

A Guide For The Sudden Infant Death Home Visit

September 2005

Sudden Infant Death
Network of Ohio



Providing Support,
Compassion, Education and Research



Acknowledgements

This Second Edition of *A Guide for the Sudden Infant Death Home Visit* is made possible by the contributions of many organizations and individuals:

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Funded by:

Sudden Infant Death Network of Ohio
and
Ohio Department of Health, Bureau of
Child and Family Health Services

August 15, 1989...

tonight
 the rain falls
 not gently
 but
 with a driving force
 like the tears
 streaming
 down my face

i cry
 for you, baby brian
 who has left us
 without a warning

i cry
 for you, my youngest daughter
 so filled with love
 for the beautiful child
 you bore

i cry
 for you my son
 who loved your son
 so deeply

i cry
 for the dreams
 you both had
 for his future
 now shattered
 like fragile
 pieces of crystal

only time
 and the love
 of those who love you
 and share your grief
 can help to ease the pain

i cry
 for myself
 who has lived life fully
 who gladly would have given
 my life for his
 a life almost over
 for a life just begun

go gently to pave the way, dear brian
 you have taken a piece of all our hearts with you

by elaine ede hornsby

dedicated to parents michelle & william blankenship
 and to brother jason brian
 in loving memory of her grandson
 brian william blankenship

Introduction

The sudden, unexpected death of a child is one of life's most traumatic events. It is both a medical and psychological crisis. It is an event that will never be forgotten, which brings great sorrow and that will change the parent's lives forever. The sudden and unexpected nature of sudden infant death syndrome (SIDS) results in a tragedy for which no one can truly prepare. The public health professionals who provide early intervention, support, counseling and comfort to the family after the baby's death play a vital role in assisting them through this life-altering experience. The purpose of this manual is to provide the public health professional with information and resources to assist families after the sudden, unexpected death of a baby.

Health professionals have long recognized the importance of providing early and continuous support and comfort for newly bereaved parents. Those who have experienced the death of a child know all too well that first responders quickly disperse after providing professional services, leaving families without the ongoing support they require. Because of this, affected families and interested health professionals responding to sudden unexpected death events have worked long and hard for legislation that provides for bereavement support after a SIDS death.

The Ohio Revised Code 313.121 requires public health departments to offer information, counseling and other supportive services to families immediately following notification of a SIDS death. Although other infant deaths are not specifically detailed in this law, it is hoped that all public health personnel will provide similar services to these bereaved families as well. The Ohio law regarding the reporting of SIDS and the provision of support to families of SIDS victims can be accessed online at <http://onlinedocs.andersonpublishing.com>.

For many families the home visit is the cornerstone of bereavement support. The public health professionals making the home visit are in a unique position to address the family's needs and can help alleviate guilt, pain and suffering by providing information in a sensitive manner; explaining autopsy results; providing community resources; and offering guidance for surviving children. Parents who receive home visits report the visits make a positive impact on the grieving process.

Sudden infant death leaves an emotional impact on everyone touched by it, including the health professionals who provide care and support for the family. The purpose of this guide is to assist public health professionals in preparation for their mandatory role in responding to infant deaths. It provides information about the essential skills needed to give effective support to families and provides suggestions and resources for coping with the emotional impact on families and health professionals. While much of the information provided in this guide deals specifically with SIDS deaths, this guide is intended to assist in all sudden and unexpected infant death situations.

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Sudden Infant Death Syndrome

Since Old Testament Bible times there have been recordings of seemingly healthy infants who have died suddenly and unexpectedly during sleep. Maternal “overlying” was thought to be the reason for these deaths. During the Middle Ages many European countries made it a crime for mothers to sleep in the same beds as their infants in an attempt to prevent infant deaths. In recent history these deaths have been called “crib death” and “cot death.” In spite of considerable research, babies continue to die suddenly and unexpectedly and experts still do not know the cause of sudden infant death syndrome.

What is SIDS?

Sudden infant death syndrome (SIDS) has been defined as the sudden death of an infant less than 1 year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene and a review of the clinical history (Willinger et al., 1991). This definition is the most widely accepted.

In 2004, scientists proposed a revision in the definition of SIDS to incorporate more recent knowledge about the epidemiology and pathology of SIDS: “The sudden unexpected death of an infant less than 1 year of age, with the onset of the fatal episode apparently occurring during sleep that remains unexplained after a thorough investigation including performance of a complete autopsy and review of the circumstances of death and the clinical history.”

Regardless of the definition, SIDS remains a diagnosis of exclusion. It is the leading cause for infant deaths age 1 month to 1 year of age. According to the National Center for Health Statistics, there were 2,295 SIDS deaths in 2002 in the United States and more children will die of SIDS than will die from cystic fibrosis, congenital heart disease, childhood cancer and child abuse combined.

In Ohio, SIDS accounted for 72 infant deaths in 2003. About 75 percent of SIDS deaths in Ohio occur within the first five months of life. As the awareness of the risk factors has increased, the infant death rate from SIDS has decreased by two-thirds in the last decade, from 1.5 deaths per 1,000 live births in 1992 to 0.5 in 2003. Although the decreased rate has been noted in both white and black races, a disparity remains. In 2003, the SIDS rate for black infants was 2.5 times higher than for white infants. The disparity is greatest between the ages of 1 and 2 months, where the SIDS rate for black infants is about three times the SIDS rate for white infants. Geographically, the disparity is greatest in the metropolitan counties of Ohio.

SIDS – A Diagnosis of Exclusion

SIDS is a diagnosis of exclusion, meaning all other reasonable causes must be ruled out before a death is labeled SIDS. Diseases or conditions that have known markers or causes are ruled out through autopsy findings, a death scene investigation and a thorough review of the victim's and family's health history.

An autopsy is needed to confirm the absence of disease, illness, congenital conditions, abuse, neglect or injury. Tissue samples and autopsy reports also help researchers find characteristics that may lead to discovering the cause of SIDS, which in turn, will prevent more infant deaths from SIDS. A qualified pathologist using a standard protocol should do the autopsy. In the State of Ohio, an autopsy is required on all infants under 2 years of age who die suddenly and unexpectedly and/or under unexplained circumstances.

A death scene investigation requires interviewing parents, caregivers and other people who have been involved in the care of the infant or who may have been on site at the death scene. The investigation includes the examination of the place of death. Information obtained and items gathered are evaluated for clues in an attempt to determine the cause of death. Unfortunately in Ohio, death scene investigations are not done consistently or routinely in every community for every child death.

A comprehensive history of the victim and family helps to differentiate a SIDS death from an unsuspected genetic disorder, a congenital condition or from any other unknown health problem. Finally, when no other explanation is found, the diagnosis of SIDS is made.

Differential Diagnoses

Many conditions can result in the sudden unexpected death of an infant. A complete autopsy, review of the medical history and scene investigation can provide information to distinguish SIDS deaths from other conditions. Even before a final diagnosis is determined, families need information and bereavement support. All of the following conditions can result in the sudden, unexpected death of an infant:

- Anomalous Left Coronary Artery from the Pulmonary Artery
- Asphyxia due to Overlay
- Aspiration Syndromes
- Bacteremia
- Bronchiolitis
- Brochopulmonary Pneumonia
- Cardiomyopathy, Hypertrophic
- Child Abuse and Neglect: Physical Abuse
- Coarctation of the Aorta
- Congenital Heart Failure
- Coronary Artery Anomalies
- Epiglottitis

- Foreign Bodies in Esophagus
- Head Trauma
- Hypoplastic Left Heart Syndrome
- Intestinal Volvulus
- Long QT Syndrome
- Long-Chain Acyl CoA Dehydrogenase Deficiency
- Meningitis, Bacterial
- Meningococcal Infections
- Myocardial Infarction in Childhood
- Viral Myocarditis
- Overlay
- Positional Asphyxia
- Respiratory Tract Infection
- Respiratory Syncytial Virus (RSV)
- Sepsis
- Sleep Apnea
- Ventricular Fibrillation

SIDS Characteristics and Risk Factors

SIDS victims share three major epidemiological characteristics:

- 1) The infants appear healthy prior to death. There may be evidence of a slight cold or stuffy nose, but there is usually no history of a significant respiratory infection.
- 2) The infants die during sleep. The death occurs silently, with no warning.
- 3) The infants are most often between the ages of 28 days and 1 year of age. Ninety percent of the deaths occur under 6 months of age; the majority between 2 and 4 months.

Other common characteristics of SIDS victims have been identified. These characteristics are called risk factors because they seem to put a baby at higher risk for SIDS. **They do not cause SIDS.** Risk factors can be categorized as infant, maternal and environmental. Some of these risk factors can be modified, giving a baby the best chance for survival. Information on reducing the risk of SIDS by modifying risk factors is found in a later section of this manual.

Infant risk factors include:

- Male
- Low birth weight
- Prematurity
- Multiple births (twins, triplets, etc.)
- African American (2-3 times greater risk)
- Native American (2-3 times greater risk)

Maternal risk factors include:

- Under 20 years of age at the first pregnancy
- Short interval between pregnancies
- Late or no prenatal care
- Smoking during or after pregnancy
- Placental abnormalities
- Low weight gain during pregnancy
- Anemia
- Alcohol and substance abuse
- History of sexually transmitted disease (STD) or urinary tract infection (UTI)

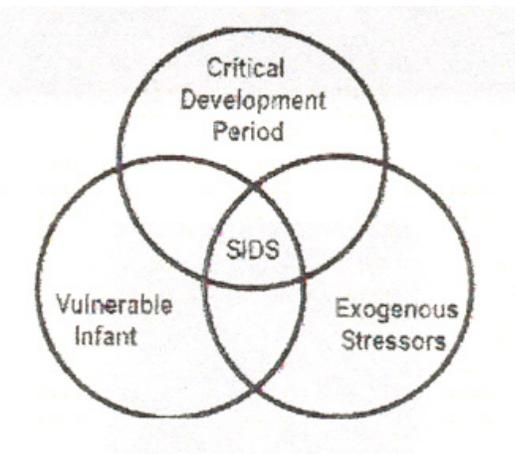
Environmental risk factors include:

- Fall and winter months
- Stomach or side-lying positioning for sleep
- Exposure to cigarette smoke during pregnancy or after birth
- Overheating by warm room temperature or excessive clothing
- Soft bedding including loose sheets, bumper pads, fluffy blankets, pillows, cushions, sheepskin and waterbeds
- Stuffed toys, extra clothing, wedges and other objects in the crib
- Bed sharing
- Sleep surfaces including recliners, couches, mattresses that are meant for adults, not infants

Theories about the Pathology of SIDS

The Triple-Risk Model

Recent studies suggest SIDS is likely a multifaceted syndrome involving the interaction of many factors resulting in the death. The “Triple-Risk Model” was developed by Filiano and Kinney (1994) to describe the possible interaction of the environment, the age of the infant and underlying abnormalities. The model illustrates that when certain environmental stressors are applied to a vulnerable infant at a critical point in development, SIDS results.



Vulnerable Infant

An undetected genetic, developmental or anatomical defect may predispose an infant for SIDS.

Critical Developmental Stage

The peak incidence of SIDS is between 2-4 months of age. Ninety percent die under 6 months of age. During this time, dramatic changes in the infant’s growth and development are occurring including changes in metabolism, sleep state organization and cardio respiratory controls. The brain nearly doubles in size during these months. These rapid changes may produce an instability in the vulnerable infant.

Exogenous Stressors

All infants are exposed to a variety of environmental stressors, such as exposure to second-hand smoke, overheating, rebreathing of carbon dioxide and simple colds and viruses. Normal, healthy infants are able to cope with these stressors with nonfatal results. The vulnerable infant at a critical developmental stage is not able to overcome the challenge of the exogenous stressor and a sudden unexpected death results.

The Triple-Risk Model helps explain why some babies who appear to have no external risk factors die of SIDS, while other babies who have many risk factors survive. The model does not explain all SIDS deaths such as those that occur during the first month or those that occur late in the first year. Continued research is needed to identify which infants are vulnerable and the how they react to exogenous stressors.

In the search for the cause of SIDS, scientists have investigated many possibilities. Researchers have discovered several disorders that can now be diagnosed to explain a small number of sudden unexpected infant deaths such as long QT syndrome, metabolic abnormalities and certain

gene mutations. Research continues to probe the autonomic nervous system, neurotransmitters and the brain stem looking for clues to SIDS. Of particular interest in current research are several areas of the brain including the arcuate nucleus, which plays a crucial role in respiratory, cardiac, temperature and arousal controls. Decreased binding of serotonin in the nucleus raphe obscurus, slower development of myelin and brainstem abnormalities have been found in some SIDS victims.

While the cause of SIDS remains unknown, we do know:

- ◆ SIDS is not caused by immunizations, apnea, child abuse or suffocation
- ◆ SIDS is not communicable
- ◆ Cardiac and respiratory monitoring does not prevent SIDS
- ◆ SIDS is not the result of any action of the parents or caregivers
- ◆ Because the first symptom of SIDS is the sudden death, it is not predictable or preventable.

References:

Filiano, J and Kinney, H. A perspective on neuropathologic findings in victims of the sudden infant death syndrome: the triple-risk model. *Biology of the Neonate*. 1994. Vol 65(3-4), pg. 194-7.

Guntheroth, WG and Spiers, P. The triple risk hypotheses in sudden infant death syndrome. *Pediatrics*. Nov 2002. Vol 110(5), pg. 64.

National SIDS/Infant Death Resource Center (NSIDRC). "What Is SIDS?"
<http://www.sidscenter.org/Downloads/SIDS-English.pdf>

The National Response to SIDS

- The 1950s were marked with a growing interest in the phenomenon known as crib death.
- SIDS was defined as a distinct medical entity in 1969.
- Federal hearings were held during 1972 and 1973 regarding SIDS.
- The Sudden Infant Death Act of 1974 introduced by Senators Ted Kennedy and Walter Mondale was passed as Public Health Law 93-270. The law recognized SIDS as a significant public health issue and provided funding for research and for the establishment of information and counseling programs in all 50 states.
- During the late 1980s growing public and legislative concern developed about the impact of SIDS on parents, caregivers, medical emergency services personnel and first responders experiencing a SIDS death.
- The American Academy of Pediatrics (AAP) recommended putting babies on their backs or sides to sleep in 1992.
- In 2000 the *Healthy People 2010* national health promotion and disease prevention initiative established goals and objectives related to SIDS:
 - 16-1: Reduce deaths from SIDS.
 - 16-13: Increase the percentage of healthy full-term infants who are put down to sleep on their backs.
- In 2004 scientists proposed a new definition of SIDS which incorporates more recent knowledge of the epidemiologic and pathologic features of the deaths.
- In 2005 the AAP issued a new policy statement, no longer recognizing side sleeping as a safe alternative to back sleeping. The policy stresses the need for a safe sleeping environment and encourages the use of pacifiers at sleep time.

Ohio Response to SIDS

- ◆ SIDS legislation in Ohio (House Bill 244) was passed May 4, 1992. This law mandates autopsies for all sudden and unexpected deaths to children less than 2 years of age and requires local health departments to offer information, counseling and other supportive services to affected families.
- ◆ Child Fatality Review legislation in Ohio (House Bill 448) passed in July 2000. This law mandates multi-agency boards in each county to review the deaths of all children under the age of 18.

Role of the Sudden Infant Death Network of Ohio

In response to the mandated responsibilities for SIDS reporting and support, and in response to the needs created by the continuing racial disparity in SIDS, the Ohio Department of Health (ODH) created the Sudden Infant Death Program. Through a competitive grant award, the Sudden Infant Death (SID) Network of Ohio was selected to act as the agent of ODH to assure parents are offered bereavement and supportive services and to monitor and assure that coroners and local health departments (LHDs) are compliant in responding to SIDS.

The SID Network of Ohio is designated by ODH as the initial intake agent for the State of Ohio. The Network is to be notified of all sudden and unexpected infant deaths by the coroners at the time of death using the Notification of Infant Death form. (A copy of this form and the Final Diagnosis of Infant Death form are included in the Appendix. Coroners complete both of these forms and send them to the Network.) The Network identifies appropriate bereavement resources in the geographical locale of the family and sends a condolence letter and packet of grief-related materials to the families. The Network then notifies the appropriate LHD so that its staff may offer supportive services to the family as soon as possible.

Many weeks may pass between the time of the death and the final diagnosis based on findings of autopsies, death scene investigations and review of medical history. The coroners complete the Final Diagnosis of Infant Death after reviewing all the available information. Although the final cause of the death is not known when the initial notification of infant death is received, the Network acts quickly to assure sympathy and support are provided to grieving families as soon as possible regardless of the final diagnosis. It is hoped that LHDs will also act quickly in responding to immediate needs of families at the time of a sudden unexpected infant death.

By partnering with ODH, the SID Network of Ohio serves as the state's expert consultant on SIDS, providing a liaison with national and local SIDS organizations; acting as a resource for current information on SIDS research and risk reduction; and distributing educational materials to health professionals and the public. The Network is also involved in helping communities develop sustainable and effective strategies to address the racial disparities in SIDS.

SID Network of Ohio Mission Statement

The mission of the SID Network of Ohio is to work towards the reduction and eventual elimination of SIDS through a multidisciplinary approach of promoting infant health and wellness, community outreach, education, and medical research. In addition, the SID Network is dedicated to providing supportive services to those who have been affected by the loss of a child, age 2 and under, from Sudden Infant Death Syndrome (SIDS) or Other Infant Death (OID).



To contact the SID Network of Ohio, call 1-800-447-7437 or e-mail SIDNetwork@sidsohio.org

When a Sudden Infant Death Occurs

Case Scenario

The most common case scenario for a SIDS death is one in which parents put their apparently healthy infant to bed. Later when the parents check on the child, they find the baby lifeless. There has been no cry, no warning, no signs of illness or of anything wrong and no hint of what has happened. The emergency medical team is called. They perform CPR, as well as other life-saving measures. The baby is taken to the hospital emergency room where more life-saving techniques are attempted, after which the baby is pronounced dead. In complete shock, the parents are allowed to see and hold their baby, whose body often appears bruised and battered due to the circumstances of death and the resuscitation attempts. Most parents will have an intense need to hold their baby and will need to have information repeated many times. Their infant is dead, leaving both parents and families with unbearable grief, doubts, guilt, unanswered questions and even suspicion related to the suddenness and unexpectedness of their baby's death.

At this time the parents are informed Ohio law requires an autopsy for all infants age 2 and under, who have died suddenly and unexpectedly. The idea of an autopsy can be very distressful to grieving parents. Parents will be questioned about the life and death of their baby many times in the coming hours and days by the emergency medical team, the hospital staff, law enforcement, the coroner's office and other public health investigators. At the time of death, health care providers can assist the parents by being nonjudgmental, respectful and caring. Health care providers need to be sensitive to the manner in which parents react to the death, as each person involved will react in his or her own unique way: some quietly, others more vocally. Culture and beliefs also play a role in the grief response. Withdrawal, denial and anger are just a few of the emotions parents might display. Parents must be allowed to grieve in their individual manner.

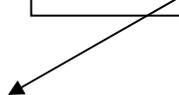
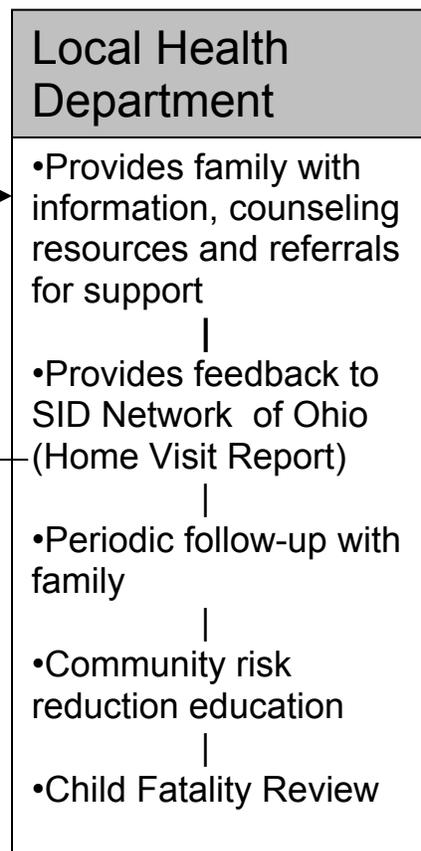
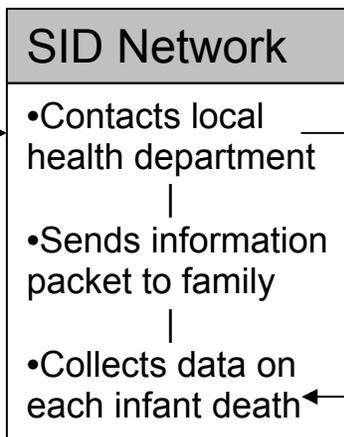
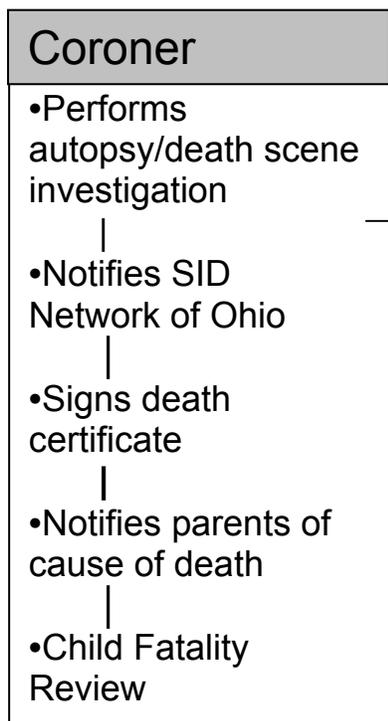
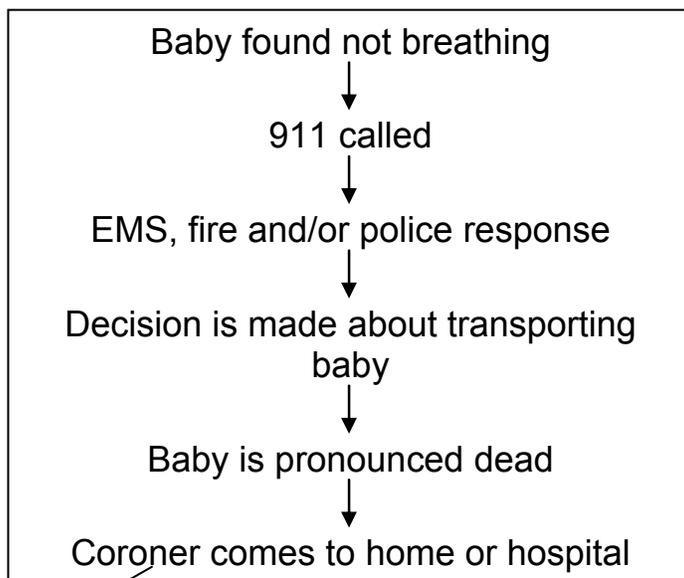
It is important that health care providers and emergency responders understand external markings that a SIDS baby may have. The knowledgeable provider will be more capable in helping parents understand the SIDS infant's appearance and hopefully, will not make judgments concerning the death on the basis of the baby's appearance.

Externally, babies who die of SIDS appear to be in a good state of nutrition and well hydrated. They are well developed, although they may be small for their age. They may have white or blood-tinged frothy fluids around the mouth or nostrils from mild pulmonary edema. When found, their bedclothes may be in disarray with the infant in an unusual position due to the normal muscle spasms following death. Their diaper may be wet and full of stool due to the relaxation of sphincter muscles. Vomit may be found on the face because the relaxation of muscles forces the stomach contents upward. The head or limbs of the infant may have bruise-like marks in addition to pale blanched areas where the body was in contact with the bed surface. Minor diaper rashes and scratches appear more vivid and pronounced after death. If the infant was prone at the time of death, the contours of the face may have a depressed appearance. Rigor mortis in infants may occur within a few hours. It is important that health care providers

understand and communicate to parents that these findings are the result of the death process and are not the cause of the death:

- ◆ Lividity
- ◆ Petechiae
- ◆ Mottling
- ◆ Blood-tinged or frothy drainage from nose or mouth
- ◆ Cool body temperature
- ◆ Clenched fists
- ◆ Distorted face
- ◆ Exacerbated appearance of minor skin rashes
- ◆ Marks from resuscitation attempts.

Response to a Sudden Unexpected Infant Death



Grief Reactions

Grieving is the process that begins when an individual experiences a life-changing event. The death of a child alters a person's future. The feelings of grief can be extremely intense and long lasting. Many researchers have described a series of tasks or stages that an individual must experience in order to realize a sense of healing. One such researcher, J.W. Worden, describes four such stages in his book, *Grief Counseling and Grief Therapy*.

- | | |
|----------|---|
| Task I | To accept the reality of death, including the meaning of the loss and finality of death. |
| Task II | To experience the pain of grief, the actual physical pain as well as the emotional and behavioral pain associated with death. |
| Task III | To adjust to an environment in which the deceased is missing, realization of the loss and how it affects the circumstances of life, the family's roles and relationships to others and the need to redefine their world. |
| Task IV | To withdraw emotional energy from the absent family and reinvest it in another relationship. This involves being able to identify the uniqueness of the relationship with the infant. It may also involve the acceptance of previous and subsequent siblings as unique individuals. |

Supportive intervention by health providers as well as family and friends can help grieving individuals negotiate these tasks. While grieving individuals may be comforted knowing their feelings and reactions are common, it is important for the health professional to understand each grief response is unique. Gender, culture, religion and personal history all affect the expression of grief. Some common grief reactions to be familiar with include:

- | | |
|----------------------|---|
| Feelings: | <ul style="list-style-type: none"> * Anger * Shock * Sadness * Guilt * Loneliness * Anxiety * Fatigue * Helplessness |
| Physical Sensations: | <ul style="list-style-type: none"> * Hollowness in the stomach * Tightness in the chest * Tightness in the throat * Over sensitivity to noise * Sense of depersonalization |

- * Breathlessness
 - * Weakness in muscles
 - * Lack of energy
 - * Dry mouth
- Frequent Thought Patterns:
- * Disbelief
 - * Confusion
 - * Preoccupation with death or deceased
 - * Sense of presence; arms ache to hold infant
 - * Hallucinations: auditory or visual
- Behaviors:
- * Sleep disturbances
 - * Appetite disturbances
 - * Absent-minded behaviors
 - * Social withdrawal
 - * Dreams of the deceased
 - * Avoidance of reminders of deceased
 - * Searching or calling out
 - * Sighing
 - * Restlessness
 - * Crying
 - * Visiting places or carrying objects of the deceased
 - * Treasuring objects that belonged to the infant

When a baby has died, the following questions can help the health professional understand the grief response of the family. The questions acknowledge the unique nature of each family and can also help families identify sources of comfort within their own culture or traditions. The Resource Section of this manual includes more detailed information on the grieving traditions of selected ethnic groups.

- ◆ What in your culture/tradition would be an explanation for your baby's death?
- ◆ What is your belief about what happens when a baby dies?
- ◆ What does your culture/tradition expect of you as a parent of a baby who died?
- ◆ What will be the role of the extended family in this situation?
- ◆ What is the most comforting factor that you derive from your culture/tradition that helps you deal with the baby's death?
- ◆ What is the most troublesome issue for you as a result of your baby's death?
- ◆ What previous experience have you had with the death of a child? How was that event explained? How was it handled?
- ◆ Are there some things that you believe or want to do as a bereaved parent that do not fit into the ways of your traditions?
- ◆ Is there anything I can do to help you?
- ◆ What would be some ways your culture/tradition would encourage you to remember your baby who died?

Responsibilities of Local Health Departments in Response to a Sudden Infant Death

- The local health department is notified of a sudden, unexpected infant death by written correspondence from the SID Network of Ohio.
- A designated public health professional should contact the family as soon as possible, ideally within 24-48 hours of the referral. The nurse/social worker introduces himself/herself and explains the purpose of the contact with an expression of sympathy and offers to arrange a home visit, if possible, to the newly bereaved family. The nurse/social worker should take the initiative in suggesting the date and time of the meeting as even minor decision making is often difficult for families at this time.
- The nurse/social worker should attempt to visit when both parents and any other grieving family members are at home together, if possible.
- During a home visit or by phone contact, the nurse/social worker should provide information about the preliminary diagnosis, the grief process and resources for supportive services.
- The nurse/social worker should provide the family with factual information about the preliminary diagnosis if appropriate, emphasizing that the diagnosis may not yet have been confirmed by the coroner. She/he should make the parents aware the autopsy report can be made available to them; however, it would be advisable for them to review the autopsy with their infant's physician and/or with the coroner or his designee.
- The nurse/social worker should provide information about peer support groups and other support services and should make referrals to appropriate community resources.
- The nurse/social worker should provide referral feedback to the SID Network of Ohio by completing the Infant Death Home Visit Report Form fax or send one copy to:

SID Network of Ohio
421 Graham Rd., Suite H
Cuyahoga Falls, Ohio 44221

Fax: 330-929-0593

- Retain a copy at the local health department.
- If you have questions or need assistance, contact the SID Network at 1-800-477-7437.

Preparation

Assisting a family that has just lost a baby suddenly and unexpectedly can be a difficult task that may be easier with careful preparation and an acceptance that we are all helpless when it comes to the unexpected death of a child. The role of the public health professional responding to a sudden, unexpected infant death requires many skills. The health professional should be knowledgeable about SIDS, empathetic to the family, trained to listen and share information and able to respond to the needs of the family and caregivers. Because these skills can greatly influence the outcome for the family, the nurse/social worker should pay special attention to the following key points:

◆ **Good Understanding of SIDS and Current Research**

Review current SIDS information. The health professional should have the knowledge to explain the facts concerning SIDS to parents or caregivers. This information should be in a language that is easy for them to understand.

◆ **Listening and Supportive Skills**

Ohio Law requires local health departments to provide counseling and referral information about available support systems. Therefore, the health professional should understand the special needs of SID families and assist the families in verbalizing their fears and frustrations. It is important that the health professional realize he/she may stir up uncomfortable emotions (e.g., crying, anger) as a part of allowing families to verbalize their feelings. While the health professional should be able to accept these reactions and use them constructively, he/she also needs to be alert to abnormal or extreme reactions and should not hesitate to contact a mental health professional and make a referral when indicated. The health professional should act as quickly as possible to assist families in coping with their grief.

◆ **Knowledge of the Grieving Process**

The health professional should understand the grieving process and have the ability to recognize and assess the difference between normal and abnormal reactions to grief. The health professional should also have a good understanding of individual differences and socio-cultural expressions of grief. More importantly, the health professional should be able to assess his/her own feelings of grief and separate them from those of the grieving family.

◆ **Knowledge of Referral Services**

The health professional should understand how to respond to the different types of problems these grieving families are experiencing. Therefore, the health professional should be familiar with community resources such as bereavement counselors and support groups, clergy, financial resources, and mental health professionals, if indicated. Bereavement services often focus on the parents, but the needs of others affected by the infant's death should not be overlooked. Bereavement support and factual information should be made available to child care providers, grandparents and siblings as well.

Contacting Families

Personal contact by a knowledgeable, understanding health professional can assist grieving families in coping successfully with the sudden death of their infant. It is the responsibility of the local health department to provide that personal contact to offer bereavement and other supportive services. Every effort should be made to ensure all families are contacted after the sudden, unexpected death of an infant. While a scheduled home visit may be the most effective way for the health professional to assess the family's need and provide information and support, contact can also be made by telephone or by mail.

Initial Contact

The initial contact with the family is usually by telephone. It is important in the initial contact to explain to the family the role of the health professional as a source of support. Offer an expression of sympathy. Use the child's name. Allow the family time to process what is being said to them. The initial contact may follow this script:

“My name is Jane Smith. I am a public health nurse with the local health department. I have just received notification of your son John's death. I am so sorry about your loss. I know that the death was sudden and unexpected. I hope that I can be of some assistance to you and your family by providing you with information and connection to supportive services to help you in the coming days and months. May I schedule a time to visit with you in the next few days?”

Just as the expression of grief varies from family to family, reaction to this initial offer of support will also vary. Rarely will a family graciously accept the intervention at the beginning. More commonly, they will display some type of apprehension and on occasion will become defensive or avoid contact altogether. These reactions are based on a variety of environmental and cultural factors surrounding the issue of death and professional intervention. In many cases not only are these families grieving the death of their child, they are also defending themselves against societal biases. It is important for the health professional to anticipate this initial resistance and maintain an attitude of sympathy and understanding. The family should clearly understand the health profession is not part of any investigation. Emphasize the role of the health professional to provide information and support.

During this initial contact the health professional should be prepared to provide concise answers to questions the parents may ask about the preliminary diagnosis, community resources and bereavement. Encourage the family to allow a home visit, so the health professional can provide more individualized information and assistance.

The Home Visit

Plan at least one hour for the visit. The family's greatest need may be to reflect on their child and the death. The willingness of the health professional to listen as the family verbalizes their loss will help build a supportive relationship. Be prepared to discuss the preliminary diagnosis as well as SIDS and SIDS research. Even though an autopsy may confirm an alternative cause of death, providing this information is crucial in circumventing the guilt of the SIDS family.

Initially, parents may not be ready to discuss or utilize information on local support resources. The health professional may schedule a second visit at a later time to discuss support options and to follow up with the family. Grieving parents will not be able to retain many of the details that are spoken to them. By providing a folder with written information about SIDS and local support services, parents are able to review information as they feel comfortable. Always include contact information for the health professional making the visit.

Special Considerations

Occasionally, a family member will experience a severe reaction, which will require professional mental health intervention. The health professional should assess for severe grief reactions, noting the following:

- Inability to return to a daily routine several months following the death
- Auditory and visual hallucinations
- Suicidal ideations
- Parental neglect or extreme over protection of other children
- Marked increase in the use of alcohol, drugs or tobacco
- Hostile or aggressive behavior

Review the local crisis intervention plan before the visit and be prepared to facilitate referrals.

Regardless of the family living situation prior to the infant's death, the health professional should assess the needs of each parent. When possible schedule the home visit when both parents can be present. If it is not possible to meet with each parent, inquire about the absent parent's need for information and support and leave duplicate information packets for the absent parent.

The health professional should also assess the needs of other family members such as grandparents and siblings. Information and support services should be provided for them as needed. Day care providers are often deeply affected by a SIDS death, especially if the death occurred while the infant was in their care. If the family is unwilling to share day care provider information, the coroner's office can provide contact information.

Follow-up

Parents may experience intense feelings of grief and sadness for a year or longer after the sudden death of their infant. Informal support systems often break down within a couple of months as friends and relatives move on with their lives, not understanding the lingering process of grief for the parents. Therefore, the health professional should continue to provide reminders throughout the first year that supportive services are available at any time. These reminders may be in the form of letters, cards or telephone calls. The anniversary of the child's death and the child's first birthday may be especially difficult times for the family and they may appreciate contact. Do not worry that such contact will bring up sad memories for the parents. They have not forgotten their baby and they will be happy to know others have also not forgotten.

Provide referral feedback to the SID Network of Ohio, using the Infant Death Home Visit Report Form to document contact with the family, whether by mail, telephone or personal visit. The Infant Death Home Visit Report Form can be found in the Appendix, downloaded from the ODH

Web site at <http://www.odh.ohio.gov> or obtained directly from the SID Network by calling 1-800-477-7437. The purpose of the form is to document contact with the family in response to the referral from the SID Network. Fill in all sections as completely as possible from information learned from the death certificate and from the interaction with the family. Use the form to document the discussion. The form should not be the focus of the discussion. Remember that the purpose of the home visit is to provide information and bereavement support to the family, not to gather information. Retain a copy of the form for your records. Fax or send a copy to:

SID Network of Ohio
421 Graham Rd., Suite H
Cuyahoga Falls, Ohio 44221

Fax: 330-929-0593

Suggestions for Helping Grieving Families

Do:

- Do listen quietly, allow them to express their feelings and tell their story without passing judgment.
- Do refer to the baby by name and ask about the child's special endearing qualities.
- Do offer your condolences and ask about the funeral or memorial service.
- Do ask about other family members and include significant others in your home visit.
- Do give special attention to siblings. They are hurting and confused. Their parents may be incapable of being very supportive at this time. Consider a social service consult for a sibling in crisis.
- Do reassure parents that they did everything they could, that the medical care their child received was the best or whatever else you know to be true or positive about the care given to their child.
- Do encourage parents to talk freely about their feelings and to be honest about what kind of help they really want from others.
- Do encourage family members to be patient with their own grieving process.
- Do answer their questions and refer them to the appropriate local support/counseling providers.
- Do call them again after your initial visit and let them know you are thinking about them.
- Do remember them with a note or phone call on special occasions; birthday, death anniversary and holidays.
- Do remember that every ethnic and cultural group has unique expressions of grief.

Don't:

- Don't ask one question after another without a break.
- Don't use clichés.
 - "I know how you feel."
 - "At least you have other children."
 - "You can always have another baby."
- Don't pass judgment.
- Don't answer a question if you do not know the answer.
- Don't give legal or medical advice.
- Don't make comments that suggest the care given to the child was inadequate.
- Don't assume that their grieving is over in a few weeks or months. They may need ongoing support for at least a year.
- Don't try to find something positive such as a moral lesson or closer family ties because of the child's death. The family will come to this realization on their own, if or when it occurs.
- Don't talk only with mothers. Include fathers, children, grandparents, significant others.
- Don't assume you know what the family needs. Everyone's needs and desires are different. Be sure the kindness you plan is acceptable.

Questions to Facilitate Conversation with Families

How did the baby seem to you the week or so before his death?

This may bring forth a history of respiratory or other minor illness. There may be guilt feelings if the infant was not taken to the doctor. If a doctor treated the child, the parents may blame the doctor for what they feel is inadequate treatment. The nurse should take this opportunity to reassure the family that there is nothing that could have been detected or done to prevent the death, even by a doctor.

Can you tell what happened? (Time of last feeding? When put down? Was the baby in a crib, bed, etc? What position placed in? When found?)

This may bring forth feelings of guilt about propping the bottle, not having checked often enough, putting the baby on his tummy, finding the baby with covers over his head, etc. Reassurance must be given that babies do not normally choke to death on a bottle in bed, no matter what the placement of the bottle or position of the baby. Checking a baby will not prevent a death of this type.

Had you heard of SIDS or “crib death” before?

This will give the nurse an idea of how much information is needed. The response also may provide the nurse with clues as to how much misinformation the family has received and from what sources.

Does your partner understand SIDS? (When interviewing only one parent.)

This may bring out differences in adjustment or the problem of one partner blaming another. Individuals often express themselves differently and communication problems may develop. Men and women deal with grief differently.

Do your relatives and friends understand what SIDS is? Who is providing the most support? Who, if anyone, is most difficult to talk to about the death?

This will provide a picture of how much help is available from those who are close to the family. Those who care most for the family make often disturbing comments out of ignorance. If these can be ferreted out, dealt with and accurate information passed on to the offenders, much family turmoil will be avoided. An understanding and informed extended family could be of great help.

Have you experienced other tragedies in your life prior to the death of your baby? Were there any deaths among your family or friends that were sudden and unexpected?

Discussion of their previous experiences with crises can provide information that may be helpful in determining how the family copes in a stressful situation.

Questions the Family Might Ask

What causes SIDS?

The exact cause or causes of SIDS are yet unknown by medical science. Much promising research currently is being done in the areas of immunology, infection, neurology and in the mechanisms that regulate the heart and respiration. Researchers are particularly interested in possible abnormalities in the baby's ability to regulate breathing during periods of sleep.

Do these deaths always occur at night?

Studies have shown that the majority of SIDS deaths occur at night or at naptime, when the baby is sleeping. However, SIDS has occurred at other times.

Do these deaths always occur during sleep?

SIDS almost always occurs unobserved while the baby is sleeping.

Are all infants found on their tummies?

No. Infants have died in many different positions - on their tummies, sides and backs. Most SIDS infants do die on their tummies or sides.

What causes blotches on the infants face when found face down? (Does not happen in all SIDS cases).

Gravity causes blood to pool after death, causing discolored blotches.

What causes the baby's face to be turned down into the mattress? (Does not happen in all SIDS cases).

This occurs frequently when the baby has been sleeping on his/her tummy. This position also can result from the body having normal muscle spasms following the death. In addition, blankets often are found pulled over the baby's head.

How do you know if the death wasn't suffocation?

Studies have been done which prove babies do not suffocate in ordinary bedclothes. The changes at autopsy in babies whose faces were uncovered in the crib were identical to those babies whose faces were covered by bedding.

What caused blood around the baby's nose and mouth? (Does not happen in all SIDS cases).

This is found frequently and results from drainage of fluid from the lungs, which occurs as a result of post-death muscle relaxation. Tiny pinpoint hemorrhages occur in the lungs in SIDS and these can discolor the lung fluid that drains out after death.

Could he/she have cried and I not heard him/her?

No. In interviewing hundreds of families, many slept in the same room with their infants, often with the bassinet right next to the parents' bed. Even some have been holding their sleeping infant when SIDS struck. However, no one has reported hearing any sound at all at the time of death.

Did my baby suffer?

Evidence indicates that a SIDS death occurs quickly, with no sound and with no struggle. Infants appear to fall asleep, then just stop breathing. In some cases, infants have been found in unusual positions or with bedclothes in disarray. This occurrence is attributed to normal muscle spasms, which occur in the baby following death, rather than due to a struggle.

Does this occur more often in low-income families?

Yes. The rate is higher in low-income families living in crowded conditions. However, SIDS does occur in middle- and high-income groups.

Why was an autopsy done?

An autopsy is done to try to answer questions parents have about how and why the baby died. Because little is known about the nature of SIDS, an autopsy is currently the only way to validate a SIDS diagnosis. An autopsy can rule out all other possible causes of sudden death in infants.

SIDS parents have reported receiving autopsy results as to how their child died was one of the most effective therapeutic measures in coping with their loss. Having concrete information from medical-legal authorities reinforcing the fact that their child's death was neither predictable nor preventable helped them greatly in resolving the feelings of guilt and/or blame. As they worked through their doubts and suspicions, they could fall back upon the autopsy findings for comfort.

Prior to the mandatory autopsy law in Ohio, parents did not have the benefit of autopsy results, whether because an autopsy was not available or because they had objected to one. Without the autopsy results parents had a more difficult time coming to terms with tormenting feelings of guilt and/or blame because they did not have the support of factual, absolving information.

What about having another baby? Can this happen again? How long should we wait?

Current research shows that the risk of having another SIDS baby is no greater than it was the first time. There is less than one SIDS death per 1,000 live births in Ohio. SIDS has been known to happen more than once in a family, but those cases are extremely rare.

The family should not be discouraged from having another baby. They should only do so when they feel they are ready and provided their physician feels there are no contraindications. Information on this topic can be obtained from the SID Network of Ohio (1-800-477-7437).

How will I survive raising another child?

Some mothers may already be pregnant at the time of the baby's death; others will have the option of waiting to have another child when they feel they are ready.

For those parents who do have another baby, there is a tendency to be overprotective. However, it is unrealistic and physically and emotionally draining to attempt to keep a 24-hour vigil over the new baby.

There will be many uneasy moments, but parents need to relax and concentrate on developing a new relationship with this baby. Usually, after this baby passes the age of the baby who died,

parents will become much less anxious and will be able to settle into a comfortable routine. Talking to another SIDS parent who has had a subsequent child may be helpful and supportive.

Do you know of other parents whose baby died in this way? Can you help me locate a parent who would be willing to talk with me?

The SID Network of Ohio may be contacted for this service. This organization exists primarily to assist bereaved families and to help increase the awareness of SIDS among public and professional groups. There are many other organizations that offer support to families experiencing death from SIDS and other causes. These include, but are not limited to, Share and Compassionate Friends. A chapter may or may not exist in your area. The SID Network of Ohio can help in making referrals for those families who might be interested in participating in any of these groups. Some parents may not be interested in participating in a group, but may want to make themselves available for contact with another SIDS parent.

Common Obstacles to Bereavement Home Visit

Issues	Concerns	Practical Solutions
Another nurse has been working with the family on other issues.	Family may be more comfortable with a familiar face at this time of crisis.	Contact other nurse, coordinate services and make joint visits.
The parents are divorced, separated, not together or having relationship issues.	May not be able to visit and assist them together.	Set up separate appointments or have a second nurse on case to maintain confidentiality.
		Notify SID Network of Ohio to send each parent a SID Informational Packet.
		Focus on each individual's grieving needs.
The family refuses a visit.	Family may be in crisis and not receiving support.	If willing, link the family to a local support group.
		Provide information by phone. Send or deliver a packet of information.
Other mental or health issues are discovered during the interview.	Nurse may not have experience or qualifications to properly deal with the issue.	Refer to appropriate program or health professional.
Family disappears.	Family may be in crisis and not receiving support.	The local coroner's office or the SID Network may have more recent contact information for the family.
Death occurs in child care/foster care.	Two families in crisis.	Provide services, education and information to both families.
	Two nurses may be involved with the case.	Contact other nurse, coordinate services and make joint visits.
	Family may be in one county and the child care provider in another.	Contact the SID Network of Ohio.
	Are there issues between the family and the child care provider?	Provide education and support for both.
		Visit the child care provider when other children in her care will not distract her from your visit. Know the phone numbers of local agencies; set up communication and coordination with those professionals already servicing the family.
Parent(s) lack resources for the funeral or other expenses connected with the death.	Money worries may interfere with them benefiting from your visit.	Social Services may provide funds for low-income families.
	Family may need to be prepared that donated services will only cover costs for basic services.	Check with local funeral homes to find out about programs for low-income families (some have them).
		Other options for assistance are local churches, service clubs and crisis programs. Some may have programs or will make contributions to needy families.

Taking Care of Yourself

When a health professional helps others experiencing death, it is a startling reminder of one's own mortality. Even when dealing with the expected death of an elderly client, we are reminded that life is uncertain and it eventually comes to an end. When a baby dies, it is a shock. Our expectations are that babies are not supposed to die. They are supposed to grow, develop and have a life expectancy of 70-plus years.

When responding to the sudden and unexpected death of a baby, the health professional must also be prepared to experience the grieving process, including the entire spectrum of physical and emotional reactions.

Helping grieving families can leave the health professional feeling exhausted, overwhelmed and helpless. It is not unusual for health professionals to feel depressed, fatigued, have appetite changes and have difficulty sleeping. The health professional must be able to recognize and deal with their own unique reaction to the death.

If the health professional does not acknowledge the impact of grief and learn to restore themselves, they may be hindered in their ability to give council or compassionate care in future grief situations. If unresolved, grief feelings can spill over into other areas of their lives, even to the extent of affecting relationships within their own family. Advocating for oneself can ensure the health professional will be able to advocate for future clients as well as safeguard their own well-being.

Others have found the following suggestions helpful in dealing with the intensity of grief:

- ◆ Most importantly, acknowledge your personal feelings of grief.
- ◆ Allow yourself to grieve.
- ◆ Have a support person with whom you can share your feelings.
- ◆ Contact other health professionals who have had similar experiences for support, advice and understanding. See <http://www.odh.ohio.gov/localHealthDistricts/localHealthDistricts.aspx>.
- ◆ Seek out a workshop to learn more about grief resolution.
- ◆ Take part in life-affirming activities such as walking, cooking and gardening. Look at sunsets, works of art, nature. Listen to music, birds and rain.
- ◆ Avoid using drugs and alcohol to numb feelings.
- ◆ Keep a journal.
- ◆ Pray. Rely upon your own personal religious beliefs or spirituality.
- ◆ Do something for others. Adopt a pet.
- ◆ Rest, eat regular, well-balanced meals and exercise.
- ◆ Give yourself a treat. Get a manicure, take a bubble bath and go shopping.
- ◆ Use humor and laugh.
- ◆ Use the Employee Assistance Program as needed.
- ◆ Remain committed. Recognize your work as valuable.
- ◆ Evaluate what you did well in the situation and what you could have done better.
- ◆ Be knowledgeable about SIDS, other sudden infant deaths, and the grieving process.
- ◆ Attend the seminars and workshops; read journals and books.
- ◆ Keep a grief notebook with relevant journal articles, newspaper clippings and resources.
- ◆ Stay in touch with the family by telephone or by sending a card.

Risk Reduction Factors

While the cause and mechanism of SIDS eludes researchers, several factors appear to put an infant at higher risk for SIDS. These factors do not cause SIDS but the presence of these factors increases the risk of SIDS. By eliminating or reducing the factors, the risk of the baby dying of SIDS is reduced. Public health professionals have an important role in educating parents and the public about the risk factors and ways to eliminate or reduce them.

“Back to Sleep”

In 1992 the American Academy of Pediatrics (AAP) released a recommendation that healthy infants should be placed to sleep on their sides or backs to reduce the risk of SIDS. In 1994 a coalition of public and private organizations launched a national public education campaign, “Back to Sleep,” recommending infants be placed on their backs or sides to sleep. Based on research findings, both the AAP and “Back to Sleep” campaign revised the recommendations in 1996 to state that the back is the safest sleep position. The AAP no longer recognizes side sleeping as a safe alternative to back sleeping. According to Ohio Vital Statistics, the Ohio SIDS rate has decreased by two-thirds in the last decade, from 1.5 deaths per 1,000 live births in 1992 to 0.5 in 2003.

While most new mothers acknowledge having received the “Back to Sleep” message, many still place their babies on their stomach for sleep, citing cultural influences, advice from relatives and a perception that the baby sleeps better on their stomach.

Infants accustomed to sleeping on their backs appear to be particularly vulnerable to SIDS when they are placed on their stomachs for sleep the first time. This situation can occur when a back-sleeping baby is left with a caregiver who is unfamiliar with the “Back to Sleep” message. According to AAP research, about 20 percent of SIDS deaths occur in child care settings. Parents must be sure babysitters, grandparents and other family and friends who might care for the baby are aware and will comply with putting the baby on the back for sleep.

Safe Sleep Space

Accidental suffocation is difficult to distinguish from SIDS because autopsy findings may be similar and the age of greatest risk overlaps. Providing a safe sleep space for infants reduces the risk of both causes of death. Ohio Child Fatality Review (CFR) reports only 31 percent of the 107 SIDS deaths in 2003 occurred in a crib or playpen. Sleep surfaces such as chairs, sofas, adult beds, waterbeds and futons are particularly dangerous for infants. Cribs should be safety approved, with a firm, flat mattress covered by a tight-fitting sheet. The crib should be free of soft, fluffy materials such as bumper pads, sheepskins, comforters, pillows and stuffed animals. Sleep sacks or blanket sleepers can be used to eliminate the need for additional loose blankets. Educating parents about the dangers of soft, fluffy bedding is a challenge with the marketing of elaborate crib sets and nursery décor.

The risk for SIDS and accidental suffocation is lower when infants do not share a sleep surface. According to Ohio CFR, in 2003, 43 percent of infants who died of SIDS before age 3 months were sleeping with someone else at the time of death. While mothers and infants sleeping

together is widely practiced throughout the world, characteristics of the bed and bedding as well as the number of people sharing the bed create a potential for entrapment and overheating that greatly increases the risk of SIDS. Research has shown that if an infant is sleeping in the same room with the mother but on a separate sleep surface (crib or bassinet), the risk for SIDS is reduced. In a policy statement released in 2005, the AAP describes the hazards of bedsharing and recommends that babies sleep in a crib placed in the parents' bedroom.

Elimination of Second-hand Smoke

According to the National Institute of Health, maternal cigarette smoking during pregnancy increases the risk of SIDS about threefold, independent of the birthweight of the baby. Increased risk of SIDS has also been demonstrated when babies are exposed to cigarette smoke after birth. At least 47 percent of the SIDS deaths reviewed by Ohio CFR involved cigarette smoke in utero or after birth. Strategies to help parents eliminate smoking can improve the health of the whole family.

Maintaining Even Temperature

Recent laboratory research on SIDS has focused on microscopic brain abnormalities that affect the development and control of breathing, blood pressure, temperature regulation and sleep and arousal reflexes. Overheating may hinder the development of the autonomic nervous system and its ability to regulate many of the responses necessary to maintain life. As a general rule, babies should be dressed in the same number of layers as their adult caregivers. Elevated room temperatures are not necessary for babies. Excessive layers of clothing and blankets increase the risk of overheating and SIDS.

Breastfeeding

Research has not been able to directly link breastfeeding with a reduction in the risk of SIDS, but the health advantages of breastfeeding include the protective effect on the immune system are well documented. Efforts to encourage the initiation and continuation of breastfeeding throughout the first year of life may result in a reduction in infant mortality and in SIDS.

Pacifiers

Although the mechanism is not known, the reduced risk of SIDS associated with pacifier use during sleep has been demonstrated in numerous research studies. The 2005 AAP policy statement recommends babies be offered pacifiers at sleep time. Pacifier introduction should be delayed until 1 month of age for breastfeeding infants.

Prenatal Care

Case-control studies have identified late or no prenatal care as increasing the risk for SIDS. The risk of SIDS increases with decreasing birthweight and decreasing gestational age. Mothers who receive early and adequate prenatal care have the best chance for having a healthy baby.

References:

AAP, Task Force on Sudden Infant Death Syndrome. Policy Statement. *Pediatrics* 2005; 116:1245-1255. <http://pediatrics.aappublications.org/cgi/content/full/peds.2005-1499v1>

National SIDS/Infant Death Resource Center (NSIDRC). "What Is SIDS?" <http://www.sidscenter.org/Downloads/SIDS-English.pdf>

Community and Individual Interventions

Public health professionals are in an ideal position to have a positive impact on reducing the risk for SIDS by both community and individual interventions. By mobilizing community partnerships, the public health professional can identify influential stakeholders and increase their awareness of SIDS and the risk factors. Public health professionals can facilitate partnerships among groups not typically considered to be health related such as faith-based organizations, to expand outreach for risk-reduction messages and support groups. Health education and health promotion program partnerships with schools, faith communities, work sites, child care providers and others can target the risk-reduction messages to vulnerable populations. Through individual encounters, the health professional can inform, educate and empower clients about SIDS and risk reduction methods.

The SID Network of Ohio can provide technical assistance and material resources to help in community and individual intervention programs. Some recent activities of the SID Network include:

- ◆ SIDS awareness media campaigns.
- ◆ Community baby showers and baby fairs.
- ◆ Community outreach forums for organizations, clubs and churches.
- ◆ SIDS newsletter.
- ◆ Training for child care workers, migrant outreach workers and first responders.
- ◆ Training for health professionals.
- ◆ Training for community leaders on promoting safe sleep within their communities.
- ◆ Crib programs that provide safe cribs for needy families.
- ◆ New Web site at <http://www.sidsohio.org>.

The SID Network has also been involved in risk-reduction outreach specifically addressing the racial disparity in SIDS death rates. Health summits have been held in all major Ohio cities to build partnerships with African-American women leaders, educating and empowering them to repeat the risk-reduction message throughout their communities. Culturally appropriate “Back to Sleep” training kits are available with materials and curricula for community presentations to groups of any size.

Opportunities to provide risk-reduction messages can be incorporated into the regular workflow of the local health department. Accurate, consistent, culturally appropriate education materials can be made available at any client contact point such as perinatal, well-baby and immunization clinics, as well as WIC, Help Me Grow and Vital Statistics. In addition to the resources and materials available from the SID Network and from many of the organizations listed in this manual, the simple, one-page flyer on page 34 can be duplicated.

Reducing the Risk of SIDS

1. Place infant on his or her back for every sleep



2. Provide a smoke-free environment



3. Receive early and regular prenatal care



4. Breastfeed



5. Use tight, firm-fitting mattress in a safety-approved crib in the same room, placed close to parents' bed



6. Avoid soft adult sleeping surfaces such as couches or recliners



7. Use a sleep sack instead of blankets



8. Do not overdress an infant or keep the temperature too high

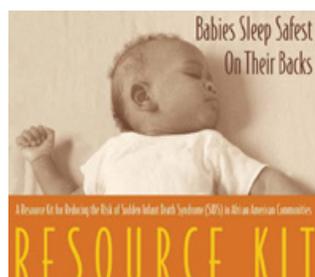


9. Offer a pacifier at sleep time



Resource Materials for Risk Reduction

There are many printed resources on risk reduction for SIDS available. Many of these resources are aimed at specific populations such as African Americans, grandparents or child care workers. Materials are available in Spanish and other languages. The resources shown below are just a few available free in limited quantities from the National Institute for Child Health and Human Development at <http://www.nichd.nih.gov/publications/pubskey.cfm?from=sids>. An order form is included in the appendix of this manual. The SID Network also has a variety of materials available for individuals and groups.



Babies Sleep Safest on Their Backs: A Resource Kit for Reducing SIDS in African American Communities (Includes training modules, background material on SIDS, resources, 10 brochures, 10 magnets, and 1 video) This information kit, part of the *Back to Sleep* campaign, includes materials and resources for conducting community-based training sessions on ways to reduce the risks of sudden infant death syndrome (SIDS) in African American communities.



Back to Sleep Easel—Stand up Display for Back to Sleep Brochures

This standing poster allows for countertop or table top display of *Back to Sleep* brochures.



Dormir Boca Arriba Sticker

Este adhesivo muestra el logotipo de la campaña “Dormir Boca Arriba” e indica donde se puede obtener más información.



Back to Sleep Refrigerator Magnet – African American Outreach

This refrigerator magnet, part of the *Back to Sleep* campaign, lists seven key ways parents and caregivers can reduce the risk of sudden infant death syndrome (SIDS) in African American infants.



Safe Sleep for Your Baby: Reduce the Risk of Sudden Infant Death Syndrome (SIDS)—General Outreach

This brochure, part of the *Back to Sleep* campaign, explains ways parents and caregivers can reduce the risks of sudden infant death syndrome (SIDS). Three versions of the brochure are available (General Outreach, African American Outreach, and Spanish Outreach).

Ohio Department of Health Notification of Infant Death

Infant's Name Last			First	Middle	Date of Birth		Date of Death			
Gender	Age	Hispanic Ethnicity	Race (Check all that apply)							
<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> White <input type="checkbox"/> Black / African American <input type="checkbox"/> American Indian / Alaskan Native <input type="checkbox"/> Hawaiian Native / Pacific Islander		<input type="checkbox"/> Asian <input type="checkbox"/> Unknown <input type="checkbox"/> Other _____					
County of Death			County of Residence		County of Autopsy					
Father's Name Last		First	Middle	Area Code and Phone Number			Age			
Residence	Street Address			City		State	Zip			
Mother's Name Last		First	Middle	Area Code and Phone Number			Age			
Residence	Street Address			City		State	Zip			
<p>The Preliminary diagnosis of this death is:</p> <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; vertical-align: top;"> <input type="checkbox"/> SIDS <input type="checkbox"/> Unintentional Injury / Accident <input type="checkbox"/> Undetermined (Natural) <input type="checkbox"/> Other (Please Explain) </td> <td style="width: 50%; vertical-align: top;"> <input type="checkbox"/> Undiagnosed Disease / Natural <input type="checkbox"/> Inflicted Injury / Homicide <input type="checkbox"/> Undetermined (Not Natural) <input type="checkbox"/> Circumstances dictate that ____ NO contact with the family should be made until Final Diagnosis </td> </tr> </table>									<input type="checkbox"/> SIDS <input type="checkbox"/> Unintentional Injury / Accident <input type="checkbox"/> Undetermined (Natural) <input type="checkbox"/> Other (Please Explain)	<input type="checkbox"/> Undiagnosed Disease / Natural <input type="checkbox"/> Inflicted Injury / Homicide <input type="checkbox"/> Undetermined (Not Natural) <input type="checkbox"/> Circumstances dictate that ____ NO contact with the family should be made until Final Diagnosis
<input type="checkbox"/> SIDS <input type="checkbox"/> Unintentional Injury / Accident <input type="checkbox"/> Undetermined (Natural) <input type="checkbox"/> Other (Please Explain)	<input type="checkbox"/> Undiagnosed Disease / Natural <input type="checkbox"/> Inflicted Injury / Homicide <input type="checkbox"/> Undetermined (Not Natural) <input type="checkbox"/> Circumstances dictate that ____ NO contact with the family should be made until Final Diagnosis									
Form Completed by: Area Code and Phone Number: County:										

Please send this report to:

SID Network of Ohio
 421 Graham Road, Suite H
 Cuyahoga Falls, OH 44221
 or Fax (330) 929-0593

If you have questions regarding this form, please call Leslie Redd at (800)-477-7437

Ohio Department of Health Final Diagnosis of Infant Death

Infant's Name Last			First	Middle	Date of Birth	Date of Death
Gender	Age	Hispanic Ethnicity	Race (Check all that apply)			
<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown		<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> White <input type="checkbox"/> Black / African American <input type="checkbox"/> American Indian / Alaskan Native <input type="checkbox"/> Hawaiian Native / Pacific Islander	<input type="checkbox"/> Asian <input type="checkbox"/> Unknown <input type="checkbox"/> Other _____		
County of Death			County of Residence		County of Autopsy	
Parents' Name			Address		City	State
Final Diagnosis						
Part I. Enter the diseases, injuries or complications that caused the death. Do not enter the mode of dying, such as cardiac or respiratory arrest, shock or heart failure. List only one cause on each line. Type or print in permanent black ink.						
Cause of Death					Approximate Interval between Onset and Death	
Immediate Cause (Final disease or condition resulting in death)			A.			
Sequentially list conditions, if any, leading to the immediate cause			B.			
			C.			
Enter underlying cause last (Disease or injury that initiated events resulting in death)			D.			
Part II. Please list other significant conditions contributing to death but not resulting in the underlying cause given in Part I.						
Was an autopsy performed? <input type="checkbox"/> Yes <input type="checkbox"/> No						
Were autopsy findings available prior to completion of cause of death? <input type="checkbox"/> Yes <input type="checkbox"/> No						
Manner of death: <input type="checkbox"/> Natural <input type="checkbox"/> Accident <input type="checkbox"/> Homicide <input type="checkbox"/> Could not be determined						
Comments:						
Form Completed by: Area Code and Phone Number: County:						

Please send this report to:
 SID Network of Ohio 421
 Graham Road, Suite H
 Cuyahoga Falls, OH 44221
 or Fax (330)929-0593

If you have questions regarding this form, please call Leslie Redd at (800)-477-7437

Ohio Department of Health • Sudden Infant Death Program
Infant Death Home Visit Report

Section A: Demographic Information

Infant's name Last		First		Middle initial	Sex Male Female	Date of birth (DOB) //
Date of death //	Date notified of death //	Gestational age in weeks	Ethnicity White Black, African American	Native American	Hawaiian or other Pacific Islander Indian or Alaska Native	Asian Unknown
Place of birth (Hospital)			City	State	Birthweight lbs _____ ozs _____ or grams _____	

Section B: Parent Information

Mother's name Last		first		middle initial maiden		Age	Telephone ()
Address		City	State	ZIP		County	
Father's name last		First		Middle initial	Age	Telephone ()	
Address		City	State	ZIP		County	

Section C: Death Information

Place of death-Street address		City	State	ZIP	County
Who found the infant? Name		Relation	Phone ()		Household information Number of adults Number of children
Tentative Diagnosis at Pronouncement SIDS None Unknown Other (specify)			Final (Death Certificate) diagnosis SIDS Pending Other (specify)		
Other SIDS deaths in family? Yes No Unknown		If other SIDS death Name		Relation	
Position of infant at discovery On stomach, face down On back On side On stomach, face to side Unknown			Location of infant when found Crib Playpen Couch Floor Other Bed Unknown Other, specify _____		
Illness in the 2 weeks prior to death Yes, specify illness No Unknown			Infant sleeping with others Yes, specify whom No Unknown		
Infant sleeping alone Yes No Unknown		Secondhand cigarette exposure Yes No Unknown		Overheating Yes No Unknown	

Section D: Home Visit Information

Date of first contact with family / /	Contact type Phone In person Letter Other Unable to contact			Date of home visit / /	Duration of home visit (in minutes)
Were any of the following helpful or supportive?					
Rescue Squad	Yes	No	N/A	Police	Yes No N/A
Clergy	Yes	No	N/A	Funeral Director	Yes No N/A
Other (specify)					
Did you or anyone else:					
a. Provide the family with written information about SIDS, other causes of death or bereavement?			Yes	No	Unknown
b. Inform the family about supportive services?			Yes	No	Unknown
c. Which referrals to community resources were made? No referrals made					
			1)	2)	
			3)	4)	

Section E: Contact Information For Person Completing Report

Name	Agency		Telephone ()	Date / /
Address	City	State	ZIP	County

Sample Letter to Family

This template can be used to make initial contact with a family when you have not been able to reach them by telephone. Use your agency letterhead, and personalize it so it does not seem like a form letter.

Date

Parent(s) Name

Address

City, State, Zip

Dear (Name of Parent(s)),

I am writing to you on behalf of the (name of) Health Department, to express my deepest sympathy and concern on the recent death of your son/daughter (baby's name). I have been notified that (name of baby) died suddenly and unexpectedly. This must be an extremely difficult time for you and your family members.

I would like to offer you my support and help. I am available to help you search out the answers to your many questions. I would like to put you in touch with other parents (or child care providers, etc.) who have lost their baby as well. It can be very comforting to talk to other people who have gone through the same experience as you are going through now.

The Sudden Infant Death Network of Ohio may have already contacted you. They will be sending you some grief-related literature and offering referrals to supportive agencies. Hopefully this information will better assist you in your grieving process. I will be calling you soon to arrange an appointment to see you. In the meantime, please feel free to call me at (phone number) if you would like more information or have questions.

Sincerely,



0261

0164

0263



0170



0258

Back

0259

Front

0260

Front



0234

0166



0157



0269



0159

The *Back to Sleep* campaign is coordinated by the National Institute of Child Health and Human Development (NICHD), part of the National Institutes of Health, at the U.S. Department of Health and Human Services.

Back to Sleep Order Form

Free Campaign Materials

Item Description	Item No.	Quantity
Safe Sleep for Your Baby This 8-panel brochure lists the risks for SIDS and explains ways to reduce the risk. For all caregivers. (2003)	General Outreach: 0261	
	African American Outreach: 0164	
	Spanish Outreach: 0263	
Pongo al Bebé Dormir Boca Arriba: Reduzca el Riesgo del Síndrome de Muerte Súbita del Bebé Tearpad Single-page Spanish-language information sheet explains ways to reduce the risk of SIDS and shows a safe sleep environment. Each tearpad has 50 sheets. (2002) Coming soon in English!	0234	
Babies Sleep Safest on Their Backs: A Resource Kit for Reducing SIDS in African American Communities Includes materials for community-based training sessions, 15-, 30-, and 60-minute training modules, background material on SIDS, resources, 10 brochure and magnets, and 1 video. Limit 10. (2000)	0170	
Reduce the Risk of SIDS Magnet 4 inch x 6 inch; lists ways to reduce the risk of SIDS. (2000)	0166	
Infant Sleep Position and SIDS: Questions and Answers for Health Care Professionals This 11-page booklet answers frequently asked questions about SIDS, ways to reduce the risk of SIDS, safe sleep environment, and research on SIDS. For health care professionals. (2003)	0157	
Back to Sleep Logo Sticker 3 inch x 3 inch (2003)	English: 0159	
	Spanish: 0269	
Please Put Me on My Back to Sleep Door Hangers Front illustrates safe sleep environment; back lists ways to reduce the risk of SIDS. (2003)	General Outreach: 0258	
	African American Outreach: 0259	
	Spanish Outreach: 0260	
SIDS A Video on Helping to Reduce the Risk 4-minute segment; demonstrates safe sleep position; loops for 1 hour. VHS. (1996)	English: 0163	
	Spanish: 0241	
Make a Difference—Help Reduce the Risk of SIDS 7-minute multi-cultural video; loops for 1 hour. VHS. (1999)	0242	
Back to Sleep Order Form	0305	

To Order Free Materials:

Fax: 301-984-1473 Phone: 1-800-505-CRIB Mail: P.O. Box 3006, Rockville, MD 20847

E-mail: NICHDInformationResourceCenter@mail.nih.gov

Internet: <http://www.nichd.nih.gov/SIDS>

Name: _____

Organization/Title: _____

Address: _____

Telephone: _____ E-mail: _____

Child Fatality Review

Child Fatality Review (CFR) is a process for the in-depth review of the circumstances and contributing factors of child death. The purpose is to reduce the incidence of child deaths, including SIDS.

In 2000, Ohio law mandated that all counties establish CFR boards to examine all deaths of children under age 18 years. Board members consist of designees from the county coroner, sheriff or police, children's service agency, public health services mental health services, and a pediatrician or family-practice physician. Causes and circumstances of children's deaths are reviewed to determine if the death was preventable, to identify risk factors and to develop preventive strategies.

Since CFR began collecting data in Ohio, the findings have confirmed the risk of exposure to cigarette smoke; soft, fluffy bedding; infants sleeping on surfaces other than cribs; and bedsharing. CFR boards have made many recommendations for the continued repetition of the "Back to Sleep" message, especially targeting minority families, grandparents and caregivers. Many boards have made recommendations to broaden the message to include "Back to Sleep" in a safe sleep environment.

Recommendations become initiatives only when resources, priorities and authority converge to make changes happen. CFR boards are continually seeking partners to carry out SIDS risk-reduction initiatives in local communities.

Because CFR boards seek to understand the circumstances of each child death, the health professional making a bereavement visit after a SIDS death may be asked to provide information to the CFR board for review. Ohio law requires any individual or agency that provided services to a child or family whose death is being reviewed must provide a summary to the CFR board upon request. All statements and records provided to the CFR are strictly confidential.

For questions regarding the role of the health professional in CFR, please contact the Ohio CFR Coordinator, Merrily Wholf, RN, MPH, at 614-728-0773.

For more information about CFR and to view annual CFR reports, visit <http://www.odh.ohio.gov>.

Ethnic & Religious Expressions of Grief					
Ethnic Group	Religion	Religious Attitude	Grief Expression	Death Rituals	Resource for Support
African Americans	Baptist, Methodist, Episcopal, Roman Catholic, Congregational and more recently Muslim and Pentecostal	Commonly recognized western concept of heaven/hell Deceased do not watch over earth things	Very expressive, especially Pentecostal	Funeral rite in church is common Also a more informal gathering includes prayers, scripture reading, songs and crying Usually have a ground burial but occasionally cremation	Minister, family and friends Strong family kinship that usually includes extended family
Amish	Christian	Afterlife is considered a blessing. God is in control of all things, so whatever happens is part of God's plan. Children who die go to heaven, as they are still pure	Excessive display of grieving may be seen as a weakness of faith	The body is usually embalmed by a mortician, but the family bathes and dresses the body, usually in white. The funeral rite is usually held at home three days after death. Simple wood coffin; no flowers	Faith is central to how life events are viewed. Close-knit communities and families

Ethnic Group	Religion	Religious Attitude	Grief Expression	Death Rituals	Resource for Support
Chinese	Older are Buddha or Confucian Younger may be Christians	Whole family goes to make funeral arrangements	Both men and women express great emotion with loud crying and outbursts	Family elders determine the “right day” for the burial, usually between a day and a week Family has great concern for the image and body of deceased	Families and community
Greek	Greek Orthodox	Death is always considered a tragedy	Emotions are expressed very openly	Service is held in church and then to cemetery Prayer services held on ninth and fortieth day after burial	Family, friends and priest
Haitians	Roman Catholic	Very open expressions of grief with crying and wailing	Children of all ages will attend Ground burial is usual and all stay until coffin is covered	A wake and funeral service are held Older Haitians may be shipped back to Haiti for burial Much attention is paid to clothing	Strong family and friend kinship A unifying event that brings many together, even from great distances The welfare of remaining members of the family is carefully watched

Ethnic Group	Religion	Religious Attitude	Grief Expression	Death Rituals	Resource for Support
Indochinese (Vietnamese, Cambodians, Laotians, Thai and Hmong)	Buddhist traditionally but many have adopted Protestant or Roman Catholic	After death, soul lives in land of “tlan” or land of benevolent spirits. Deceased baby return in body of another child Stillborns are “marked” on soles of feet. Assign number of baby instead of name for first few days of life	May weep and wail out loud	May cover baby’s head after death as a sign of respect for soul believed to be housed in the head Mourning attire consists of a white outfit worn by women mourners Black armbands worn by men	Families
Japanese	Buddhist	Extremely intimate bond exists between baby and mother. With a death, others are very protective of one’s feelings, hoping to prevent undue sadness	Japanese do not usually grieve openly in public	Chanting at the bedside of the dying child Babies are thought to return in a spirit-like form to “Nirvana” and become little Buddhas Those in heaven watch over those on earth	Family Death should always be announced by family or friend, not health care professional

Ethnic Group	Religion	Religious Attitude	Grief Expression	Death Rituals	Resource for Support
Jewish	Reform Conservative Orthodox	Shiva is a 7-day mourning period in the home	Symbolic grief in the form of torn clothing or covered mirrors or curtailed social activities	Jewish person is buried within 24 hours	Faith and culture strongly support the emotional needs of mourners and well-being of survivors
Mexican Americans	Catholic	Illness and death are God's will	Very emotive and expressive	Baptism of dying or dead infant is very important as are prayers offered by family and friends	Family and Church

References:

Lawson LV. Culturally Sensitive Support for Grieving Parents. *American Journal of Maternal Child Nursing*. March-April, 1990. Vol 15, pgs. 76-79.

York CR, Strichler JF. Cultural Grief Expressions Following Infant Death. *Dimensions of Critical Care Nursing*. March-April, 1985. Vol 4(2), pgs. 120-127.

Helpful Web Resources

Sudden Infant Death Network of Ohio

<http://www.sidsohio.org>

Provides general information on SIDS and risk reduction. There is a grief support section with a link to join a SIDS support group specific to Ohio.

Ohio Department of Health

<http://www.odh.ohio.gov>

Contains information on health related programs offered in Ohio. Health statistics and vital statistics related to births and deaths in Ohio are also available through the information warehouse and other statewide surveys.

American Academy of Pediatrics

<http://www.aap.org>

AAP's site includes general information on children's health with a section on SIDS prevention included. Information on ongoing research and advocacy related to SIDS is listed.

Association of SIDS & Infant Mortality Programs (ASIP)

<http://www.asip1.org>

The focus of this site is on the membership and purpose of ASIP. ASIP is an association of health and human service providers focused on SIDS prevention.

CJ Foundation for SIDS

<http://www.cjsids.com>

This national organization offers general information on SIDS and prevention. There is a large Internet-based resources page with information on national SIDS-related events. Printable educational resources are available free of charge.

First Candle / SIDS Alliance

<http://www.sidsalliance.org>

<http://www.firstcandle.com>

Includes prevention information for expectant parents as well as coping and bereavement information and resources for families who have suffered a SIDS-related death. Advocacy opportunities and information for child care providers are also available.

Healthy Child Care America

<http://www.healthychildcare.org>

This site provides information for care givers and parents on SIDS prevention. Publications on SIDS and other child care safety issues are available for purchase.

Healthy People 2010

<http://www.healthypeople.gov>

The Healthy People 2010 document is available to viewing. HP 2010 contains the national goals and objectives related to health. Included in the document are goals to reduce deaths from SIDS.

National Center for Education in Maternal & Child Health

<http://www.ncemch.org>

Offers a large library of maternal and child-related literature including information on SIDS. This site offers access to national maternal and child health databases.

National Institute of Child Health & Human Development

<http://www.nichd.nih.gov>

This national institute provides general information on child health. Resources for SIDS are available for order. The site includes the SIDS national strategic plan and statistics on SIDS death.

National SIDS/Infant Death Resource Center (NSIDRC)

<http://www.sidscenter.org>

Offers free information brochures related to SIDS and cultural competency. The site also lists periodical resources for bereavement.

National SIDS & Infant Death Project IMPACT

<http://www.sidsprojectimpact.com>

This site introduces information on the national project promoting communication between SIDS organizations, advocacy and legislation related to SIDS. Information, statistics and legislation about SIDS are also available.

SIDS Support for Families

<http://www.sidsfamilies.com>

<http://www.sids-network.org>

This site provides many opportunities for memorials for the child's death. Families affected by SIDS can post and read personal stories. Faith-based support for bereavement is also included.

U.S. Consumer Product Safety Commission

<http://www.cpsc.gov>

The site contains a wide variety of consumer safety information. Many Web-based publications are available on SIDS prevention.

Bereavement Support Resources for Families

SID Network of Ohio

<http://www.sidsohio.org/>

Provides general information about SIDS, grief support and risk-reduction information. Parents can be connected with a support group and/or create a memorial for their child.

Alliance of Grandparents, a Support in Tragedy

<http://www.agast.org/>

AGAST is volunteer organization created to help grandparents through the trauma, stress and grief after the loss of a grandchild. Offers newsletters and a place for memorials to the lost child.

Empty Cradles

<http://www.empty-cradles.com/sids.htm>

Web site for support for all infant deaths. Information given on cause and statistics surrounding SIDS. Offers a place for a memorial to the lost child as well as message board for families who have suffered a SIDS-related loss.

First Candle/SIDS Alliance

http://www.firstcandle.org/memorial_page/memorial.htm

Memorial page for babies lost to SIDS.

http://www.firstcandle.org/whenababy/when_cop_par.html

Information for parents coping with SIDS loss.

http://www.firstcandle.org/whenababy/when_cop_grpar.html

Information for grandparents coping with SIDS loss.

<http://www.firstcandle.org/advocacy/advocacy.html>

Information on SIDS advocacy.

SIDS Families

<http://www.sidsfamilies.com>

This site provides many opportunities for memorials for the child's death. Families affected by SIDS can post and read personal stories. Faith-based support for bereavement is also included.

Share Pregnancy and Infant Loss, Inc.

<http://www.nationalshareoffice.com/index.shtml>

Web site serves those who have lost a baby through early pregnancy loss, stillbirth or in the first few months of life. All information packets, correspondence and support are free of charge for bereaved parents.

Sudden Infant Death Syndrome and Other Infant Death (SIDS/OID)

<http://www.sids-network.org/defaultindex.htm>

Not-for-profit organization provides information on SIDS death. Offers opportunities for memorials to the child and the chance for parents to become SIDS advocates.

Bereavement Support Resources for the Health Professionals

The American Academy of Bereavement

<http://www.bereavementacademy.org/>

Provides education and training for health care professionals, counseling professionals and the general public on topics related to palliative care, bereavement, serious illness, grief and loss.

Association for Death Education and Counseling

<http://www.adec.org>

A multi-disciplinary professional organization dedicated to promoting excellence in death education, bereavement counseling and care of the dying. Current information in the field of thanatology and counseling, as well as links to special interest topics on grief and bereavement.

Centering Corporation—Your Grief Resource Center

<http://www.centering.org>

This site aims to provide access to the best grief literature available on the Web. They also work to develop needed books and caring workshops on grief for adults and children.

The Centre for Grief Education

<http://www.grief.org.au>

An independent, nonprofit opened in 1996 and based in Melbourne, Australia, the Centre for Grief Education offers links to education programs, individual counseling, a journal called *Grief Matters*, a bereavement support directory and grief-support information.

First Candle/SIDS Alliance

http://www.firstcandle.org/health/health_families.html

Printable grief brochure for families who have experienced a SIDS death.

http://www.firstcandle.org/health/health_medical.html

Guidelines for medical professionals related to SIDS bereavement.

SIDS and Kids

http://www.sidsandkids.org/wa/resources_publications.html

Can order free information on bereavement to give to families.

Sudden Infant Death Syndrome and Other Infant Death (SIDS/OID)

<http://sids-network.org/grievingpeople.htm>

Information for providers on how to help families cope with the loss.

Children's Grief and Loss Issues

<http://www.childrensgrief.net/>

Information on children and grief.

Grief Watch

http://www.griefwatch.com/info/how_to_help_your_children.htm

Information on how to help grieving children.

General Information on Grieving

Bereavement Magazine: A Journal of Hope and Healing

<http://www.bereavementmag.com>

Designed to be “a support group in print,” *Bereavement Magazine* includes articles, stories and poetry. Readers have full access to archived issues at this Web site, as well as access to some material available only on the Web.

The Compassionate Friends

<http://www.compassionatefriends.org/>

The Compassionate Friends is a national nonprofit, self-help support organization that offers friendship and understanding to bereaved parents, grandparents and siblings. The mission of The Compassionate Friends is to assist families toward the positive resolution of grief following the death of a child of any age and to provide information to help others be supportive.

The Dougy Center: The National Center for Grieving Children and Families

<http://www.dougy.org>

This center based in Portland, OR offers support services to children, teens and adult caregivers grieving a death. The site has information about training, books, videos and training manuals for those interested in constructing grief programs in their own communities.