

# **ROLE OF THE CLERGY**

*Helping Families Coping with Sudden Infant Death*

## **PROBLEM DEFINITION**

Sudden Infant Death Syndrome, more commonly known as SIDS or "crib death," is a medical mystery which, as of this brochure's revision, affects roughly 3,000 infants each year in the United States alone. Although there are several theories of causation, none have yet to withstand the careful scrutiny of medical investigation. It is defined as the sudden death of an infant which is unexpected by history and for which there is no satisfactory explanation as to a specific cause of death, following a thorough scene and postmortem examination, including an autopsy, and a review of the case history. In other words, the death is inexplicable and can neither be predicted nor prevented. It is this aura of lack of explanation which greatly exacerbates the grief process. But you, the spiritual helper to the family, can be of enormous help.

Guilt is perhaps the most characteristic response of the bereaved, particularly since there is no accident or illness to blame. Implications of neglect or inappropriate care on the part of the caretaker of the deceased infant - parents, grandparents, baby-sitters, etc. - are often voiced and further compound already severe guilt feelings.

## **MEASURES FOR AMELIORATING THE GRIEF PROCESS**

We have found that there are six basic measures for helping the survivors of SIDS victims cope effectively with such a loss. These include:

- a) A thorough autopsy and postmortem examination to rule out any other cause of death.
- b) Use of the term "Sudden Infant Death Syndrome" when appropriate, on the death certificate, rather than non-descript terms such as "natural causes," or terms which imply neglect such as "pneumonitis."
- c) Notification to the parents or guardians of the deceased of the findings of the autopsy.
- d) The offer of information about SIDS and professional counseling to the bereaved.
- e) Access to other SIDS parents either individually or in a group setting.
- f) Community awareness about SIDS and the bereavement process

## **ROLE DEFINITION FOR THE CLERGY**

These sources of help are most often interdependent with that of the family's clergy, who obviously plays a major role during the initial period following a loss and, ideally throughout the process of grief and bereavement which ensues. Your awareness of the aforementioned resources, as well as an appreciation for the vital role which you, as a spiritual leader, can play, may avert inappropriate grief and the emotional and psychological disasters which could consequently result.

There are specific measures which the clergy can take, both direct, in terms of helping a family in coping with a loss, and indirect, in terms of helping the family understand and deal with the concept of death and the physical and emotional reactions of grief, i.e., to know what one can expect. It is particularly the unexpected which tests one's ability to cope.

Direct measures which help define the role of the clergy can be explained as follows:

#### 1. BE IN TOUCH WITH ONE'S OWN FEELINGS ABOUT DEATH

Rev. Edgar Jackson, a noted clinical pastoral counselor, points out that although many clergy have some training in basic psychology and in understanding the importance of the emotions, this does not preclude blind spots, ". . .for some of the best trained have such fear of death that they distort their thinking in relation to it" (Jackson, *Understanding Grief*). Therefore, the clergy would necessarily have to be in touch with her/his own feeling about death before s/he can be effective in helping others. Becoming an honest part of the hurt establishes a relationship for sharing. Showing emotion does not mean the loss of objectivity and professionalism.

#### 2. THE BLAMELESSNESS OF SIDS

Help convince, not persuade, the family of blamelessness. Most often feelings of guilt arise, especially on the part of the parents. It is important to note that this is a normal and appropriate feeling in the experience of grief, and will occur in spite of any evidence concerning the death that is to the contrary. What is important for the clergy to recognize is that these feelings of guilt (or any other feelings which may arise) should not be denied. Rational or not, they are true emotional responses. They cannot be reasoned away, but can and should be allowed as expressions of normal, temporary grief reactions. In other words, the clergy can point out the blamelessness of SIDS, but should feelings of guilt be expressed, it is not helpful to tell the bereaved that they should not feel that way.

There is a danger, of course, that this guilt may be internalized, not allowed expression and discussion. This can be destructive to the parents and relationships between themselves and others, especially their surviving and subsequent children. Guilt can also be expressed as anger and displaced by blaming the family physician, God, the clergy, etc. This is not unusual, but can also become destructive, if not dealt with properly.

Convincing the family of blamelessness can be most difficult, since in SIDS there is no identifiable cause and effect of illness or injury, making the seeming injustice of their baby's death that much more difficult to bear. A careful autopsy, factual information, and use of the term "Sudden Infant Death Syndrome" in documenting the cause of death can help reduce feelings related to blame. These are most helpful, however, only after strong emotions have subsided and the family is predisposed to accepting such information. Predisposition is partly dependent on the experience of the bereaved with those professionals whom they encounter during the initial reactions to their loss, including, and especially their clergy.

### 3. THE CLERGY AS A FAMILY ADVOCATE

When necessary, the clergy should also function as a family advocate in matters other than spiritual and emotional, such as dealing with hospital personnel, coroner, funeral director, or other family members. And if need be, members can be referred to appropriate sources of help should the grief become psychologically destructive.

### 4. THE EFFECTIVE USE OF RITUAL AND CEREMONY

Help the family with decisions that need to be made about viewing the body of the loved one, funeral arrangements, visitation and personal involvement in the service. Remember that parents have to live a lifetime with decisions that are made. Do not allow grandparents to take over and make decisions for the immediate family.

Families in our society tend to minimize ritual and ceremony at the death of an infant. The family may very well have the need to more effectively ritualize the death of their infant, but social custom discourages this. The funeral service should maintain a balance between the acknowledgment of pain, suffering, grief and the assurance of God's love, God's aid, hope and life. Use the baby's name in prayers and in the homily. One of the most common complaints of bereaved parents is that the clergy never once spoke the name of the deceased baby. Personalize the service as much as possible while maintaining theological and religious integrity. Share with the family the Foundation's brochure "Have You Considered?...Planning Your Child's Service" to help identify options in planning the good-bye.

### 5. REMAIN OPEN TO LONG-TERM CARE

Attention is given to bereaved families for the first 4-5 weeks, but from then on many families feel lonely and isolated. Make a personal visit. Telephone the family from time to time to let them know that they are remembered. Try to be particularly sensitive around holiday times, the baby's birthday and the anniversary of the death. Mention the baby's name and help parents recall the joyful as well as the sorrowful memories.

### 6. MAKE USE OF AVAILABLE RESOURCES

The family's clergy can be an important link between health professionals, public agencies, and the parents. The SIDS Foundation of Washington can provide support through individual or group contact with others "who have been there." Your personal encouragement of the concept of self-help actually will strengthen the pastoral relationship rather than threaten it. In addition, the Foundation can provide literature and speakers about Sudden Infant Death Syndrome and/or grief to the family, co-workers, or your church community.

**Northwest Infant Survival & SIDS Alliance**  
4649 Sunnyside Ave. N Ste. 350 Seattle, WA 98103, 1-800-533-0376, [info@nwsids.org](mailto:info@nwsids.org)

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## SUGGESTED READINGS

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