National SIDS/Infant Death Resource Center

SUDDEI INFANT DEATH

Helping Children Cope with Grief When an Infant Dies

Our lives consist of beginnings and endings. Many of them we share with our children: the beginning of a summer vacation and returning home, sunrise followed by sunset. Because death is the ending of life, this

too must be shared with our children if they are going to have a chance to mature normally and see the world for what it is. Unpleasant as it is to think about, as hard as it is to apply to those we love, and as much as we would like

"If a child is old enough to love, He or she is old enough to grieve."

(Goldman, 1994)

to believe otherwise, all of us are mortal (Fitzgerald, 1992). We can provide our children with an explanation to help them understand the death and how to cope with the loss.

Explaining the death of an infant sibling or loved one can be a very difficult, sensitive, and painful process, especially when parents are also

grieving. Because some adults have problems dealing with the reality of death themselves, they may have difficulty explaining the death to a child. Children grieve the death and react to the emotions in the household. Children also need reassurance that they are not the cause of these intense emotions. The best approach is to be truthful and explain what is known about the cause of death.

"If there is no discussion or attempt to explain the death, children often imagine the worst, including that they did something to cause it. It's terribly scary and unsettling to lose the family unit as it has been known. But, handled openly, the death can actually open a door for families to grow together in a positive direction."

(Fitzgerald, 1992)



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Sudden Unexpected Infant Death

When a baby dies suddenly, there is a great sadness, and every family member experiences the death and walks the path toward grief recovery in a unique way. Children who are too young for complete explanations need love from their parents to feel secure. Some young children may be frightened about sudden, unexpected death. They may cling to parents and misbehave to get attention. Others feel responsible about the death and need reassurance that sudden infant death syndrome (SIDS) is a serious medical problem that occurs suddenly and unexpectedly (Shaw 1994). If the baby's death is due to SIDS, children need reassurance that this happens to infants and will not happen to them.

Age	Child's Reactions	How To Help
Birth to 3 years	Affected most by the mood of their caretaker. You may see changes in sleeping and eating patterns, mood. Older infants and toddlers may demand more attention.	Maintain routines and familiar places. Provide abundant love, attention and reassurance. Provide a caring substitute if parent is too distraught to respond.
3 to 6 years	Does not understand that death is permanent. Fears the dead person is cold or hungry. Repeats questions and fears that others and/or self will die. Afraid to go to sleep, may have bad dreams. May play-act events around the death. May revert to earlier behaviors and/or physical symptoms.	 Maintain routine; provide lots of affection and attention. Repeat answers as often as child asks. Look into child's eyes, gently hold them when speaking of death. Allow expression of feelings—re-enacting events, drawing, reading. Avoid words like <i>sleeping, resting, lost, passed away, God took him.</i> Use concrete terms like <i>the baby died, Ryan doesn't eat or grow.</i>
6 to 9 years	Views death as mysterious—takes baby away or caught like a cold. Some still think death is not permanent. May be obsessed with cause of death, what happens to the body. May feel responsible due to past actions, words, wishing sibling dead. May be distressed, sad, or show no signs. Fears loss or abandonment by family members.	Maintain routine. If leaving, tell child when you will return and how to reach you. Listen to child express thoughts and feelings; provide a journal. Answer questions honestly. Reassure that the death was not child's fault. Contact child's teachers.
9 to 12 years	Understands that death is permanent. May seem unaffected by death. May see the death as punishment for bad deeds. May show anger, guilt, grief. Physical symptoms are common.	Provide lots of time and affection. Encourage child to express feelings. Reassure that death was not child's fault. Be honest about what you are feeling. Contact child's teachers.
Teens	May feel confused, sad, guilt, angry, lonely, afraid. May experience physical symptoms. May try to hide feelings to protect parents. May assume responsibilities for family well-being.	Talk without criticizing or judging. Be willing to talk in the teen's time frame. Be honest about your feelings. Allow the teen time alone and to grieve in their own way. Discourage teen from assuming too much responsibility.

Adapted from The California Department of Health Services. Maternal, Child, and Adolescent Health Branch. The California SIDS Program. A Practical Guide to the SIDS Home Visit, pp 2-20, 2-21.

"Sudden Infant Death Syndrome (SIDS) is the sudden death of an infant under 1 year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history."

Willinger et al, 1991

Seeking Support Services

Each child will react to the death of an infant in a very different way. Parents and caregivers should keep in close touch with the child's health care provider in the months after the infant's death for questions and/or concerns about how the child is coping. Mental health professionals can also provide support to parents and children. Additional resources for families include hospice organizations, local health departments, bereavement support programs, and community or religious leaders or healers.

Funerals and Family Rituals

Allow children to be included, if they wish to participate, in family mourning rituals such as funerals, memorial services, wakes, or shivas, as appropriate for the family's culture. Rituals are part of life and a source of help in gaining comfort and building memories of the infant who died. It is important to explain to children beforehand

"As difficult as it may be, children need to participate in the rituals surrounding death—the viewing, wake, funeral, and burial—to acknowledge that the person has really died and to start the mourning process. These rituals provide special times and places to remember and honor the baby and to begin the natural quest for the meaning of the death." what will take place during the ritual and that those attending may be sad, may cry, or otherwise be emotional. Younger children should have a trusted person with them, as parents may have difficulty being supportive. It is important to help children understand that these rituals provide the grieving family and friends a time, place, and occasion to cherish and remember the infant who died, and a way to say goodbye.

References

Fitzgerald, H. *The Grieving Child: A Parent's Guide*. New York: Simon & Schuster, 1992.

Goldman, L. Life & Loss: A Guide to Helping Grieving Children. Muncie, IN: Accelerated Development, Inc., 1994.

Horchler, J. The SIDS and Infant Death Survival Guide: Information & Comfort for Grieving Family & Friends & Professionals Who Seek to Help Them. Hyattsville, MD: SIDS Educational Services, 2003.

Johnson, S.E. *After a Child Dies: Counseling Bereaved Families.* New York: Springer, 1987.

Shaw, E. What To Do What A Loved One Dies. Irvine, CA: Dickens Press, 1994.

Willinger, M., James, L.S., and Catz, C. "Defining Sudden Infant Death Syndrome (SIDS): Deliberation of an Expert Panel Convened by the National Institute of Child Health and Human Development." *Pediatric Pathology* September-October 1991; 11(5): 677-84.

Wolfelt, A. Understanding Grief: Helping Yourself Heal. Muncie, IN: Accelerated Development, 1992.

Selected Organizations that Provide Support and Services to Bereaved Children

The Dougy Center

National Center for Grieving Children, P.O. Box 86852, Portland, OR 97286. (503) 775-5683, help@dougy.org (e-mail), www.dougy.org (Web site)

KIDSAID (Internet)

This is an extension of GriefNet, a comprehensive Internet community that has provided support to over 3 million people in the last year. This is a safe place for kids to ask questions and obtain information. Visit www.griefnet.org or http://kidsaid.com

Raindrop. A cartoon story that explains death to children. www.iul.com/raindrop

The Waterbug Story. A brief, beautifully written story on death—for all ages. www.fortnet.org/WidowNet/poems/waterbug.htm

Resources to Help Children Cope with Loss

Brown LK, Brown M. When Dinosaurs Die: A Guide to Understanding Death. North Dartmouth, MA: Baker Books, 1998. Available from Baker Books, 96 State Road, North Dartmouth, MA 02747. (800) 339-6705 (toll-free), (508) 997-6700.

Durant A, Gliori D. *Always and Forever*. San Diego, CA: Harcourt Children's Books, 2004. Available from Harcourt Children's Books, 15 East 26th Street, 15th Floor, New York, NY 10010. (212) 592-1000.

Gryte M. No New Baby: For Siblings Who Have a Brother or Sister Die before Birth. Omaha, NE: Centering Corporation, 1988. Available from Centering Corporation, 7230 Maple Street, Omaha, NE 68134. (402) 553-1200.

Johnson J, Johnson M. *Where's Jess?* (Revised Edition). St. Paul, MN: A Place to Remember, 2003. Available from A Place to Remember, 1885 University Avenue West, Suite 110, St. Paul, MN 55104. (800) 631-0973 (toll-free), (651) 645-7045.

Mundy M, Alley AW. *Sad Isn't Bad: A Good-Grief Guidebook for Kids Dealing with Loss.* St. Meinrad, IN: Abbey Press, 1998. Available from Abbey Press, One Hill Dr., St. Meinrad, IN 47577. (888) 374-4226 (toll-free).

Old WC. *Stacy Had a Little Sister*. Morton Grove, IL: Albert Whitman & Company, 1996. Available from 6340 Oakton Street, Morton Grove, IL 60053-2723. (800) 581-0033 (toll-free).

Roper J, Grimm L. *Dancing on the Moon*. Hyattsville, MD: SIDS Educational Services, Inc., 2001. Available from SIDS Educational Services, Inc., PO Box 2426, Hyattsville, MD 20784. (877) 935-6839 (toll-free), (301) 322-2620.

Sanders DB, Ed. *Helping Children Grieve: Sudden Infant Death Syndrome*. Rancho Cordova, CA: California SIDS Program, Maternal and Child Health Bureau, California Department of Health Services, 2001. Available from California SIDS Program, 3164 Gold Camp Dr., Suite 220, Rancho Cordova, CA 95670. (800) 369-7437 (toll-free), (916) 266-7437. Schweibert P, Deklyen C. *Tear Soup, a Recipe for Healing After Loss.* Portland, OR: Grief Watch, 2001. Available from Grief Watch, 2116 NE 18th Avenue, Portland, OR 97212. (503) 284-7426.

Simon J. This Book Is for All Kids, but Especially My Sister Libby. Libby Died. Riverside, NJ: Andrews McMeel Publishing, 2002. Available from Andrews McMeel Publishing, Simon & Schuster, Inc., 100 Front Street, Riverside, NJ 08075. (800) 943-9839 (toll-free).

Wolfelt AD. Healing a Child's Grieving Heart: 100 Practical Ideas for Family, Friends and Caregivers. Fort Collins, CO: Companion Press, 2001. Available from Companion Press, Center for Loss and Life Transition, 3735 Broken Bow Road, Fort Collins, CO 80526. (970) 226-6050.

Wolfelt AD. *How I Feel: A Coloring Book for Grieving Children*. Fort Collins, CO: Companion Press, 1996. Available from Companion Press, Center for Loss and Life Transition, 3735 Broken Bow Road, Fort Collins, CO 80526. (970) 226-6050.

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