

Helping SIDS Survivors Heal

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How Can You Help?

You are helping someone who has experienced Sudden Infant Death Syndrome (SIDS). You want to help, but are not sure how to go about it. This article will guide you in ways to turn your cares and concerns into actions.

Educate Yourself About SIDS

A vital part of helping SIDS survivors is to educate yourself about the syndrome. The term itself can be difficult to comprehend. Why? Because it is really a non-definition. This clinical-sounding term doesn't describe what doctors know, but, instead, what they don't know. For example, a formal definition of SIDS is: the sudden death of any infant which is unexpected by history, and in which a detailed exam after death fails to find an adequate cause for the death. Essentially, no one knows what causes these deaths.

What we do know is that each year in the United States over 7,000 families experience the death of their babies to SIDS. These sudden deaths occur in apparently healthy infants, almost always while the child is asleep. This experience creates an overwhelming crisis for parents, brothers and sisters, grandparents, other family members and friends.

Learning a Few More Facts

- SIDS is not hereditary. There is no greater chance for it to occur in one family than in another.
- SIDS is not caused by aspiration, regurgitation, or suffocation.
- SIDS and apnea (cessation of breathing) are two different things. Do not assume that if the baby had been on a breathing monitor, she would not have died. Remember--SIDS cannot be predicted or prevented.
- SIDS is slightly more common in the winter months, but occurs at any time of the year.
- Birth control pills do not cause SIDS.

Learning these and other facts about SIDS can help prevent harmful accusations.

Accept the Intensity of the Grief

Grief following a SIDS death is always complex. The infant has died at a time when the family is very focused on caring for him or her. The lack of knowledge about SIDS often adds to the trauma. All too often a SIDS death is not socially supported in the way other deaths are.

Some people fail to realize that despite the shortness of the infant's life, the family's feelings of love for him have existed since conception. Survivors are confronted with

mourning not only the immediate death, but also the loss of hopes and dreams for the child's future.

Don't be surprised by the intensity of their feelings. Sometimes when family members least suspect it, they may be overwhelmed by grief. Accept that survivors may be struggling with feelings of guilt, anger and fear well beyond those experienced after other types of deaths. Be patient, compassionate and understanding.

Absence of Cause Complicates the Grief

With SIDS, the lack of a definitive cause of death makes it especially difficult for families to understand what has happened. Not knowing what caused the death, both adults and children naturally assume responsibility and guilt, even though nothing they did or didn't do caused the death. Try to listen patiently as families explore their "If only's" and "Why didn't we's."

Legal System Complicates the Grief

Because SIDS is sudden and has no known cause, families may be confronted with an onslaught of questions from emergency medical personnel, hospital workers, medical examiners and sometimes the police. Of course, these questions are asked in an effort to protect the interests of the child, yet they can leave parents wondering if they were at fault. This necessary, but painful experience, if handled inappropriately, may place additional guilt and trauma on the family.

Listen With Your Heart

Helping begins with your ability to be an active listener. Your physical presence and desire to listen without judgment are critical helping tools. Willingness to listen is the best way to offer help to someone who needs to talk.

The SIDS survivor's thoughts and feelings may be frightening and difficult for you to acknowledge. Don't worry so much about what you will say. Just concentrate on the words being shared with you. Do use the baby's name when you talk about the death, however. For survivors, hearing the name can be comforting, and it helps confirm that the baby was not just a baby, but an important person in their lives.

They may tell the same story about the death over and over again. Listen attentively each time. Realize that repetition is part of the healing process. Simply listen and understand. And, remember, you don't have to have the answer.

Avoid Simplistic Explanations and Clichés

Clichés, though they are often intended to diminish the pain of loss, can be extremely painful for survivors of Sudden Infant Death Syndrome. Comments like, "You can have another baby," "They died young and avoided life's hurts" and "Think of what you still

have to be thankful for" are not constructive. Instead, they hurt and make a friend's journey through grief more difficult.

Instead of simplistic explanations, familiarize yourself with the wide spectrum of emotions your friend or family member may experience. Allow the person to experience all the hurt, sorrow and pain that he or she is feeling at the time. And recognize that tears are a natural and appropriate expression of the pain associated with the death of the infant.

Remember That Siblings Mourn, Too

Often ignored is the grief of siblings. Why? Because adults have an instinct to protect children from painful realities. Yet any child old enough to love is old enough to mourn.

When a child's brother or sister dies, another young person has died. So, for a child, confronting this reality can mean confronting the possibility of one's own death. Be prepared to honestly but reassuringly answer questions such as, "Will I die, too?"

Also, don't expect young people to acknowledge the reality of death in the same way adults do. Many children naturally embrace the reality slowly and may at times seem indifferent. Typically, the full sense of loss does not come about until several months after the death.

Offer Practical Help

Preparing food, washing clothes, cleaning the house or answering the telephone are just a few practical ways to show you care. And, just as your presence is needed, this support is helpful at the time of the death and in the weeks and months ahead.

Your presence at the funeral is important. As a ritual, the funeral provides an opportunity for you to express your love and concern. At the funeral, a touch of your hand, a look in your eye or even a hug often communicates more than any words could ever say.

Don't just attend the funeral, then disappear. Be sure to remain available afterwards as well. Remember, your grieving friend or family member may need you more in the days or weeks after the funeral than at the time of the death. A brief visit or a telephone call in the days that follow are usually appreciated.

Be Aware of Support Groups

Support groups are one of the best ways to help families who have experienced SIDS. In a group, survivors can connect with other people who share their experience. They are allowed and encouraged to tell their stories as much, and as often, as they like. Sharing the pain won't make it disappear, but it can ease any concerns that what one is experiencing is crazy, or somehow bad. You may be able to help survivors locate such a group. This practical effort on your part will be appreciated.

Understanding the Importance of the Loss

Remember that the death of a child to SIDS is a shattering experience. As a result of this death, your friend's life is under reconstruction. Be gentle and compassionate in all of your helping efforts. While the above guidelines in this brochure will be helpful, it is important to recognize that helping others after a SIDS death will not be an easy task. You may have to give more of your concern, time and love than you ever knew you had. But this effort will be more than worth it. As a "helping friend," you need to join with other caring persons to provide support and acceptance for people who need to grieve in healthy ways.

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