



Sudden Infant Death Syndrome:

*For Grandparents . . .*

*A "Double" Grief*

— *ℳ*

# Grandparent Grief



**F**rom 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, the power to lessen hurts.

Suddenly, your 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 child.

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 that first tricycle or that special doll). Your grief may 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."<sup>1</sup> You had a special relationship with your grandchild—one of unconditional love unhampered by parental responsibility.<sup>2</sup>

You are 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 child learn to live with this loss.<sup>3</sup>

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, baby-sitting, experience, and help, is not accepted, asked for, or is even rejected, they feel guilt, frustration and anger."<sup>4</sup>

Guilt and anger. One often causes the other, soon the two are so intermingled that it is difficult to determine where one begins and the other ends. Grandparents experience "survival guilt" . . . it seems unnatural that a grandparent live longer than a grandchild, grandparents often express the wish that they "could change places" with the lost child. You may be feeling guilty for things that you didn't do (Why didn't I baby-sit every time I was



asked? Why didn't I spend more time with the baby?). It doesn't help to know that you thought you had forever—that time is gone.<sup>5</sup> Perhaps you aren't well, or for some other reason, were unable to see the baby at all.

You may be very, very angry. Angry at God for “taking” the child, angry at the doctors, nurses or paramedics for being unable to save the child's life, angry at your other children whose families are intact (though a common reaction, grandparents feel a great deal of guilt because of this anger.)<sup>6</sup> You might even find yourself angry at your own child if your understanding of SIDS is incomplete and you wonder if there was anything they could have done or should have seen. Finally, you might be angry at yourself as you wonder if your genes or chromosomes were “responsible” for the child's death.

We do not grieve according to the age of a baby.<sup>7</sup> Psychologists have determined that the grief period following the death of a child is between 18 and 36 months. Some of the emotions that your child will have will sound strange to you, some will sound familiar because you will be having similar reactions. These emotions are, however, NORMAL GRIEF REACTIONS. Helping your child to grieve will facilitate your own grief.

Your child will be going through a grief “process”. He or she will proceed through four “stages” (although these stages may often overlap each other during the process): SHOCK and DISBELIEF, SEARCHING and YEARNING, CONFUSION and DISORGANIZATION and RESOLUTION.<sup>8</sup> Normal grief reactions during these stages can be summarized as follows.



## **SHOCK and DISBELIEF**

The initial "reaction" to the loss is intense and, relatively, short lived; it is the period during which the bereaved seem to be "in shock." The bereaved parent . . .

- May appear stunned or dazed or may be continually crying.
- May experience intense panic, anger or distress.
- Usually denies death, feels that what is happening is "unreal".
- Has difficulty concentrating, and normal functioning is impeded.

## **SEARCHING and YEARNING**

This stage is the bereaved parent's attempt to "test reality". It is the time when parents work through the extent of their responsibility for the death. The bereaved . . .

- May experience restlessness, pronounced mood swings.
- May constantly search for cause of death through questioning and conjecturing (e.g. What if I had checked on her more, had taken CPR, hadn't slept in, etc? or If only I hadn't left him with a sitter, had been there, had heard him, etc.)
- Yearns for child. May "hear" baby cry or "see" baby in shopping mall.
- May continue to check on baby.
- May be a period of great irritability and anger...at God, at doctors, at parents, other children, spouse, self.
- May experience need to "do something".

## **CONFUSION and DISORGANIZATION**

Often the most "dangerous" stage, this period will see the highest rate of separation or suicide. The bereaved parent, in the process of reorganizing his role . . .

- May feel empty and helpless.
- May feel deeply depressed.
- May be weak and exhausted.
- May have very little interest in anything.



- May neglect basic needs (may have large weight gain or loss, may have difficulty in going to sleep at night, may have frequent nightmares, may have trouble getting up in the morning).
- May experience somatic complaints (headaches, aching arms, stomachaches).
- May experience panic attacks, may be afraid to be alone, may be overly fearful for spouse or other children.
- May “pretend” to be happy.
- Is beginning to accept the reality of death.

## RESOLUTION

As the bereaved parent adapts to the loss of his child and accepts the changes in his life, he...

- Will experience periods of normalcy.
- Enjoys renewed energy and interest.
- Has renewed ability to make decisions.
- Returns to normal eating and sleeping patterns.
- Is now able to remember the child as living—not only at the moment of loss.

Grief is, however, a highly individual process. People do not need to be urged to grieve in some predetermined way. There are tremendous cultural differences in how people will grieve—even a husband and wife will seldom grieve in the same way. The resolution of grief takes a long time: years, not weeks. As parents move ahead in resolving their grief, there will always be setbacks, some triggered by specific events related to the child (birthdays, anniversaries, etc) and some seemingly unrelated.<sup>9</sup>

A SIDS 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 SIDS is vitally important.

## FACTS ABOUT SIDS

Sudden infant death syndrome (SIDS), or crib death, is defined as the “sudden death of an infant under one 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.”<sup>10</sup>



## SIDS ...

- Is the number one cause of death in infants between one month and one year of age. Occasionally, an older or younger child may die of SIDS.
- Is NOT a rare disease. About 3,000 babies will die each year in the United States (less than one per 1,000 live births). SIDS will take more lives than cystic fibrosis, childhood cancer and heart disease, and child abuse, combined.
- Is NOT predictable and NOT preventable. A minor illness (such as a cold) may precede the death but many victims display no observable symptoms.
- Is NOT caused by suffocation, aspiration or regurgitation.
- Is NOT painful. Death occurs within seconds, usually during sleep.
- Is NOT contagious.
- Does occur in families of all races, religions and living circumstances.
- Is often referred to as “crib death” and is as old as the Old Testament. The term sudden infant death syndrome came into general medical use after 1969.
- probably has more than one cause, although the final process of death is similar in most cases. <sup>11</sup>

As a parent, you want to know how to help your child proceed through the grief process. Your role is to guide and support—and that role will require great patience and understanding.

The Compassionate Friends, a support group for parents who have lost children of all ages to all causes, devised a list of "DO'S and DON'TS" for the families and friends of bereaved parents. Their suggestions, along with a few of our own, include:

## DO...

- Let your genuine concern and caring show.
- Be available...to run errands, to listen, to help with the other children, to do whatever else needs done at the time.
- Allow them to express as much grief as they are feeling at the moment and are willing to share.
- Say that you are sorry about what happened and about their pain.



- Encourage them to be patient with themselves, not to expect too much of themselves and not to impose any “shoulds” on themselves.
- Allow them to talk as much and as often as they wish about their child.
- Reassure them that they did everything they could, that there was nothing that they missed and that there was nothing else ANY ONE could have done to save their child's life.
- Help them let go of the questions and the guilt.
- Remember the child's birthday and anniversaries with the parents.
- Do give special attention to the child's brothers and sisters (they are hurt and confused too and in need of attention which their parents may not be able to give at this time).

## DON'T...

- Let your own sense of helplessness keep you from reaching out.
- Say you know how they feel unless you have also lost a child.
- Say "you ought to be feeling better by now" or anything else which implies a judgement of their feelings.
- Change the subject when they mention their child.
- Remove pictures of the child from your own home (they need their child remembered.)
- Avoid mentioning the child out of fear that you will remind them of their pain (they haven't forgotten it).
- Point out that at least they have their other children (children are not interchangeable).
- Say that they can always have another child (even if they want to, or can, another child will not replace the child that they have lost).
- Make any comments that suggest that the care given their child at home, in the emergency room, etc., was inadequate.

You can't make the pain go away, you can't bring your grandchild back, but you can help make YOUR child's adjustment to the loss much easier. By grieving together, you reaffirm that grief is normal and that life will go on.

*Someday there will be peace again.*



## References

1. Gyulay, Jo-Eileen. "The Forgotten Grievors", *American Journal of Nursing*, September, 1975. 1476-1479.
2. Gerner, Margaret. "To Bereaved Grandparents". The Compassionate Friends.
3. Gerner, Margaret. "To Bereaved Grandparents". The Compassionate Friends.
4. Gyulay, Jo-Eileen. "The Forgotten Grievors", *American Journal of Nursing*, September, 1975. 1476-1479.
5. Gerner, Margaret. "To Bereaved Grandparents". The Compassionate Friends.
6. Gerner, Margaret. "To Bereaved Grandparents". The Compassionate Friends.
7. "The Grief of Grandparents". La Crosse Lutheran Hospital, Resolve Through Sharing, 1984.
8. Davidson, Glen W., Ph.D. and Davidson, Shirlee, BSN, "A Training Manual for SIDS Parent Counselors and PHNs", Department of Health, State of Illinois.
9. D'Antonio, Michael, Ph.D. "A Manual for Nurse Counselors in the Pennsylvania Sudden Infant Death Syndrome Program". Pennsylvania SIDS Center.
10. Willinger, M., James, L.S., and Catz, C. "Defining the Sudden Infant Death Syndrome (SIDS): Deliberations of an Expert Panel Convened by the National Institute of Child Health and Human Development." *Pediatric Pathology* 11:677-684, 1991.



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