A Guide For The Sudden Infant Death Family Contact

July 2018

BABY 1ST NETWORK

Infant safe sleep education, community outreach and family support.

Ohio.gov So much to Discover.

Ohio Department of HEALTH

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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 parents' lives forever. The sudden and unexpected nature of these deaths 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 guide 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 on-going 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 sudden, unexpected infant death (SUID).

The Ohio Revised Code 313.121 requires public health departments to offer information, support and other bereavement services to families immediately following notification of a SUID. Although the law specifically mentions deaths from sudden infant death syndrome (SIDS), it is hoped that all public health personnel will provide similar services to these bereaved families of all SUID cases. The Ohio law regarding the reporting of infant deaths and the provision of support to families of SIDS victims can be accessed online at http://codes.ohio.gov.

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.

This guide is intended to assist public health professionals in preparation for their mandatory role in responding to infant deaths from all sudden and unexpected causes. 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 the health professionals. This guide also recognizes that health care professionals have multiple roles and opportunities to reduce the risk of these tragic deaths. Section Four of this guide provides information and resources for risk reduction activities.

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Section One:
Sudden, Unexpected Infant Death and the Ohio Revised Code

What is Sudden, Unexpected Infant Death (SUID)?

"During the night this woman's son died because she lay on him." I Kings 3:9

Since Old Testament biblical times, there have been recordings of seemingly healthy infants who have died suddenly and unexpectedly during sleep. Maternal "overlaying" 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.

Sudden, unexpected infant death (SUID) is a term used to describe any sudden and unexpected infant death, whether explained or unexplained, that occurs during infancy. After investigation, the cause of SUIDs may be attributed to accidental suffocation, positional asphyxia, overlay, entrapment, infection, ingestions, metabolic disorders, trauma, SIDS or undetermined causes. SIDS, or sudden infant death syndrome, is a subset of SUID. SIDS is a medical cause of death assigned to the sudden death of an infant that remains unexplained after the performance of a complete postmortem investigation, including an autopsy, an examination of the scene of death and a review of the infant's health history. Sleep-related deaths are those SUIDs from all causes, including SIDS, that occur while the infant is sleeping. The distinction between SIDS and other SUIDs is challenging. Many of the risk factors for SIDS and asphyxia are similar. Incomplete investigations, ambiguous findings and the presence of known risk factors for other causes of deaths result in many SUIDs being diagnosed as "undetermined cause" rather than SIDS.

While it is not always possible to determine a specific cause for each SUID, we do know these deaths occur all too often. More than three Ohio infant deaths each week are sleep-related. Sleep-related deaths account for more infant deaths than any single cause except prematurity. Infant sleep-related deaths outnumber deaths of children of all ages (0-17 years) from vehicular crashes. About 40 percent of infant deaths from age one month to one year are sleep-related.

All infants are at risk for SUID, but some infants seem especially vulnerable. More than 90 percent of sleep-related deaths occur before 6 months of age and about half occur before 3 months of age. Approximately 40 percent of the deaths occurred to black infants, even though black infants represent only 15 percent of Ohio's infant population.

The sudden death of a seemingly healthy infant is devastating for parents. The death of a child creates a profound void and sense of loss, changing the lives of the family forever. The goal of bereavement services is to connect families with available support as they grieve and attempt to find a new equilibrium for their lives.

The National Response to SUID

- 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 Senator Ted Kennedy and Senator 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 fifty 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 that 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.
- In 2011, the AAP again revised and expanded its recommendations for a safe infant sleep environment. The policy statement acknowledged the difficulties in diagnosing SUIDs, and recognized the similarity between risk factors for SIDS and for suffocation.
- In October of 2016, the AAP expanded its recommendations even further. Many of the risk factors for SIDS and sleep related infant deaths are similar so the AAP focused on safe sleep environments that will reduce the risk of all sleep related infant deaths including SIDS. They advise that infants sleep on a bare, separate surface, such as a crib or bassinet, with a tight fitting sheet. Never use soft bedding, including crib bumpers, blankets, pillows and soft toys. Infants should never sleep on a couch, armchair or soft surface. The recommendations also advise breastfeeding and call for infants to share their parents' bedroom for at least the first six months and, optimally, for the first year of life.

Ohio Response to SUID

- SIDS Legislation in Ohio (H.B. 244) was established May 4, 1992. This law mandates autopsies for all sudden and unexpected deaths to children less than two 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 (H. B. 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.

- Since the 1990s, the Ohio Department of Health (ODH) has partnered with the Baby 1st Network (formerly the SID Network of Ohio) to serve as the state's expert in SUID bereavement. The Baby 1st Network is the intake agent for the mandatory reporting of SUID cases by coroners.

- Legislation passed in 2014 requires a standardized death scene investigation for all SUID cases where the cause is not immediately known. ODH offered training sessions for local law enforcement and coroner offices in performing a systematic death scene investigation. The purpose of the investigation is to improve understanding of the risk factors involved, leading to development of prevention strategies.

- Coinciding with the national "Safe to Sleep" campaign, ODH launched a multifaceted risk reduction campaign in 2014. Materials are available at http://www.odh.ohio.gov.

From the Ohio Revised Code – September 2014

313.121 [Effective 9/17/2014] Autopsy of child in apparent good health who dies suddenly.
(A) As used in this section, "parent" means either parent, except that if one parent has been designated the residential parent and legal custodian of the child, "parent" means the designated residential parent and legal custodian, and if a person other than a parent is the child's legal guardian, "parent" means the legal guardian.
(B) If a child under two years of age dies suddenly when in apparent good health, the death shall be reported immediately to the coroner of the county in which the death occurred, as required by section 313.12 of the Revised Code. Except as provided in division (C) of this section, the coroner or deputy coroner shall perform an autopsy on the child. The autopsy shall be performed in accordance with rules adopted by the director of health under section 313.122 of the Revised Code. The coroner or deputy coroner may perform research procedures and tests when performing the autopsy.
If the child was one year of age or younger at the time of death and the death occurred suddenly and unexpectedly, the cause of which is not immediately obvious prior to investigation, the coroner, deputy coroner, or other individual who has been designated to investigate the child's death shall complete a sudden unexplained infant death investigation reporting form (SUIDI reporting form) developed by the United States centers for disease control and prevention or an alternative reporting form. The director of health may develop an alternative reporting form in consultation with the Ohio state coroners association. The individual who completes the reporting form shall retain the form and send a copy of it to the appropriate child fatality review board or regional child fatality review board established under section 307.621 of the Revised Code. If a coroner or deputy coroner completes the reporting form, a copy of the coroner's report described in section 313.09 of the Revised Code shall also be sent to the board.
A completed reporting form and copies of completed reporting forms are not public records under section 149.43 of the Revised Code.
(C) A coroner or deputy coroner is not required to perform an autopsy if the coroner of the county in which the death occurred or a court with jurisdiction over the deceased body determines under section 313.131 of the Revised Code that an autopsy is contrary to the religious beliefs of the child. If the coroner or the court makes such a determination, the coroner shall notify the health district or department of health with jurisdiction in the area in which the child's parent resides. For purposes of this division, the religious beliefs of the parents of a child shall be considered to be the religious beliefs of the child.
(D) If the child's parent makes a written or verbal request for the preliminary results of the autopsy after the results are available, the coroner, or a person designated by the coroner, shall give the parent an oral statement of the preliminary results.
The coroner, within a reasonable time after the final results of the autopsy are reported, shall send written notice of the results to the state department of health, the health district or department with jurisdiction in the area in which the child's parent resides, and, upon the request of a parent of the child, to the child's attending physician. Upon the written request of a parent of the child and the payment of the transcript fee required by section 313.10 of the Revised Code, the coroner shall send written notice of the final results to that parent. The notice sent to the state department of health shall include all of the information specified in rules adopted under section 313.122 of the Revised Code.
(E) On the occurrence of any of the following, the health district or department with jurisdiction in the area in which the child's parent resides shall offer the parent any counseling or other supportive services it has available:

(1) When it learns through any source that an autopsy is being performed on a child under two years of age who died suddenly when in apparent good health;

(2) When it receives notice that the final result of an autopsy performed pursuant to this section concluded that the child died of sudden infant death syndrome;

(3) When it is notified by the coroner that, pursuant to division (C) of this section, an autopsy was not performed.

(F) When a health district or department receives notice that the final result of an autopsy performed pursuant to this section concluded that the child died of sudden infant death syndrome or that, pursuant to division (C) of this section, an autopsy was not performed but sudden infant death syndrome may have been the cause of death, it shall offer the child's parent information about sudden infant death syndrome. The state department of health shall ensure that current information on sudden infant death syndrome is available for distribution by health districts and departments.

Role of the Baby 1st Network

In response to the mandated responsibilities for sudden infant death 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. For many years through a competitive grant award, the Baby 1st Network (formerly the SID Network of Ohio) was selected to act as the agent of ODH to assure that parents are offered bereavement and supportive services and to monitor and assure that coroners and local health departments are compliant in responding to SIDS. Since 2011, the Baby 1st Network has been the recipient of a contract award for this program through the state of Ohio.

The Baby 1st Network 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 within 72 hours of the 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 condolence letter also indicates that a public health nurse, social worker or designee will visit, call or write as required by the state of Ohio and not to feel threatened by their involvement as this is a normal requirement of the state. The Network then notifies the appropriate local health department/district so that the local health department 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* form after reviewing all the available information and ruling on the official cause of death. Although the final cause of the death is not known when the initial *Notification of Infant Death* form is received, the Network acts quickly to assure that sympathy and support are provided to grieving families as soon as possible regardless of the final diagnosis. It is hoped that local health departments will also act quickly in responding to immediate needs of families at the time of any SUID.

By partnering with ODH, the Baby 1st Network serves as the state's expert consultant on SIDS and SUID, providing a liaison with national and local SIDS organizations; acting as a resource for current information on SIDS, SUID, sleep related infant death, research, infant safe sleep recommendations and SIDS 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 SUID.

Baby 1st Network Mission Statement

The mission of the Baby 1st Network is to provide educational material and support for all who work to reduce Sudden Unexpected Infant Death (SUID). We are committed to providing the tools necessary to empower and engage communities to keep their infants safe. We also provide compassionate support services to families who have experienced the sudden unexpected loss of an infant.

To contact the Baby 1st Network, call (330) 929-9911 or e-mail stacy.scott@baby1stnetwork.org

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

- The local health department is notified of a sudden, unexpected infant death by written correspondence from the Baby 1st Network.

- A designated public health professional should contact the family as soon as possible, ideally within 48 to 72 hours of the referral. Although a home visit with the family is the preferred method of contact, it is understood that this may not be possible for every health department. In these instances, a phone call and letter of sympathy including local supportive services is acceptable with a future follow-up.

- The purpose of the family contact is to provide support, not to investigate or interrogate regarding the circumstances of the death.

- To schedule a home visit, 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 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 most likely may not yet have been confirmed by the coroner. She/he should make the parents aware that 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.

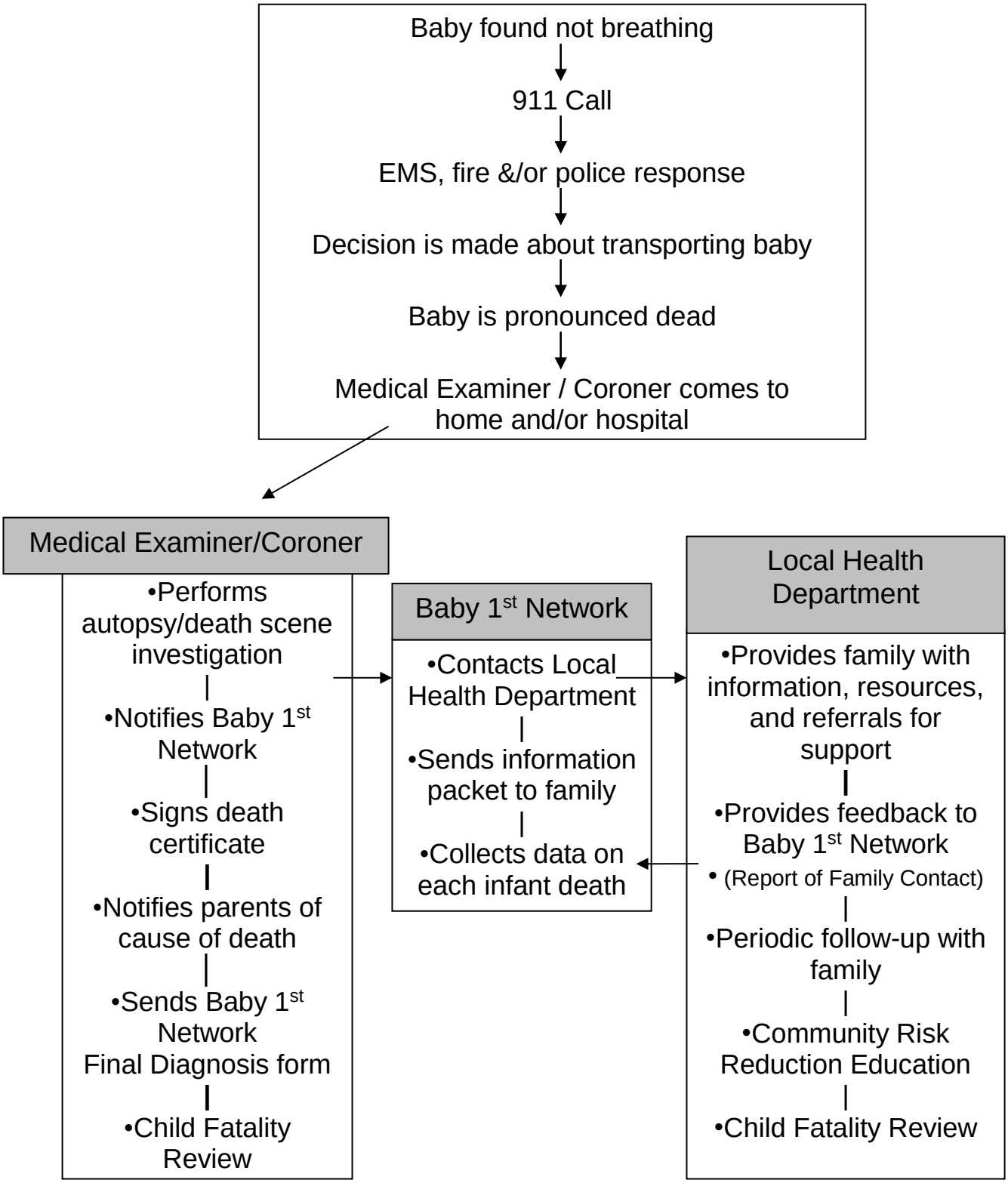
- The nurse/social worker should provide information about peer support groups and other support services and should make referrals to appropriate community resources.

- The nurse/social worker should provide referral feedback to Baby 1st Network by completing the *Report of Family Contact* form. Fax, email or send one copy within the 45-day deadline to:
  Baby 1st Network
  P.O. Box 403
  Toledo, Ohio 43697-0403
  Fax: (330) 929-0593

- Retain a copy at the local health department.

- If you have questions or need assistance, contact the Baby 1st Network at (330) 929-9911

Model of Response to a Sudden, Unexpected Infant Death



Section Two:
When a Baby Dies Suddenly and Unexpectedly

Case Scenario

The most common case scenario for a SUID is one in which parents put their apparently healthy infant to sleep. Later when the parents check on the child, they find the baby lifeless. Often, there has been no crying or warning sign. A frantic call is made to 911 and the emergency medical team arrives. The scene can become chaotic as the team moves swiftly to assess the baby and perform CPR and other lifesaving measures. Stunned parents struggle to understand the reality of what seems like a horrible nightmare. The baby is often taken to the hospital emergency room where more life-saving techniques may be attempted, after which the baby is pronounced dead. In complete shock, the parents are usually 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 that Ohio law requires an autopsy for all children, age two and under, who have died suddenly and unexpectedly. The idea of an autopsy can be very distressful to grieving parents. Parents will also be informed that Ohio law requires a death scene investigation to gather as much information as possible to assist with determining the cause of death. Parents should be told the autopsy and scene investigation are routine procedures for SUID case and in no way reflect suspicion on the parents. The purpose of both the autopsy and scene investigation is to provide some of the answers the parents seek.

The death scene investigation will be conducted as soon as possible by law enforcement or a coroner investigator, who will want to recreate the exact sleeping environment and positioning of the baby and other items in the sleep environment. 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. All professionals, including health care providers can assist the parents by being nonjudgmental, respectful, and caring, and reassuring the parents that these procedures are routine and required by law.

First responders and 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.

At some point, the coroner will assume responsibility for the infant's body. Surviving parents often report leaving their lifeless baby behind, having held the baby for the last time, is one of their worst memories. Depending on the circumstances and the timing of the autopsy, the body may not be released to the funeral director for a couple days.

The days following the funeral or memorial service can be filled with intense grief for parents as they continue to struggle with the reality that their baby has died. Their lives are forever changed, while friends and family return to their normal routine.

Appearance of the Infant

The human body undergoes many changes at the time of death. Depending on the length of time between the death and the discovery, the deceased infant's body may exhibit several externally visible changes. It is important that health care providers and emergency responders understand these markings as a normal part of the death process. The knowledgeable provider will be more capable in helping parents understand their infant's appearance and should not make judgments concerning the death on the basis of the infant's initial appearance.

Externally, infants that die suddenly and unexpectedly generally 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

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 that their feelings and reactions are common, it is important for the health professional to understand that 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:

- Anger
- Shock
- Sadness
- Guilt
- Loneliness
- Anxiety
- Fatigue
- Helplessness

Physical Sensations:

- Hollowness in the stomach
- Tightness in the chest

- Tightness in the throat
- Oversensitivity to noise
- Sense of depersonalization
- Breathlessness
- Weakness in muscles
- Lack of energy
- Dry mouth

Frequent Thought Patterns:

- Disbelief
- Confusion
- Pre-occupation 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

Section Three:
Responding to Families after a Sudden, Unexpected Infant Death

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 will require many skills. The health professional should be knowledgeable about SIDS/SUID, empathetic to the family, trained to listen and share information and able to respond to the needs of the family and caregivers. As 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, SUID, Sleep-Related Infant Deaths and Current Research**

Review current SIDS/SUID information. The health professional should have the knowledge to explain the facts concerning both 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 supportive services and referral information about other 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 her own feelings of grief and separate them from those of the grieving family. Realize that this family's life has been forever changed.

- **Knowledge of Referral Services**

The health professional should understand how to respond to the different types of problems 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. Please note that the Baby 1st Network has a statewide database of local bereavement support groups that may be of assistance to you. Contact our office for this information. 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 childcare 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 that 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. It may be helpful to search the Internet for the child's name and/or obituary before contacting the family as it may give additional information that is not provided on the *Notification of Infant Death* form.

Initial Contact

The initial contact with the family is usually by telephone. It is recommended that the family be contacted as soon as possible but be mindful of the funeral and/or memorial service. Plan on making the call in a quiet place where the necessary time can be devoted to the call. 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. Always use the child's name. Allow the family time to process what is being said to them. It may be helpful for the health professional to have the Baby 1st Network website, www.baby1stnetwork.org, opened to the *Grieving Families* tab and *Seeking Support.* Often times the family will not answer the phone either because they are not available or they are screening calls. In this instance, be sure to leave a voice mail message. If unable to reach the family by phone, it is recommended to send a handwritten letter of sympathy and follow up with the family at a later date. An example is included in this manual.

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, protective, mistrustful or avoid contact altogether. In addition, the family may find it threatening to have a health professional visit their home, particularly if they are unfamiliar with the health professional and in light of the recent death scene investigation.

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 professional is not part of any investigation and will not be interrogating them. Emphasize the role of the health professional to

provide information and support.

Be prepared in case a family member or friend answers the phones as they may be very protective and will not let the health professional speak with the family. Remember that grandparents, aunts, uncles, cousins, childcare providers, co-workers and the religious community are also grieving the loss of this child and it may be necessary to speak with them if they have answered the phone. It is appropriate to ask how these family members/friends are coping as well.

During this initial phone 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 that the health professional can provide more individualized information and assistance.

The Home Visit

Plan at least one hour for the visit after an acceptable time and location has been established by the family. It may be helpful to take written grief materials to the home visit since many families do not have access to the Internet. Be on time and do not appear rushed or distracted. Thank the family for allowing you to visit in their home and always call the child by name. 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. If a preliminary diagnosis is available at the time of the visit and the family is aware of that information, be prepared to discuss the preliminary diagnosis in concise and accurate terms. The health professional should be familiar with current SIDS/SUID research. SUIDs (particularly sleep-related deaths including SIDS and other accidental deaths) are inherently met with incredible guilt and emotional pain as families live with the "what ifs." Providing this information is crucial in circumventing the guilt of a family who has lost their baby suddenly and unexpectedly.

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/SUID and local support services, parents are able to review information as they feel comfortable. If there are local bereavement support services for children in the area, it is a good idea to include the contact information for these resources as well. In addition, the Baby 1st Network has a list of volunteer SUID parents who are available to speak with families and the health professional is encouraged to offer this information to parents. 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's living situation prior to the infant's death, the health professional should assess the needs of each parent. Be sensitive to individual needs and responses as we all react differently to grief of this magnitude. 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. The Baby 1st Network has an entire grief library with materials for children, parents, single parents, dads, grandparents and friends that they will send free of charge to those who are in need. If the death occurred while with a daycare provider, ask the family for contact information for the daycare provider who are often deeply affected by an SUID death. (If the family is unwilling to share daycare provider information, the coroner's office can provide contact information.)

Follow-up

It is important to offer to follow up with the parents at a later date. Families often have a strong support network of family, neighbors, co-workers, friends, community and religious affiliations immediately after an infant death. 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 Baby 1st Network, using the *Report of Family Contact* Form to document contact with the family, whether by mail, telephone or personal visit. The *Report of Family Contact* Form can be found in the Appendix, downloaded from the ODH website at www.odh.ohio.gov, or obtained directly from the Baby 1st Network. The purpose of the form is to document contact with the family in response to the referral from the Baby 1st 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, not as 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 interrogate them or specifically to gather information. Retain a copy of the form for your records. Fax or email a copy to:

Baby 1st Network
P.O. Box 403
Toledo, OH 43697-0403

Fax: (330) 929-0593
stacy.scott@baby1stnetwork.org

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?
Allow the parent to share memories of the baby in happy times. This question may also 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 or social worker should take this opportunity to reassure the family that it is very unlikely that a minor illness contributed to or caused the death of the infant.

Can you tell me about what happened to the baby?
Let the parent freely recount the last time the baby was seen alive, and later found unresponsive. Ask for details to clarify, but avoid an interrogative tone. In telling their story, parents may express feelings of guilt about not using a crib, propping the bottle, not having checked often enough, putting the baby on its tummy, finding the baby with covers over his head, etc. Reassurance must be given that babies usually can tolerate all of these risks and we are not always aware of which babies cannot.

Had you heard of sudden infant death before?
This will give the nurse/social worker 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 what happened to the baby?
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 sudden infant death? 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 often make 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

Why did my baby die?
It is likely the final cause of death will not be determined before the health professional contacts the family. Autopsies and death scene investigations are the best tools we have for determining the cause of sudden, unexpected infant deaths. After investigation, the cause of may be attributed to accidental suffocation, a previously undiagnosed infection or metabolic disorders, SIDS, or other undetermined causes.

What causes sudden, unexpected infant deaths?
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. We are also gaining a greater understanding of the risks of suffocation in the sleeping environment.

I didn't think this happened to families like mine!
Sudden, unexpected infant deaths occur to all races, all income levels and in all geographic regions. It is true that the rates of SUID are higher in African-American infants compared to white infants. Research shows that some risk factors are more common among low-income families, such as lack of safe sleep space and exposure to smoking.

Do these deaths always occur at night?
The majority of sudden, unexpected infant deaths occur at night or at naptime, when the baby is sleeping. However, there are reports of these deaths occurring at other times, when the baby is awake.

Do these deaths always occur during sleep?
The majority of sudden, unexpected infant deaths occur unobserved while the baby is sleeping.

Are all infants found on their tummies?
The risk of sudden, unexpected death is greater for infants placed to sleep on their sides and tummies, but infants have died in all positions. Because of the normal movements before the death occurred and muscle spasms that immediately follow death, infants are frequently found in a different position than when they were put down to sleep.

What causes blotches on the infants face when found face down?
Gravity causes blood to pool after death, causing discolored blotches. Bruise-like marks or pale blanched areas of skin may occur where the body was in contact with the bed surface.

What causes blood around the baby's nose and mouth?
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, and these can discolor the lung fluid that drains out after death. The baby may also have vomit about the face as the stomach contents are pushed upward by muscle relaxation after death. The vomit and fluid from the lungs are the result of the death, not the cause of the death.

Could he/she have cried and I not heard him/her?
It is unlikely that the baby cried out before the death. Sudden, unexpected infant deaths have occurred in many families where parents were sleeping in the same room with their infants. Some parents have been holding their sleeping infant when the death occurred.

Did my baby suffer?
Evidence indicates that sudden, unexpected infant deaths occur 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.

Why was an autopsy and death scene investigation done?
Ohio law requires autopsies for all children younger than two years and death scene investigations for all children younger than one year. Everyone, especially parents, want to understand how and why the infant died. An autopsy and death scene investigation are the best tools we have for determining the cause of sudden, unexpected infant deaths. Parents whose babies have died suddenly and unexpectedly have reported that receiving autopsy results as to how their child died was one of the most effective therapeutic measures they received in coping with their loss.

What about having another baby? Can this happen again? How long should we wait?
It has been known for sudden, unexpected infant death to happen more than one in a family, but those cases are extremely rare. Current research shows that the risk sudden, infant death occurring in a family a second time is no greater than it was the first time. The risk is less than one per 1,000 live births in Ohio. 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. Birth intervals of at least 18 months reduce the risk of low birth weight, preterm birth, and small for gestational age, placental abruption and other poor birth outcomes and maternal morbidities. The Baby 1st Network (300.929.9911) has more information available to families on this topic.

How will I survive raising another child?
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 the new 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. The Baby 1st Network (300.929.9911) has more information available to families on this topic.

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 Baby 1st Network may be contacted for this service. This organization exists primarily to assist bereaved families and to help increase the awareness of SIDS and SUID among public and professional groups. The Baby 1st Network has regional bereavement support contacts who are parents who have lost their babies to SIDS/SUID and are willing to talk to families one-on-one. These parents know firsthand what families are going through and can relate on a personal level to the feelings they are experiencing. Any parent or professional can contact the Baby 1st Network at any time for contact information and phone numbers. This information is also included in the bereavement letter each family will receive from the Baby 1st Network. In addition, there are many other organizations that offer support to families experiencing a sudden infant death and the Baby 1st Network has an updated resource listing of these support groups for all regions of the state. The Baby 1st Network can help in making referrals for those families who might be interested in participation in any of these groups.

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 Baby 1st Network 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 Baby 1st Network may have more recent contact information for the family.
Death occurs in childcare/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 childcare provider in another.	Contact the Baby 1st Network.
	Are there issues between the family and the childcare provider?	Provide education and support for both.
		Visit the childcare 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.
		Contact Baby 1st Network, who may be able to provide names of organizations who can offer financial assistance.

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 that 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 seventy-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 difficulty sleeping. The health professional must be able to recognize and deal with their own 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 that 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. You may feel a little "out of sorts" after the visit as it may bring up some of your own personal experiences.
- Allow yourself to grieve.
- Have a support person with whom you can share your feelings.
- Realize that any negative reaction from the family is not directed at you but most likely grief and anger talking.
- Acknowledge that sometimes you will not have words but that is OK.
- Often times, you may cry with the family, or by yourself, after the visit.
- Contact other health professionals who have had similar experiences for support, advice and understanding. Contact the Baby 1st Network for references.
- 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. Spend time with a pet.
- Rest and 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 do better.
- Be knowledgeable about SUID and the grieving process.
- Attend 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.

Section Four:
Reducing the Risk

The primary goal of this guide is to prepare health professionals to provide bereavement support to families after the sudden, unexpected death of their infant. However, public health professionals are in a unique position to reduce the risk of these tragedies by sharing the latest research and recommendations with clients and the community. This section is included in the guide to provide information and resources to support risk reduction activities.

Terminology

As research has increased our understanding about infant deaths, terminology has evolved to better describe deaths by cause and circumstance. Sudden, unexpected infant death (SUID) is a term used to describe any sudden and unexpected infant death, whether explained or unexplained, that occurs during infancy. After investigation, the cause of SUIDs may be attributed to accidental suffocation, positional asphyxia, overlay, entrapment, infection, ingestions, metabolic disorders, trauma, SIDS, or undetermined causes. SIDS, or sudden infant death syndrome, is a subset of SUID. SIDS is a medical cause of death assigned to the sudden death of an infant that remains unexplained after the performance of a complete postmortem investigation, including an autopsy, an examination of the scene of death and a review of the infant's health history. Sleep-related deaths are those SUIDs from all causes, including SIDS, that occur while the infant is sleeping where the environment appears to play a role in the death.

The distinction between SIDS and other SUIDs is challenging. Many of the risk factors for SIDS and asphyxia are similar. Incomplete investigations, ambiguous findings and the presence of known risk factors for other causes of deaths result in many SUIDs being diagnosed as "undetermined cause" rather than SIDS. Studies have shown inconsistencies between regions of the country and over time in how coroners and medical examiners use the terms SIDS, SUID and "undetermined cause."

What is SIDS?

Sudden infant death syndrome (SIDS) has been defined as the sudden death of an infant under 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.

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 and family's health history.

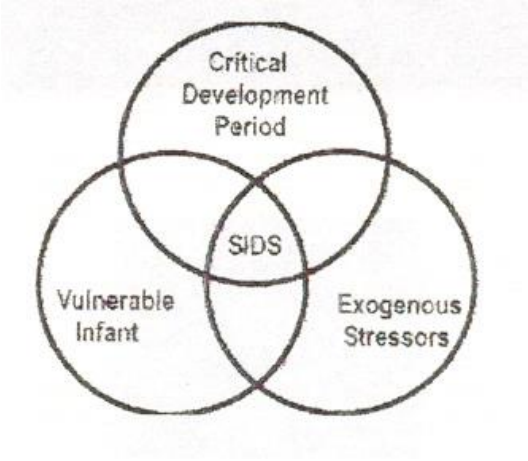
- An autopsy is needed to confirm the absence of disease, illness, congenital conditions, abuse, neglect or injury. Tissue samples and autopsy reports also help researchers find characteristics that may lead to discovering the cause of SIDS, and hopefully prevent more infant deaths from SIDS. A qualified 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. Recent changes in Ohio law mandate death scene investigations for all sudden, unexpected deaths of infants younger than one year.
- 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 all other causes are ruled out, the diagnosis of SIDS is made.

Research into the cause of SIDS led to the development of the "Triple-Risk Model" by Filiano and Kinney (1994). The model describes 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. For example, there may be an underlying abnormality or defect in the brain that controls respiration, heart rate or cardiac function. Normal infants do not die of SIDS.
- Critical Developmental Stage: The peak incidence of SIDS is between 2 to 4 months of age with ninety percent occurring before 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 cardiorespiratory controls. The brain nearly doubles in size during these months. These rapid changes may produce 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 non-fatal 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.

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.

What are Sleep-Related Deaths?

Sleep-related deaths are those sudden, unexpected infant deaths where some element of the sleep environment appears to have played a factor in the death. The causes include SIDS, accidental suffocation, positional asphyxia, overlay and undetermined causes. Deaths from specific medical causes are excluded from this category, even if the infant was sleeping when the death occurred.

Common Risk Factors

SUID victims share three major epidemiological characteristics:

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

Other common characteristics have been identified. These characteristics are called risk factors because they seem to put a baby at higher risk of SUID. These are not the causes of SUID. Risk factors can be categorized as infant, maternal and environment. Some factors cannot be modified, such as race and gender. Other factors can be modified, such as improving the sleep environment, to give the infant the best chance for survival.

Infant risk factors include:

- Male gender
- Low birth weight
- Prematurity
- One of twins or triplets
- African-American
- Native American

Maternal risk factors include:

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

Environmental risk factors include:

- Stomach or side-lying position for sleep
- Soft bedding including loose sheets, fluffy blankets, pillows, sheepskins, bumper pads, and waterbeds
- Stuffed toys, extra clothing, wedges and other objects in the crib
- Bed sharing
- Sleep surfaces such as couches, recliners, chairs, air mattresses, and adult mattresses
- Exposure to cigarette smoke during pregnancy or after birth
- Overheating by warm room temperature or excessive clothing and bundling

The Ohio Child Fatality Review (CFR) data system captures information about sleep-related deaths regardless of the cause of death. In order to better understand the contributing factors for these deaths and to develop prevention strategies, sleep-related deaths, including SIDS, are analyzed as a group.

In Ohio, from 2012 – 2016, sleep related infant deaths (714) account for 15% of all infant deaths reviewed (4,680) and 58% (415) for infants aged one month to three months. Eighty-eight percent of sleep-related deaths were for infants between 29 days and 1 year of age.

- Bed-sharing was reported at the time of the death in 53 percent (378) of reviews. Among reviews indicating bed-sharing, infants most often shared a sleep surface with an adult only (70 percent), an adult and another child (16 percent), or another child only (6 percent).
- Of the 349 reviews that indicated bed-sharing with an adult or adult and child, 48 percent indicated the supervisor was impaired at the time of the incident with 92 percent impaired by sleep and 13 percent impaired by alcohol or drugs.
- Forty-two reviews (11 percent of those indicating bed-sharing) indicated an adult fell asleep while feeding the infant, with twenty-two bottle-feeding, seventeen breastfeeding, and three unknown.
- Infants were put to sleep on their back in only 44 percent of reviewed deaths, and found on their back in 30 percent of reviewed deaths.
- Of the 175 infant sleep-related deaths in which a crib or bassinette was indicated as the incident location, seventy-four percent (120) reported object(s) found in the sleep space. Among the 120 reviews indicating objects in the crib or bassinette, the most commonly found objects were thin blankets (68 percent), comforters or quilts (34 percent), and pillows (24 percent).
- Secondhand smoke exposure was reported for 248 (35 percent) of the infant sleep-related deaths.
- Often times, sleep related infant deaths are difficult to diagnose even after a complete autopsy and diagnosis. Forty-nine percent of the sleep-related deaths were diagnosed as unknown or undetermined cause.

Risk Reduction Recommendations

As mentioned earlier, the distinction between various causes of sleep-related deaths is challenging. Many of the risk factors for SIDS and suffocation are strikingly similar. For this reason, the American Academy of Pediatrics has expanded its recommendations from being SIDS-focused to focusing on a safe sleep environment that can reduce the risk of all sleep-related infant deaths, including SIDS. The original AAP recommendations of the early 1990s that lead to the *Back to Sleep* campaign were broadened in 2011, leading to the *Safe to Sleep* campaign. The new recommendations are supported by scientific research and are the basis for the ODH Infant Safe Sleep policy and safe sleep campaign.

Always place infants wholly on the back to sleep for every sleep, nap time and night time.
While most new mothers acknowledge having received the "Safe 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. Babies who sleep on their stomach have a five times greater risk of dying from SUID. Infants accustomed to sleeping on their backs appear to be particularly vulnerable to SUID 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 "Safe to Sleep" message. Babies who are put on their tummies to sleep but are accustomed to sleeping on their backs have a seven to eight times greater risk of dying from SUID. Once an infant can turn from their back to front (supine to prone) and from front to back (prone to supine), place the infant to sleep on their back, but allow the infant to sleep in the position he or she assumes.

Use a firm sleep surface for infants.
A firm crib mattress covered by a fitted sheet is the recommended sleeping surface. A crib, bassinet, or portable crib/play yard that meets the current Consumer Product Safety Commission standards is recommended. Sleep surfaces such as chairs, sofas, adult beds, waterbeds and futons are particularly dangerous for infants. Ohio CFR reports that 61 percent of sleep-related deaths occurred in adult beds, on couches or on chairs. Car safety seats, infant seats, bouncers and swings should not be used as regular sleep places. If an infant falls asleep any place that is not a safe sleep environment, the infant should be moved to a firm, safety-approved sleep surface right away. When using sling carriers, caution must be used to ensure that the infant's head is up and above the fabric, the face is visible, and the nose and mouth are not obstructed.

Keep soft objects and loose bedding out of the crib.
The crib should be free of soft, fluffy materials such as bumper pads, sheepskins, comforters, blankets, 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 displayed in stores and online.

Room sharing without bed sharing is recommended. Ohio CFR reports that 55 percent of sleep related deaths occurred to infants sharing a sleep surface with another person. The infant's crib should be in the parent's bedroom, close to the parents' bed. Infants can be brought into bed for feeding or comforting but should be returned to their own crib when they fall asleep.

Avoid overheating.
Research into the causes of 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. Do not let the infant get too hot or cover the infant's head when sleeping. The area where the infant sleeps should be well-ventilated and at a temperature that is comfortable for a lightly-clothed adult. An infant is too hot if they are sweaty or their chest is hot to the touch. Infants should be dressed in no more than one layer more than an adult is wearing.

Avoid commercial devices marketed to reduce the risk of SIDS.
None have been proven safe or effective. Commercial devices such as wedges, positioners, special mattresses or other types of sleeping products should be avoided. There is no evidence that these devices or products protect against SUID or that they are safe. Home monitors that check the infant's breathing and/or heart rate are not advised as a way to prevent SIDS, and should be used only under a physician's advice.

Do not smoke during pregnancy. Avoid exposure to secondhand smoke.
Ohio CFR reports that infants were exposed to smoke either in utero or after birth in 43 percent of the sleep-related deaths. There should be no smoking near pregnant women or infants. No one should ever smoke around an infant, especially in the same room, in a car or in the room where an infant sleeps. Strategies to help parents eliminate smoking can improve the health of the whole family.

Breastfeeding is recommended.
Recent research shows that breastfeeding is protective against SIDS and this effect is stronger when breastfeeding is exclusive. The health advantages of breastfeeding include support of the immune system are well-documented. The recommendation to encourage the initiation and continuation of breastfeeding throughout the first year of life should be included with other SIDS risk reduction messages to both reduce the risk of SIDS and for its many other infant and maternal health benefits.

Offer a pacifier at naptime and bedtime.
Although the mechanism is not fully understood, the reduced risk of SIDS associated with pacifier use during sleep has been demonstrated in numerous research studies. Pacifier introduction should be delayed until approximately one month of age when breastfeeding has been firmly established.
Do not attach a pacifier by a string around the infant's neck or to their clothing or other object. Once the infant is asleep, it is not necessary to reinsert the pacifier.

Pregnant women should receive regular prenatal care.
The risk of SUID increases with decreasing birth weight and decreasing gestational age. Mothers who receive early and adequate prenatal care have the best chance for having a healthy infant.

Avoid alcohol and illicit drug use during pregnancy and after birth.
There is an increased risk of SUID with prenatal and postnatal exposure to alcohol or illicit drug use. Mothers should not use alcohol or illicit drugs during pregnancy and after the baby is born.

Infants should be immunized in accordance with AAP and CDC recommendations.
There is no evidence that there is a causal relationship between immunizations and SUID, while there is some evidence suggesting that immunizations might protect against SIDS. It is also important that infants have regular well-child checkups.

Provide supervised "tummy time" when infants are awake.
Tummy time promotes motor development and facilitates development of upper body muscles needed to reach important developmental milestones such as rolling over, sitting up, and crawling. It also minimizes the risk of plagiocephaly (flat head).

The AAP policy statement includes four recommendations directed toward health policy makers, researchers and professionals, to endorse and model the recommendations; continue research and surveillance; adhere to safe sleep guidelines in media and manufacturing advertising; and expand the Back to Sleep campaign for parents, grandparents and all other caregivers with major focus on the safe sleep environment.

References:
American Academy of Pediatrics' (AAP) 2011 policy statement, *SIDS and Other Sleep-Related Infant Deaths: Expansion of Recommendations for a Safe Infant Sleeping Environment*. http://pediatrics.aappublications.org/content/early/2011/10/12/peds.2011-2285

NIH, Eunice Kennedy Shriver, National Institute of Child Health & Human Development, *NIH Expands Safe Infant Sleep Outreach Effort* http://www.nichd.nih.gov/news/releases/pages/091212-safe-to-sleep.aspx?enderforprint=1

Ohio Child Fatality Review Seventeenth Annual Report (This report includes reviews of child deaths that occurred in 2016 and aggregate reviews for 2012-2016) http://www.odh.ohio.gov/-/media/ODH/ASSETS/Files/cfhs/Ohio-Childhood-Fatality-Review-16th-Annual-Report.pdf?la=en

Safe Sleep Recommendations

The American Academy of Pediatrics (AAP) provides the following evidence-based recommendations to parents, grandparents and all caregivers for reducing the risk of SIDS and other sleep-related infant deaths:

- Place infants for sleep wholly on the back for every sleep, nap time and night time.
- Use a firm sleep surface. A firm crib mattress is the recommended surface.
- Room-sharing without bed sharing is recommended. The infant's crib should be in the parents' bedroom, close to the parents' bed.
- Keep soft objects and loose bedding out of the crib.
- Pregnant women should receive regular prenatal care.
- Do not smoke during pregnancy. Avoid exposure to secondhand smoke.
- Avoid alcohol and illicit drug use during pregnancy and after birth.
- Breastfeeding is recommended.
- Offer a pacifier at sleep time after breastfeeding has been established.
- Avoid overheating.
- Avoid commercial devices marketed to reduce the risk of SIDS. None have been proven safe or effective.
- Encourage supervised "tummy time" when infant is awake to avoid flat spots on the back of the infant's head and to strengthen the upper torso and neck.
- All infants should be immunized in accordance with AAP and CDC recommendations.

- The AAP also includes four recommendations for health policy makers, researchers and professionals:
    - Endorse the recommendations.
    - Continue research and surveillance.
    - Adhere to safe sleep guidelines in media and manufacturing advertising.
    - Expand the Back to Sleep campaign for parents, grandparents and all other caregivers with a major focus on the safe sleep environment.

Community and Individual Interventions

Public health professionals are in an ideal position to have a positive impact on reducing the risk of SIDS and other sleep-related infant deaths 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 that will also impact the rate of other sleep related deaths. 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 SUID and risk reduction methods.

The Baby 1st Network can provide technical assistance and material resources to help in community and individual intervention programs. Some recent activities of the Baby 1st Network include:

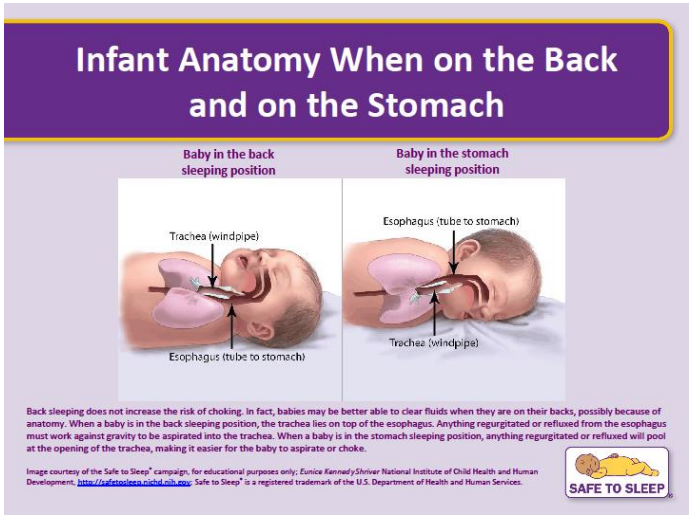
- Infant Safe Sleep awareness campaigns.
- Participation in healthy baby fairs.
- Community outreach forums for organizations, clubs, and churches.
- Training workshops for health professionals, childcare workers and first responders.
- Training forums for community leaders on promoting safe sleep within their communities.
- Mini-grant funding opportunities for neighborhoods and community groups to conduct outreach projects in an effort to reduce the rate of SIDS and sleep related infant deaths.
- Baby 1st Network online newsletter.
- Website - www.baby1stnetwork.org and real time updates via Facebook and Twitter.

The Baby 1st Network has also been involved in risk reduction outreach specifically addressing the racial disparity in the SUID death rates. Community health forums have been held in many Ohio cities where the disparities are the greatest to build partnerships with key stakeholders and community leaders, educating and empowering them to share the risk reduction and infant safe sleep messages throughout their communities.

Opportunities to provide infant safe sleep and SIDS risk reduction messages should be incorporated into the regular workflow of the local health department. ODH has implemented an infant safe sleep policy, which can be adapted and endorsed by local health departments. Accurate, consistent, culturally appropriate education materials should 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.

Resources

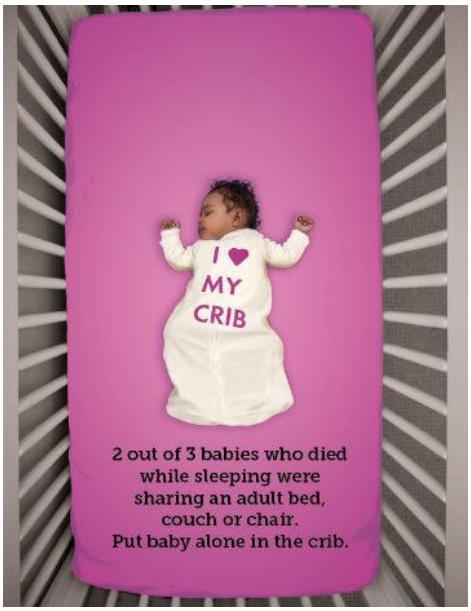
There are many printed resources available on infant safe sleep and SIDS risk reduction. Many of these resources are aimed at specific populations such as African-Americans, American Indians, grandparents or childcare workers. Materials are also available in Spanish and other languages. SIDS and infant safe sleep materials can be ordered directly from the Baby 1st Network, the Ohio Department of Health (ODH) and the Eunice Kennedy Shriver National Institute of Child Health and Human Development's *Safe to Sleep Campaign.*



The Baby 1st Network website offers many resources and useful to professionals. Materials can be downloaded or ordered in bulk from the website, including the NICHD's anatomy poster, as well as a grandparent brochure. The website is http://www.baby1stnetwork.org/publications.

ODH has made safe sleep campaign materials available for download on the Safe Sleep page of the department's website at http://www.odh.ohio.gov/-/media/ODH/ASSETS/Files/cfhs/infant-safe-sleep/Materials/Safe-Sleep-Order-1-23-18.pdf?la=en

Materials available include brochures in several languages, a flyer, a poster, a video public service announcement.



Among the many other resources available from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development's *Safe to Sleep Campaign* is this two-sided flyer. It can be downloaded at https://www.nichd.nih.gov/publications/pages/SearchResults.aspx . An order form for ordering materials in bulk is included here.

Safe to Sleep® Campaign Materials Order Form

MATERIALS FOR ALL CAREGIVERS	-	QTY
***Safe Sleep for Your Baby: Reduce the Risk of Sudden Infant Death Syndrome (SIDS) and Other Sleep-Related Causes of Infant Death* Brochure** Explains SIDS and describes ways to reduce the risk of SIDS and other sleep-related causes of infant death.  0481 0482 0484 0485	General Outreach *0481*	
	African American Outreach *0483*	
	American Indian/Alaska Native Outreach *0484*	
	En Español *0485*	
***What does a safe sleep environment look like?* Single Sheet** Shows a safe sleep environment and lists ways to reduce the risk of SIDS and other sleep-related causes of infant death. (In sets of 25 sheets)	English *0482*	
	En Español *0486*	
***Safe Sleep for Your Baby* Door Hanger** Designed to hang on a doorknob, shows a safe sleep environment and lists ways to reduce the risk of SIDS and other sleep-related causes of infant death.	General Outreach *0494*	
	African American Outreach *0495*	Online Only
	En Español *0496*	Online Only
***Safe Sleep for Your Grandbaby* Brochure** Explains how grandparents can reduce the risk of SIDS and other sleep-related causes of infant death when caring for their grandchildren.	English *0497*	
	En Español *0498*	
***Safe Sleep for Your Baby* DVD** Explains SIDS risks and ways to reduce the risk of SIDS and other sleep-related causes of infant death. English and Spanish subtitles. Running time 9:55.	English *0487*	
	En Español *0506*	
***Honor the Past, Learn for the Future: Reduce the Risk of SIDS in Native Communities* Flyer** Lists ways to reduce the risk of SIDS and other sleep-related causes of infant death among American Indian/Alaska Native babies.	*0434*	
Safe to Sleep® Campaign Materials Order Form	*0327*	

MATERIALS FOR HEALTH CARE PROVIDERS, EDUCATORS, AND COMMUNITY HEALTH WORKERS	-	QTY
***Continuing Education (CE) Program on SIDS Risk Reduction: Curriculum for Nurses* (Workbook and Handouts - Online Only)** Approved for 1.1 CE credit hours, offers communication strategies for nurses on SIDS, SIDS risks, and risk-reduction recommendations. *Available at http://www.nichd.nih.gov/cbt/sids/nursececourse/Welcome.aspx.*	-	-
***SIDS Risk Reduction: A Continuing Education (CE) Activity for Pharmacists* (Online Only)** Approved for 0.125 CE units, explains how pharmacists can communicate safe sleep messages to caregivers. *Available at http://www.nichd.nih.gov/cbt/sids/pharmacistcecourse/Welcome.aspx.*	-	-
***Sudden Infant Death Syndrome (SIDS) and Other Sleep-Related Causes of Infant Death: Questions and Answers for Health Care Providers* (Booklet)** Answers to common questions about sleep position, sleep environment, and Sudden Infant Death Syndrome (SIDS) for health care providers.	*0524*	*Limit 25*
***Healthy Native Babies Project Facilitator Packet* (Facilitator's Guide, Cards, Chart, Flipchart)** For leading training sessions for those who work with parents and caregivers in American Indian/Alaska Native communities. Includes training modules and materials for leading 2-hour or 1-day sessions.	*0457*	*Limit 1*
***Healthy Native Babies Project Workbook Packet* (Workbook, Handouts, and Toolkit Disk)** For conducting outreach in American Indian/Alaska Native communities. Toolkit creates custom outreach materials that incorporate Tribal and regional photos, languages, and graphic elements.	*0435*	*Limit 1*

TO ORDER MATERIALS, CONTACT US:

Phone: 1-800-505-CRIB (2742)
Fax: 1-866-760-5947
TTY: 1-888-320-6942
Mail: P.O. Box 3006, Rockville, MD 20847
Email: NICHDInformationResourceCenter@mail.nih.gov
Website: http://safetosleep.nichd.nih.gov

Name/Title			
Organization/Business			
Street Address			
City, State, ZIP		❒ Residential Address ❒ Business Address	
Telephone		**Email***	

**Optional: If you want confirmation that your order has been placed.*

The Safe to Sleep® campaign is led by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), part of the National Institutes of Health, within the U.S. Department of Health and Human Services. Safe to Sleep® is a registered trademark of the U.S. Department of Health and Human Services.

December 2015

Appendices

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)
□ Male □ Female □ Unknown		□ Yes □ No	□ White □ Black / African American □ American Indian / Alaskan Native □ Hawaiian Native / Pacific Islander □ Asian □ Unknown □ 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

The **Preliminary** diagnosis of this death is:

- □ SIDS
- □ Unintentional Injury / Accident
  - □ Asphyxia
  - □ Other Unintentional Injury
- □ Inflicted Injury / Homicide
- □ Undetermined (Natural)
- □ Undetermined (Not Natural)
- □ Undiagnosed Disease / Natural
- □ Other (Please Explain)

□ 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:
Baby 1st Network
P.O. Box 403
Toledo, OH 43697-0403
Or Fax (330) 929-0593

If you have questions regarding this form, please call Dr. Stacy Scott at (330) 929-9911

HEA 7721 – Revised 07/18

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)
□ Male □ Female □ Unknown		□ Yes □ No	□ White □ Black / African American □ American Indian / Alaskan Native □ Hawaiian Native / Pacific Islander □ Asian □ Unknown □ Other _____

County of Death	County of Residence	County of Autopsy

Parents' Name	Address	City	State	Zip

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? □ Yes □ No

Were autopsy findings available prior to completion of cause of death? □ Yes □ No

Manner of death: □ Natural □ Accident □ Homicide □ Could not be determined

Comments:

Form Completed by: _____

Area Code and Phone Number: _____

County: _____

Please send this report to:
Baby 1st Network
P.O. Box 403
Toledo, OH 43697-0403
Or Fax (330) 929-0593

If you have questions regarding this form, please call Dr. Stacy Scott at (330) 929-9911

HEA 7722 – Revised 07/18

Ohio Department of Health • Sudden Infant Death Program

Report of Family Contact

Date Referral Received:_____

Infant's name			Date of birth	Date of death
Last	First			
Gender ☐ Male ☐ Female	Ethnicity ☐ Hispanic ☐ Non-Hispanic	Race ☐ White ☐ Black ☐ Asian ☐ Other_____		
Mother's Name				
Last	First		Phone	
Address		City		Zip
Father's Name				
Last	First		Phone	
Address ☐ Same as Mother		City		Zip
Other Family				
Last	First		Relationship	Phone
Address ☐ Same as Mother		City		Zip

Family Contact Record				
Date	Type of Contact			Next Steps
	☐ Mail	☐ Phone	☐ Visit	
	☐ Mail	☐ Phone	☐ Visit	
	☐ Mail	☐ Phone	☐ Visit	
	☐ Mail	☐ Phone	☐ Visit	

Information Provided to Family

Referrals Made for Family

Family Notes/Comments (Use back of form if needed)

Please record the following information only if it is learned through conversation with the family. Your role is to assist with bereavement, not to investigate the death.

Location at time of death ☐ Crib/bassinet ☐ Playpen ☐ Adult Bed ☐ Couch/Chair ☐ Infant Seat ☐ Other _____

Infant placed to sleep ☐ On Back ☐ On Stomach ☐ On Side ☐ Other _____

Infant sharing sleep surface with ☐ Adults ☐ Children ☐ Blankets ☐ Pillows ☐ Other _____

Report Completed By			
Name		Agency	
Address		City	Zip
Phone	Cell		County

For guidance in contacting families or completing report, refer to Guide for the SID Home Visit at www.odh.ohio.gov or call (330) 929-9911.

Return completed report to: Baby 1st Network, P.O. Box 403, Toledo, Ohio 43697-0403. Or Fax (330) 929-0593

HEA 1403 Revised 07/18

Sample Letter to Family

This template can be used to make initial contact with a family when you have learned through any source that their baby died suddenly and unexpectedly. 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 childcare 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 Baby 1st Network 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,

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 and SUID.

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 preventative strategies.

Since CFR began collecting data in Ohio, the findings from reviews of sleep-related deaths have confirmed many of the risk factors identified in research: exposure to cigarette smoke; soft, fluffy bedding; infants sleeping on surfaces other than cribs; and bed sharing. CFR boards have made many recommendations for the continued repetition of the "Safe to Sleep" message, especially targeting minority families, grandparents and caregivers.

Recommendations become initiatives only when resources, priorities and authority converge to make changes happen. CFR boards are continually seeking partners to carry out safe sleep education and 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 sudden, unexpected infant death may be asked to provide information to the CFR board for review. Ohio law requires that 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, Matt Slanoc**,** at (614) 728-0773.

For more information about CFR and to view annual CFR reports, visit www.odh.ohio.gov.

Additional Resources

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 earthly 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 Buddhist. 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 commun-ity.
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 40th 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 tradition-ally but many have adopted Protestant or Roman Catholic.	After death, soul lives in land of "tlan" or land of benevolent spirits. Deceased baby returns 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 profess-ional.

Ethnic Group	Religion	Religious Attitude	Grief Expression	Death Rituals	Resource for Support
Jewish	Reform Conserva-tive 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.	

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

Bereavement Support Resources for Families

Baby 1st Network - www.baby1stnetwork.org
Provides general information about SIDS/SUID, risk reduction, infant safe sleep practices, SUID statistics, grief support for families, a memorial page for babies who have passed, and resources for both professionals and community members. In addition, parents can be connected with a support contacts located throughout the state.

First Candle - www://firstcandle.org
First Candle is a leading national nonprofit organization dedicated to safe pregnancies and the survival of babies through the first years of life. Current priorities are to eliminate Stillbirth, Sudden Infant Death Syndrome (SIDS) and other Sudden Unexpected Infant Deaths (SUID) with programs of research, education and advocacy. They also provide compassionate grief support to all those affected by the death of a baby through a dedicated crisis hotline at 800.221.7437

CJ Foundation - https://www.facebook.com/cjsids/
The CJ Foundation is a national non-profit devoted to eliminating the tragedy of sudden unexpected infant deaths and early childhood deaths, supporting grieving families, advancing medical research, furthering parent and professional education, and advocating for the health and survival of all children.

Empty Cradles - www.emptycradle.org/
Empty Cradle is a non-denominational, non-profit organization dedicated to providing support to families who have experienced the loss of a baby due to miscarriage, stillbirth, infant death or SIDS.

Share Pregnancy and Infant Loss, Inc. - www.nationalshare.org/
Learn ways to care for yourself as you travel the journey of grief following the death of your precious baby. Watch personal testimonials, read heartfelt stories, and find ritual planning examples.

Support for Grandparents
http://missfoundation.org/support/articles/grandparents
MISS Foundation – Grandparents grief page.

Bereavement Support Resources for the Health Professionals

The American Academy of Bereavement - www.thebereavementacademy.com
The American Academy of Bereavement is a national association devoted to the education, preparation, and advancement of bereavement specialists. We serve our members by providing educational opportunities, stimulating research and addressing issues relevant to the field of thanatology.

Association for Death Education and Counseling - 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 and links to special interest topics on grief and bereavement.

Centering Corporation - www.centering.org
The Centering Corporation is a non-profit organization dedicated to providing education and resources for the bereaved. Centering was founded in 1978 by Joy and Dr. Marvin Johnson. They also work to develop needed books and caring workshops on grief for adults and children.

The Centre for Grief Education - 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 - www.firstcandle.org
First Candle is a leading national nonprofit organization dedicated to safe pregnancies and the survival of babies through the first years of life. Current priorities are to eliminate Stillbirth, Sudden Infant Death Syndrome (SIDS) and other Sudden Unexpected Infant Deaths (SUID) with programs of research, education and advocacy. They also provide compassionate grief support to all those affected by the death of a baby through a dedicated crisis hotline at 800.221.7437

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.

Grief Watch - www.griefwatch.com
Information on how to help those who experience a loss.

General Information on Grieving

Bereavement Magazine: A Journal of Hope and Healing
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 website, as well as access to some material available only on the Web.

The Compassionate Friends - 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
www.dougy.org
This center based in Portland, Oregon 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.

SIDS/SUID and Risk Reduction

Baby 1st Network - http://www.baby1stnetwork.org
Provides general information on SIDS risk reduction and infant safe sleep practices. There are pages specific to professionals, statistics, grief information for parents and caregivers and a memorial page for babies who have passed.

Ohio Department of Health - www.odh.ohio.gov/safesleep
Contains information on infant safe sleep practices – the ABCs of safe sleep. Safe sleep facts, partners, resources and family stories can be found here. Their main website, www.odh.ohio.gov, has information regarding 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 - 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.

First Candle - www.firstcandle.org
Includes risk reduction information for expectant parents as well as coping and bereavement information and resources for families who have suffered a SIDS/SUID related death. Advocacy opportunities and information for childcare providers are also available.

CJ Foundation for SIDS - www.cjsids.org
This national organization offers general information on SIDS cause and risk reduction. There is a large internet based resource page with information on national SIDS/SUID related events. Printable educational resources are available free of charge.

National Institute of Child Health & Human Development - www.nichd.nih.gov/Pages/index.aspx
This national institute provides general information on child health. Resources for SUID/SIDS and infant safe sleep are available for order and information pertaining to these topics can be found here.

National SUID/SIDS Resource Center – www.sidscenter.org/
Offers free information brochures related to SUID/SIDS and cultural competency. The site also lists periodical resources for bereavement.

Healthy Child Care America - www.healthychildcare.org/
The HCCA Child Care Health Partnership is a collaborative effort of health professionals and child care providers working to improve the early education and health and safety of children in out-of-home child care.

Healthy People 2030 - www.healthypeople.gov
Healthy People provides science-based, 10-year national objectives for improving the health of all Americans. For four decades, Healthy People has established benchmarks and monitored progress over time in order to: encourage collaborations across communities and sectors; empower individuals toward making informed health decisions; and measure the impact of prevention activities.

National Center for Education in Maternal & Child Health - 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.

U.S. Consumer Product Safety Commission - www.cpsc.gov
The site contains a wide variety of consumer product safety information including product recalls and information on infant safe sleep.