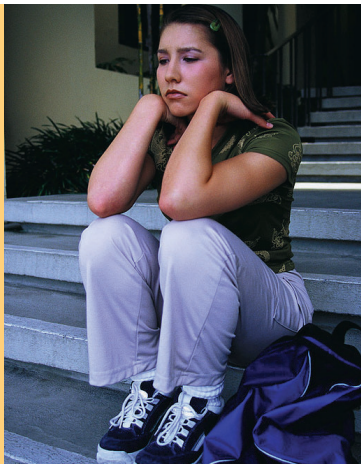


SURVIVING THE DEATH OF A BABY



First
Candle

HELPING BABIES SURVIVE & THRIVE

SIDS
Alliance



FIRST CANDLE SIDS ALLIANCE

1314 BEDFORD AVE, SUITE 210
BALTIMORE, MD 21208
PHONE: (800)221 • SIDS
FAX: (410)653 • 8709
E-MAIL: INFO@FIRSTCANDLE.ORG
WWW.FIRSTCANDLE.ORG



If Your Baby Has Died...

No matter how deep your grief and how great your pain, remember that you are not alone. First Candle/SIDS Alliance is here to help you through this difficult time, just as we have been helped by others who have traveled this road before us.

It is very important that all those touched by the sudden, unexpected, death of a baby at anytime during the prenatal period through age two, understand that in most cases there are no specific symptoms or anything that would have alerted us to the problem, and many times we may not have specific answers to our questions about why the baby died. These tragic deaths happen in the best of families and to the most capable, careful and loving parents.

Because these infant deaths occur unexpectedly, nearly every parent feels in some way responsible for the baby's death until the facts are explained. Often one parent blames the other, or relatives blame one or both of the parents. Families sometimes blame a childcare provider or the doctor who told them the baby was healthy a short time before the death.

Sometimes, even after receiving as much information as possible about the cause of the baby's death, some family members find it difficult to accept these facts. They may continue to search for answers or to blame themselves or others. It is important, since the cause of most miscarriage, stillbirth and SIDS deaths remain unknown, parents should refrain from concluding that something they did caused their baby's death.

The death of a child is the most painful loss a family can sustain. The impact of a child's death is pervasive and far-reaching, affecting parents, siblings, extended family and all those in the community involved in their own special way. A child's death alters the family constellation and threatens the fabric of the community and society.

As we've discussed, the sudden, unexpected death of an infant is devastating and often leaves families in intense shock and confusion, with overwhelming feelings of self-blame and with little or no energy to seek help and support. There was no way to predict that their baby would die, no time to prepare for the death, and no direct answer as to why the baby died. These families are in acute crisis and need immediate intervention to cope with their loss and grief. First Candle/SIDS Alliance offers compassionate grief services to all those experiencing a sudden infant death through availability of a 24-hour, 7-day per week, crisis hotline; grief packets specifically designed to meet the needs of various family members and caregivers; and the availability of accurate, up-to-date information on what is known about these tragic causes of infant death.

The Grieving Process

Most parents who experience the death of an infant describe the pain that follows as the most intense they have ever experienced. Many parents wonder if they will be able to tolerate the pain, to survive it, and to be able to feel that life has meaning again. The intense pain that bereaved parents experience may be eased somewhat if they know what has helped other families overcome a similar grief.

Emotions that may be experienced include sadness, guilt, anger, and fear. Sadness is a normal emotion felt as a result of your loss. Parents may blame themselves for something they did or neglected to do. "If only" becomes a familiar phrase. Parents may feel angry at themselves, their spouse, the childcare provider, the physician, or their baby for having died. Parents might find themselves angry at God, and religious beliefs may be questioned. Many parents experience an overall sense of fear that something else horrible is going to happen. Grieving parents often fear that they are "going crazy." These are all normal reactions.

After the initial shock and numbness of the first few days begin to wear off, parents find that they are left with prolonged depression. There are "ups-and-downs" that can be brought on by unsolicited mail giveaways of baby products; thoughtless or innocent remarks from persons who do not understand the death; or by the parents, themselves remembering that it is the same day of the week or date that the baby died. At these low points, it is often very helpful to talk to another bereaved parent. For some families, support may be obtained from friends and relatives, the clergy, physicians, counselors or other health professionals who have helped others in similar situations.

Bereaved parents find it difficult to concentrate for any length of time, making it hard to read, write or make decisions. Some people experience sensations of dizziness or pressure in the head. These feelings are common in grief and do not indicate that the person is losing mental balance.

Sleep is difficult, leaving parents fatigued. If they have a family to care for or a job to get back to, they may need temporary assistance from their doctor in the form of mild medication to help them rest. Even with sleep, the feeling of exhaustion may persist.

Those in grief often experience muscular problems or other physical symptoms centering around the heart or stomach. Often they have no appetite, and they eat only because they know they must. They feel "tied in knots" inside. Parents often say that their arms "ache" to hold the baby. Some suggestions to help breast-feeding mothers are available from First Candle/SIDS Alliance.

Bereaved parents may have an irresistible urge to get away, a fear or dread of being alone, or unreasonable feelings of danger. If they have other children, parents fear for their safety, yet at the same time they may be afraid of or shun the responsibility of caring for them. Even with this extreme concern about their children, parents may be irritated or impatient with the children's behavior.

Bereaved parents rely heavily on family and friends, but at the same time they may resent that help and even feel guilty about their feelings. The situation is made even more difficult when the community around them does not understand the death. Friends and relatives trying to help seem to say the wrong things or appear not to understand.





Grief Reactions of Parents May Be Different

Mothers and fathers express their grief in different ways. This fact is not always understood. For instance, mothers generally need to “talk out” their grief, while fathers tend to suffer in silence.

Parents working outside the home are diverted by their work, while parents working as homemakers are surrounded by constant reminders. Fathers may find it more difficult to ask for help and support from others and may seek diversions through their work; they may even take on extra work to escape “thinking about it all the time.”

Often the loss of the baby is the first grief situation either parent has experienced. Grief is so intense that they find themselves struggling for ways to relate to each other as well as to their friends and relatives. In order to prevent misunderstanding, most families find it helpful to maintain an atmosphere in which their feelings can be discussed openly, even though that is difficult.

Coping with Birthdays, Anniversaries and Holidays

In the beginning, the day of the week and the hour your baby died will be the most difficult times. After awhile, the date of death in each month will have significance. Later it will stretch out to other dates such as your baby's birthday or the anniversary of your baby's death. Holidays and other family celebrations may also be painful reminders to you about your baby who is gone. Sometimes, the anticipation of these events is worse than the actual day. Unfortunately, it's hard for many of us to predict how we might feel.

What's most important, and sometimes most difficult, is to decide for yourself what you want to happen on those days. Special days are often family-oriented, focusing on togetherness, plans for the future and remembrances of the past. These can be painful; yet at other times, you may find this togetherness acceptable and even comforting.

You may find consolation in long-held family holiday traditions, you may want to do everything different, or you may decide to “get away from it all” this year. Let others know your needs, limits and feelings. Don't be afraid to ask for help and support. First Candle/SIDS Alliance can provide you with suggestions of how other families have commemorated individual days.



The Journey of Living On

*Don't lose the past
Its vision is blurred with tears
Always...
- a hole in my heart
- still a mommy - still a daddy
Seek the future
Fill the gap with love
Will I get lost in the distance
between us?*



Written by
participants in the
interactive writing workshop,
Listening to Your Voice,
presented by
Debbie Gemmill
at the 2001 National
First Candle/SIDS Alliance
Conference

Even though you want to believe that you will recover quickly and completely from the death of your baby, that is rarely the case. It is a journey that takes time and much work. As time passes, the difficult days become less frequent and the pain less intense. There is no magic date, such as a one or five year anniversary, when you will feel instantly healed. Some of the pain might always be with you, as will the memory of your baby. Milestone events of other children, family and friends (such as 16th birthdays, graduations, weddings, etc.) may trigger emotions and reopen old wounds. Healing, gaining perspective, finding hope and living on have different meanings for everyone. Though each person must heal at his or her own speed and in his or her own way, remember that others share your sorrow, know your pain, have lived through this, and are here to help.



Another Baby. . . Maybe?

Maybe you are one of the many people trying for another baby soon after a baby has died. It's natural - you want to fill your empty arms and heart. Yet you may feel frightened that the next baby will die as well. You will need to figure out how long to wait and what seems right for you. For many parents, the thought of having another baby brings comfort. Others comment that they feel they are betraying their baby who has died. The "right" time to embark on this will vary depending on your individual circumstances. Trust yourself about the timing.

When a baby dies, well-intentioned people often try to persuade parents that having another baby as soon as possible is the only way to accept that death and to heal. If you had infertility problems or other losses this advice may seem especially cruel. But "healing" is actually nothing more than incorporating an event into your life in a way that enables you to live with it. Doing that takes time. You cannot necessarily speed up the process of healing by having or not having another baby.

If you decide not to have another baby and that decision is based upon your own reasons, be secure with the fact that this decision is right for you. If you decide not to have another baby, but you think this decision is based more on fear than on practical considerations, do not hesitate to seek some counseling. You will not be the first or the last person to experience this feeling.

If you are expecting a baby, you will probably be excited as well as afraid. It is hard to be patient. It's also unfair to have to wait and go through this all again. Building a good support system can really help. Talk with your doctor or another health professional; you can also contact First Candle/SIDS Alliance. Speaking with other bereaved parents who have had subsequent children may help. Search within your group of relatives and friends for people who will listen to your fears, not give you lots of unsolicited advice. Reviewing the facts about sudden infant deaths and reducing the risks may also be reassuring.

For lack of a better term, your next child has been called the "subsequent child." This new child is indeed a very special one, to you and to everyone else. The birth of a subsequent child can be an overwhelming emotional experience. When you see and hold your new baby for the first time, you may find that difficult memories come flooding back and intermingle with the pleasure you are feeling. The moment can be a mixture of great joy and intense pain.

Will you spend twenty-four hours a day by the crib? The answer is no. Even if you try, eventually you will get tired; which isn't good for you or your baby. That is when you learn to trust - in living, in yourself and your values. You will probably check on your sleeping baby more frequently than you did your other children. Parents of subsequent children are the first to admit that in the past they used to check their babies to see if they were covered, whereas now they check breaths and heartbeats. Many babies are quiet sleepers; a gentle hand on the tummy can reassure you. Babies do pause in their breathing periodically and

sometimes pant for a breath or two. If you remember this, you will spare yourself some moments of uneasiness.

The most uncomfortable period will be the point when your pregnancy or subsequent baby nears the age of the baby who died. It is one of those milestones that has to be reached and passed. Once it is, most parents report that their moments of uneasiness start to decrease. Most of all, be assured that you are not the only person to experience discomfort or panic. Nearly everyone does. You can only do your best in finding ways to handle it. If you find that you are feeling uneasy most of the time, be sure to consult your doctor, other health professional or First Candle/SIDS Alliance for some additional help.

The success of your pregnancy and/or the birth of your newborn represents hope, and a promise of the continuity of life. Joy and sorrow are memories in your life that enable you to know the importance of hope. Many parents have weathered the crises, panic, and great joy of their subsequent child's infancy. They acknowledge that while it was not always easy and that they had to work at handling their emotions, their effort was rewarded by one of the most wonderful periods in their lives.

Children's Reactions to Death

Brothers and sisters will also be affected deeply by the death of the baby. Smaller children who are too young for explanations need only to be shown love and affection by their parents. They may have some very frightening thoughts that they cannot express. (Did I cause the baby to die? Will I die too? Will Mommy and Daddy die? Am I still a big sister or brother? Who will take care of me now?) They may cling to their parents and do other things to get attention. It is most important for them to know that they are loved and secure.

Older brothers and sisters experience grief reactions which may vary depending on their ages and past experiences. Sometimes they feel guilty because they mistakenly think they may have caused the baby's death. They may be very sad or may appear not to have any feelings.

Children should be told as much about the facts as they are able to understand. All older family members should be open to expressing their thoughts and feelings. This openness will enable the children to express how they feel and to ask questions about the death. It is best not to say, "The baby went away," or "The baby is sleeping in peace." It is important to explain that this type of death occurs only in very little babies and not in older children or adults.

Many youngsters have been sources of strength for their families. They have written poetry and often exhibit simple, unshakable faith about the pattern of life and death. Some children, on the other hand, because of circumstances of age or emotional makeup, have felt terrible insecurity after a sibling's death. This loss of security has manifested itself in nightmares, bed-wetting, difficulty in school and other disturbances. Any such problems should be discussed with the child's doctor. Other bereaved parents can also offer practical tips and reassurance.

Lines of communication about the death should be kept open for years since children's questions and ability to understand change as they develop. They will need more complete information over time.





For Grandparents... A "Double Grief"

From the moment you became a parent yourself, you have sought to protect your child from the pain and sorrows in life. Mostly, you have been successful - you've had the ability to solve problems and the power to lessen hurts. Suddenly your adult child is facing a pain far deeper than any other pain in life. It may be deeper than anything that you have ever experienced, or perhaps you can understand this sorrow because you, too, have lost a baby.

Either way, you are now experiencing a variety of emotions: helplessness, frustration, grief, guilt, and anger. You are suffering a "double grief." You are grieving for your grandchild; all your hopes and dreams have been shattered, your "promise" of immortality has been broken. You had wondered if he or she would favor your side of the family, wondered what he would become, and had perhaps even bought gifts for later on (like a first tricycle or special doll). Your grief might not even be recognized by your own child, but you are, most definitely, entitled to it. Grandparents are often referred to as "the forgotten grievers." You had a special relationship with your grandchild - one of unconditional love unhampered by parental responsibility.

You are, at the same time, grieving just as deeply for your own child. You feel frustrated and helpless because this is one pain that you can't "just kiss away." All the little ways that you had to coax a smile from that child are useless now; all the magic words that used to solve the problems are empty. You can only sit by, offer support, and watch your adult child learn to live with this loss. Grandparents often think that they should cope better, have all the answers, control the situation and be an example. When all that they have offered: advice, financial aid, babysitting, experience, and help, is not accepted, asked for, or is even rejected, they feel guilt, frustration and anger.

A baby's death is uniquely difficult because of its very nature. Its suddenness and the lack of answers to important questions intensify the grief reactions. As grandparents, understanding what is known about sudden infant deaths is vitally important. Talking with other bereaved grandparents may help. First Candle/SIDS Alliance can help put you in touch with other grandparents that have experienced a similar death.

Childcare Providers



While the majority of sudden infant deaths occur at home, as more and more mothers return to work, an increasing number of infant deaths are occurring in childcare settings. Because childcare providers have often become an extension of the baby's family, a baby's death may cause feelings of grief for the care provider which mirrors those felt by a parent. Coupled with grief are feelings of fear that they may be blamed for the baby's death, and concern for the reactions of other children (and their families) in their care.

Despite reassurances from the family, counselors, and healthcare or other professionals, the death of a baby in childcare may leave providers hesitant to care for other infants. Sometimes childcare providers are so overcome with grief or lack of self-confidence after a death that they will leave the profession entirely.

Accurate information about sudden infant deaths and reducing the risks, peer support and counseling for all of those affected by a baby's death are essential. Information and referral to local contacts for support are available through First Candle/SIDS Alliance.

Stop the Mail and the Calls

Unsolicited reminders of your baby's death can appear by phone or mail in the form of unwelcome advertisements for baby products. If you would like to stop this type of promotional assault, contact the following organizations in writing and ask to have your name deleted from their lists. Be sure to provide your name, address and phone number. Sometimes it takes up to 90 days to be removed from the lists.

Mail Preference Service
Direct Marketing Association
P.O. Box 9008

New York, NY 11735-9008
Telephone Preference
Service



For Information and Support

First Candle/Sudden Infant Death Syndrome Alliance is a national, non-profit, voluntary health organization dedicated to the promotion of infant health and survival during the prenatal period through age two through programs of advocacy, education and research; while at the same time providing compassionate grief support to those affected by an infant death. Forged through the merger of national and regional SIDS groups formed nearly four decades ago, the SIDS Alliance was established in 1987 in an effort to unite parents and friends of SIDS victims with medical, business and civic groups concerned about the health of America's babies.

The evolution of SIDS Alliance into First Candle is the result of our research and education programs that help save over 3,000 precious infant lives each year. It is our goal to take the knowledge and expertise we have gained within SIDS into stillbirths, miscarriages and other causes of sudden infant death - in the hope of eventually eliminating infant mortality in the United States.

With help from over fifty local programs and partner organizations, First Candle/SIDS Alliance strives to achieve increased public participation and support in the fight against our nation's high rates of infant mortality.

A nationwide, toll-free information, referral and crisis hotline (1-800-221-SIDS) is available for parents who wish to discuss their concerns with a counselor, request additional information, or be connected to support services in their area. Our world-wide website at www.firstcandle.org provides the latest facts about reducing the risks of infant death, as well as online links to other families and local programs.

Each year, First Candle/SIDS Alliance convenes a national conference, enabling bereaved family members and others interested in infant mortality throughout the U.S. the opportunity to connect, share experiences, and gain the comfort and skills necessary to assist themselves and their local programs. The First Candle/SIDS Alliance National Conference also serves as a vital communications link, allowing for rapid exchange and dissemination of high quality research and risk reduction data and improved service strategies. Conference information is available on the website or through the national hotline number.

What You Can Do To Help

Sudden infant deaths cannot be solved through the efforts of bereaved families alone. Opportunities exist for people interested in becoming involved with the work of First Candle/SIDS Alliance at both the national and local levels: you could become a volunteer, an educator, a fundraiser, or an activist. Just call or write First Candle/SIDS Alliance to learn more about how you can make a difference to this very important infant health cause.

Friends and Relatives: Some Suggestions on How to Help

If someone you care about has experienced the death of a baby, there are things that you can do to help them through the grieving process and cope with the death of their baby. The avoidance by friends and family, unsure of what to say or do, only adds to the pain and isolation felt by bereaved parents. The following suggestions are offered to assist you:



DO'S

- Do get in touch. Let your genuine concern and caring show.
- Do be available to listen, to help with the other children, or whatever else seems needed at the time. Offer help with practical matters like house cleaning and meals.
- Do say you are sorry about what happened to their baby and about their pain.
- Do allow them to express as much grief as they are feeling at the moment and are willing to share. Accept silence; if the family doesn't feel like talking, don't force conversation. Follow their lead.
- Do encourage them to be patient with themselves, not to expect too much of themselves and not to impose any "shoulds" on themselves.
- Do allow them to talk about their baby.
- Do give special attention to the siblings of the baby that died.
- Do reassure them that they did everything that they could, the medical care they received was the best, or whatever else you know to be true and positive about the care given their pregnancy or baby.
- Do encourage them to seek outside help, either from a health professional or another bereaved parent.
- Do remember the family on the baby's birthday, anniversary of death, Mother's and Father's days, and other occasions. Permanent memorials, such as First Candle/SIDS Alliance Tree of Hope, helps families know that their baby has not been forgotten.
- Do be patient with them. Coping with the death of their baby may take a long time. Stay in touch.

DON'TS

- Don't let your own sense of helplessness keep you from reaching out to the bereaved family.
- Don't avoid the family because you are uncomfortable.
- Don't say you know how they feel (unless you've lost a child yourself, you probably don't know how they feel).
- Don't probe for details about the baby's death. If the family offers information, listen with understanding.
- Don't tell them what they should feel or do. Don't impose your religious or spiritual views on them.
- Don't change the subject when they mention their dead child.
- Don't point out that at least they have another child; or could have more children in the future.
- Don't blame anyone for the death. Don't make comments which suggest that the care at home, at the childcare provider's, in the emergency room, hospital or wherever was inadequate.
- Don't try to find something positive about the baby's death. Avoid clichés and easy answers.
- Don't avoid mentioning the baby's name out of fear of reminding them of their pain.
- Don't say "you ought to be feeling better by now" or anything else which implies a judgment about their feelings, or sets time expectations or limits their healing process.

Call First Candle/SIDS Alliance for
more



Last Day

*Oh little one
if I had known it was to be
our last day together
I would have done it all
differently.*

*I would have taken you
to the beach to hear the waves
and to the mountains
to feel the snow.*

*I would have shown you
rainbows and
Christmas trees
and Ferris wheels.*

*Or maybe
I would have done exactly
what I did
Sing you to sleep
tuck you in
and whisper goodnight.*

*excerpted from
The Chance to Say Goodbye
by Deborah R. Gemmill
mother of Tyler Dean Gemmill 10/22/81-5/25/82*



Funding for this brochure has been provided by
the New York City Council and
the New York City Department
of Health and Mental Hygiene.

