



# *The Death of a Child*

## THE GRIEF OF THE PARENTS: A LIFETIME JOURNEY

There is no more devastating loss than the death of a child. Losing a child is a disruption in the natural law and order of life. It is heartbreak like no other. Parental grief is different from other grief—it lasts longer and is more intense. Yet, for most grieving parents, the hope and desire that healing will come eventually persists.

“Children are not supposed to die. . . . Parents expect to see their children grow and mature. Ultimately, parents expect to die and leave their children behind. . . . This is the natural course of life events, the life cycle continuing as it should. The loss of a child is the loss of innocence, the death of the most vulnerable and dependent. The death of a child signifies the loss of the future, of hopes and dreams, of new strength, and of perfection.”<sup>1</sup>

Parents who lose a child seek ways to continue to love, honor, and value the life of that child and to make the child’s presence known and felt in the lives of family and friends. Bereaved parents often try to live their lives more fully and generously because of this painful experience.

### COMMON AND UNIQUE CHARACTERISTICS OF PARENTAL GRIEF

Bereavement specialists point to the shared characteristics of parental grief, which may include an overwhelming feeling that the pain will last forever. Two normal responses commonly experienced by bereaved parents are a baffling sense of disorientation and a deep conviction that they must never let go of their grief.

Grief may be experienced physically, emotionally, and socially. Many parents have difficulties with eating, sleeping, and exhaustion; many feel overwhelmed, off-balance, and depressed; and many feel lonely, abandoned, or isolated. These feelings, too, are normal.

As our understanding of grief has evolved, we have learned that bereaved parents express their grief in ways that are individual and unique—there are no set phases or stages, no rules, no timetable.

*Grief is a binding experience; its universality binds sufferers together. More is shared than is different.*<sup>2</sup>

Grieving, like healing, is a journey. Parents need to know that there are many paths they can follow. Grieving parents respond differently, learn to live with their grief separately, and express their sadness uniquely. Individual responses are influenced by many factors, including life experiences, coping skills, personality, age, gender, family and cultural background, support and/or belief systems, and even the type of death that occurred.

## UNDERSTANDING THE GRIEF PROCESS

One approach that may be helpful in understanding the grief process is to visualize it not as a succession of phases over which one has little or no control but as a fluid process, a series of “tasks” that can be revisited and reworked over time.<sup>3,4</sup>

*Accepting the reality of the child's death:* At first, parents usually experience a sense of disbelief or denial. After a child's death, grieving parents might say, “I can't believe this is happening to us,” or “how could my baby be dead? He seemed fine when I put him to bed.” The parents' first “task,” then, is to accept the reality that the child has died.

*Experiencing the pain of grief:* Initially, shock may numb the pain of loss. Parents may not experience the full range of feelings—which may include anger, fear, or guilt—until after they have accepted their loss and are trying to resume their daily lives. Experiencing these feelings is the next task. Unfortunately, around this time, parents generally stop receiving comforting calls and notes from friends and are expected to return to usual productivity at work or at home. Such a sudden absence of attention and increased (often unrealistic) expectations from others may lead parents to feel isolated and to suppress or avoid their pain.

*Adjusting to everyday life without the child:* Caring for a child takes an amazing amount of time and energy. Parents and other caregivers who were consumed with meeting their child's needs or preparing for their child's birth are suddenly faced with inactivity. Where once there was responsibility, now there is emptiness.

As the pain of grief is released and begins to subside, parents tackle the next task: finding ways to adapt to the changes in their lives. During this adaptation period, parents can work to prevent a sense of helplessness by gradually re-forming schedules and responsibilities. Creating meaningful rituals or keeping a journal or writing poetry may help.

*Moving on with life while staying connected with the child:* Grieving parents sometimes believe that if they let go of the emotional attachment to mourning their loss, they are somehow dishonoring the memory of their child. For many, the task of re-engaging is the most difficult. They may get “stuck” at this point and later realize that their life in some way stopped at the point of loss.

Some bereavement experts note that the parents' grieving process includes not only adapting to the loss and returning to functioning in their lives but also changing their relationship with their deceased child. “The task for bereaved parents is to evolve some ongoing relationship with the thoughts and memories that they associate with their child, but to do this in a way that would allow them to continue with their lives after such a loss.”<sup>5</sup>

## SIDS AND OTHER SUDDEN UNEXPECTED INFANT DEATHS

The sudden and unexpected death of a baby causes unique and profound grief and raises painful emotional issues for the parents and family as well as for those who love, care for, and counsel them. Parents must deal with a death so abrupt that it leaves no time to prepare or to say good-bye. Parents whose baby dies suddenly and unexpectedly are often plagued by “if only’s” that can never be resolved. They replay thoughts such as, “if only I hadn’t put my baby down for a nap when I did,” or “if only I had checked on the baby sooner,” or “if only I had not returned to work so soon.” If the death occurs in a child care setting, the parents may experience overwhelming guilt or anger, feeling that their baby might still be alive if they had been caring for the baby at home.

Feelings of shock and grief are compounded as parents struggle to cope with a loss for which there are more questions than answers. “Why did this happen?” “Is there anything I could have done to prevent my baby’s death?” “Can it happen again?”

*Need for Reliable Information.* Each year in the United States, about 4,500 babies die suddenly and unexpectedly. About half of these deaths are diagnosed as sudden infant death syndrome (SIDS), the sudden unexplained death of a baby younger than age 1. Many other infant deaths have been diagnosed as SUID—the sudden death of an infant under 1 year of age that when first discovered did not have an obvious cause. These include deaths that are later determined to be from explained (e.g., metabolic disorders; accidental suffocation) as well as unexplained causes. An infant or early childhood death forces adults to think about their own vulnerability, but a SIDS death also brings with it mystery and a frightening loss of control. The chaos surrounding a SIDS death leaves most parents feeling that nothing is predictable; the death throws everything off balance.

Grieving parents need reliable information as well as emotional support. In many sudden infant deaths, the autopsy findings may help to answer questions. Many parents are anxious to consult with the pathologist, who should explain the findings in language the parents can understand and take time to answer their questions.<sup>6</sup> But, frequently, the findings cannot provide parents with the information they seek. Parents whose baby dies as a result of SIDS are often denied the sense of closure that comes from knowing the exact cause of their baby’s death. Discussing the autopsy findings can help them begin to accept the death.

The sudden unexpected death of a baby often occurs in the home, where parents and sometimes their children witness a terrible tragedy and possibly scenes of intense confusion. If the parents themselves find their baby lifeless, they will always live with that memory. Parents and others feel helpless in trying to explain the unexplainable to children who may have been present at the time of the baby’s death.

*Showing Support.* When a baby dies, parents want their child’s brief life to matter not only to them, but to others. “All too frequently, the sudden unexpected death of a baby is not socially validated in the same way other deaths are.”<sup>7</sup>

Family members and friends can play a valuable role in sharing their concern and in helping parents honor their baby’s memory. Most parents feel reassured when friends and family members mention special things they noticed about the baby or remember the baby’s birthday or the anniversary of the death. By extending these sensitive gestures, loving and concerned relatives, friends, and caregivers can be a source of reassurance and comfort for grieving parents.



## WAYS TO COMFORT A GRIEVING PARENT

Bereaved parents need to know that their child will be remembered, not just by them but also by family and friends. They need to have the child acknowledged and referred to by name. There are many ways to honor parents and the child:

- Acknowledge the child's death by telling the parent(s) about your sadness.
- Allow the parent(s) to express feelings without imposing your views or feelings about what is appropriate.
- Avoid telling the parent(s) you know just how they feel.
- Allow the parent(s) to cry—it is appropriate to cry with them.
- Visit and talk with the parent(s) about the child who died; ask to see pictures or mementos the family may have.
- Refer to the child by name.
- Extend gestures of concern such as bringing flowers or writing a personal note expressing your feelings and support.
- Attend the child's funeral or memorial service.
- Offer to go with the parent(s) to the cemetery in the days and weeks after the funeral.
- Remember anniversaries and special days.
- Donate to a specific memorial in honor of the child.
- Provide practical help, such as offering to stop by at a convenient time, bringing a meal, purchasing a comforting book, offering to take the other children for a special outing, or treating the parent(s) to something special.
- Respect the dynamics of each person's grief. Grief is an ongoing and demanding process.
- Keep in mind that the parent(s) may not be able to ask for help or tell you what they need.

## FATHERS AND GRIEF

Mothers and fathers grieve differently. Traditionally, fathers are expected to be strong and to carry on. They are usually expected to attend to the practical but not the emotional aspects of their child's death. Fathers tend to feel that they must handle all the decisions at this time, but these decisions can have lasting effects on the family, so it is important for parents to make them together.

Each father grieves in his own way. Some may express their emotions openly; others may process their feelings internally. Each father must be allowed to process his grief in a way that is natural for him. Fathers often fear that if they release their emotions, they will erupt like volcanoes; for many men, anger is the predominant emotional reaction to the death of their child. Ignoring, denying, or running from anger and other intense feelings will not make them go away. Channeling the energy of overwhelming emotions through physical activity or other healthy activities can help ease the tension.

The loss of a child can also place tremendous stress on parents' relationship with each other. Grieving parents often feel alone, disconnected, and alienated. Parents can try to reach across the emptiness by asking how their partner is doing and by listening. It's helpful to set aside time every day to talk, share closeness and comfort, and express needs and feelings when partners are ready. This becomes even more important as parents return to work. If possible, parents should avoid becoming overly busy or exhausted with too many commitments; "grief work" is real work, and it takes time and energy.<sup>8</sup>

## FAMILIES THAT NEED ADDITIONAL SUPPORT

The tragedy of a child's death brings profound pain and can present difficult problems for grieving parents. For some, the effects of such a devastating tragedy can become even more intense when the family is already experiencing stresses such as economic difficulties, substance abuse, or domestic problems. A number of factors may interfere with the grief process. These include avoiding or suppressing emotions, overactivity leading to exhaustion, use of alcohol or other drugs, unrealistic promises made to the child who has died, unresolved grief from a previous loss, judgmental relationships, and resentment toward those who try to help.

Family structures and relationships are diverse; some parents have no extended family or community supports. Single or divorced parents, teen parents, gay and lesbian parents, and those living away from family or community may need support networks.

Each family's unique needs, beliefs, and preferences should be honored during the bereavement process. Additional supports for families include grief counseling via telephone help lines, grief support groups and organizations, faith-based bereavement support, state and local health departments, and an array of print and online resources. (See the link to the list of resources at the end of this publication.)

## WAYS PARENTS CAN HELP THEMSELVES HEAL

- Admit to yourself and others that your grief is overwhelming and exhausting and should not be diminished or ignored.
- Allow yourself to be angry, and recognize that you are vulnerable and disoriented.
- Begin to understand that to grieve is to heal and that integrating grief into your life is necessary.
- Acknowledge the need and desire to talk about your child who died, as well as about moments and events that will never be experienced.
- Honor the significance of your child's life, no matter how brief.
- Create memorial services and other rituals to commemorate your child's life.
- Draw strength and support from your spiritual beliefs or faith community.
- Express your feelings in journals, poetry, prayers, or reflective writings or through other creative activities such as art or music.
- Try to be patient and forgiving with yourself and others; avoid making hasty decisions.
- Trust and confide in those who care.
- Get more physical activity and eat healthy foods.
- Volunteer your services to organizations that support bereaved parents.
- Obtain help from traditional support systems such as family, friends, professionals or faith-based groups; join a parent support group; seek professional counseling if needed; or learn more about death and the grieving process.
- Recognize that you were, and still are, a loving parent.
- Let go of fear and guilt when the time seems right and the grief seems less.
- Give yourself permission to feel pleasure and continue with your life, knowing that your love for your child transcends death.

## COMPLICATED GRIEF

During the months immediately following a loss, the symptoms of normal grief are the same as those of complicated grief. Many newly bereaved parents feel that life without their child has lost its meaning and is not worth living. But, while normal grief begins to ease after a while, in complicated grief the symptoms remain or become more severe. After several months, if a parent still has problems accepting the reality of the child's death, cannot return to everyday functioning, feels detached or socially withdrawn, or feels that life has no purpose, these may be signs of complicated grief.<sup>9</sup> The intense and prolonged grief surrounding a child's death is unique in its challenges and may require attention from a trained grief counselor, family physician, mental health professional, or member of the clergy.

## FROM ONE BEREAVED PARENT TO ANOTHER

All newly bereaved parents must find ways to get through, not over, their grief—to go on with their lives. First Candle<sup>10</sup> offers the following suggestions to help grieving parents make it through difficult times:

- *Take care of yourself.* Eat well. Get plenty of rest.
- *Express yourself in a way that fits who you are.* Talk about your baby, your feelings, your fears, your grief. Keep a diary, write a journal, create a flower garden or another special project.
- *Explore available resources.* There are many books, articles, poems, videos, and websites that provide information, guidance, and support.
- *Build a support network.* This network may be your family, your friends, or your faith community. You may want to contact a support group for parents who have experienced a similar loss.
- *Try to be understanding of your partner's needs.* There may be times when it is difficult to comfort each other. Being sensitive to your partner's needs and finding others you can lean on during difficult times can help.

## JOURNEY TOWARD HEALING

Eventually, time ceases to stand still for grieving parents. Painful moments still occur—striking, poignant, but in some ways comforting reminders of the child who died. At some point, parents realize that there can be happy and beautiful moments, and it does not seem impossible or wrong to smile or laugh. One day, bereaved parents may come to be “surprised by joy.”<sup>11</sup>

When are parents ready to live again? There is no list of events or anniversaries to check off. In fact, parents are likely to begin living again before they realize they are doing it. They may catch themselves laughing. They may pick up a book to read for pleasure. They may start playing happier music. When they do make these steps forward, they are likely to feel guilty at first. And yet, they will feel as though they are being nudged in this positive direction. They may even have the sense that this nudge is from their child.<sup>12</sup>

## RESOURCES

For additional resources on bereavement, see the following:

- Bereavement support resource brief (<http://www.sidscenter.org/Bereavement/index.html>)
- *Helping Babies, Healing Families Program Manual*, bereavement support resources ([http://programmanual.info/chapter3/resources3\\_0.html](http://programmanual.info/chapter3/resources3_0.html))
- First Candle's bereavement hotline available 24 hours, 7 days a week: (800) 221-7437 (<http://www.firstcandle.org>)

## REFERENCES

1. Arnold JH, Gemma PB. 1994. *A Child Dies: A Portrait of Family Grief* (2nd ed., pp. iv, 9, 39). Philadelphia, PA: The Charles Press, Publishers.
2. Arnold JH, Gemma PB. 1991. In Corr CA, Fuller H, Barnickol CA, Corr DM, eds. *Sudden Infant Death Syndrome: Who Can Help and How* (p. 55). New York: Springer Publishing Company, Inc.
3. Worden JW. 2009. *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner* (4th ed.). New York: Springer Publishing Company.
4. California SIDS Program. The Tasks of Grieving [under Crisis Support/Parents], available online at <http://www.californiasids.com/Universal/MainPage.cfm?p=34>; accessed September 30, 2010.
5. Worden JW. 2009. *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner* (4th ed.). New York: Springer Publishing Company.
6. Valdes-Dapena M. July 1995. The Postmortem Examination. *Pediatric Annals* 24(7):365-372.
7. Rando TA, ed. 1986. *Parental Loss of a Child* (p. 167). Champaign, IL: Research Press Company.
8. First Candle. 2009. *Surviving Stillbirth for Fathers* [brochure]. Baltimore, MD: First Candle.
9. Mayo Clinic. Complicated Grief. Available online at <http://www.mayoclinic.com/health/complicated-grief/DS01023>; accessed September 21, 2010.
10. First Candle. 2009. Coping with Grief [fact sheet]. Available online at <http://www.firstcandle.org/grieving-families/sids-suid/coping-with-grief/>; accessed November 18, 2010.
11. Moffat M, ed. 1992. *In the Midst of Winter: Selections from the Literature of Mourning* (p. xxvii). New York: Random House.
12. Horchler JN, Morris RR. 1994. *The SIDS Survival Guide: Information and Comfort for Grieving Family and Friends and Professionals Who Seek to Help Them*. Hyattsville, MD: SIDS Educational Services.

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The federal Maternal and Child Health Bureau supports a consortium of four national centers that address issues surrounding sudden unexpected infant/child death and pregnancy loss:

- National Sudden and Unexpected Infant/Child Death and Pregnancy Loss Resource Center (<http://www.sidscenter.org>)
- National Sudden and Unexpected Infant/Child Death and Pregnancy Loss Program Support Center (<http://www.firstcandle.org>)
- National Sudden and Unexpected Infant/Child Death and Pregnancy Loss – Project IMPACT (<http://www.suid-im-projectimpact.org>)
- National Sudden and Unexpected Infant/Child Death and Pregnancy Loss Project at the National Center for Cultural Competence (<http://nccc.georgetown.edu/projects/sids/index.html>)

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