units, social work, spiritual care, medical research or the general fund among others.

"We created a scholarship at our church to assist families facing financial hardship to be able to send their kids to the camp our son treasured attending. It seemed like the perfect way to honor his memory"

— Stacey, mother of Kodey




“Talking to someone who had already walked in the shoes I was walking in and hearing words come out of her mouth that matched what I was thinking was such a relief. Talking with another mom who could say, ‘I have been there. I understand,’ made me feel connected to someone else during the most horrible time in my life. Feeling less alone eased the pain.”
— Michelle, mother of Lauren

MEDICAL INFORMATION

Autopsy Reports

For many families, information from an autopsy can help bring closure; but for some families, an autopsy can be a difficult decision, which may seem like an unnecessary distraction. Autopsies do help advance medical science by allowing doctors and scientists to better understand many kinds of disease and accident-related injuries. Rest assured that whether an autopsy has been performed or not, you and your child will always be treated with the utmost dignity and respect.

If an autopsy has been completed, you may request a copy of the full report be mailed to you, which should arrive within 6–8 weeks. It is recommended that you make an appointment with your child’s doctor to review the report with you so that you fully understand the cause of death and what this might mean for your family. To order an autopsy report or to arrange a meeting with a doctor to discuss the report, please contact U-M Office of Decedent Affairs at (734) 232-4919.



“After our infant son passed away, we had many questions. Several weeks after his death, we asked to meet with one of the lead physicians in the NICU. The doctor spent a long time meeting with us explaining the medical issues surrounding our son’s death. No one can ever tell us truly ‘why’ our son passed away. But we so appreciated the doctor’s compassion and the time he took to meet with us and answer our questions.”

— Robyn, mother of Isaac

Medical Discussions

There are three main reasons for medical staff to discuss a child’s death. First and foremost, the University of Michigan Health System strives to deliver the safest and highest quality care possible, so staff may review the circumstances surrounding death. Secondly, medical discussions further education within the hospital. It is very important for health professionals, especially those in training, to understand how and why patients die. Finally, medical staff also finds the death of a child stressful and even traumatizing. While not comparable to the grief and loss a family experiences, healthcare professionals benefit from having understanding and closure when patients they have cared for die.

Organ and Tissue Donation

State and Federal regulations require the University of Michigan to consider the question of organ and tissue donation for each death that occurs within our hospitals, and to approach families to inform them about this option under some medical circumstances. For many, making this decision was likely very difficult. Please be assured that there is no wrong or right answer. The choice to donate or not to donate is deeply personal and completely an individual choice.

For more information on organ and tissue donation, you may contact Gift of Life Michigan at www.giftoflifemichigan.org or call (800) 482-4881.

Families who have donated organ and tissues may wish to contact the Michigan Donor Family Council at www.michigandonorfamilycouncil.org or (517) 759-8984 for information and support.

“Making the decision to donate was easy; carrying through with the process was incredibly difficult. Next to losing our child, this was the most difficult thing my husband and I had to deal with. Looking back on it, I can say with all honesty that it was worth the emotional pain, and I would do it again in a heartbeat.”

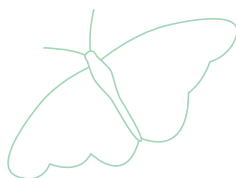
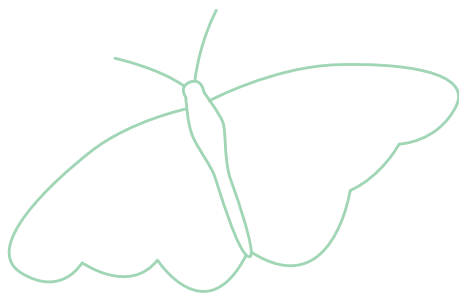
— Shannan, mother of Maddie

“We were able to donate John’s corneas. We received a wonderful letter notifying us that his corneas went to two people. It was a great feeling for our family.”

— Paula, mother of John

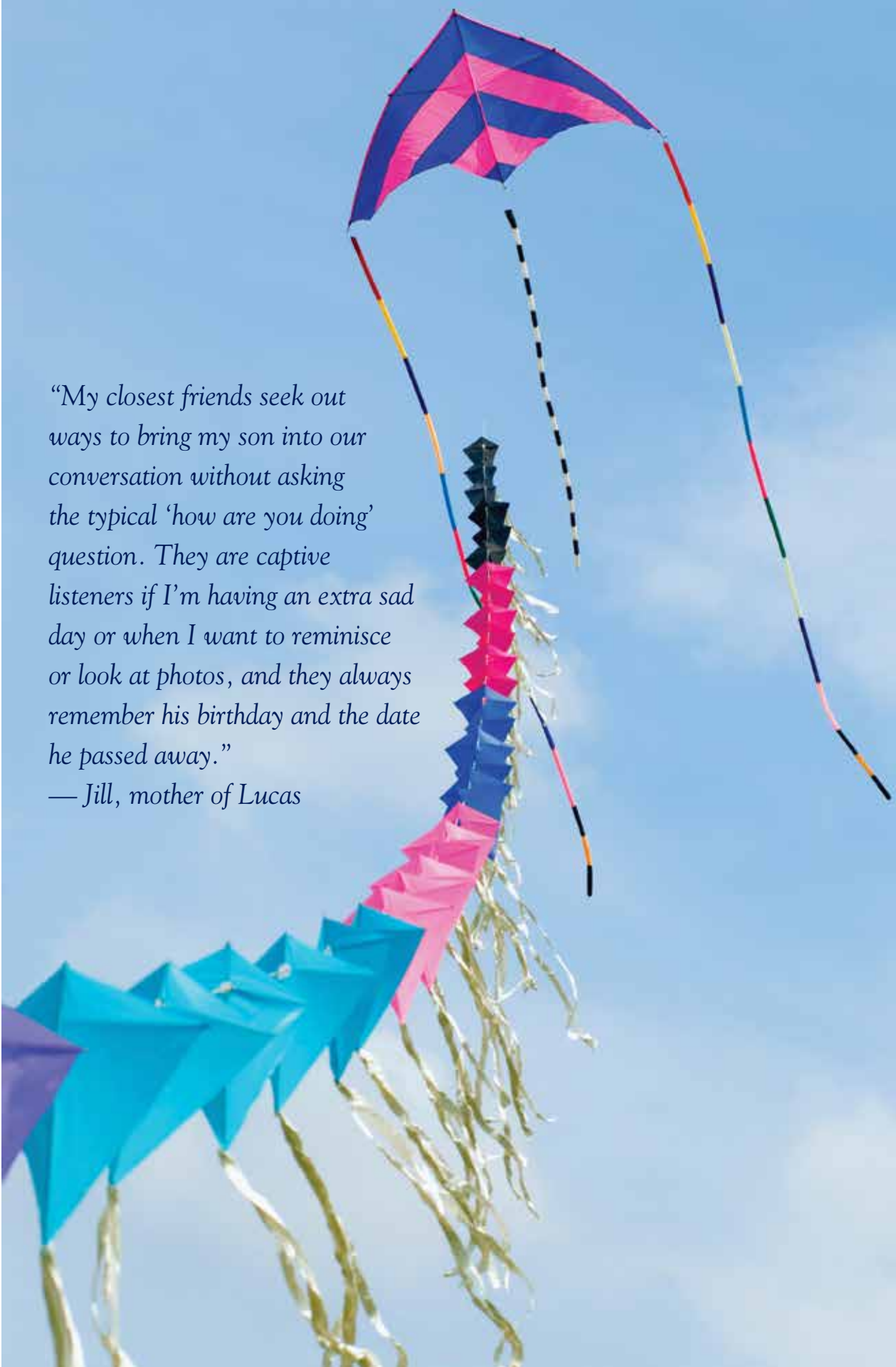
“We did not pursue organ donation because of all the meds he took over the years and the way in which he died — at home. At the time, that was just one more thing on my plate and I was already overwhelmed. I did not want the medical staff to take his body from me immediately. I needed the time to hold him and say good-bye — slowly. I think I sat holding his lifeless body for nearly three hours before I could summon up the courage to hand him over. I have no regrets.”

— Nancy, mother of Louie



“My closest friends seek out ways to bring my son into our conversation without asking the typical ‘how are you doing’ question. They are captive listeners if I’m having an extra sad day or when I want to reminisce or look at photos, and they always remember his birthday and the date he passed away.”

— Jill, mother of Lucas



SUPPORTIVE RESOURCES

Do's and Don'ts for Families and Friends

Many times, family members and friends want to say and do the right thing, but do not know how. Feel free to show them or explain to them some “do’s” and “don’ts.” Many hurtful instances can be avoided when people understand how to respond appropriately.

- **Do** say you are sorry about what happened and about their pain.
- **Do** be a good listener and allow them to express as much unhappiness as they are feeling and willing to share. People need to talk about the death of their loved one. If you have trouble thinking of something to say, just be there for the person. Saying too little is better than saying too much or saying something unintentionally hurtful.
- **Do** talk about the special, endearing qualities of the person they've lost. By talking about the loved one, you validate that he or she was important to you as well and is not forgotten.
- **Do** inquire about the well being of friends and family members. Some people may be presumed to be okay, such as dads or siblings, when in fact they are not.
- **Do** stay in touch. People will not have the energy to call you. Reach out and make contact by phone, email, or a personal visit. Invite the bereaved family out for a meal.
- **Do** encourage them to be patient with themselves, not to expect too much of themselves, and not to impose any “shoulds” on themselves.
- **Do** try to understand the grieving process. There are many good reference books on the market and in libraries.
- **Do** look for an immediate need and fill it. This could be shopping, preparing a meal, answering phone calls, babysitting, or helping with out of town relatives. Check back periodically to offer support.
- **Do** remember that they will continue to need your caring support past the first weeks and months and especially on holidays, birthdays, and anniversaries.



“The ‘real world’ has a hard time dealing with us, they don’t know what to say or how to react.”
— Scott, father of Evan

“Someone told us to expect friends, family, and just people in general to say the wrong thing. It is helpful to know that everyone has the best intentions even if not the best understanding of what you are going through.”
— Shannan, mother of Maddie

- **Don't** let your own sense of helplessness keep you from reaching out.
- **Don't** avoid them because you are uncomfortable.
- **Don't** be judgmental. There is no timetable for the grieving process. Don't say things like "you ought to be feeling better by now." Adjusting to grief is a long and difficult journey, even if people return to their routines quickly.
- **Don't** use clichés such as : "At least you have your other...You can always have another... God will...he/she is in a better place...you should be grateful for/that..."
- **Don't** say that you "know how they feel." Unless you've experienced their loss yourself you don't know how they feel.
- **Don't** tell them what they should feel or do.
- **Don't** be afraid to bring up the subject for fear of making the person feel worse. They are already feeling badly and thinking about their loved one much of the time.
- **Don't** try to find something positive (e.g., a moral lesson, closer family ties, etc.) about the loss.
- **Don't** make any comments that in any way suggest that the loss was their fault. There will be enough feelings of doubt and guilt without any help from friends.
- **Don't** tell a grieving child that they have to grow up, that they have to be strong for their parents.
- **Don't** tell a bereaved parent that you could never be as strong as them if the tables were turned.

"I used to cringe when people would say, 'You are so strong. I could never be as strong as you if I lost a child.' What I heard through my filter of grief was, 'You must not love your child as much as I love mine, because you are obviously functioning, and I wouldn't be.'"

— Julie, mother of Lauren

"Sometimes adults will say things to you, like, 'You need to be a rock for your parents right now,' or 'Your parents need you to be strong and not cry.' Don't listen to those people. You're allowed to be sad. You're allowed to grieve. Your parents don't need you to be their rock."

— Jackie, sister of Lauren

BEREAVEMENT PROGRAMS

University of Michigan Health System Bereavement Programs

A Walk to Remember – an annual event for families of Mott Children’s intensive care units, Von Voigtlander’s Women’s birthing center, and UMHS fertility clinic, who have experienced the loss of an infant or pregnancy. The event is co-sponsored by UMHS and Nichols’ Arboretum and is open to the public. For more information call (734) 763-4111.

Remembering the Children of Mott – an annual memorial service for families and friends who have experienced the death of a child either during or following hospitalization. The memorial service is sponsored by The Department of Spiritual Care. For more information, call (734) 936-4041 or e-mail chaplain@med.umich.edu

U-M Office of Decedent Affairs – a central place at U-M Health System for ongoing questions or concerns after the death of a family member. This can include funerals, autopsy reports, bereavement resources, or any other question related to the post-mortem or bereavement process. For more information, call (734) 232-4919.

Community Bereavement Programs

Hospice Grief Groups – programs that offer grief support programs to families/friends who have lost a loved one. Services are available even if you did not receive hospice services prior to your child’s death. You will find a list of local hospice agencies in Michigan at: www.mihospice.org and click on the link “Find A Hospice.”

Arbor Hospice – offers a variety of support groups and programs for families experiencing or anticipating loss including Loss of a Child group and Memory Book creation, as well as Art from the HeART, a support group facilitated by an art therapist available to grieving children kindergarten-8th grade. For more information or to register for a group, call 1-888-992-CARE (2273) or visit www.arborhospice.org.

Camp Heart 2 Heart – an annual two-day camp designed to meet the needs of children and teens (ages 7–18) who have experienced the death of a family member or other significant person. The weekend combines traditional camp experiences with age-specific grief support activities to help participants gain coping skills and build friendships with others who have experienced similar losses. The camp is held at Camp Munhacker in Gregory, MI and is offered through the collaborative efforts of Arbor Hospice (888) 992-2273 and Ele’s Place (734) 929-6640.

Ele’s Place – a program for grieving children that offers ongoing peer support group programs to help children and teens in the Lansing and Ann Arbor regions cope with the death or life-threatening illness of a parent, sibling or other close family member or friend. www.elesplace.org

Ann Arbor

p: (734) 929-6640
f: (734) 926-0985
1582 Eisenhower Place
Ann Arbor, MI 48108

Grand Rapids

p: (616) 301-1605
f: (616) 301-0508
2000 Michigan Street NE
Grand Rapids, MI 49503

Lansing

p: (517) 482-1315
f: (517) 482-6608
1145 W. Oakland Ave
Lansing, MI 48915

Flint

p: (810) 232-3040

The Kite Network – a non-profit organization located in southeast Michigan that provides one-on-one peer-based counseling, free-of-charge, to support those whose lives are darkened by grief. Counselors are volunteers who have traveled on their own personal grief journey, and who have been trained to provide a supportive presence to their clients. For more information, contact www.thekitenetwork.org or call (734) 975-0238.

SandCastles – provides a caring place for children, teens and their families who have experienced a death, to share their loss and journey through grief in a safe and supportive environment. SandCastles offers grief support groups, an annual weekend camp and community education and awareness. Call 313-874-6881 to learn more.

Camp Erin-Detroit – Camp Erin-Detroit is an annual, overnight, weekend-long camp experience for children and teens that have experienced the death of someone close to them. It is offered free of charge and is facilitated by professional staff specialized in grief and trained volunteers from Henry Ford Hospice **SandCastles** Grief Support Program. Grief is a normal, natural response to death and individuals need to be supported in order to heal. Camp Erin offers that support. Call 313-874-6881.

Web-Based Resources

Centering Corporation-Grief Resource Center – a non-profit organization that provides education and resources for those experiencing loss. They also provide educational offerings and workshops for caregivers and families. For more information, contact www.centering.org or call (402) 553-1200

Center for Loss and Life Transition – a website dedicated to “companioning” grieving people and serving as an educational resource and professional forum. Visit their website at www.centerforloss.com

Center for Loss in Multiple Births – www.climb-support.org provides parent-to-parent support for those who have experienced a multiple birth loss.

Compassionate Friends, Inc. – a national, non-profit, self-help organization that offers friendship, understanding and hope to bereaved adults and children following the death of a child of any age. The organization provides emotional support and information free of charge. For more information, visit www.compassionatefriends.org or call (630) 990-0010.

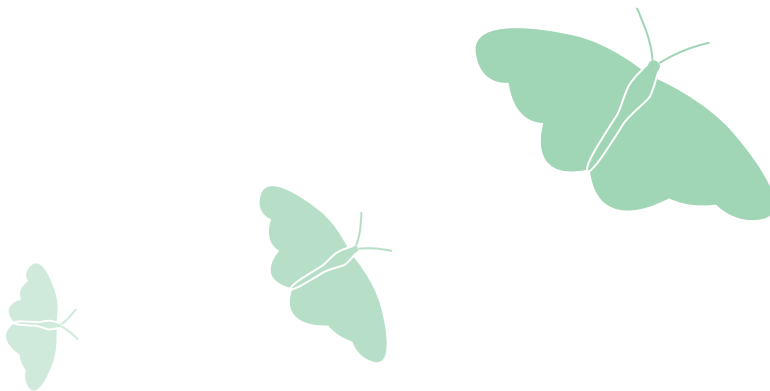
Day by Day – a support group for parents who have lost a child to cancer or who have exhausted treatment options. For more information, visit www.groups.yahoo.com/groups/daybyday.

Dougy Center for Grieving Children – an organization that provides support for children, teens and their families who are grieving a death. Educational materials are available to adults to help grieving children as they move through their healing process. For more information, visit www.dougy.org or call (866) 775-5683.

Griefnet — an on-line community of persons supporting each other through grief, death, and major loss. There are almost 50 e-mail support groups that help to people work through loss and grief issues of many kinds. For more information, visit www.griefnet.org or www.KIDSAID.com

Kara — a non-profit organization staffed primarily by trained volunteers who have experienced healing from personal loss that provides free grief support to those experiencing loss. For more information, visit www.kara-grief.org or call (650) 321-5272.

Miss Foundation — a non-profit organization that provides crisis and long-term support to families after the death of a baby or child at any age and from any cause. Visit www.missfoundation.org





USEFUL UNIVERSITY OF MICHIGAN HEALTH SYSTEM TELEPHONE NUMBERS

Hospital Operator: (734) 936-4000

For questions and resource information about after-death issues

Office of Decedent Affairs: (734) 232-4919

For spiritual care and referrals to local clergy

Spiritual Care: (734) 936-4041

For emotional support

Social Work: (734) 764-3140

For questions regarding sibling grief

Child Life: (734) 936-6519

For more information about the Patient & Family-Centered Care Program

Mott Children's and Von Voigtlander Women's PFCC Program: (734) 763-5770

To reach your child's physician, please call the appropriate pediatric medical clinic

Bone Marrow Transplant	(734) 936-4015
Cardiology	(734) 764-5176
Endocrinology	(734) 764-5175
Gastroenterology	(734) 763-9650
Genetics	(734) 764-0579
Hematology-Oncology	(734) 936-9814
Infectious Disease	(734) 763-2440
Kidney Transplant	(734) 615-2040
Liver Transplant	(734) 615-2462
Neonatology	(734) 936-6379
Nephrology	(734) 936-4210
Neurology	(734) 936-4179
Pediatric Intensive Care Unit	(734) 763-2401
Surgery	(734) 764-4151
Rheumatology	(734) 764-2224
Urology	(734) 936-7030
Ventilator Program	(734) 615-3267
UMHS Main Phone Number	(734) 936-4000

For questions regarding personal belongings

Security Services: (734) 936-7890

For questions regarding medical bills

Billing Hospital Service: (734) 936-6939

Billing Professional Service: (734) 647-5225

For questions regarding medical records

Release of Information Unit: (734) 936-5490

A message of hope

Let me begin by sharing how very sorry I am for the loss of your child. As a parent who has also lost a child, I know how devastating and overwhelming it can be and hope the information in this book will be of help to you and your family as you try to move through the days ahead.

I am one of several bereaved family members who work with Mott staff on ways to help bereaved families. We understand what a difficult time this is and hope this booklet has provided you with as much information and support as possible. As you have seen from the many family quotes in this book, we all grieve differently. Please feel free to re-read and use this book when it feels right to you. We hope that some of it may be helpful immediately after your loss, such as the section on funerals and memorial services. You may be ready for other sections at a later time.

Your child's medical team, hospital social workers, and spiritual care team are here to help you. It can be hard to reach out and ask for help during this time. But know that the hospital staff is here to address your questions and provide support to your family. Additionally, there are several other programs and resources listed in this book which can be very helpful to grieving families.

Please know that you are not alone. We are here to help you in any way we can.

We honor the life of your child and are so sorry for your loss. We hope for your family healing and peace in the difficult days ahead.

— Robyn, mother of Isaac



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**C.S. MOTT
CHILDREN'S HOSPITAL**

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