

AFTER SUDDEN INFANT DEATH

*Facing
Anniversaries, Holidays,
and Special Events*



U.S. Department of Health and Human Services
Health Resources and Services Administration
Maternal and Child Health Bureau





*Light a candle for hope,
for remembrance.*

*No matter where you are,
or which holiday it is for you,
light a candle for love,
it is the greatest light of all.*

— Darcie Sims and Andrea Gambill

This document was developed by the U.S. Department of Health and Human Services, Health Resources and Services Administration (www.hrsa.gov), Maternal and Child Health Bureau under a contract with the National Sudden Infant Death Syndrome (SIDS)/Infant Death Resource Center, Contract No. [NIH IDIQ-263-01-D-0208]. The National SIDS/Infant Death Resource Center is operated by Circle Solutions, Inc.

Revised 2005

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Now it's hard
to go down the baby food aisle at the supermarket
to drive around town and find out that life goes on
to walk up on someone sleeping
to see pregnant women
to see ambulances
to see small babies
to see little girls
to hear babies cry
to hear sirens
to get through the holidays
to get through birthdays
to get through the first day of school
to get through the day...

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We Bring Her Flowers,
poems by Sharon A. Dunn

This booklet is dedicated to parents who have experienced the painful times during anniversaries, holidays, and special events after losing their baby to a sudden, unexpected infant death.

The sudden death of your baby is a shock for you, your family, and your friends. Every detail of what happened plays over and over in your mind. The loss hurts deep inside, and sometimes you can't stand the pain. It is hard to believe that your baby is dead. You dearly want your baby back. Grieving can be very personal and lonely.

Facing anniversaries, holidays, and special events is a painful fact of life after your baby has died. These occasions often test already fragile and weakened spirits.

The quotes by Sims and Gambill are taken from *Tinsel and Tears*, Bereavement Publishing Inc., 5125 North Union Boulevard, Colorado Springs, CO 80918.

Sudden Infant Death Syndrome

Sudden infant death syndrome (SIDS) is the sudden death of a baby under 1 year of age that cannot be explained even after an autopsy, a thorough investigation of the scene of death, and a review of the case history. No one understands why some babies die like this, not even doctors and scientists.

There are some things that are known about SIDS:

- ☞ There is no way to tell when SIDS will happen. There are no medical tests to detect it.
- ☞ It is sudden and silent—the infant was seemingly healthy.
- ☞ Most SIDS babies die while apparently asleep.
- ☞ The baby does not cry out. Death happens quickly, and the baby does not suffer.
- ☞ It is a diagnosis after every other possible cause has been considered.
- ☞ No one is to blame for the baby's death.

Researchers who study SIDS think that some babies have problems that doctors and medical tests still cannot find. These problems cause babies to die suddenly, even when they do not seem sick. SIDS is very hard for parents and even professionals to understand.



Light a special candle—not in memory of a death, but in celebration of a life shared.

— Darcie Sims and Andrea Gambill

You Are Not Alone

You are among the mothers, fathers, families, and friends of over 2,000 babies who die each year from SIDS. You are not alone in feeling confused and very sad in trying to live without your baby. Difficult days may rule your life for a long time, and many unanswered questions will remain.

You try to piece together clues, signs, or reasons why a healthy baby died. You talk to other people about your baby and about SIDS. You may find this hard and tiring.

Losing track of time and being unable to perform simple activities are normal after a baby dies. The daily routine changes in a lot of ways. Regular activities such as weekly grocery shopping or visits with friends or family become more difficult.

After a while, you will probably resume some of your usual activities. But you also may decide that some activities are too painful, such as visiting friends with children and seeing them at play. Take your time deciding what is comfortable for you.



*Facing anniversaries,
holidays, and special
events...*

Anniversaries, Holidays, and Special Events

Families observe cultural and religious traditions on occasions such as reunions, weddings, graduations, and anniversaries.

During the days and weeks after the baby dies, there will be special events that will certainly be different without your baby. You will face celebrations that focus on the joy of children such as Christmas, Mother's Day, Father's Day, and Halloween. Holiday reminders will be all around you in the stores, on television, and in newspapers and magazines.

Holidays and special events are reminders that life goes on around you. You will be torn between how holidays and festive occasions are normally celebrated and how you are going to celebrate them without your baby. You may feel anxious, sad, and empty and may long to have your baby be a part of the special times that usually involve the whole family.

Some people may not understand your need to talk about and remember your baby at these times because they want you to "get on with your life." You may want to talk about the loss of your baby to SIDS for a long time. This does not mean that you are not recovering and coping with the death.

What to Expect as You Face the Special Times

The first year after your baby's death is very hard, and your baby's first birthday and the anniversary of his or her death may also be very difficult.

Even if you seem better, the sadness and pain may return. It will be hard to be around other children, especially babies. These are normal feelings.

It is OK to celebrate and enjoy these times. It is OK to laugh and cry at the same time. You can go from laughing to crying very quickly.

Other children in your family will need help during the holidays to celebrate as they have in the past or to understand why things are different.



*What some
parents do...*

Some parents...

Choose to celebrate and participate in these occasions as they always have in the past, but find it is a struggle. Sometimes they even avoid talking about the baby who died.

Choose to do completely different things during the holidays and special events. They may not participate in any of the usual activities or traditions.

Try to balance their participation in holiday activities and cope with the pain and sadness of missing their baby.

These are difficult and personal choices.

Remember...

What you and your family decide to do for anniversaries, during the holidays, or for special events is your choice.

Your participation in these events may be very different during the first year or so. After a while, you may go back to normal activities or permanently change how you remember some holidays and special occasions.

Celebrating holidays and special events will reflect your cultural background and traditions. It is important for you to value these traditions because they are part of your life during happy and sad times.

Family Gatherings

Families gather for both sad and happy occasions. Happy times and sad times often bring families closer together.

Holidays, weddings, graduations, and reunions are times for celebration. Everyone is expected to be happy. Relatives and friends want you to join in as you have in the past.

Family and friends usually provide the most comfort and listen to you as you try to cope with your loss. But even the closest of relatives and friends cannot completely understand the hurt that you feel.

Friends and relatives want...

To take your pain away...to offer you hope for better times...to see you “back to normal again”...to help you “forget about what happened.”

But...

No one can take your pain away...there will be better times, but they will be different without your baby...your life does not feel like it will ever be “normal” again...you will never forget your baby.



*Talking about SIDS
with others...*

Talking About SIDS

It is hard to understand how babies can die for no apparent reason. Explaining SIDS to others is difficult. Sometimes it is helpful for a close friend or relative to provide information to others for you.

Sometimes people have wrong ideas about SIDS. SIDS is not caused by smothering, choking, infections, or allergies. People may say things that are not true. Some people might give you information that has not been proven or compare the death of your baby to another death they know about. They offer many types of information in the hope of helping you feel better.

Others may ask questions and make comments about your baby. Sometimes their remarks will make you feel like you did something wrong or that you did not take proper care of your baby.

Remember...

You did not do anything wrong to cause your baby to die. There was nothing you could have done.

Making Special Times Easier

As you approach an anniversary, holiday, or special event, do something to remember your baby and to help ease your anxiety. Thinking about how you are going to handle such an occasion is often worse than the actual event. For example, having a memorial service or going to the cemetery before the occasion might comfort you.

Realize that sadness and confusion may remain with you during these times. Feelings of anger, pain, and loss of control do not necessarily mean that you are not recovering from the loss.

Make changes in the way you celebrate holidays and special events. These changes may be temporary or permanent.

Take care to remember that other children and family members will want to continue to celebrate the occasion as usual.

Start a new tradition in memory of your baby.

Talk or write to other parents whose baby has died. Find out how they have coped with the special occasions.



*Celebrating the special times
does not mean forgetting about
your baby...*

Memories

The memories you have of anniversaries, holidays, and special events are of celebrations and family times together. Now you face these times feeling empty without your baby. You have a different outlook about such occasions and may have images of how you would have shared the moments with your baby.

While sadness will remain with you forever, the memories of your baby are some of the most important “keepsakes” you will have. You can treasure them. You can share them with others.

Family and friends often feel they will cause you more pain by talking about your baby. Let them know if you want to talk, and together you can build memories.

As time passes, happy memories of your baby will gradually replace the sad ones, and you will be able to laugh again.



What we have once enjoyed and deeply loved we can never lose, for all that we love deeply becomes a part of us.

— Helen Keller

For More Information

Contact

The National SIDS/Infant Death Resource Center (NSIDRC)

8280 Greensboro Drive, Suite 300

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(703) 821-2098 (fax)

sids@circlesolutions.com (e-mail)

www.sidscenter.org (Web site)

Publications

The publications listed below are available free of charge from the NSIDRC.

Fact Sheet: What Is SIDS?

Fact Sheet: Parents and the Grieving Process

Selected Resources for Grieving Parents, Their Families,
Friends, and Other Caregivers

Other Organizations

The following organizations may be helpful sources of information on coping with a SIDS death or other early infant loss. Every effort is made to ensure that the details for each entry are as current as possible.

Alliance of Grandparents A Support in Tragedy (AGAST)

P.O. Box 271386
Salt Lake City, UT 84127-1386
(888) 774-7437 (toll-free)
reachout@agast.org (e-mail)
www.agast.org (Web site)

Association of SIDS and Infant Mortality Programs (ASIP)

8280 Greensboro Drive, Suite 300
McLean, VA 22102
(800) 930-7437 (toll-free)
(703) 902-1320 (fax)
info@sidsprojectimpact.com (e-mail)
www.asip1.org (Web site)

Centering Corporation

7230 Maple Street
Omaha, NE 68134
(402) 553-1200
(402) 553-0507 (fax)
centering@centering.org (e-mail)
www.centering.org (Web site)

CJ Foundation for SIDS

The Don Imus-WFAN Pediatric Center
Hackensack University Medical Center
30 Prospect Avenue
Hackensack, NJ 07601
(201) 996-5111
(201) 996-5326 (fax)
(888) 825-7437 (toll-free)
www.cjsids.com (Web site)

The Compassionate Friends

National Office
P.O. Box 3696
Oak Brook, IL 60522-3696
(630) 990-0010
(877) 969-0010 (toll-free)
(630) 990-0246 (fax)
nationaloffice@compassionatefriends.com (e-mail)
www.compassionatefriends.org (Web site)

First Candle/SIDS Alliance

1314 Bedford Avenue, Suite 210
Baltimore, MD 21208
(410) 653-8226
(800) 221-7437 (toll-free)
(410) 653-8709 (fax)
info@firstcandle.org (e-mail)
www.firstcandle.org (Web site)

National SIDS/Infant Death Program Support Center

1314 Bedford Avenue, Suite 210
Baltimore, MD 21208
(410) 415-6628
(800) 638-7437 (toll-free)
(410) 415-5093 (fax)
kathleen.graham@firstcandle.org (e-mail)
www.firstcandle.org/health/health_human.html (Web site)

International Stillbirth Alliance

1427 Potter Road
Park Ridge, IL 60068
info@stillbirthalliance.org (e-mail)
www.stillbirthalliance.org (Web site)

M.I.S.S. Foundation

P.O. Box 5333
Peoria, AZ 85385-5333
(623) 979-1000
(623) 979-1001 (fax)
info@missfoundation.org (e-mail)
www.missfoundation.org (Web site)

National Center for Cultural Competence (NCCC)

SIDS/ID Project
Georgetown University Center for Child and Human
Development
3307 M Street, N.W., Suite 401
Washington, DC 20007
(800) 788-2066 (toll-free)
(202) 687-8899 (fax)
cultural@georgetown.edu (e-mail)
www.guccdc.georgetown.edu/nccc (Web site)

National SIDS and Infant Death Project IMPACT

(Infant Mortality and Communication Tools)
8280 Greensboro Drive, Suite 300
McLean, VA 22102
(703) 902-1260
(800) 930-7437 (toll-free)
(703) 902-1320 (fax)
info@sidsprojectimpact.com (e-mail)
www.sidsprojectimpact.com (Web site)

SHARE Pregnancy and Infant Loss Support, Inc.

St. Joseph Health Center
300 First Capitol Drive
St. Charles, MO 63301-2893
(636) 947-6164
(800) 821-6819 (toll-free)
(636) 947-7486 (fax)
share@nationalshareoffice.com (e-mail)
www.nationalshareoffice.com (Web site)

SIDS Educational Services, Inc.

2905 64th Avenue
Cheverly, MD 20785
(301) 322-2620
(877) 935-6839 (toll-free)
(301) 322-9822 (fax)
sidses@aol.com (e-mail)
www.sidssurvivalguide.org (Web site)

SIDS Network, Inc.

P.O. Box 520
Ledyard, CT 06339
(860) 892-7042 (toll-free)
(860) 887-7309 (fax)
sidsnet1@sids-network.org (e-mail)
www.sids-network.org (Web site)



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2005