

Bereavement Resource Guide

A Handbook for Families After the Loss of a Child



Nemours® Children's Hospital

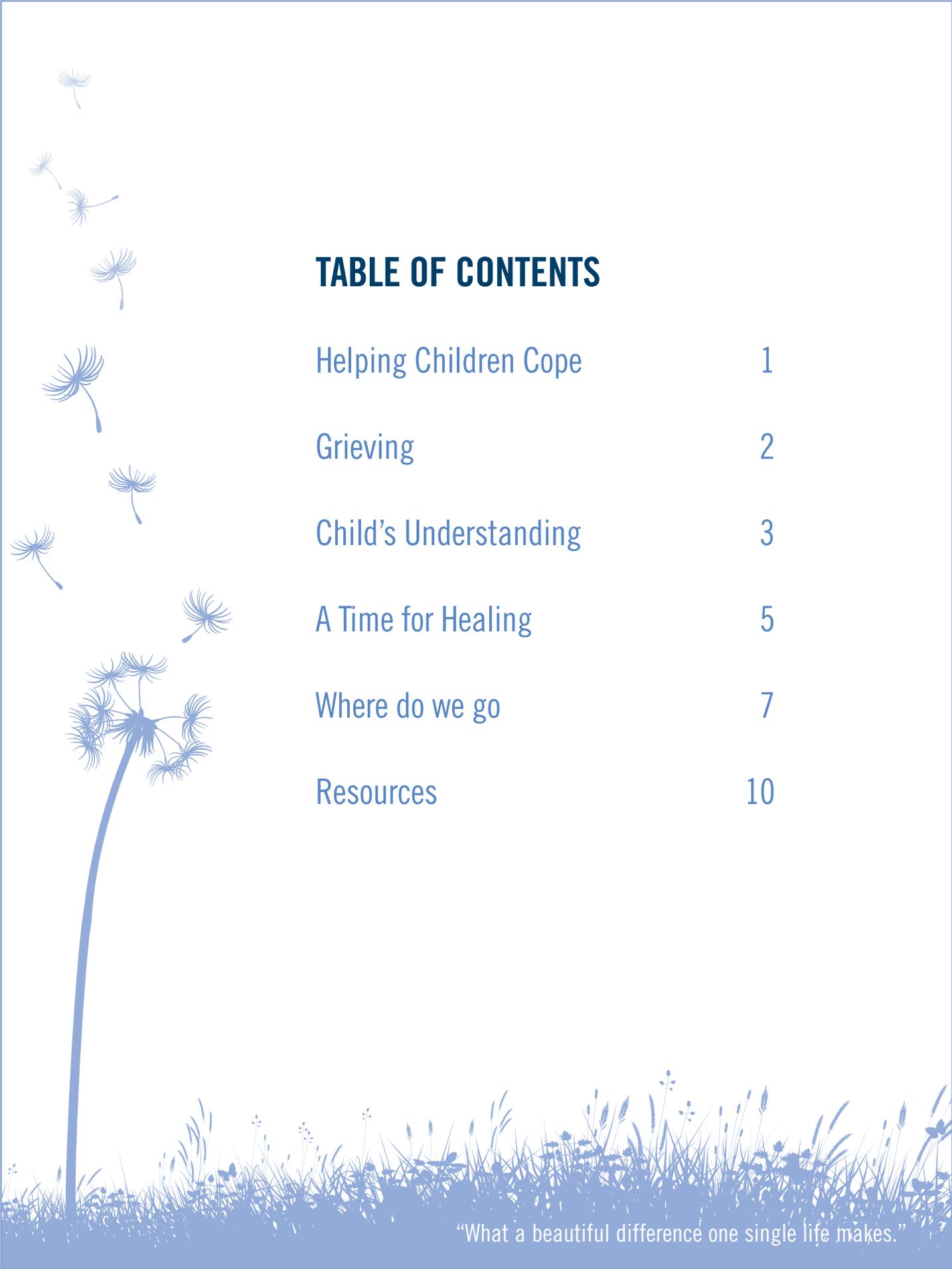


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"What a beautiful difference one single life makes."

Helping Children Cope

- Children should be informed as soon as possible about the death. If the children are not present at the time of death someone close to them should deliver the news at home or in familiar surroundings. Holding and physical closeness may be better than too many words.
- Young children are very literal. Avoid phrases such as “gone to sleep” as they may then fear they will die if they go to sleep; or “lost” as they may think the person can be found; or “good people go to heaven” as they may fear they will die if they are good.
- Before answering children’s questions, listen to them and watch them. It is important to know what they know about death, how they feel and what they believe.
- Allow children to feel and express whatever they feel no matter how uncomfortable it may be for others.
- Children’s grief comes and goes. They cannot sustain grief for long periods at a time. They may be sad one minute and involved in play the next.
- Maintaining routines, rules and stability as much as possible will offer your child a sense of security.
- Do not be afraid to let a child see your tears. Let them know that it is natural to cry when you are sad.
- Sometimes it may be necessary to repeat things in words that the child understands.
- Children may ask the same questions over and over even though you have already answered them. Be patient with them as this is a normal behavior.
- Expect grieving to resurface at each new developmental stage.
- Offer activities that may help your children express feelings and cope with the death. You could consider storytelling, art work, music, journaling and physical activity.



Grieving

Following the death of a loved one you may experience intense and overwhelming feelings. These feelings might include shock, sadness, despair, emptiness, anxiety, fear, anger, guilt or powerlessness. You may even experience physical pain. People are usually so unfamiliar with the intensity of such feelings that they begin to think there is something wrong with them or that they are “losing it.” It is important to understand that these feelings and emotions are a normal part of the grieving process; they are also necessary for the grieving process to begin.

Each person’s grief is unique. No one can tell you how to feel, when to feel or for how long to feel the pain of loss. It is important that you not deny your feelings but instead learn to express them. Sharing your feelings with a close friend, in a journal, through a support group or with a professional counselor can be very helpful.

Since grief is such a difficult process, it is important to take good care of yourself. Eating well, sleeping well and getting adequate exercise are essential. Over time, you may start to notice some behaviors or feelings that come with healing. Some of these may be:

- I can handle the tasks at home that I was managing before the loss such as cooking, cleaning, mowing the lawn, etc.
- I can enjoy being with the people I care about without feeling they expect too much from me.
- I take an interest in current happenings around me.
- I participate in activities outside my home such as church, clubs, sports or work.
- I take care of myself, whether I want to or not.
- I think about other things besides my loss.
- I am beginning to enjoy the things I enjoyed before the loss.
- I don’t feel worried or frantic about dealing with minor changes.
- I am feeling stronger and more in control of my emotions.
- I sleep and awaken refreshed.
- I can enjoy intimacy.
- I believe there is still meaning in my life.

Remember, grief is a process and it will take time to get back to a more predictable and normal life. You will continue to have strong feelings that will come and go. If you ever feel “stuck” and unable to move forward, please seek professional help.



Child's Understanding of Death and Response to Loss

Generally, as children grow older, so does their ability to understand and talk about the concept of death. While every child is different, child development experts do give us some general guidelines of what to expect from children at different ages. Regardless of their age, children usually benefit from maintaining their typical daily routine as much as possible.

Birth to Two Years:

- don't understand what death is
- can sense that something is different
- eating and sleeping patterns may change
- may be more fussy and may cling more to adults
- probably will not have direct memories of the person who died

Three to Five Years:

- think death is reversible and temporary and may believe the person will return or can be visited
- may forget that the person died
- may not have direct memories of the person who died
- tend to be concrete, literal thinkers
(Do not describe the dead person as sleeping, as children may then be afraid of going to sleep.)
- might go back to earlier behaviors such as bed wetting, thumb sucking, clinging to parents or talking "baby talk"
- might be aggressive, have temper tantrums, nightmares

Six to Eight Years:

- begin to understand that death is permanent and that the person will not come back
- grief may be expressed in play
- interested in how the body works so may ask questions about the body and details about the death
- may believe death is violent, sudden or only happens to bad people as they see on television, in movies or in video games
- still have "magical thinking" and may see death as a monster, ghost or spirit that "gets" people and that there are ways to escape from them so they won't die
- may feel they caused the death or didn't prevent it or may see it as punishment
- may have more fears, nightmares or bodily complaints such as headaches or stomach aches
- may be concerned about who is going to take care of them, how things will change in the family or who else might die



Nine to Twelve Years:

- understand that death is a part of life and that everyone will die at some time
- begin to see how the death has affected other people around them
- may be interested in what the dying person may have felt; Was there pain? Were they afraid?
- may be interested in what happens to the body and the spirit of the person who died
- may hide emotions and try to be “normal” (joking, acting strong, not crying)
- may be worried about other family members and concerned about their own future and security
- may have physical complaints such as headaches, stomach aches, difficulty sleeping
- may avoid school, activities with other children or may do poorly in school

Teenagers:

- understand that death is final, irreversible and universal
- may still feel that they are invincible and don't need to worry about death
- may take part in risky behaviors
- may feel that life is unfair
- may ask questions about spiritual beliefs as they search for meaning in life and death
- may talk more to their friends than their family about the death and their feelings about it
- may hide their feelings to protect their family
- may be angry
- may be afraid that friends will treat them differently so may hide their feelings by joking, pretending that nothing has changed or acting “cool”
- may have body complaints such as headaches, stomach aches, changes in sleep or eating
- may be depressed and withdrawn



A Time for Healing

Healing is a process that takes time and is hard work. There is no right or wrong way to grieve. These suggestions may help you find ways to cope with your feelings and begin to heal.

Spending Time With Others

Don't feel you need to deal with this alone. Balance private time and time with others. Find a family member, friend or clergy member who you can talk with and share your feelings or just sit with quietly. Grieving with someone can often be healing.

Asking For What You Need

People want to help during a time of loss, but they need you to tell them what you may need and what you don't need. Whether it is sharing memories or doing an errand, let people know specifically what they can do to help. You may need to avoid those people who are not supportive.

Facing Your Feelings

Whatever your feelings are, accept them. They are yours and it is okay to have them. There is no weakness in expressing your feelings. You may feel sadness, anger, guilt or even disbelief. It is important to allow yourself to express all of the feelings that go with your grief.

Dealing With The Stress

Taking care of yourself physically is just as important as caring for yourself emotionally. Be sure to get plenty of rest, eat healthfully and exercise. It is not uncommon for people to become ill or have sleeping difficulties or shortness of breath during times of loss. Quiet activities such as listening to music or writing in a journal can be very relaxing and very healing for some people. Caution should be used with alcohol and prescription drugs. Their numbing effects may ease the grief temporarily, but they do nothing to help you deal with grief over time.

Finding Joy Again

You might feel as though you may never enjoy life again, but try. It is okay to have some fun – have dinner with a friend, go to the park with your dog, see a movie or bake a cake. You don't need to feel guilty about finding pleasure again in your life. Begin looking ahead.

Setting Realistic Goals

All people grieve in their own ways and in their own time frames. Don't let others' expectations affect how you grieve. Set goals for yourself that are achievable and realistic so that you don't become overwhelmed.



WHEN TO CONSIDER SEEKING PROFESSIONAL HELP

There is no timetable for grieving and strong emotions are a normal part of the process. While the support of family and friends is invaluable, some people who are grieving benefit from talking to an experienced grief counselor. People who make the decision to seek professional counseling often do so based on the length and/or intensity of their grief. Other people make the decision because they find it difficult to function in their day-to-day life. Calling a counselor or therapist is not a sign of weakness, but rather of strength. If you feel any of the following, you may want to consider seeking professional help.

- feeling extremely angry about the death
- having no desire to interact with other people
- feeling hopeless about the future
- having thoughts of wanting to harm yourself in order to join your deceased child
- disinterest in or inability to care for yourself and or your surviving children
- using alcohol or drugs to escape from your grief

To find a counselor or therapist in your area, contact your insurance company, your hospital social worker or your local mental health center.



Where do we go from here?

Planning the Funeral

As a parent, you have always tried to make careful decisions about your child's care. While planning your child's funeral you will again be making caring decisions. We hope this information will help you make thoughtful and loving choices for your child. The suggestions included here are just that, suggestions. You may have other ideas or wishes about how to handle the final arrangements for your child. You may find it helpful to contact a clergyman of your faith to clarify any religious traditions or practices you may want to include in the funeral arrangements for your child. Clergy are often very experienced in planning and participating in funerals and may be able to support or guide you through this process. Hospital social workers, chaplains and Child Life specialists also are available to provide information, support and guidance.

Making Arrangements

Following the death of your child you will need to contact a funeral home. The funeral director will discuss the full range of services they have to offer. Things to consider are:

- You may want to have a viewing or a visitation. Some families choose to have a viewing open to the public, others want only a private viewing for family and close friends, while others choose to have a closed casket.
- To have a viewing or not is a personal choice. Some families feel that it allows them to pay their final respects and to help them overcome any lingering feelings of denial. For surviving children a viewing may help them to better understand the concept of death.
- Families may choose not to have a viewing because their religion prohibits it, because they do not want their last memory of their child to be as he or she looked in death or for a variety of other reasons.
- Burial and cremation are two types of final arrangements. Decisions about cremation or burial may be based on personal preferences, family traditions or religious practices. Some families choose burial so that they have a place to go to visit their child and so their child may be laid to rest near other relatives in a family plot. Other families choose cremation and make a variety of different choices about what to do with their child's ashes.
- There is no right or wrong decision to make about viewings, burials or cremations. It is important to make the decisions that feel most comfortable for you and your family.

Choosing a Funeral Home

In choosing a funeral home you may wish to:

- Ask a hospital social worker or chaplain, family, friends or clergy to suggest a funeral home that may best meet your family's needs or preferences.
- Consider past experiences. Have you, a relative or trusted friend used a funeral home in the past that served the family well?
- Consider location. Choose a funeral home that is conveniently located, especially if you think you would like to have a viewing, visitation or service there.
- Consider cost. Once you have narrowed your choice to two or three, call the funeral director and ask about cost. Be sure to mention that the deceased is a child since many funeral homes offer reduced fees for children. Ask about payment arrangements that can be made. If you are worried about how to afford the cost of the funeral, you may contact a social worker or clergy person for suggestions.



Choosing a Funeral Home *(continued)*

Once you have selected a funeral home, you will need to meet with the funeral director to finalize your plans. The funeral home services could include the following:

- bringing your child from the hospital or, if your child died in your home, from there to the funeral home
- providing you with an opportunity to see your child
- providing a room for visitation or a funeral service, if desired
- helping you make decisions about services, burial or cremation
- providing a casket, urn, flowers and other supplies
- notifying your local paper to provide the obituary
- processing the paperwork for the death certificate and for cremation or burial

Planning Services

At a time when you may feel helpless and powerless, it is important to remember that you have the right to make decisions and to plan your child's funeral in a way that is comforting and feels right for you and your family. Here are some suggestions that other families have found helpful:

- Remember that this is your service for your child and you will hold these memories throughout your life. It is important for you to be comfortable with the major decisions even if you choose to have others assist you in the planning.
- If two parents are grieving, it is helpful to plan the service together, honoring the wishes of both.
- Single parents may receive suggestions, advice and support from others that are helpful, but it is important for you to be able to plan the service that you want for your child and that will be most meaningful to you.
- If there are siblings who are old enough, you may want to include them in some way in the planning of the service.
- Regardless of your choice about having a viewing or visitation, if you want to see your child again or feel you still have things you need to say to your child, talk with the funeral director. Arrangements can be made for you to have a chance to do those things.
- Take your time in making decisions. The funeral is an important occasion and is the time for you, your family and friends to remember and to say good-bye to your child. Take the time you need to plan carefully so that the service expresses what you want.

There are many ways to make the service personal and to share your child's life with others at the funeral. Some ideas are:

- Place favorite toys in or around the casket.
- You may want to ask people who were important in your child's life to participate in the service. Examples could be a teacher, a family friend, aunt or uncle.
- Some families have asked someone to take photos or a video of the funeral. You may not want them now, but later you may wish you had them available. Ask the person who takes the pictures or video to keep them for you until you request them.
- Have a large banner or poster board available for attendees to write notes to your child or to you and your family.
- Create a photo collage of happier days in your child's life. Include as many of the people who were important in your child's life as you can.



Please remember that all of the information here is only meant to provide guidance and ideas. Many of the suggestions have come from other families who have had to plan funeral services for their children. Your child's funeral is a personal event so you may have your own special ideas or things you want to include in the funeral service to make it uniquely yours. The important things to include are the things that will bring you comfort, will allow others to support you and will provide you with a meaningful way to say good-bye to your child.

Should Children Attend the Funeral?

- If a child is old enough to have some understanding, you should consider allowing him or her to go to the funeral.
- It is important to ask your children about their wishes and needs related to the funeral. Some children want to attend the funeral; others do not. Children should not be forced to attend a service, however, if they choose not to go, it is important to ask them why. Perhaps, addressing their concerns or fears will reassure them and they will feel more comfortable attending.
- Although sad, funerals help children in dispelling fantasies and acknowledging the finality of death. Funerals allow children the chance to say good-bye, to receive support from others and to be included in an important family time. Even being present at the burial is not necessarily traumatic if children are prepared ahead of time.
- Tell the children what to expect and explain the ceremony in detail. Include such information as who they will sit with, that people will be sad and crying, if there will be a casket whether it will be open or closed, what the room may look like and who might be there.
- Ask an adult friend or family member to pay special attention to your children during the funeral. That person should be someone who the children know and are comfortable with and who is willing to take your children away from the service if they are uncomfortable in any way.
- Encourage children to ask questions both before and after the funeral.
- If there is a way for children to actively participate, they should be invited to express their love through the ceremony. Examples of this may include participating in a reading, sharing a story, drawing a picture for the deceased person or leaving a special token of their love in the casket.
- After the funeral, children should be allowed to participate in any gathering of family and friends and encouraged to share their own memories, feelings or experiences.



Resources

FLORIDA GRIEF SUPPORT SERVICES

Angel of Hope of Central Florida provides grief support after the death of a child at any age. (407) 260-9222, www.AngelofHopeCFL.org

Begin Again Children's Grief Center in Daytona, Fla., provides support to grieving children who have experienced the loss of a loved one. (386) 258-5100, <http://www.hovf.org/childrens-grief-center>

Bereaved Survivors of Homicide in Orlando, Fla., is a professionally facilitated support group for the friends and family members who have had a loved one taken by murder. (407) 254-7248, www.bshofcentralflorida.org

Children's Bereavement Center in Miami, Fla., provides peer support groups for children, teens and young adults who are grieving the death of a loved one. (305) 668-4902, <http://www.childbereavement.org>

Dustin Project in Longwood, Fla., is a spiritually-based grief counseling program designed to assist students in the bereavement process following the death of someone they love or know. (407) 701-9207, www.dustinproject.org

GriefShare is a national organization that serves grieving children and adults throughout Florida. (800) 395-5755, www.griefshare.org for local chapter information in your state.

Growth from Grief in Orlando and Kissimmee, Fla., serves grieving children who have experienced a loss of a parent or sibling. (727) 599-4506, www.growthfromgrief.com

H.A.L.O.S. – Healing After a Loved One's Suicide in Pinellas, Clermont, Orlando and Lutz, Fla., provides support to grieving adults who have experienced the loss of a loved one to suicide. (352) 978-6081, www.halosflorida.org

H.E.A.L. Helping Endure Infant Loss in Orlando, Fla., provides grief support after miscarriage, stillbirth and infant death. (407) 303-5715, www.floridahospitalwomen.com

Hospice of the Comforter's Horizons Bereavement Center in Altamonte Springs, Fla., serves grieving students and adults. (407) 682-0808, www.hospiceofthecomforter.org

New Hope for Kids in Maitland, Fla., serves grieving children, adolescents and their family members. (407) 599-0909, www.newhopeforkids.org

Suncoast Kid's Place in Lutz, Fla., serves children, teens and their families that have experienced the death of a significant person. (813) 990-0216, www.suncoastkidsplace.org

The Compassionate Friends, Inc., is a national organization that provides grief support after the death of a child. (877) 969-0010, www.compassionatefriends.org for local chapter information in your state.

Should you require assistance identifying a grief support group in your local area, please contact KidsTRACK at (407) 567-3208.



Resources

ADDITIONAL RESOURCES

- **The Foundation for Grieving Children** identifies state-by-state grief support services for children and families. www.foundationforgrievingchildren.org
- **Community Hospice Programs** exist in most communities throughout the country. Some of these programs offer bereavement services to the general community. To find a hospice near you, go to the National Hospice and Palliative Care's website, Caring Connections. Website: www.caringinfo.org
- **Summer Bereavement Camps** for children exist throughout the United States. Conduct an Internet search for your geographic area. One such program is Comfort Zone Camps, located in Richmond, Va., and with satellite locations in N.J., Calif., and Mass. Contact (866) 488-5679 www.comfortzonecamp.org
- **Additional Bereavement Resources** such as family counseling programs, mental health agencies and faith-based programs may be identified by consulting with clergy, social workers, school guidance counselors, community information and referral programs like Contact or Mental Health Associations.
- **Professional Counselors in Private Practice** are available in most communities. These individuals may be credentialed as social workers, psychologists, psychiatrists or professional counselors. Depending on the state, some nurses and clergy have counseling certification as well. Many counselors are covered by health insurance plans, however not all accept insurance so this is important to clarify. Ask for recommendations from people you know. You may want to speak with the counselor over the phone before scheduling an appointment to see if you think he or she is the right person for you. Clarify information about fees and their experience in working with bereavement issues.

INTERNET RESOURCES

Hello Grief: an online support community for children, teens & parents

Dougy Center: the National Center for Grieving Children & Families

Hospice Net: online bereavement articles

Grief Net: Internet grief support community

MISS Foundation: support for grieving families

Nemours KidsHealth

Grieving Dads Project

Grief Share: faith-based grief support groups

KIDSSAID: Website to help children cope with grief and loss

First Candle (Neonatal loss/SIDS)

Mommies Enduring Neonatal Death, MEND

Pregnancy Loss and Infant Death Alliance

Sudden Infant Death Syndrome Resource Center

Mothers Against Drunk Driving

Mothers in Sympathy and Support, M.I.S.S. Foundation

Compassionate Friends

Children's Grief Education Association

Survivors of Suicide, SOS

Alive Alone

Bereaved Parents of USA

SHARE Pregnancy and Infant Loss Support

Kidsaid

www.hellogrief.org

www.dougy.org

www.HospiceNet.org

www.Griefnet.org

www.missfoundation.org

www.kidshealth.org

www.grievingdads.com

www.griefshare.org

www.kidsaid.com

www.firstcandle.org

www.mend.org

www.plida.com

www.sidscenter.org

www.MADD.org

www.misschildren.org

www.compassionatefriends.org

www.childgrief.org

www.survivorsosuicide.com

www.alivealone.org

www.bereavedparentsusa.org

www.nationalshare.org

www.kidsaid.com



Resources

CRISIS HOTLINE NUMBERS National – (800) 273-8255 You will be routed to your local crisis center.

BOOKS FOR GRIEVING FAMILIES

Corr, Charles – *Helping Children Cope with Death and Bereavement*
Doka, Kenneth – *Children Mourning, Mourning Children*
Fitzgerald, Helen – *The Grieving Child*
Grollman, Earl – *Talking About Death: A Dialogue Between Parent and Child*
Krauss, Pesach – *Why Me? Coping with Grief, Loss and Change*
Kushner, Harold – *When Bad Things Happen to Good People*
McCracken, Anne and Mary Semel – *A Broken Heart Still Beats: After Your Child Dies*
Mitchell, Ellen and others – *Beyond Tears: Living After Losing a Child*
Rosof, Barbara – *The Worst Loss*
Sarnoff Schiff, Harriet – *The Bereaved Parent*
Schaefer, Dan and Christine Lyons – *How Do We Tell The Children?*
Schwiebert, Pat and Chuck DeKlyen – *Tear Soup: A Recipe for Healing After Loss*
Volkan, Vamik D. and Elizabeth Zintl – *Life After Loss: The Lessons of Grief*

CHILDREN'S BOOKS

Brown, Krasny – *When Dinosaurs Die: A Guide to Understanding Death*
Hanson, Warren – *The Next Place*
Goldstein, Ray and Jody – *Where's Jess? A book for siblings*
Johnson, Joy and Marv – *Tell Me, Papa*
Karst, Patrice – *The Invisible String*
Old, Wendie – *Stacy Had a Little Sister*
Mellonie, Bryan – *Lifetimes: The Beautiful Way To Explain Death To Children*
Rudowsky, Colby – *What About Me?*
Sabin, Ellen – *The Healing Book*
Traisman, Enid – *Fire in My Heart, Ice in My Veins*
Thomas, Pat – *I Miss You: A First Look At Death*
White, E.B. – *Charlotte's Web*
Williams, Margery – *The Velveteen Rabbit*

Centering Corporation: A grief resource center where many of these books can be purchased. www.centering.org