

## **USC DIVISION OF NEONATAL MEDICINE**

**WEB AUTHOR'S NOTE:** A significant contribution indeed to a challenging topic in pediatrics, please enjoy this publication, “SIDS”, free of charge, by Toke Hoppenbrouwers, PhD & Joan Hodgman, MD. Chapters and others sections of the book have been hyperlinked from the **Table of Contents** for easy navigation. Start there, or better yet, view the **book's cover**.

Martin J. Blahnik, MD

# sids



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Monte Nido Press

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# Acknowledgment

**J**OAN HODGMAN AND I MET each other for the first time in 1972 during a meeting organized by Eileen Hasselmeyer, RN, PhD, who was then in charge of Sudden Infant Death Syndrome (SIDS) research at the National Institute of Child Health and Human Development (NICHD). She and Jehu Hunter, her close collaborator came to Los Angeles to explore funding of a research program in SIDS with investigators at the University of Southern California (USC) and the University of California, Los Angeles (UCLA). Perhaps Dr. Hasselmeyer can be considered the most influential, *single* person in the progress of SIDS research. It was through her efforts that most of the early studies dealing with the regulation of the heart and breathing, sleep and arousal and their role in SIDS began. These studies revealed information about the development of the fetus and normal babies, findings that benefit *all* infants.

Soon after we began our large-scale study we became aware of the extent parents who had lost a baby to SIDS contributed to this research effort. The Orange County, California chapter of the Guild for Infant Survival under the leadership of Chris Elliott was active not only in supporting parents who lost a baby to SIDS, but also in raising

money for research and awareness among politicians. The same was true for parents in Los Angeles who came together as a chapter of the National SIDS Foundation and in the San Gabriel Valley where another chapter of the Guild for Infant Survival was doing important work. We as scientists were beneficiaries of their efforts and those who followed them, and so were all people who choose to have children.

At the time of our first meeting, Joan Hodgman was already a nationally known Neonatologist in charge of the Newborn Division at Los Angeles County, USC Medical Center. At one time during her tenure, over 17,000 babies were delivered each year which made it one of the largest hospitals in the world for babies. I was about to receive a doctoral degree from UCLA where I had studied what would now be called Neuroscience and Clinical Psychology. We have been involved in SIDS research ever since. In 1990 we began a large, federally funded, national study of SIDS. This is called the Collaborative Home Infant Monitoring Evaluation (CHIME). We were fortunate to be able to collaborate with three members of our faculty, Doctor Ramanathan and Doctors Keens and Davidson-Ward, from Children's Hospital, Los Angeles.

We thank the individuals who have given us valuable support and feedback: Dr. Bruce Beckwith, Ms. Barbara Crane, Ms. Chris Elliott, Ms. Debbie Gemmill, Mr. Mason Johnson, Dr. Jeffrey Johnson, Mrs. Rose LeVantine, Lady Limerick, Mr. Colt Luse, Dr. John O'Brien, Dr. Thomas Keens, Dr. Paula Palmer, Mrs. Reed, Ms. Jill Singer, Ms. Pamela Shandel, Ms. Penny Stastny, Dr. Annabel Teberg and Ms. Lynne Trujillo. While we believe that we represent the opinions of the majority of our colleagues in the scientific community, we as authors should be held solely responsible for what we present.

We also gratefully acknowledge the contributions of the individuals who have shared their personal experiences and have allowed us to include these in this booklet. SIDS has touched each of these individuals.

Ms. Leena Hannonen, Macnetic Design designed and produced this booklet. Ms. Talita Long, a well-known Los Angeles artist, made the beautiful poster, a small version of which can be found in the back of the booklet. By writing to the e-mail address provided you can purchase this poster.

To make this information available to as many people as possible we used computer technology which allows us to produce the booklet inexpensively and to revise the text whenever new important information appears. One dollar of every copy sold will be set aside for meritorious research and service projects.

# Preface

**W**HEN SIDS HAPPENS IN A family, a flood of emotions overwhelms the parents and others who were close to the baby. Questions such as “Why my baby? How could this have happened?” or, “What did I do wrong?” go through their minds over and over. On top of this is the need to take practical steps for which parents are frequently not prepared such as making arrangements for the funeral. Although nothing can lessen the shock and the grief of this unforeseen tragedy, the purpose of this booklet is to provide information to parents who have lost a baby to SIDS and to the people who come in contact with these parents. These include physicians, law enforcement personnel, nurses, paramedics, personnel from the coroner’s office and teachers, friends and relatives.

Information that is particularly important for parents who have recently lost a baby has been marked by a vertical grey column. This booklet contains a discussion about how the coroner decides on the diagnosis of SIDS. We also discuss feelings following the death of an infant from SIDS. In the italicized sections you will find accounts of people’s personal experiences as well as practical suggestions.

Common sense ways to foster good health in the unborn baby and the newborn are detailed. These measures cannot prevent SIDS, but they will decrease the possibility of serious illness and death. Listing these suggestions does not mean that, had you followed them in the past, you would have prevented the death of your child. However, from the history of other diseases such as tuberculosis, we have learned that the disease was reduced by 50% before the cause was discovered. This decrease occurred because, through education, people began to pay attention to healthier ways of living.

In the final third of the book we have reviewed the scientific findings of the past 30 years. Health professionals and others who come in contact with SIDS can select what seems useful to them. Medical terms have been explained in the Glossary. We present the potential mechanisms of death and risk factors for SIDS. While there is no treatment for SIDS, we discuss approaches that have been used to try and decrease the risk. We conclude with theories, discredited, controversial and promising to explain the death.

Bringing an end to SIDS, however, will require more than education. Short of finding the medical solution, important socio-economic changes are needed. Although SIDS happens in all socio-economic groups, babies of childbearing women without healthcare insurance are at

increased risk for SIDS. Providing this group with access to timely prenatal and postnatal care should make a significant dent in the incidence of SIDS.

*Los Angeles, August 2003*  
*Toke Hoppenbrouwers Ph.D.*  
*Joan Hodgman, M.D.*

*“I WOKE UP WITH THE SUN SHINING IN MY FACE. That was odd because Christopher always woke me up early. It took me awhile to orient myself...then in a flash I jumped out of bed.... Why didn't the baby wake me up this morning? There was an eerie quietness all around. When I approached the bed I saw him lying on his stomach. He didn't move. I picked him up, but he was limp. He didn't breathe. I began to shake him softly first, then hard. When it dawned on me that he wouldn't respond I wanted to push my own breath into him, clutch him to me at the same time and from deep within I felt a wave of fear tear loose and escape as a scream.”*



*Eliza was born at the beginning of February. An Aquarian baby. Unlike Janey she was tall and skinny, with a long, protruding backbone with tiny black hairs around it, and dark hair rather than blonde. As I cuddled her, I realized she looked like me, which meant she was not as good-looking as Janey. I felt extra protective of her because of that.*

*The first few weeks of her life were sheer joy. I didn't work. Janey, who was nineteen months old, adored Eliza.*

*“Love the baby. Love the baby,” she would say.*

*I'd push my two babies to the shops in the weak, late winter sun and feel completely happy.*

*Saturday March sixteenth, six thirty am. My beautiful Eliza was six weeks old. It was a bright spring morning. Golden light flooded through the window as I drew back the curtains and walked over to Eliza's crib. Sam and I were to take her to the synagogue that day to give her a Jewish name. We had chosen 'Chai' which means 'life'. I reached down towards my baby. She was asleep. She lay on her tummy. I looked at her anticipating holding her in my arms, her lips to my nipples. Feeling her heartbeat next to mine.*

*Everything stopped. There was something wrong. Her tiny arms and legs looked strange, like rubber.*

*I couldn't breathe as I picked her up, held her, tried to warm her body, little bones of jelly, her skin translucent.*

*“No”*

*Did I whisper this or scream?*

*“No”*

*Gingerly holding her, kissing her moist cheek, her dry lips, my ear to her chest.*

*No, please dear God. No.*

*I'd been so scared with Janey that something terrible would happen. But I had no such fear with Eliza. Her impish smile fooled me.*

*As I picked her up, her funny rag-doll body sagged.*

*I remembered how I had said to Carol, my friend, "She's like a little mole, or a fish; see the dark downy hair on her backbone?" That was last night. Was it only last night, I was feeding her? Well attempting to. She turned her head away and smiled.*

*"It's as if this baby has great wisdom. As if," I had said, "she knows something I don't."*

*I still did not believe what I already knew. This can't be true. This can't be what it seems. It's simply not true. I haven't been that wicked! Carefully I placed Eliza on the bed. Her eyes were closed. Deep shadows had formed beneath them, just like Janey when she was asleep. Eliza's cheeks were pink.*

*She can't be dead!*

*Her dark hair shone red in the morning sun.*

*I breathed into her mouth. I breathed and breathed. Her belly moved up and down. I held my baby and breathed.*

*Sam called our doctor, and a neighbor called hers. Now the two medical men arrived. Still I breathed into Eliza.*

*I remembered that as a child I used to breathe into Reynald, my doll. I remembered her taste and smell. The sound of my breath as it passed into her. Now I desperately wanted Eliza to live.*

*The doctors separated us. They took my baby from my arms.*

*I never saw Eliza again.*

*I never said "Goodbye".<sup>1</sup>*

---

<sup>1</sup> Eliza, from Part 1 of *Double Doors*, an autobiographical novel by psychotherapist, Jill Singer, Director of Clinical Services, North West London Psychotherapy Centre

# Overview for parents

EVERY YEAR AN ESTIMATED 3,000 babies in the United States die in a similar manner to the babies just described. Their parents go through a devastating experience, one feared by many parents of newborns. It is called Sudden Infant Death Syndrome or SIDS. There is no clear explanation for this death. No cause has been discovered. SIDS remains the unexplained death of an infant that could not have been prevented. There is no way to tell beforehand whether an infant will die of SIDS. It is important to know that nobody can be blamed for the baby's death.

It is common for SIDS infants to die when parents think that they should be asleep. Babies are often found in the morning after they were seen alive during their last feed. Other babies die during an afternoon nap. Some have died in a car seat, others in day care centers. Every once in a while, a nurse or a physician was present just when a baby was about to die. Even they cannot always revive the baby. In answer to the question asked by parents, "would it have mattered if I'd gotten to him sooner?" we would reply: "Probably not." A small comfort perhaps is the knowledge that the baby most likely did not suffer prior to death.

When a baby dies officials from the coroner's office will be called upon to perform a death scene investigation and an autopsy. For the first, they will come to the home where the death happened and for the second the baby is brought to the coroner's office where an examination of the brain, internal organs, blood and urine takes place. The purpose of both of these is to determine why the baby died. If the coroner cannot find a specific cause of death such as pneumonia or an accident, the death will be attributed to SIDS. These investigations also serve to prevent parents from being accused of child abuse or neglect, when they have done nothing wrong.

Even though we don't know the cause of SIDS, doctors have been studying SIDS intensely for the past thirty years. It is now clear that SIDS cannot be explained by vomiting, by immunizations or by suffocation. SIDS is neither inherited nor contagious. Therefore other living children are not at risk to die after a baby dies of SIDS in the family. Lastly, SIDS is not child abuse.

What else have we learned about SIDS? Here are some additional facts:

SIDS has been observed in many countries and the rates are very similar everywhere it has been studied. SIDS happens in all families whether rich or poor and among all ethnic groups and races. The risk for SIDS is highest when a baby, born at term, is between 2 and 4 months of age. SIDS seldom happens during the first week of life. Babies who were born prematurely have a higher risk to die, not while they are still in the hospital but during the 6-8 weeks after their discharge.

Most SIDS victims were healthy prior to death. They may have had a cold, but they do not have more colds than babies who do not die. Breastfeeding, although good for the baby, decreases the risk but does not prevent SIDS.

Fewer babies who have well-baby care and whose mothers had prenatal care have died from SIDS. There are ways to minimize the risk that a baby will die. The most important one is **placing babies to sleep on their back**. Another is **not smoking during pregnancy and keeping all smokers away from babies during their first year of life**. The baby should also be kept neither too hot, nor too cold.

Sleeping safely is important for the baby. This means placing babies on a firm mattress **without** pillows or quilts, preferably in their own crib. Some parents choose to have the baby in their own bed. This is definitely not recommended if

either of the parents is obese or when alcohol, smoking or other drugs are involved. Occasionally, a baby stops breathing and turns either blue or white and limp. Shaking or mouth-to-mouth resuscitation revives the baby. This is called an apparent life-threatening event (ALTE). During an emergency room visit, tests are performed to determine the cause. When nothing can be found, the baby is sent home. Very rarely, the baby will have another such event. When the baby gets to be older it outgrows these events completely and it is unlikely that there will be any bad consequences.

There is no reliable test to predict which baby will die of SIDS or which baby will experience an ALTE. Sometimes babies with ALTE are sent home with an apnea or event monitor. These are instruments that sound an alarm when either the breathing or the heart stops or slows down. While this provides parents with a warning, such instruments do not prevent SIDS. In some countries such as the United States such instruments are used rather often, in other countries such as England or the Netherlands, such instruments are seldom used. This is not because they are not available but because doctors and families are not all convinced that they are useful.

Grief and mourning are inevitable after a baby dies. This booklet contains a long chapter on what are normal feelings



and how others can help when a baby dies. It is important to involve surviving siblings in the rituals that help adults come to terms with a death. Children need to be told the truth. In the United States and many other western countries there is support available for parents who lost an infant to SIDS. The most important are parent groups and public health nurses who devote themselves to grieving parents. Specific resources can be found in the back of this booklet. Having another child might at first seem a way to find comfort, but it is generally agreed that a new baby can never replace the one who died of SIDS. Experts as well as parents with experience counsel that it is better to wait awhile before becoming pregnant again.

There is an irony with SIDS research. Despite the millions of dollars in research spent over three decades, worldwide, we still don't know the cause of SIDS. Yet, a simple measure, *placing babies to sleep on their backs*, has decreased the rate of SIDS by more than 40 percent. Thus, despite our lack of understanding about the cause, the chance that your baby will die is considerably less than 30 years ago. That is good news for all parents, and especially rewarding for those parents who lost a baby and who have in the past worked hard to help solve the riddle of SIDS.

There is also good news for scientists: First, this decrease in SIDS has given us

new clues where in the brain we might look to find the cause. Second, our technology is improving with leaps and bounds. Computer technology has brought new ways to scan the brain and organs, to discover what areas are active during sleep and arousal and how these develop in fetal life and infancy. Moreover, this technology has given us ways to look at smaller and smaller parts such as nerve cells, **enzymes**, **chromosomes** and **genes**, all of which work together to sustain life. Abnormalities that might not have been picked up in the past may now come to light.

At present, the mechanism of death, that is whether the heart or the breathing stops first, is not known. We also do not know what the cause may be for either heart or breathing problems. Ultimately there may be more than one cause. The Federal government and a number of private agencies are funding many research programs here in the United States. Doctors at universities in other countries are also at work to solve the mystery of SIDS.

# Dedication

**T***O SOME PIONEERS IN SIDS RESEARCH:*  
Marie Valdes Dapena M.D., Sydney Segal M.D.,  
Bruce Beckwith M.D., Abraham Bergman M.D. and  
Richard Naeve M.D.

## Practical Information

### A. WHAT IS SIDS?

SIDS refers to the sudden, unexpected death of an infant, which cannot be explained by the infant's medical history or by a thorough **death scene investigation** and **postmortem examination**.

A postmortem examination is also called an **autopsy**. A coroner or pathologist will perform this examination after death.

SIDS is also known as **crib death** and occasionally **cot death** because about 80 percent of its victims are found dead in their crib. The majority of SIDS babies are discovered in the morning, while others die during a nap. However, SIDS can also strike while an infant travels in a car or is at the grocery store with a parent. Babies have even died while in the arms of a family member or just after a well-child visit to their pediatrician. With more parents working outside of the home, an infant may die while in the care of a baby-sitter or at a daycare center.

### B. THE CAUSE OF SIDS IS UNKNOWN

Death due to SIDS is silent, appears quick and is probably painless. SIDS can neither be explained nor prevented. It is neither contagious nor inherited. The baby who will die of SIDS cannot be identified ahead of time.

Babies may be found on their tummies, but also on the side or back. Frequently their face is down, but they are also found in other positions. There are certain physical signs that may be present when a SIDS baby is discovered. These include: frothy fluid in the mouth and nostrils, sometimes tinged with blood, soiled diapers, blanket fibers clutched in the infant's hand and a small amount of vomit on the baby's mattress or bedding.

This often prompts parents to ask: "*Could he have died from choking on his vomit?*"

While vomiting can occur in the process of dying, it does not cause death and certainly does not cause SIDS.

Parts of the baby's body may look bruised and discolored. This is called **post-mortem lividity**. When the heart stops, the blood tends to settle in the lower parts. This discoloration normally occurs after death and has no relation to bruising before death.

**C. *WHAT EVENTS WILL HAPPEN RIGHT AFTER A BABY DIES OF SIDS?***

SIDS is baffling because it happens so unexpectedly. It is impossible for parents or caregivers to prepare themselves. In addition to the loss of their baby, parents must contend with visits from the police, coroner and paramedics. A SIDS death may be the first major loss encountered by young parents. For many families, especially those who have recently come to this country, the experience can be especially confusing and frightening. Parents usually blame themselves and anguish over what they might have done differently to prevent the SIDS.

Most babies, who die of SIDS, die at home. In most cases, a parent or another family member calls the paramedics upon discovery of the baby who is not breathing.

In Los Angeles, and many other large cities, when the paramedics are called, police are automatically notified as well. Both may arrive at almost the same time. Paramedics will either immediately try to resuscitate the baby and transport her to

a local hospital, or, if they determine that the baby has been dead for a while, summon the **medical examiner** or coroner to the home.

In some states a death scene investigation is mandated for all unexpected infant deaths. It is the duty of the police to question the parents and anyone else who was present, about the circumstances surrounding the death when the baby's body was discovered. The purpose of this investigation is to determine the cause of death and look for things that might explain why the baby died, such as illnesses or accidents as well as child abuse, neglect or murder. Understandably, this can be a trying, painful and seemingly insensitive experience for parents.

Upon their arrival, investigators from the coroner's office search the home and examine the baby. When the coroner's investigators leave the home, it is necessary for them to take the baby's body with them so that a pathologist can perform a state-mandated autopsy.

If the paramedics or parents transported the baby to the hospital, the experience of the parents may be different. Upon arrival at the hospital, the child is typically rushed to the emergency room, where a medical team makes an attempt at resuscitating the baby. This is a particularly difficult time for parents. They are separated from their baby and uncertain about the baby's condition. If it is determined that the baby cannot be resuscitated, hospi-

tal personnel will notify the coroner's office so that an investigator can be assigned to the case.

The thought of having their baby autopsied creates feelings of fear and anguish in parents that should be acknowledged and respected. Mothers and fathers have scarcely had time to deal with the fact that their child has died.

*"Everything has gone so fast, we have barely had a time to say good-bye to our child, it appears that there will be no time in the hospital either. People in the hospital are ready to wheel our baby out to the morgue and from there to the coroner. When will we get time to hold the baby for a last good-bye? How will he look when he gets back from the coroner, will we still get a chance to see the baby? Will we want to see the baby then or will that be too frightening?"*

These are questions that race through a parent's mind. Zoë Smialek<sup>2</sup>, a registered nurse with many years of experience dealing with bereaved parents, suggests that prior to the autopsy parents should be given an opportunity to spend time with and to hold their baby whether at home, in the hospital or at the coroner's office. She also recommends that families be prepared for the differences they may notice in the appearance and feel of the child:

*"One adolescent girl, her mother, and her aunt came to the Medical examiner's office to identify her baby. They all expressed the desire to hold the baby again. After I explained to them that the baby would no longer look or feel the same, they still wanted to do this. Therefore I prepared the child and accompanied the family to view their child. They spent one-half hour with their baby, holding her, rocking her and talking to her. All four of us were crying as the mother talked to her baby about all the things she wanted for her child and what she thought she would be when she grew up. What impressed me the most about the situation was that initially, as she was talking to her baby, she said things like, 'You know Mummy loves you, don't you, Sweetheart? You know I take good care of you'. And then as time went on, she changed to the past tense and said to us 'I took such good care of her, and I loved her so much.' It was as though she finally realized the reality of the situation. They all then kissed the baby good-bye, hugged me and went home."*<sup>2</sup>

Parents should not hesitate to ask to be with their baby for the last time. According to a number of SIDS parents, this experience can be at once comforting and a helpful first step in the grief process. Of course, some families will choose neither to see nor hold their baby again, and this choice should also be respected.

<sup>2</sup> Quotes from an article by Ms. Zoë Smialek, published in *Pediatrics*, volume 62, 1978, pages 160-165

## D. HOW IS THE DIAGNOSIS OF SIDS MADE?

### 1. DEATH SCENE INVESTIGATION

Determining the cause of an unexpected infant death begins with a **death scene investigation**.

*“A teenage mother watched television until 3 am and fell asleep holding her infant. The mother was suspected of drug use. The description of mother and infant positions on awakening was unclear. No autopsy was performed. Diagnosis: “suspected overlying.”*

This statement comes from a study entitled “Death Scene Investigations in Sudden Infant Death”<sup>3</sup> which appeared in a scientific journal in 1986. In New York, investigators from the coroner’s office went to homes where a baby died and reconstructed how the death might have happened. All the babies they investigated were born to mothers who were living in poverty. Several of these mothers slept in the same bed with their babies. This account lacks convincing information that the baby described above died as a consequence of the mother rolling onto the baby, thus causing **suffocation**. The mother was “suspected” of drug use but the charge was not substantiated, and the baby did not receive an autopsy. Probably the infant died silently of SIDS. This example underscores the importance of proper investigation when diagnosing an infant death.

Most authorities recommend a careful review of conditions surrounding the death.

Officers may scrutinize bedding, clothing and even remove some as potential evidence. They will be interested in the presence of alcohol or illegal drugs. Information from a properly conducted investigation can be helpful in ruling out child abuse. A good death scene investigation can prevent superficial, prejudiced conclusions as reported above.

The death scene investigation is followed by a review of the infant’s medical history and, finally, an autopsy.

### 2. AUTOPSY OR POSTMORTEM EXAMINATION

To search for clues about the cause of death the baby’s organs, such as the brain and lungs as well as samples of blood and urine, are examined. An autopsy protocol has been developed in California and is now being used nationwide and internationally. This protocol encourages the gathering of complete and consistent information for diagnosis and future research.

Pathologists, doctors who actually perform the autopsy, may differ in their opinion about the cause of death especially when traces of pneumonia are present. If a baby was healthy before death, most pathologists will cite SIDS as the cause of death, even if they note a touch of pneumonia in the lung. However, some pathologists who have less experience with babies may offer a diagnosis of **interstitial pneumonia**, instead of SIDS even if only mild signs of this disease are present.

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<sup>3</sup> Quotes from an article by Bass, Kravath and Glass in *New England Journal of Medicine*, volume 315, 1986, pages 100-105.

Coroners assign the official cause of death. While some coroners receive specialized training in the causes of infant and child death, others have more general training. This may cause differences in the diagnosis of SIDS. Most coroners in the United States will assign the cause of death to SIDS if there are no findings in the brain or other organs that can explain the death.

Death from SIDS is assigned after other causes have been eliminated.

Not all sudden, unexpected infant deaths are a result of SIDS. Some deaths are the result of **meningitis**, **cerebral hemorrhage** (bleeding into the brain), and **pneumonia** or, rarely, a drug overdose or child abuse.

The initial findings from the autopsy will usually not be available for 24 - 48 hours after the baby's death. In most cases, parents can receive preliminary information from the coroner's office about the cause of death within 72 hours because often a positive diagnosis of SIDS can be made at that time. However, sometimes more extensive testing is necessary which can delay information about the diagnosis. Nowadays, microscopic slides are made and examined and **toxicology studies** are usually performed. Therefore the Death Certificate with the final cause of death may take 2-3 months before it is sent to the parents.

### 3. INFANTICIDE

**Infanticide**, a special term for homicide in an infant, is a frightening issue for everybody including health professionals. *Very few people fail to respond with indignation and anger when they see a baby mistreated, no matter what the circumstances. Parents of children, who later turned out to be abused, were often as upset as parents of children who died naturally<sup>2</sup>. These parents deserve compassion and need our professional help. More importantly, it is unwise to jump to conclusions. Given the prevalence of SIDS, in most of the cases if we assume a child was abused we will be wrong. Parents may arrive disheveled, unshaven and confused. It is important to realize that because of the crisis they ran out of the house without the usual care. If they show anger when asked to give permission for an autopsy, and shout: "Don't you dare touch my baby! Or, "You are not cutting my baby up," they are expressing their shock, fear and confusion and in a sense their disbelief; perhaps the baby still lives. Their shouting does not prove anything about their guilt or innocence.*

In California and other states, an autopsy is performed by law or at the discretion of the Coroner. Parents are not asked permission.

In cases where infants die suddenly, the physician and coroner must consider infanticide. Parents should realize that the authorities do not wish to torture them

<sup>2</sup> See page 13.

during their grief, but an investigation of the death must be carried out.

Infanticide by suffocation cannot be easily differentiated from SIDS at autopsy. During the autopsy the pathologist checks for bruises, broken bones and other signs of trauma. The pathologist also looks for traces of poisons or drugs in the infant's blood or urine and on samples of clothes and bedding. A properly conducted death scene investigation may help with the diagnosis as well. While the majority of infants who die in the first year of life are either SIDS, victims of congenital defects or accidents, a small number are the victims of murder, or infanticide. Currently the best estimate of the incidence of infanticide as compared to SIDS is one in 35 SIDS deaths but this number remains an estimate.

#### ***E. INFORMATION ABOUT FUNERALS***

Parents may choose to have their baby either cremated or buried. Increasingly, people are turning to **cremation**. Burial entails a cemetery plot, casket and, possibly, a grave marker. These items can vary considerably in cost and parents are encouraged to contact more than one funeral director when making a choice. Additional information is provided in Appendix 1.

Whether a baby is buried or cremated, **mortuary** personnel will transport the baby from the Coroner's office to the mortuary. The Coroner's office is responsible for issu-

ing the death certificate. The Coroner's office will want to know the name of the mortuary you have selected. If parents lack money for a funeral, the coroner can help with arrangements to cremate the baby. After the cremation, the coroner will often store the baby's ashes at some cost, until the family can afford to pay for the cremation.

Parents often ask whether the autopsy causes damage to the baby that later is visible should the family choose to have a viewing for the funeral ceremony. Typically, the baby's clothing conceals incisions due to the autopsy, especially if a bonnet or cap is used to cover the baby's head. It is always a good idea for families to notify the coroner if they plan to have an open casket.

#### ***F. HEALTH DEPARTMENT VISITING PROGRAM***

In California and other states in the nation, local Public Health Departments have initiated programs to assist parents who have lost an infant to SIDS. Public health nurses visit parents in their homes within a few days after the death and provide information about SIDS and grief counseling. The purpose of this visit is *not* to investigate the cause of death or the parents' behavior.

While visiting the family, the nurses also inquire about the baby's health prior to death and assess how the family is adjusting. Parents may be offered a number of



services or referrals if the nurse deems this necessary.

To date almost all states in the US have an active SIDS counseling and visitors program as part of their Public Health Department. Public Health Departments also function as a clearinghouse for SIDS information. The Black Infant Health Program of California has the goal of reducing deaths of African-American infants, including deaths from SIDS. For addresses see Appendix 2 and 3.

**G. *WHERE CAN I GET MORE INFORMATION AND HELP?***

Many SIDS parents feel that only another SIDS parent can understand their grief. This fact has led parents to form two national organizations, with chapters in many communities: The National Sudden Infant Death Syndrome Foundation and the Guild for Infant Survival (GIS). For the past several years,

these two organizations have collaborated on a national level under the name: First Candle/SIDS Alliance. Both organizations have been very important in drawing attention to SIDS, in educating the public and professionals, in stimulating funding for research and, most importantly, in helping parents cope with their loss. The First Candle/SIDS Alliance is an invaluable source of information and we strongly recommend contacting them at 1(800) 221-SIDS (7437). For other resources see Appendix 3.

Research projects dealing with SIDS are carried out in several universities across the United States and abroad. By contacting a large university close to you, you may find helpful people who can give valuable information. Thus far, when contacted at USC, we have been able to provide interested individuals with a reply. We have every intention of continuing this service and urge you to contact us at the address printed on page 86.



## SIDS and Grief

*Forget Me Not*

*The little one  
no longer here  
comes quietly in  
the morning sun  
reminding me of  
midday walks  
and midnight feedings*

*The little one  
no longer here  
sits quietly in my  
heart  
whispering in my dreams  
forget me not.*

DEBBIE GEMMILL<sup>4</sup>

## A. INTRODUCTION

The feelings and experiences surrounding infant death to be described are typical for many people in the United States and elsewhere in the Western world. However, if you are a SIDS parent who does not recognize your own grieving response, or a health care provider who is baffled by the differences in people's responses to the death of a baby, it may be helpful to know that the perception of and reaction to an infant death can vary between individuals, cultures, ethnic groups and social classes. People's manner of grieving is also impacted by gender, family influences and the unique way in which they view the world.

More than half a million people legally immigrate to the United States every year. In fact, the richness of American culture is a direct result of the influence of the many immigrant groups that have settled in the U.S. The way people deal with death is impacted by their religious beliefs. If you arrived here recently from a Spanish-speaking country, it is likely that you are Catholic. If

<sup>4</sup> Debbie Gemmill, *From a Parent's Point of View*. Ms. Gemmill has published three other books: *Beginning Again*, *The Chance to Say Goodbye* and *Getting Through Grief*. Beachcomber Press PO Box 300578, Escondido, CA 92030-0578.

you came from South East Asia, your religious background is perhaps Buddhist, Hindu, or Confucian. People coming from Middle Eastern and Eastern European countries may be Christian, Muslim or Jewish.

In addition to the people that have immigrated recently to this country, it is important to remember that the U.S. has always been a country of immigrants. As such, many of the ethnic groups that first arrived here generations ago still retain some of the beliefs and practices of their native culture. This would include groups such as Irish Americans and Italian Americans. The ancestors of many African Americans did not come of their own free will. Together with Native-Americans who have lived here longer than anybody else, they have also retained many of their own rituals and beliefs.

Despite the tremendous diversity of the American population, most of what we know about how people grieve is based on research conducted with middle-class white families. While this information has provided valuable insights, it has failed to add to our understanding of what death and, particularly infant death, means to minority populations. While recognizing that it is difficult to generalize, we will begin by exploring the different ways ethnic minority groups in the U.S. may view a SIDS death.

#### 1. WHY DID MY BABY DIE?

Families from non-western cultures may attribute the SIDS to fate or supernatural forces. The Buddhist expression: “*Shikata ga nai*” (It couldn’t be helped) is an example of this. In Hinduism there are three main gods: Brahma, Vishnu, and Mahesh. Vishnu’s wife, the goddess Luchmi is in charge of all babies. Hindus believe in having a past and present life. The death of a baby is believed a punishment of the goddess Luchmi. Perhaps in their past life one of the parents has done something wrong and now the baby has paid the price during his short present life. Hindus comfort themselves, however, with the knowledge that the goddess Luchmi is taking care of their baby in heaven<sup>5</sup>.

In a number of other Asian cultures, a sudden infant death is considered a “bad” death and may be looked upon as an unfavorable omen for their ancestors, themselves and future generations. These views are different from those of many families from western cultures who may seek such answers to why their child died, as “*What caused SIDS*” and “*Why did it strike my baby?*”

Socioeconomic status and how much control people feel that they have over life’s events can also shade how SIDS is viewed. For example, parents that are socially and financially less fortunate might feel less powerful to direct the course of their lives. To them the SIDS

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<sup>5</sup> As told by the grandmother of Natasha Deo

death may be seen as yet another stressor, added to the poverty, substandard living environment and, perhaps, fear of random violence that they experience daily. It is possible that their outward reaction to the SIDS may be somewhat muted. In contrast to this, many middle- and upper class parents who are well educated and financially secure often feel a certain amount of control over their lives. When a SIDS death strikes, they often experience a frightening loss of the control that they believed they had. As a result, their outward reaction to the SIDS may be particularly intense.

## 2. GRIEVING

Individuals from different cultures can exhibit varying expressions of grief. For example, in some cultures crying and sobbing are permitted and even encouraged after the loss of a loved one. This is true for some African-Americans, who are vocal in their grief during the funeral ceremony. By contrast, other African-Americans may internalize their feelings of grief to show strength, especially to their other children. A similar reaction is often found in some Asian cultures where emotional restraint is looked upon favorably.

In some cultures great care is taken to defend bereaved parents from what is perceived as added stress. For example, it may be considered disrespectful to mention the name of a child who has died, as this would inevitably elicit painful feelings in

the parents and surviving siblings. Some Asian mothers are purposely kept from taking part in the funeral arrangements for their children. This is seen as a means of protecting them from even more grief.

## 3. MOURNING RITUALS

Mourning is one way for a person to handle grief. Many religions have rituals that help a person mourn. These rituals may or may not be useful for grieving parents. For instance, in the Jewish community there is the ritual called "sitting Shiva", in the Irish community there is the wake. In both, the family and friends set aside a time for grieving for the beloved one and for helping the immediate family cope with their loss. In African-American families, friends and relatives may gather to testify about the person who died. Good things are remembered and shared openly. In the Japanese community it is customary for friends and relatives to visit the mourning family daily for the first week to offer support and make funeral arrangements. People bring small gifts of money to offset funeral expenses and the mourning family carefully records the names of the people who gave, so that they can reciprocate the gesture in the future. In the Hindu community parents partake in 'pujas' that are held daily for thirteen days conducted by the Hindu priest or pundit. Ceremonies are repeated at six months and one year after the baby's death.

Furthermore some cultures make a distinction between biological birth and social birth. Some people from southern India, for instance, do not announce the birth of an infant until after three months when it has 'proven' it can live outside of the womb. Until that time the infant is not considered a person and its death is not a significant social event. Similarly, among the Ashanti from West Africa, the newborn is considered to stay for about a week in a spiritual world before it enters the human world. Parents are taught not to get attached to the baby and if the baby dies it is considered the death of a spirit-child for whom there will not be any public mourning. There are an estimated 10,000 Ashanti living in New York City alone. Knowledge of differences can help us respond with more sensitivity to people of all cultures<sup>6</sup>.

#### 4. FAMILY SUPPORT

Family tends to play an important role at a time of loss and death. For instance, in Hispanic families an older child, an aunt or uncle may take responsibility for being translators and help with the funeral arrangements and will be the family representative to authorities and medical personnel. The traditional family, consisting of a mother, father and two children has been disappearing and several other family structures are common. Families may be smaller and

consist of a single parent, or larger, consisting of grand parents, cousins, nieces and people who are not related. There may, for instance, be a 'play' brother or 'play' cousins, who are always around, have become part of the family and perhaps took care of the baby who died. Of course, each member of the family whether directly related or not is affected when a baby dies of SIDS.

#### 5. FUNERALS

The funeral ceremony and burial site are important to many families as it allows them to return to the grave. However, for some families the death of an infant is almost like a bad omen, and therefore no attention is drawn to the death or funeral and the burial site is of minor importance. In many Asian cultures, children under one year are cremated.

This section in no way attempts to stereotype the beliefs or rituals of the culturally diverse. Rather, we have attempted to offer examples of differences that exist between people in the way that they react to death and to emphasize that all make sense in the context of their particular culture. This information is important when we now discuss what is considered 'normal'.

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<sup>6</sup> Lynne Morgan, *Christian Science Monitor*, May 1989

## B. WHAT FEELINGS ARE NORMAL?

The death of a child may be the most difficult loss that a parent can experience. When an infant dies of SIDS the loss can be especially devastating because parents and other family members are left without an explanation as to why the baby died. Researchers who study the ways that people react to death have identified certain emotions commonly experienced by people who have lost a loved one. The duration of their grief may vary tremendously. There is in fact a wide range of feelings experienced by SIDS parents and caregivers that can be considered normal. While roles of mothers and fathers have changed dramatically over the past decades, there are still differences between men and women in reactions to death. Although many people will recognize themselves in the description of the grief process that follows, we have included a special section for fathers. In many circles, fathers are still expected to respond in a more controlled fashion than mothers (see Section C, page 26).

### 1. PANIC

Panic can be one of the first emotions that parents experience. Upon first finding their baby not breathing and lifeless, parents or caregivers may not know what to do. Two SIDS mothers described their initial reaction:

*"Your mind is racing back and forth and you ask yourself questions without being able to answer them."*

*I didn't know what to do, I grabbed my baby and hid with him behind the couch."*

### 2. DISBELIEF

Another very common reaction is disbelief. It is difficult for parents to grasp that their baby has died; especially since SIDS babies typically appear healthy prior to death.

*"There was nothing wrong with him. Last week I took him to the well-baby clinic and the nurse said he had grown really well."*

### 3. SHOCK

Some parents of SIDS victims have reported that they had no memory of the moments immediately following the discovery of their baby. They were numb and in a state of shock. They found themselves scarcely able to explain either how the infant was transported to the hospital or their interactions with paramedics, doctors or nurses. Unfortunately, the effect of shock sometimes can have negative consequences. For example, a mother from Milwaukee, when asked by the police how her baby died, responded:

*"I suffocated my baby with plastic."*

As it turned out, she had left a hard plastic shopping bag next to the baby, not the kind that can suffocate an infant. The police, who did not recognize her state of shock, arrested her<sup>2</sup>.

#### 4. GUILT

Guilt is the self-blame common to people who lose someone they love. It can be extremely intense in parents and caregivers of SIDS babies. They often blame themselves for the infant's death despite numerous attempts by health professionals to convince them that nothing they could have done would have prevented the SIDS.

*"Why didn't I take my baby to the doctor when she had such a stuffy nose?" Or, "I shouldn't have left her with the baby-sitter" or "We shouldn't have had that party yesterday, I would have awakened earlier, and I would have heard him struggling perhaps."*

Guilt may also be induced by poorly informed individuals, relatives or neighbors, who imply that SIDS might have been prevented had certain precautions been taken such as not taking the baby out at night or along on the family vacation.

Some feelings of guilt are harder to shake off than others. For example, mothers who co-sleep with their infant may believe that they caused the SIDS by rolling over on the baby.

*"I slept so deeply.... did I really not roll over on my baby? Perhaps I did cause the death of my child..."*

Unless a mother is under the influence of alcohol or some prescribed or illegal drugs, it is highly unlikely that she would ever roll atop her baby. This is because healthy babies do cry or struggle and awaken their mother should their breathing be restricted.

#### 5. SADNESS

Once the panic, shock and disbelief of the baby's death begin to wear off, most SIDS parents and caregivers report a feeling of profound sadness. This sadness may last for a period of weeks, months, years or even the rest of their lives. Parents have reported that the sadness often comes and goes in waves and varies greatly in intensity. Some parents experience strong feelings of helplessness, hopelessness and loss of meaning in their life. One mother writes:

*"I felt forlorn.... totally lost...I had always been a fighter...but now I was helpless...life lost its meaning"*

#### 6. ANGER

Losing a healthy infant suddenly and without any warning, can cause more than shock, guilt and sadness, it may also cause anger. Some of the anger stems from pain, some from misunderstanding

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<sup>2</sup> See page 13.



and confusion. Sometimes parents find themselves angry with the police for initially considering them as suspects, the paramedics and doctors for not trying harder or God for taking their baby. Sometimes, mothers and fathers even direct their anger towards one another.

*“You didn’t want this baby!”, or, “Why did you pressure me into going to that party yesterday?”*

*“My husband wasn’t the man I thought he was. He let me down. He didn’t prevent this death. He didn’t spare me this pain.”*

Occasionally, parents suspect, albeit fleetingly, that other children in the home may have contributed to the baby’s death. This is especially true if the other children were nearby when the baby died. Such thoughts are often fostered either by anger or out of desperation to find a cause for the baby’s death.

*“I found the baby covered by a blanket, perhaps my three year old put the blanket over Mary’s face.”*

*“Peter seemed so jealous of the new baby, he often threw a tantrum, especially when I was feeding his brother. To tell you the truth, for one split second I thought he had done something to him. Of course, that’s unreasonable, he is only two. He cannot even reach the crib.”*

Well-meaning friends or family may not know how to respond to pain and sadness. Without thinking they may ask questions that suggest that parents did something wrong.

*“Why did you take David shopping yesterday? It was so hot (or so cold) outside?”*

This seemingly innocent question contains, in truth, an accusation that makes parents understandably angry.

Silence can also cause anger. The apparent ignoring of death can be a cause of pain and anger. Some people simply don’t know what to say when others are in pain. This may include the doctor, who seems to avoid the parent’s eyes. All doctors feel guilty for not being able to prevent the death of a baby and some have trouble contacting their patients after hearing about the death from SIDS. They have to come to terms with their own feeling of frustration, uncertainty and sadness before they can sit down and talk with parents and help them.

## 7. PHYSICAL REACTIONS

It is not uncommon for parents to have physical reactions such as hollowness in the stomach, tightness in the throat or chest, muscle weakness and dry mouth. It is also not unusual to have distinct visions of the baby, to see the baby briefly as if he had not died. Some

parents may have trouble sleeping or have emotional and painful dreams about either hearing the baby cry or seeing him. Many parents have recalled not wanting to get up in the morning and finding that nothing interested them anymore. Aching in the arms is a common complaint in SIDS mothers who suddenly are deprived from holding their baby. Some have gained weight from an increased appetite, while others have lost weight because they were unable to eat. Many parents become nervous and irritable. All of these are signs of normal grieving.

*“When my baby died, I went into my bed and couldn’t move or eat, I couldn’t even sleep. I kept hearing him cry, but I knew that he wasn’t there.”*

### **C. DO FATHERS REACT IN THEIR OWN WAY?**

It is now common for fathers to be present in the delivery room and to be actively involved in the baby’s care once home. When a baby dies a father can be deeply affected. Consequently, what has been said about grief is true for mothers and fathers alike. Some of the major differences follow, but may not apply to everybody.

Fathers often keep their feelings to themselves, especially when strangers are

present. This is in contrast to mothers who are expected and encouraged to express their feelings openly. So while mothers may cry freely, it may be more difficult for fathers to do so. Right after the death, the situation demands that a number of decisions be made and practical problems solved. Many men see their role in the family as rising to this challenge:

*“After all, someone has to keep it together....”,* they might say.

*In those first days afterward, Dessa was a zombie and I was Management Central- the one who dealt with the coroner and the cops and all those casseroles people kept bringing to the door. The covered dish brigade. Most of that stuff just sat in our refrigerator and went bad; we couldn’t eat.<sup>7</sup>*

Men may have more trouble talking about the baby’s death than women. They often fail to see any benefit from speaking about the deceased baby with friends, colleagues or professionals. Many fathers feel that no one can possibly understand their loss. This is especially true once a few weeks have passed, when they may prefer not to bring up the painful topic. Three fathers described their feelings:

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<sup>7</sup> Wally Lamb, *I Know this Much is True*, excerpts from a novel, used with permission.

*"Talking doesn't bring the baby back",*

*"No one else can know how you feel and unless they have suffered a similar loss, they can't begin to really comprehend a baby's death."*

*"Sometimes at supper or up in bed, Dessa would try to talk about her feelings. Talk about Angela. Not at first. Later. Three or four months afterward. "Uh-huh," I'd say. "Uh-huh." She'd want me to open up too. "What good would it do?" I told her once. We'll talk and cry and talk some more, and then she'll still be dead. I stood up and walked out of the room—got the f— out of there before my f— head exploded."*<sup>7</sup>

While some SIDS fathers might project a controlled external appearance, internally they suffer and struggle with the death of their child just as much as the baby's mother. As society begins to encourage more open displays of emotion in men, it will become easier for fathers to express their feelings through actions, words and even tears. This is healthy and to be encouraged.

Employers often expect bereaved fathers more than bereaved mothers to return to the job fairly soon after the death and function within a very short time span as though nothing had happened. One father relates:

*"Your company supervisors and peers may say: 'You will recover on your own schedule' or, 'Time heals all wounds' and other cliches. However, your company allows only five days bereavement, if you are lucky..."*

While five days or even two weeks may not be a very long break from work, the fact is that many men cope with death by "keeping busy." Bereaved men tend to direct their attention *outwards*, while bereaved women tend to turn *inwards*. A father may seek additional work, return to school, build things, or involve himself in tasks that require extra energy like hobbies or sports. It is important for both mothers and fathers to acknowledge these differences in coping styles.

*"My boyfriend didn't say a word all that first week. He puttered around the house and took my daughter to the store grocery shopping. And then sometimes, he just disappeared; I don't know where he went. Normally he didn't do that. I finally burst out: 'You don't care.' I suppose that wasn't true, but I was so upset."*

<sup>7</sup> See page 26.

David Delgadillo, a SIDS father from San Diego has written a number of suggestions to help men cope with the tragedy of SIDS.<sup>8</sup> The most important ones we include here:

- Talk to your family. Spend time together with your wife and your children. Let them know you are doing what you are able to do; that you want them to help.
- Have quality “alone” time. Sort out the millions of questions tumbling about in your mind. Figure out the “What’s” and “Why’s.” Gradually answers will come. Consider the use of a journal and write down your thoughts. As the days go by, read what you wrote before.
- Decrease social activities. Many men will look for new hobbies or social activities. This only serves to take time away from grief work. Back off from added responsibilities. Remember, you really cannot back away from memories. Give yourself the time that is needed for grief.
- Cry. Crying is an effective way of dealing with the painful emotions of grief. Many men will have difficulty with crying. Crying actually makes one feel better as though some tension has been released from within the body.
- Express anger. Express your anger in constructive ways. Ignoring anger does not make it go away. Anger can be expressed in physical ways that are not harmful to yourself and others. Exercise is one. Body movement and the awareness of how you feel during such movements may be helpful.
- Find a support system. This could be the hardest for a man to do. To admit to others that he needs help. I think it is easier to do if you look for other bereaved fathers. Fathers who have gone through the same thing you are now experiencing. Parent support meetings may also help to see how other families in various stages of grief are coping. What a support group gives to you is the knowledge that you are not alone-others have been there also.

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<sup>8</sup> As reported in the bulletin of the San Diego Guild for Infant Survival

**D. DOES SIDS HAVE AN IMPACT ON THE RELATIONSHIP BETWEEN MOTHERS AND FATHERS?**

The death of a child from SIDS can be a serious threat to a relationship, sometimes leading to separation or divorce. One reason for this may be that SIDS tends to occur in younger couples that are inexperienced in dealing with family crises. A father may wonder about his girlfriend or wife's ability to care for the

other or subsequent children or about his own ability to be a good parent in the future. It is essential for parents to realize the importance of increased communication at this critical juncture in their lives. To ignore this is to chance that their relationship will suffer.

Debbie Gemmill describes the support that she and her husband, John, derived from Guild meetings and how it probably helped to save their marriage:



*In this period of time between Mother's and Father's Days, I am thrown back in time. It was during these same few weeks that John and I suddenly became bereaved parents. On Mother's Day I happily opened gifts from two children; on Father's Day John sadly opened just one. Each Father's Day since has been a reminder to me of just how differently Ty's death affected each of us.*

*It is so easy for people to make flat statements about other people's grief. "If they really love each other, they can get through this." "If their marriage falls apart, there was something wrong with it to start with." "Something like this can really make or break a marriage." The feeling was that this was somehow a test of our love-if we survived then we won. Frankly we weren't up to a test. We had lost enough already.*

*As you have undoubtedly realized, everyone must bear his own pain. It is just not true that you can share it- wouldn't we all give it away if we could. I didn't know it then and what I wanted the most was to share my pain with John, and to take some from his aching heart. What we learned was what Harriet Sarnoff Schiff says in "The bereaved Parent: "A common grief is not the best possible adhesive to cement a marriage." That is a shocking disappointment to realize when you are reaching with desperate fingers from opposite ends of a sinking lifeboat. I had expected John to be his usual "tower of strength." He had expected me to be my usual organized self, to somehow put this in order. Under the weight of our individual sorrow we failed miserably at these roles we had, up till then successfully filled...*

*...The most helpful thing for our marriage was the availability of Guild Meetings. John quite honestly, went only because I asked him to, but there he learned things that helped him understand my grief. He heard other mothers describe their aching arms and he saw that I wasn't going crazy. I was grieving in a pretty usual way. I learned the same sort of things about his grief. I saw how much harder it was for the dads to express their pain. And I listened to other moms talk about the dads who weren't at the meeting, how they grieved in a solitary way, how they didn't want to talk about it, that they just grieved differently...*

*Our marriage survived our grief, and yes, I guess I'd have to agree that it was strengthened as a result. I believe the strength came largely from the realization of our differences and the acceptance of them. It was not an easy road to travel, but how glad we were when we came to the end of it and found that we were together. As Schiff says: "Value that marriage. You have lost enough."*

Debbie Gemmill in "From a Parents point of view"... Grief and Marriage"<sup>4</sup>



If misunderstandings are not addressed with promptness, negative feelings may fester and lead to isolation and pain for both partners. There is a danger of becoming a prisoner of one's own feelings. However, this does not have to happen. Experts agree that a crisis such as the death of a child can provide the opportunity for the growth of both parents and their relationship. In fact the vast majority of couples remain together despite the death of their child.

It is essential to realize that when a SIDS death occurs parents simply cannot always be there for each other. So it is important to have other people to talk to. Neither mothers nor fathers can protect one another from feelings of

sadness and anger. In fact, displaying these emotions in front of one another actually can be healing and help in the grief process.

*"Sometimes I'd wake up in bed in the middle of the night and hear Dessa in the baby's room, sobbing. One night I heard her talking to Angela-murmuring baby talk down the hall. I sat up and listened to it, telling myself that only a complete and total son of a bitch wouldn't get out of bed, go down there and hold her, comfort her. But I just couldn't do it. Couldn't quite make my feet hit the floor, no matter what basic human decency was ordering me to do."*<sup>7</sup>

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<sup>4</sup> See page 19.

<sup>7</sup> See page 26.

Couples may experience changes in their desire for sexual intimacy, with the possibility of either one losing interest. This might not be true immediately after the death, but may emerge a few months later.

Another possible area of conflict arises when one parent wishes to move from the home where the baby died, while the other wishes to stay because of earlier happy memories of the child. Apparently, the majority of SIDS families move within two and a half years after the death. However, young parents probably move often whether or not they lost a child or not. So the significance of this finding is not certain.

Many couples who have lost a baby to SIDS find that short-term counseling during the initial months after their child's death is of tremendous benefit to their relationship.

#### ***E. WHEN PARENTS ARE TEENAGERS***

A nationwide survey of SIDS deaths revealed that 25-30% of parents of SIDS babies are teenagers. At the time of the report in 1997, only one in ten SIDS programs had specialized bereavement programs for teen parents. Such programs should be initiated at least in large cities.

#### ***F. HOW ARE SIBLINGS AFFECTED?***

After the sudden death of an infant, parents can become preoccupied with the practical measures that need to be taken and by seemingly uncontrollable and overwhelming grief. Under these circumstances, it is not unusual that the other siblings in the family may fail to obtain the extra attention they need at this time. Children may feel that they have temporarily lost their parents. This is regrettable because they have their own special fears, feelings and questions following a family death and, especially that of a new brother or sister.

Additionally, children are confronted with their parents' open and over whelming sadness, something they may have never encountered before. This can result in feelings of confusion and helplessness. Small children may wonder why they are not able to make Mommy and Daddy smile like before. The manner in which children perceive and deal with the loss of a sibling to SIDS depends upon their age and stage of development. As children develop, their understanding of death changes. Thus they will re-experience the death of their sibling in new ways as they gain knowledge. Therefore parents need to be aware that they may well have to explain the death more than once to their children, as they grow older. Parents who have difficulty in talking to

their children or are too distressed to deal with their children's emotions should ask for help. This is available from their minister, rabbi or doctor. Local Public health nurses and SIDS parent groups also provide invaluable assistance.

Examples of how young and older children may react, follow.

### 1. PRESCHOOLERS

Very young children, before the age of five, are not able to comprehend that death is a permanent condition. As a result, their manner of dealing with the loss of their sibling will vary considerably from others in the family. For example, it is not unusual for small children to ask whether they can go out and play with their friends immediately after the death of their sibling, as though nothing had happened. For them life continues as usual. For parents, it is helpful to understand that it is normal child development and not a lack of love for the deceased sibling that causes small children to react the way they do.

While on the surface it may seem as though small children readily return to normal, they may harbor feelings that will need to be addressed. What child has not experienced sibling rivalry and jealousy towards the new baby who appeared to demand all of Mommy's attention? It is possible that the same child may now feel guilty and assume that she somehow caused the death. Children of this age

need to be told in a calm and direct way that it was not their fault. In addition, they may also fear that they too will be suddenly taken away, like their sibling who died of SIDS. It is important to reassure small children that nothing like that will happen to them or to their Mommy or Daddy.

Children should be told about death at a level that they can understand. After being told that her playmate won't be able to play with her anymore, a four-year-old child may ask:

*"Where did he go?"*

She should be told that he died, which may be explained by saying:

*"Jimmy's body stopped breathing and his heart stopped beating."*

The disposal of his body may need to be explained.

*"His body will be put in a small box and he'll be put in the ground."*

She might further inquire: *"How is he going to go potty there?"*

It can be explained that people who die do not need to go potty anymore.

This may be the time to discuss your religious beliefs in a way that your child can understand. Children are likely to ask questions such as *"when is the baby*



*coming back?”* In actuality, they will probably have to be told more than once that the baby will not be returning. It is fine and often desirable to involve the child in questions about the baby, such as:

*“What do you remember best about Mary?”, or, “Mary won’t be back, but we can tell her how much we love her. Is there perhaps something that you really liked about her and would like to say to her?”*

Looking toward the future, you might want to say:

*“Things are going to be different now that Mary is gone. We will put her crib and toys away, but we won’t forget her and the way she made us laugh. I’m going to cry sometimes and I’m going to miss her. What will you miss the most about her?”*



*...As a four-year-old, Jennifer had asked countless questions about Tyler’s death from SIDS, but most of her worries revolved around whether or not she too would die. I did the only thing I knew to do. I told her over and over again in firm words that no, of course not, she wouldn’t die. I recall holding my breath and crossing both my heart and my fingers as I said those words. There were so many things Jen asked I had no answers for. Why did Ty die? Did it hurt? Where is he now? Is he in heaven? Where is heaven? She was asking the same questions I was.*

*...I allowed many of her fantasies mostly because I didn’t have enough truth to disprove them. Together we decided that Heaven is not cold, has no mailboxes, but does have plenty of toys for babies to play with. We were doing okay skirting the big issues until the day she asked me “why do babies die?” There was no fantasy, no half-truth I could offer. There was no way around this one. “I don’t know?”*

*“Does it make you sad, Mommy?”*

*“You bet.”*

*“Me too.”*

From A Parent’s Point of View, From: *Getting through Grief, Surviving Siblings*, reprinted with permission<sup>4</sup>



<sup>4</sup> See page 19.

You may notice changes in your children's behavior reminiscent of when they were younger. They may seek reassurance by staying close and wanting to be held or carried. Some children who were dry at night before the death may now slip back into bedwetting or they may again ask for a bottle. In one study, parents indicated that children were more likely to have temper tantrums. One mother said:

*"I was just so exhausted and it just seemed at home Jenny would do anything to stir up my anger"*

Changes of behavior may also emerge in kindergarten or nursery school where a child may become unusually quiet, boisterous or even aggressive towards playmates. One mother relates:

*"She became so mean to her little sister and hated all babies, regardless of their gender or relationship to her. She even became angry when watching TV. When I asked her why, she says, she 'wants her (deceased) brother back.'"*

The majority of young children will show some changes in their previous sleep patterns. Some may refuse to go to bed at their normal time or in their own bed. They may awaken from nightmares. Some parents will choose to let a young child sleep with them, but later may

have some problems with getting the child to sleep in her own bed again.

*"Kate always went to bed around eight o'clock after her dad had played with her; now after Carin's death I couldn't get her to settle down, sometimes until midnight. She would beg to sleep with us."*

Here is another response:

*"Since the baby died, my 4 year old always trails behind me; he even climbs into bed with us in the middle of the night."*

Reassurance and cuddling will often help the child adjust. Surveys have shown that most behaviors, such as withdrawal or acting out will disappear spontaneously. If, however, these behaviors persist for several months, it may be wise either to speak with the family pediatrician or to seek the short-term services of a counselor. There is also the special case of a surviving twin. The baby may be restless for a few days or lose weight. Occasionally, a twin may have trouble adjusting to the excess breast milk.

## 2. GRADE SCHOOL CHILDREN

All children, regardless of age, who experience a SIDS death in their family, require extra attention in the weeks immediately following the loss. Reassurance that the remaining family members are safe and will remain together will provide a sense

of security. It is fine for parents to use the words “death” and “died” and to cry and to show their feelings. This teaches children that it is acceptable and even helpful to express their emotions. Children will ask concrete questions and should be given honest answers. Most parents will eventually choose to discuss the meaning of death with their children and will be guided by their personal, social and religious beliefs. Other adults, such as uncles or aunts can be helpful too, especially when parents are too overcome by their grief to properly attend to the children.

**a. Participation in funerals**

Many experts agree that children should be given the opportunity to go to their sibling’s funeral. The support provided by aunts, uncles and friends provides a secure and nurturing environment for bereaved children. Much depends, however, on a parent’s own experience with funerals. Some people have been so frightened by the emotions that may accompany funeral rituals, that they would rather not expose their children to such an ordeal. It is important that children are told beforehand what death is, what the purpose of the funeral is and what to expect during the ceremony. In the days after the funeral it is important to involve the children again in a discussion about what happened during the funeral to clarify their ideas and, if necessary, to help them deal with any fears.

**b. Responses to losing a sibling**

Between the ages of five and nine a child begins to develop the capacity to comprehend the meaning and permanency of death. Children of this age are likely to have a lot of questions about “why” things happen. They will want to know why their sibling died of SIDS and will in all likelihood have trouble with the explanation that there is no known cause for the disease that took their sibling away. These children may feel angry and guilty like adults and respond by withdrawing or becoming moody and throwing tantrums, like the younger ones. For a while they may dislike being alone and become fearful that their parents will also die.

**c. Physical changes**

Changes in sleeping patterns and in interactions with parents or peers may also occur in older children. Physical complaints tend to surface infrequently in the siblings of SIDS victims. However, certain symptoms associated with grief, such as stomachaches or loss of appetite might occur. For that matter, any physical complaint that happens around the time of the SIDS may be associated with the death. In such cases, it is helpful to contact the child’s pediatrician or other health care professional for assistance.

**d. Peer adjustment**

When children go back to school they will have to cope with the reactions of their peers. It may be wise to discuss with them what they would like you to do as a parent. For instance, some children may want you to talk with the principal or their teacher; others may want you to talk with their friends. We recommend that parents contact their children's teachers and make them aware of the death because many children exhibit behavioral changes once they return to school.

**3. TEENAGERS**

- Three ways parents can help:

**a. Dealing with emotions**

After the funeral, when the relatives have returned home and parents begin to resume a normal life, there are at least two ways to help children in the family. One is by not shielding them totally from the emotions that bereaved parents feel. It is preferable to talk about the baby openly with them, even if it causes tears, than to never mention the baby again in their presence.

**b. Awareness of overprotection**

Parents should try not to become over-protective. The loss of a baby may increase one's awareness of how uncertain life is, and, in turn, parents may

find themselves trying to protect the other children from all sorts of real and imaginary dangers. Children, especially the older ones may not understand this. Instead, they may see it as an infringement on their freedom. With time, fear for other children will lessen. Discussing one's fears and feelings with older children and teenagers will go a long way towards preventing problems and misunderstandings.

**c. Peer adjustment**

In the case of teenagers, special care is often required because their friends probably have had little experience with death. Teenagers may be confronted with avoidance rather than support in school. In some cases, they may be embarrassed to speak about their deceased sibling. Open communication at home will surely reduce both the pain of this loss and temporary rejection, should it occur. Parents should prepare their teenagers for these possible reactions and help them to find ways of coping. Despite their nearly adult-like appearance, adolescents are still children and extremely vulnerable to life crises such as death.

**G. GRANDPARENTS**

Grandparents are doubly affected as they worry for the parents, their child, and grieve for the grandchild they have lost. They can be helpful to the parents in

many ways. For instance, immediately after the death, they can undertake the unpleasant job of notifying babysitters, relatives and friends. They can also help with care of siblings. As time goes on, the parents will benefit from being able to talk about their loss more freely and longer with grandparents than perhaps anybody else. It is particularly important that grandparents learn as much as possible about SIDS so that their responses are appropriate.

#### **H. HOW DOES SIDS AFFECT CAREGIVERS OTHER THAN PARENTS?**

If the death occurred while the baby was at daycare or under someone else's supervision, caregivers will have their own feelings of loss, grief, uncertainty and, undoubtedly, guilt. It is important that a caregiver understands that the SIDS did not result from anything that he or she did. It may be helpful and healing for parents and caregivers to spend some time together to grieve the baby's loss. All too often, the needs and feelings of caregivers are forgotten when it comes to receiving information about SIDS and grief counseling. Caregivers may also have special concerns. For instance, he or she might say or think:

*"What if this happens again? Will people think that it was neglect, or worse, child*

*abuse? Will people still continue to bring their children to me? The police coming here to check things out can't be good for my reputation or business."*

When one takes care of infants, there is always the possibility that SIDS will strike at one time or another. If this occurs, caregivers may decide to arrange a meeting with the parents of the other children they care for to discuss the circumstances of the death. For such a meeting, the presence of a knowledgeable healthcare professional or SIDS parent is invaluable. We recommend that caregivers attend at least one SIDS support group meeting and/or information session provided by a Public Health Nurse. Such efforts assist in understanding SIDS and the feelings and reactions of both the caregiver and bereaved parent.

#### **I. WHAT ARE THE EXPECTED LONG-TERM EMOTIONS?**

Researchers have found that families who lose a baby to SIDS vary considerably in the time that they grieve and are finally able to resume normal life activities. In a study conducted in Michigan, a large number of parents were asked about their feelings after a SIDS loss.<sup>9</sup> Most indicated that it took more than a year before they were able to experience happiness in their lives. Investigators also discovered that almost half of the people experienced

<sup>9</sup> Wortman and colleagues studied the grief process in a large sample. For more information see *Journal of Consulting and Clinical Psychology* volume 57, 1989, pages 349-357

deep feelings of grief for a longer period, up to almost two years. The intensity of the feelings gradually diminished and parents began to adjust to life without the baby who had died. Interestingly, however, a third of the parents indicated that they did not experience intense feelings of grief for a prolonged period of time. Such research demonstrates just how differently people react to a SIDS death and that no one can accurately predict how or for how long grief will affect a person. It is truly an individual matter.

*“For me it was more painful two weeks after the death than immediately after the death. The intensity continued for months. One day in a shop I saw a little baby girl in an outfit identical to the one I bought for my baby. I rushed out of the shop sobbing.”*

*“Three months after my baby died, I was at a party and someone said something like, “I just had a new grandchild.” I burst into tears and rushed to the bathroom. The hostess, a woman I did not know, came after me and burst into tears too. Her baby had died twenty years before.”*

SIDS parents may notice that they want to talk about their baby for months after the death, long after friends and family have stopped.

Parents have a unique bond to their children and speaking about their SIDS baby is a way of keeping the baby alive in their memory. It is also a way of dealing therapeutically with grief. In fact, talking about the infant is a positive and effective way of working through the grief process.

Dealing with family and friends who no longer want to discuss the deceased baby can be painful for SIDS families. Ideally, people should encourage the discussion of the baby and re-live happy memories together with family members. It is usually discomfort and fear of death that discourages people from talking about infants who have died. Parents should remember that they need to grieve in their own way and at their own pace, despite what those around them say or do.

*“There were days when I wanted to hide in the closet and then there were days that I could laugh at a silly sitcom. And mostly there were days that my mood would swing hour by hour...It was a roller coaster ride<sup>4</sup>.”*

The grief that SIDS parents experience is sometimes intensified when the impact of their baby's death brings to the forefront an emotional upset that has been simmering under the surface. For instance, maybe the parents' relationship has become strained or there

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<sup>4</sup> See page 19.

was even a separation. Or, maybe the parents have been faced with financial difficulties with the birth of the new baby. When other life events complicate SIDS grief or when grief extends over a prolonged period of time and prevents parents from resuming their normal activities, counseling can often assist in alleviating the distress. This can be accomplished through a SIDS support group, religious or professional counseling. Referrals can usually be obtained through your family physician or local Public Health or Social Services department.

### J. **THINKING ABOUT A NEW BABY.**

Well-meaning, relatives and friends may tell you that you should have another baby immediately.

*“My mother began leaving an article on natural childbirth behind, and then one day I heard her ask my four year old whether he wouldn’t like to have a sister again”, one woman said.*

If a mother is still grieving the loss of her baby, she may resent this kind of pressure. For parents who have lost their child the decision to have another one can be difficult.



*Jill Singer wrote: Through Eliza’s death, I grew up. There was no place left for fantasies or denial. Soon after the birth of my son I left an unrewarding marriage with my two young children. I became a disc jockey, a teacher and finally 25 years ago, a psychotherapist. Eliza’s death brought me to that career. It enables me to reach the pain of my patients. Her death adds richness and depth to my life and work. Yet, no day passes that I don’t miss her, weep for her, and wonder could I have saved her life?*

*“Parents who suffer a SIDS loss are frequently advised by family, friends and the medical profession to immediately get another child, thinking, no doubt, it will take their mind off their loss, and that loving a new baby will repair the pain and provide a substitute. In my experience both as a substitute baby (my sister died at six months of age of pneumonia and I was born nine months and twenty three days later) and as a mother of a SIDS child, I advise against it, and I would at least think very hard before embarking on it.*

*As a substitute child, I found I was never good enough for my mother. She always compared me negatively to the child she had lost. This caused me to have a very bad self-image and also to drive myself on and on, in order to prove to myself and my mother that I was good enough. This continues today, although I am fifty-three and my mother has been dead for eight years.*

*Research shows that other substitute children have experienced similar problems. Some famous people were substitute babies and even received the name of their dead brother, for instance, Vincent van Gogh and Salvador Dali. It is anybody's guess whether they drove themselves to excel but some would call them geniuses.*

*As a mother of a SIDS baby, I was only too aware of these problems, but after six months of grief and despair I did indeed become pregnant. Determined not to repeat my mother's mistakes, I found that I, too, spent the entire pregnancy weeping for my lost baby. When my baby was born, I was extremely grateful that he was a boy, while my SIDS child was a girl. So, it was not so easy to compare them. His personality too, was quite different, and I told myself that had my other child lived, I would have had both of them. However, it did take me a long time to bond with him, and I still grieve for my SIDS baby. I do not have any real answers for this dilemma. I love my son, but I feel I should have waited, and received professional counseling, before embarking on a subsequent pregnancy.”<sup>1</sup>*



When a woman who has lost a baby to SIDS decides to become pregnant again, it is advisable to speak with a health professional to discuss both the physical and emotional aspects of a new pregnancy. The emotional stress of a SIDS loss has ramifications for subsequent pregnancies. For instance, research has demonstrated that both difficulty in conceiving and the incidence of spontaneous abortion are higher in some women who have suffered a SIDS loss.<sup>10</sup> This is especially true with women who attempt to become pregnant very soon after the death and have not yet come to terms with it. There is, however, every reason

to believe that a mother who has lost a baby to SIDS should be able to conceive and deliver a healthy baby.

It is possible during the first year of life with a new baby, that there will be periods of sadness and anxiety brought on by memories of the life and death of the SIDS baby. These worries are normal. Parents should be patient with themselves during this time. As the new baby grows older and passes the age that the SIDS baby died, the fear will lessen.

Some mothers describe the anxiety they experienced with their subsequent baby:

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<sup>1</sup> See page 6.

<sup>10</sup> Dr. Mandell has done work on the effect of SIDS on subsequent pregnancies. *Pediatrics* volume 72, 1983, pages 652-657



*“I didn’t want to leave my baby alone for even an hour during the first months; she either slept in my arms or I was hanging over the crib. Then I collapsed from sheer exhaustion and I had to let go.”*

*“I had to go to work and I couldn’t concentrate; I wanted to run to the phone and call home every free minute. Fortunately my supervisor was quite understanding.” Or,*

*“The worst for me was coming home; on the bus I kept on thinking ‘what happened to Angel?’ I was so afraid I would find the baby dead again. “When my new baby got the sniffles I ‘knew’ he had caught pneumonia.*

*It’s amazing how after two healthy children I had forgotten that sniffles are normal. They all had had sniffles”, one mother could relate with a smile, now that her ‘baby’ was five years old and in kindergarten.*

*“My three older children became quite boisterous and demanding, when I spent almost all my time with the new baby. That was their way of protesting. My husband tried to be there for them, but although he was really understanding, even he began to show impatience... like this cannot go on forever. Both of us were also worried what the effect of our anxiety would be on our new baby.”*



*The obsessive fear during my pregnancy that I wouldn’t be able to love another baby as much as Tommy, proved to be unfounded. I suppose this fear is especially prevalent among parents whose SIDS loss is their first baby. Parents with surviving children probably understand more easily that each child is unique and that we have the capacity for unending love for all our children. The moment Matt was born and I looked into his little face, the love I felt was almost overwhelming.*

One mother’s reaction to her subsequent child by Liz Berthold<sup>11</sup>



<sup>11</sup> Liz Berthold as reported in what was then the newsletter of the Greater Los Angeles Chapter of the National SIDS Foundation

**K. HELPFUL SUGGESTIONS  
FROM OTHERS WHO  
LOST A CHILD<sup>12</sup>**

**1. WRITING ABOUT YOUR CHILD**

If you have lost a baby, writing about your child assures you that you will not forget the memories. It is good to write about both the large and small details, for instance, how she smiled and the sounds that she made. You can begin anywhere, with her birth, with the events around her death or with anything you remember. Keep a journal through the times of pain.

Such writing may make you cry but will ultimately help you in your grief. Some people benefit from writing a letter to their child. Maybe you would want to tell him what you wanted for him in life, or, what you forgot to tell him when he was alive. Perhaps you want to explain your sadness and anger, or how much you miss her. If, as a father, you feel vaguely uncomfortable and sad but you cannot cry, describing a particular memory may help to get you in touch with your feelings and make it easier to express them. You may remember, for instance the first time that you held the baby and felt really comfortable. How did her body feel? Did she snuggle up to you? Did she clutch your finger? Perhaps she looked directly at you and you felt a sudden connection.

*Dear Erin,*

*I was scared when I first saw you. You were so small. You were born early and spent the first weeks in an incubator. I hardly touched you at all then. After you came home I began changing your diaper. You were not much larger than my two hands. Mom sometimes asked me to give you the bottle and slowly I began to feel comfortable. You wiggled a lot and squinted. But one time, after I fed you, you looked into my eyes for a long time. That was the first time we said hello to one another. You looked intently and seriously and then smiled suddenly. I felt a softness in me then that I still remember. We miss you, little girl. Your Dad.*

Debbie Gemmill suggests a number of other ways that you can use writing. You might write a letter to yourself and list your feelings such as anger or guilt. You can explain what makes you so angry or guilty. Then you can respond to your feelings. That way you might discover a comforting and reassuring voice in yourself. You might send a postcard to yourself, every once in while, summing up in a few sentences how you are doing, how you are handling your loss, where you are in your place of grief. When you do it again after some time, perhaps half a year or a year, you can see how your feelings have changed. The next postcard will come from a new place, Debbie counsels.

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<sup>12</sup> Suggestions for writing as reported in *Reflections*, bulletin of the Orange County Guild for Infant Survival

*"Finding the words, finding my words as I struggle to make sense out of something senseless is an ongoing challenge and a constant source of both comfort and surprise. Writing those words down has been an invaluable aid. Grab a pen or pencil and find a piece of paper. Give your grief words."<sup>4</sup>*

## 2. RITUAL OR MEMORIAL

Some families benefit from a private, individualized ritual, for instance lighting a candle or keeping one burning, writing a poem, planting a tree in memory of the child or donating a bench named after the baby in the park where you took him for walks. Parent groups in various parts of the United States have organized special memorials.

## 3. HELP WITH THE HOLIDAYS

It is impossible to pretend that everything is the same as before the baby died. Hanukkah, Christmas, New Year, Thanksgiving, Passover, Ramadan, Kwanzaa will not be the same as in previous years. The day that the baby would have turned one year old may be particularly painful and may be difficult to face for many years to come.

*"My baby was alive for six weeks. Every year during those six weeks things move in the house such as glassware falls off shelves, cups slip through my fingers. I don't know why. I know she is present in some way during those six weeks."*

Some people suggest that it is a good idea to vary some of the family customs for the first year or two after the death of a child. For example, if you used to celebrate the holiday at home, now perhaps you should accept the invitation from a close friend or relative. If you opened packages on Christmas Eve, perhaps this year you may choose to open them Christmas morning, or not have a formal gift exchange at all. If there are other children in the family, perhaps they can help to choose a special new way to celebrate a particular holiday.

## L. WHAT OTHERS SHOULD AND SHOULD NOT DO

The support of friends and relatives is invaluable immediately after the death as well as later on. Sometimes it is helpful for relatives to take care of the children before and during the funeral, although this is not always the case. Some mothers derive enormous comfort and strength from having their small children near them in their time of grief. Taking their children away from them, even temporarily, may make them feel worse.

For some parents, the time immediately after the death is not the ideal time for others to offer information regarding SIDS. In fact, a gesture of comfort, such as an arm around the shoulder or a hug often does more good than a detailed,

<sup>4</sup> Debbie Gemmill, see page 19.

scientific explanation. Being a patient and attentive listener is perhaps the most helpful thing that a person can provide for a bereaved person. Here are some **least** helpful ways to respond:

#### 1. SHOWING IGNORANCE

Demonstrating by statements or behavior that you do not know what SIDS is, or do not believe that the baby died without a cause. Saying, for instance, “the baby must have died from smothering or choking.”

#### 2. AVOIDING

Acting as if nothing happened, being embarrassed and avoiding the bereaved parents. Pretending that the baby never existed or is still alive.

#### 3. GOSSIPING

Implying that the parents were careless or contributed somehow to the death of the child.

#### 4. THOUGHTLESS ADVICE

Suggesting that by having another baby as soon as possible the pain will stop as if a new baby could replace the baby that died.

#### 5. BELITTling THE LOSS

Saying, “*at least you have other children.*” Or, stating: “*the baby was only four months old, so you could not have gotten all that attached to her.*”

If parents are given a chance to talk with their relatives and friends openly about their baby they recover from the loss sooner. Insensitive responses can make it difficult for parents to tell others that their baby has died. As long as people continue to respond in insensitive ways, the hurt of the loss will be unnecessarily prolonged and intensified. Dr. Abby Wasserman has compiled a list of suggestions that is reproduced in Appendix 4.

### ***M. WHERE CAN I FIND COUNSELING AND PRACTICAL HELP?***

Many agencies provide both marital and grief counseling and will often adjust their fees according to a family’s ability to pay. In some cases, free services may be available. Your local Public Health Department or Department of Social Services will usually be able to help you with referrals (for addresses see Appendix 2).

Many parents who have lost a baby to SIDS feel that only another SIDS parent can truly understand the impact of their loss. The support groups organized by parents who have themselves experienced SIDS serve as an invaluable resource to bereaved SIDS parents. The First Candle/SIDS Alliance has chapters in many cities. In our experience, no call to their office ever goes unanswered.

Countless people have benefited from their caring efforts, including family members and friends of bereaved parents.

There are other practical ways to help grieving parents: In some states, people on welfare are entitled to a small amount of burial money. They can benefit from practical help about how to obtain these funds and the procedures to follow.

*“Concrete help can be offered such as help in making funeral arrangements, cutting red tape through social services and transportation services.*

*Most importantly, however, it cannot be overemphasized that the person providing this assistance be a warm, caring individual who has at least partially come to terms with his or her own feelings about death, is aware of normal grieving patterns (and we add: including those of people with different traditions and backgrounds) and can handle, without personal affront, expressions of hostility and anger as well as anxiety and extreme sadness. It is important that we do not project onto a family what we think they should be experiencing, instead of assessing exactly what they are feeling.”<sup>2</sup>*

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2. Zoë Smialek, see page 13.



## Medical Information

### A. HISTORY OF SIDS

*“...and this woman’s child died in the night.”*  
(1 Kings, Chapter 3, verse 19).

SIDS is not a new problem. In fact, some people believe that this quote from the Bible may refer to SIDS. In 1969, the American Medical Association officially recognized SIDS as a disease. This in turn made it possible for pathologists and coroners to specify SIDS as a cause of death. The definition of SIDS changed slightly in 1989 and currently reads:

“the sudden death of an infant under one year of age which remains unexplained after a thorough postmortem investigation, including performance of a complete autopsy, examination of the death scene and review of the clinical history”.<sup>13</sup>

Since SIDS occurs worldwide, an attempt has been made to create an international definition both to facilitate collaboration in research and to guide the development of bereavement services to parents.

SIDS began receiving considerable attention in the medical community in the early 1970s due primarily to intensive efforts by SIDS parents. Since then, in response to lobbying of SIDS parents’ groups, numerous research projects have been undertaken. The federal government funded most of these studies. The cause of SIDS, however, still eludes researchers.

The slow progress of science is evident with other diseases as well. At the turn of the last century, the incidence of **tuberculosis** was at its peak. Several decades of uncertainty passed before the **tubercle bacillus** was finally identified in 1922. Effective treatment with the **antibiotic streptomycin** was not available until 1942, some twenty years later. Nonetheless, the incidence of tuberculosis had already decreased by half before the cause and the specific treatment were discovered. Changes in living conditions, such as improved housing and plumbing were responsible for this dramatic decrease. The recent **“Back to Sleep”** campaign which recommends that babies be put to sleep on the back rather than the abdomen has resulted in a significant decrease in SIDS

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<sup>13</sup> Definition of SIDS, published by the American Academy of Pediatrics, 1989

(Part 3, Section I 2a, page 71 for more details). This demonstrates how a simple childcare practice has reduced the incidence of SIDS even though the cause of SIDS is still unknown.

Another characteristic of science is that researchers commonly generate a number of theories about what causes a disease before the actual **etiology** or cause is discovered. For example, there were 39 theories linked to **Down syndrome**, before the true cause, the presence of an extra chromosome, was discovered. Likewise, researchers have offered numerous, yet thus far, unsupported theories regarding the etiology of SIDS.

### **B. EVALUATION OF MEDIA ANNOUNCEMENTS ABOUT SIDS**

Often an announcement appears in the media that the cause of or treatment for SIDS has been discovered. This leads to excitement and hope for parents and eventually to disillusion. To date, the cause remains unknown and there is no effective treatment. How should you evaluate these media reports? The 1999 issue of *Sunlight and Shadow*, published by the SIDS Foundation of Washington State, discussed a number of suggestions that we include here:

**Ignore the headlines.** Often they do not accurately describe the article or the contents. Headlines are written to get the reader's attention. Are the researchers nationally recognized as authorities in the stated field?

**Read the text and underline words** like "might, possibly could". This helps to emphasize any uncertainties in the report.

#### **Ask yourself these questions:**

- Are the deaths unexpected and without adequate explanation. In other words does the report deal with SIDS?
- Is the article based on an idea that has been tested properly or is it just an idea?
- Is the article based on just a few observations or on many cases? Look at the size of the study. Is it an accurate representation of all SIDS deaths in the population or are these observations seen only in isolated cases?

#### **Remember:**

- The scientist may not have said what is reported
- Most journal articles are summarized by a reviewer and not by the author of the article. This requires the reviewer to condense a detailed article into a few paragraphs. Thus the need for simplification may lead to the wrong impression.
- If you have questions contact your local SIDS support group, the State Health Department Office (see Appendix 2), the Pediatric Department of a near-by university or the First Candle/SIDS Alliance (1 800 221 SIDS).



### C. THINKING ABOUT CAUSES

While some SIDS researchers believe that SIDS is caused by a single factor, others believe that it is caused by multiple factors.

We will discuss three ways of thinking about the causes or etiology of SIDS. Refer to the diagram in figure 1.

#### 1. SINGLE CAUSE

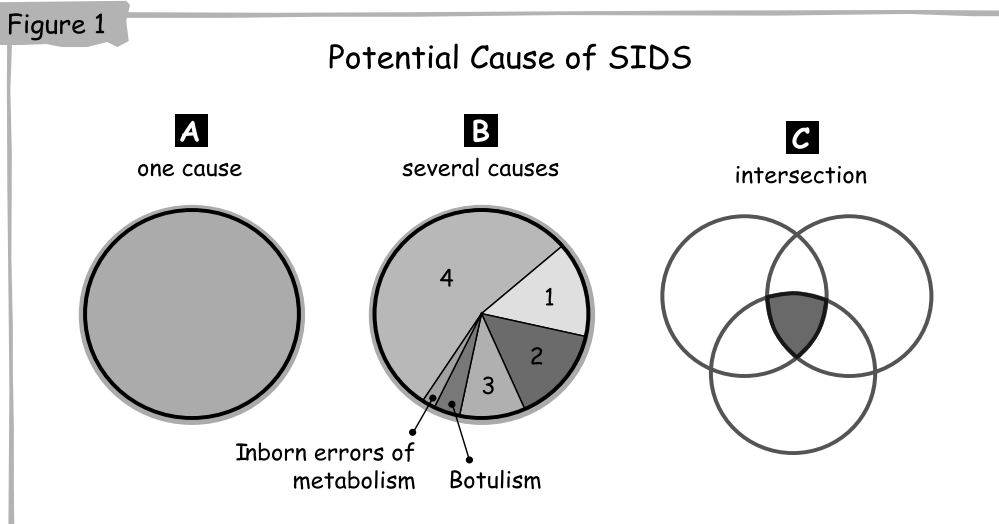
Figure 1a is not divided into sections because it presumes that SIDS has only one cause. Tuberculosis is a good example of a disease with a sole cause, the Tubercle bacillus, and specific treatment, antibiotics. Another prime example is the discovery of the **Rh factor** in blood that explained the previously very confusing severe **jaundice** and **anemia** of some newborn infants. These diseases baffled scientists and many causes were suggested until the discovery of the single cause unlocked the secret.

#### 2. MULTIPLE CAUSES FOR SIDS

Figure 1b is divided into six sections. Imagine that during the next decade scientists discover that the death of some infants who die suddenly during the first year of life can be explained by one of two specific mechanisms: a failure to wake up from sleep (section 1) or an abnormal response to an infection (section 2). The remaining cases would be due to other as yet unknown causes (section 3 and 4). Thus there could be several specific causes that may be discovered independently, over a span of time. Possibly only the death in section 4 would remain unexplained and be called SIDS.

Two very small sections in the figure are already accounted for. Perhaps less than one percent of the infants who we once believed died of SIDS, died of **botulism**. In the seventies, investigators unexpectedly isolated a **toxin** that is produced by the **bacterium clostridium botulinum** in the

Figure 1



bowels of young babies. This **toxin** affects the baby's nerves, including those that control breathing and can lead to **paralysis**. **Spores** of this organism can be found on fresh fruit, vegetables and in honey. Only young infants are susceptible to this form of botulism, because the spores do not grow in the bowels of older infants and adults. Early detection and aggressive treatment of this disease can prevent death. In the hospital infants can be placed on a ventilator that does the breathing for them while the body rids itself of the poison. Notice, however, that botulism will be the cause of very few deaths attributed to SIDS.

A small number of babies are born with what is known as an **Inborn Error of Metabolism**. In such cases, the infant inherits an abnormal gene from each parent. The absence of the normal genes blocks the ability of the infants' cells to produce energy. Under stress, the baby rapidly develops a drop in body temperature, becomes limp (**hypotonic**) and pale. The baby then slips into a coma that will lead to death unless diagnosed and treated. The most common inborn error that can be mistaken for SIDS is a defect in **fatty acid oxidation**. During periods of reduced food intake, for example during illness such as a common cold, the body cannot produce the special fats used by the brain for energy. This condition can lead to sudden death. Babies with an inborn error of metabolism tend to die either very young before they would be called SIDS, or after 6 months of age when the peak incidence of SIDS has past. To

some doctors this time frame suggests that this disease is not related to SIDS. If properly diagnosed such inborn errors of metabolism can often be treated.

If an infant dies, this condition can be differentiated from SIDS at autopsy by testing the baby's blood or urine. Confusion is therefore unlikely. It is estimated that less than one percent of cases with metabolic errors are improperly attributed to SIDS.

### 3. SINGLE CAUSE WITH PREDISPOSING CONDITIONS

There is yet a third way of looking at the cause of SIDS as illustrated in figure 1c. We can speak of the immediate cause of a disease or about the predisposing conditions that contribute to the development of the disease. In the case of cancer, what we eat and what we breathe may influence the chances that we will develop cancer. In SIDS we do not know the cause of death but we can examine factors that are associated with an increased likelihood of a baby dying of SIDS.

For example, we know that babies often have a slight cold and their mothers and other family members smoked. If the baby also slept on the stomach instead of the back, SIDS might happen. In other words, only when several of these conditions occur *together* in the same infant at a critical period of development, would the baby die of SIDS. This is demonstrated in the shaded area where the circles overlap in figure 1c.

#### 4. ASSOCIATION DOES NOT MEAN CAUSE

Because two events happen simultaneously does not prove that one caused the other.

Researchers have discovered that mothers whose babies died of SIDS have certain things in common. Sometimes people are tempted to think that these characteristics are responsible for the death. Here are some examples. Babies born to mothers who smoked cigarettes, or used heroin or cocaine were found at increased risk for SIDS. While it makes sense not to use these substances during pregnancy or after, we cannot attribute the death to the use of cigarettes or heroin alone. Many of us had mothers who smoked during pregnancy, and most babies whose mothers use heroin do not die of SIDS. Clearly these behaviors alone cannot cause SIDS but do increase the risk that the baby will die of SIDS.

Here is another example. In most surveys, some mothers whose babies died of SIDS did not have prenatal care at the same regular intervals as mothers whose babies did not die. Would it be sensible to have more regular prenatal visits? The answer is “yes”. Would it prevent all SIDS? The answer is “No”.

#### 5. DISTINGUISHING BETWEEN MECHANISM OF DEATH AND CAUSE OF DEATH.

When thinking about SIDS and its cause(s), one needs to distinguish between:

- How the baby dies or the *mechanism of death*
- Why the baby dies or the *cause of death*
- Factors that *increase the risk of dying*.

In this section we will discuss three potential ***mechanisms*** of death. Potential ***causes*** of death can be found in Part 4 (Section C, page 81). There are many factors we know that increase the risk of death from SIDS, but these are not in themselves the cause of death. These are discussed in Sections E, F and G, page 55-64.

When babies die, they stop breathing and their hearts stop beating. These are not causes of death; rather they describe the physical events associated with death. With SIDS it is not yet clear whether it is the baby's breathing or the heart that stops first. Similarly, we do not know what would **cause** either the baby's heart or breathing to cease. Information about the exact mechanism of death could be very helpful in learning about what causes SIDS. If, for example, we knew that babies died from heart failure rather than cessation of breathing, we could discard a number of theories dealing with breathing and concentrate on those that are more closely associated with heart failure. The following are three potential mechanisms for death.

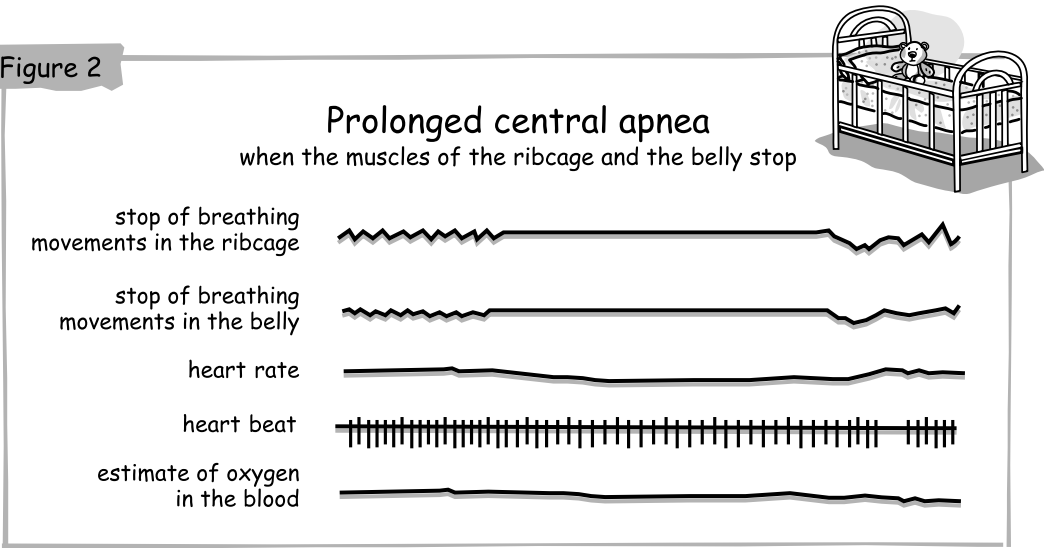
**D.    *POTENTIAL MECHANISMS OF DEATH***

**1. ABNORMAL OR  
PROLONGED APNEA**

**Apnea** are pauses in breathing which occur in everyone while awake but more often while asleep.

Usually apnea during sleep are caused by a brief failure of the brain to stimulate the muscles for breathing. These pauses in breathing are called **central apnea**. A regular series of such apnea is referred to as **periodic breathing**. With monitoring equipment doctors can obtain a recording of these breathing

**Figure 2**



**Figure 3**

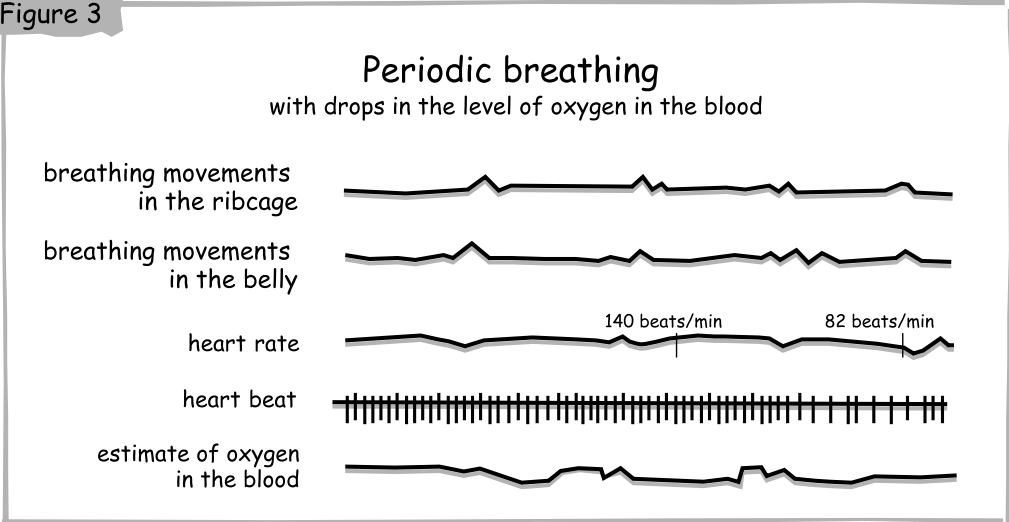
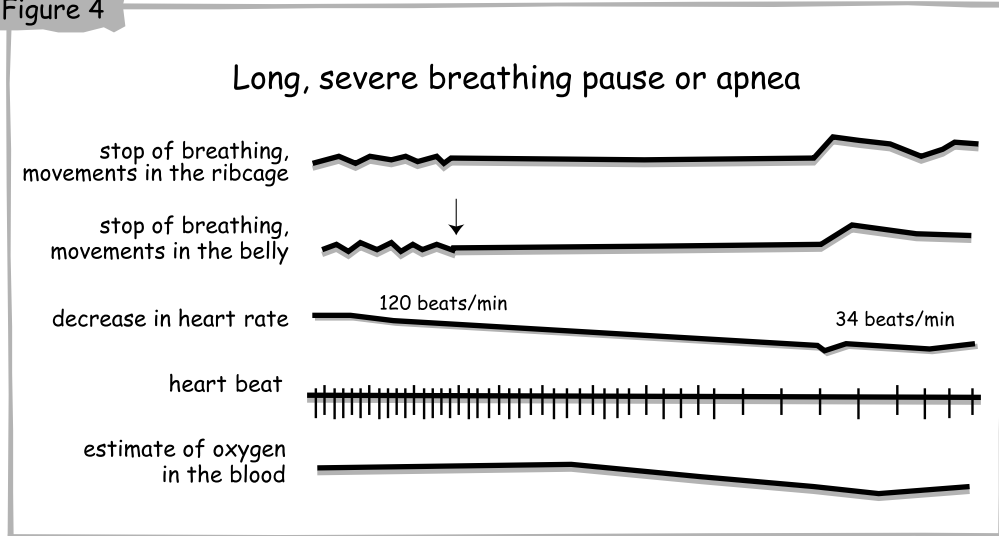


Figure 4



patterns either in the hospital or in the home. Examples are shown in figure 2 and 3.

It is important to note that all healthy infants have some apnea every night. Most infants know instinctively how to resume breathing. A few infants have prolonged apneic episodes that can endanger their life. These are called **ALTE**.

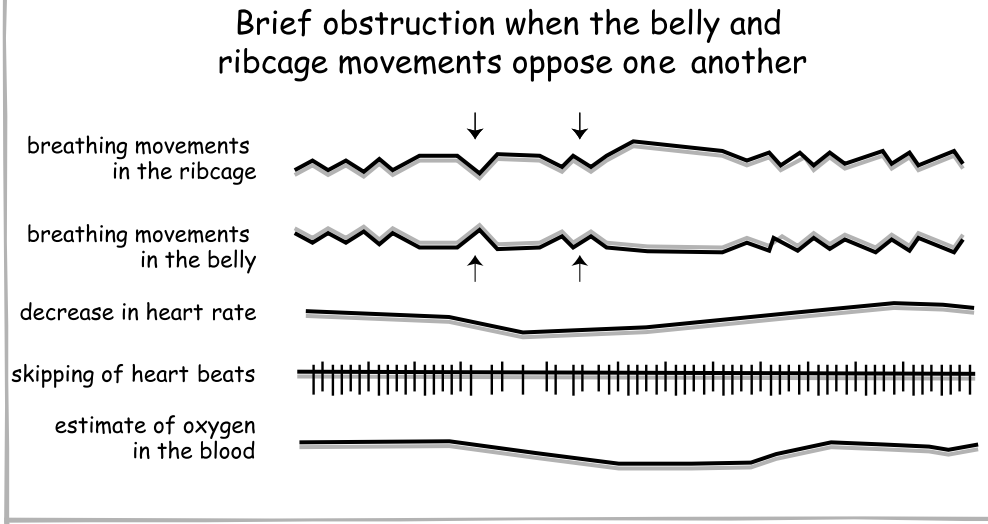
Babies with ALTE have difficulty resuming control over their breathing once it stops and require resuscitation. When babies stop breathing for as long as 1-2 minutes they do not get enough **oxygen** for the heart and the brain to function properly (see figure 4). This can lead to death. While doctors have studied apnea in infants over the last two decades, they still disagree about what constitutes a normal versus a worrisome apnea. Monitoring of apnea in the hospital or home will be discussed in Section H, page 65.

## 2. AIRWAY OBSTRUCTION

**Airway obstruction** can occur when a normal airway narrows automatically during sleep. This narrowing can cause brief pauses in breathing called **obstructive apnea**. These apnea happen frequently in healthy infants (see figure 5).

These apnea are sometimes but not always made worse when the infant has a stuffy nose. Another mechanism that can cause obstruction is **laryngospasm**, which refers to the sudden contraction of the muscles of the **larynx**. When this occurs, oxygen is prevented from entering the lungs and this may result in insufficient oxygen to the heart and brain. This lack of oxygen could be fatal. Recently, a large study supported by the National Institute of Child Health and Human Development (NICHD) entitled the Collaborative Home Infant Monitoring Evaluation (CHIME) investigated how often obstructive apnea

Figure 5



occur in babies and how the babies recover from such an event. We in Los Angeles are a part of this collaborative study; the results will be discussed in Section H, page 66.

### 3. HEART FAILURE

Two networks of nerves control the regular beating of the heart. The first is an electrical conduction system within the heart itself that carries impulses between the heart chambers. This is a backup, fail-safe system that provides a slow basic heart beat. The second network consists of two sets of nerves in a part of the brain, called the **brainstem**, one of which causes the heart beat to speed up (sympathetic system) while the other slows the heart beat down (parasympathetic system). These nerves automatically respond to a large number of stimuli both within and outside of the body such as crying, moving, breath holding, and having a bowel movement.

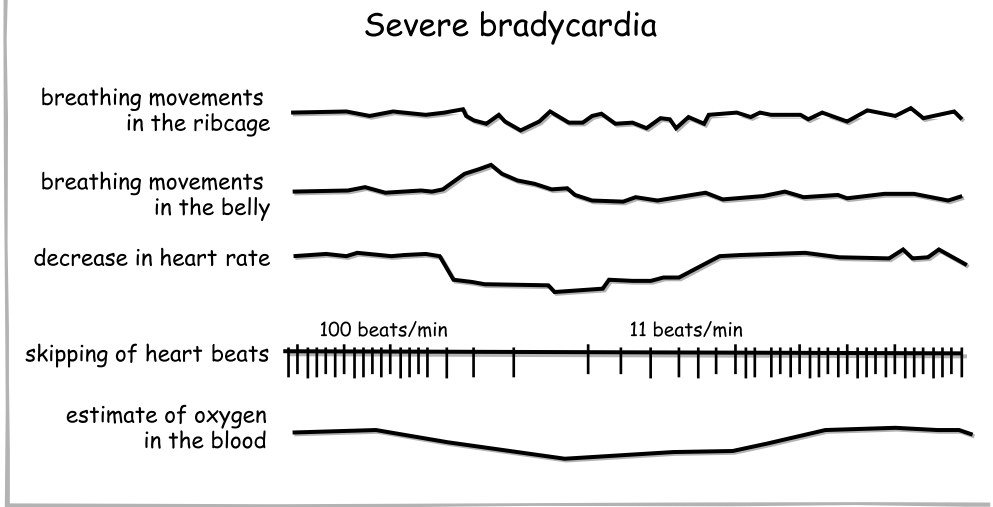
Balance between these nerve sets determines the heart rate.

Brief drops in heart rate called **bradycardia** occur frequently in the healthy infant as a response to some of these normal stimuli (see figure 5).

Failure of these regulatory systems can result in a sudden death, such as SIDS. The intrinsic system within the heart can break down causing a sudden change in the heart rate to a beat that is either much too slow or much too fast (**arrhythmia**). Together with prolonged drops in the heart beat (severe bradycardia) these can lead to a lack of blood carrying oxygen (see figure 6) to such vital organs as the heart itself and the brain thus causing death.

Another condition that appears suddenly, progresses rapidly and can lead to death from heart failure is **shock**. Shock is caused by a drop in blood pressure that

Figure 6



allows blood to pool in the arteries and veins. Too little blood containing oxygen is pumped to the body organs including the brain and the heart itself. This lack of oxygen can result in coma, failure of the heart and death.

#### E. *TIME FACTORS KNOWN TO BE ASSOCIATED WITH SIDS*

We will now discuss factors that increase an infant's risk of dying of SIDS.

##### 1. AGE

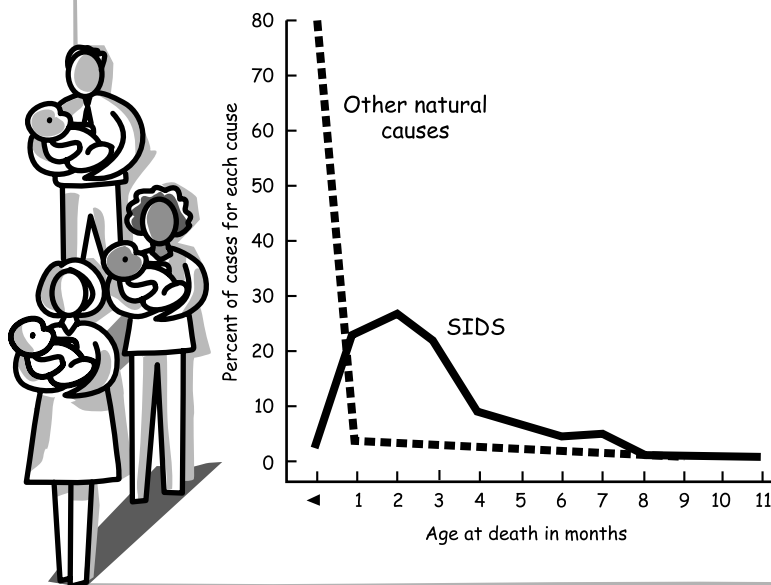
A normal baby is generally most vulnerable at the time of birth. Deaths from other causes are most common around that time. With each passing week the baby's body becomes stronger and more capable of fighting most diseases.

SIDS rarely happens right after birth. Instead, the SIDS incidence increases to a peak between two and four months of age. Thereafter, the number of infants who die of SIDS begins to decrease again until about six months of age. Between six months and one year very few babies die of SIDS (see figure 7).

The age of death is different for a **premature baby** (figure 8). In this picture it can be seen that if the baby is only 26 weeks of gestation when he is born, he is most likely to die when he is 46 weeks old. By comparison, the most common time for a term infant to die of SIDS is around 12 weeks. The *time* of death from the date of conception is not very different whether the baby is premature or born at term. Notice that the major difference is that the 26 week-old baby is 14 weeks younger than the term baby born at 40 weeks. Apparently, risk for

Figure 7

### Age at death SIDS vs. natural causes of infant death<sup>15</sup>



SIDS is mostly related to the developmental maturity of the infant regardless of whether he is born early or on time. The premature baby is older at the time of death and the time of risk extends longer after birth.

Ninety-five percent of all SIDS deaths occur in term babies by 8 months, for preterm babies 95% of the deaths occur by 10 months.

## 2. SLEEP/TIME OF NIGHT

Why does most SIDS happen during that special window of vulnerability between one and four months of age and during sleep? At present the answer is not known but scientists

believe that the combination of several simultaneous changes in the development of the brain play a role: the infant begins to sleep through the night. Besides, what is believed to be a protective kind of sleep, rapid eye movement sleep, decreases dramatically during this time.

In our research on SIDS, we have discovered a very important additional finding. In the past we did not fully appreciate how many changes take place in the brain of the baby between one and three months of age. As it turns out, the interplay

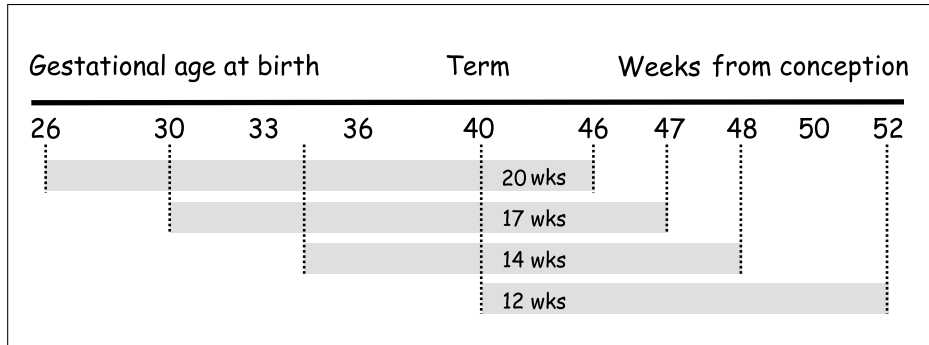
between heart rate and breathing changes and the **circadian rhythm** develops fully at this time. The circadian rhythm can be thought of as a way by which babies adjust to changes of day and night, warm and cool temperatures, light and darkness of the outside world. Their bodies under control of the brain begin to act differently at night than during the day. This time of particular change when there seems to be a major reorganization in the brain may cause a temporary instability, making the infant more susceptible to SIDS. These ideas are now being studied more fully.

<sup>15</sup> California SIDS Information and Counseling Project, Vital Statistic Branch, State of California



Figure 8

## Age at death from SIDS in premature babies



- The lower the *Gestational age*, the higher the postnatal age of death (shaded)
- The lower the *Gestational age*, the lower the post-conceptual age at death
- Compared to term infants, the peak age of death is spread out in premature infants

## 3. SEASON/TEMPERATURE

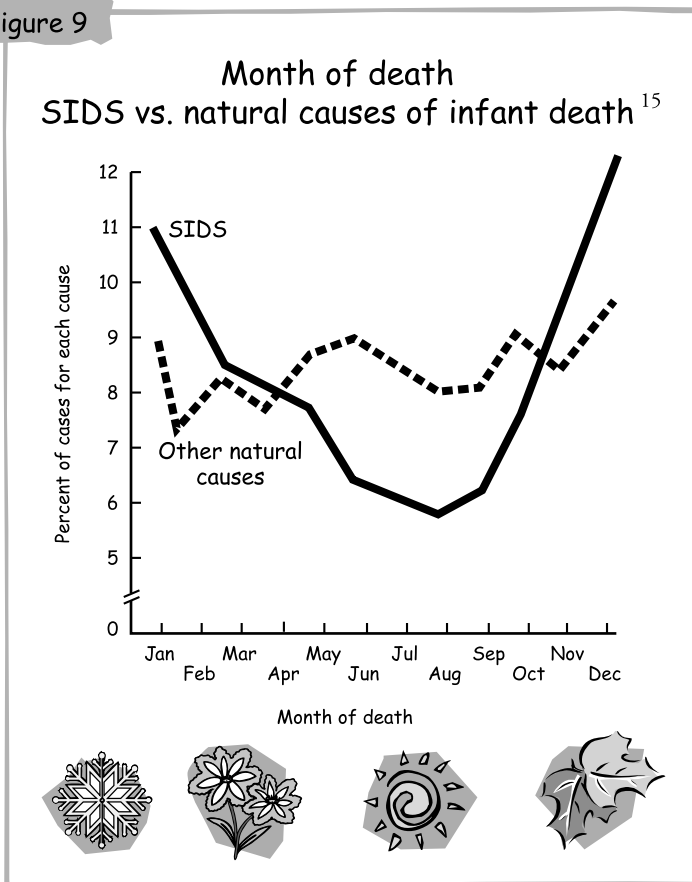
SIDS occurs more frequently in fall, winter and spring compared to summer in the northern hemisphere, including the United States (figure 9). In the southern hemisphere where it is summer when we are in winter, the highest SIDS rates occur in their coldest months as well. Everywhere in the world SIDS rates are elevated in colder climates compared to milder climates. Because babies die more frequently in the cold months, temperature plays a yet not fully understood role. Since the **Back to Sleep** campaign (see Part 3, Section I 2a, page 71 ), the incidence of SIDS has decreased approximately 50%. The decrease has not been uniform.

Relatively fewer babies now die in the cold months.

Investigators in New York reported that in order to keep babies warm in a cold apartment, several mothers bundled their infants in layers of clothes and covers. In the early morning, the duct heating system switched on, causing an elevation of body temperature<sup>3</sup>. Investigators elsewhere have proposed this same idea as a cause of death, and at this time, it must be considered unproven but plausible. One explanation for the protective effect of placing babies on their backs may be that being on the back makes it easier for the infant to get rid of body heat (see Section I 2, page 71).

<sup>3</sup> See page 14.

Figure 9



### F. INFANT RISK FACTORS

Over the past 25 years we have gained a better understanding as to which infants might be at higher risk for SIDS. Based on statistical findings, certain risk factors can be identified which are associated with an increased incidence of SIDS. However, the presence of one or more of these risk factors does not imply that your child will die of SIDS, only that he

or she may be more at risk. For example, while statistics indicate that eighteen-year old boys have more fatal accidents than 40-year-old women, most teenage boys do not have fatal accidents. The individual infant who will die cannot be identified in advance. Science can only identify groups of infants that are at higher risk for SIDS than other groups.

Statistics show that out of a thousand infants born in the United States less than one will die from SIDS. This number can be both lower and higher, depending upon the presence or absence of SIDS risk factors.

Groups that are at higher risk for SIDS are listed on the next page.

However, it should be stressed that even within

each of these at risk groups the chance that SIDS will strike is still very low.

In general, if an infant's family lives below the poverty level the risk of SIDS increases. The risk of SIDS is less than one out of 1000 in White, Asian or Latino families. In African-American and some Native American families the risk is doubled. Some of these findings are illustrated in figure 10.

<sup>15</sup> See page 56.

### Groups of infants at higher risk for SIDS

- Babies born in families living below the poverty line
- African-American and Native-American babies
- Babies born to teenage mothers
- Babies born soon after a previous pregnancy
- Babies born early especially if their birth weight is low
- One of twins
- Subsequent siblings of a baby who died of SIDS
- Babies who have had an apparent life-threatening event (ALTE)

#### 1. PREMATURE BABIES

Babies born early (premature babies) are at a higher risk for SIDS, and are more vulnerable to death from other illnesses as well. The risk of illness and death increases the smaller the baby is at birth. Approximately one of every hundred infants who weigh less than 3 1/2 pounds will die of SIDS. Consequently, 99 of every 100 very low birth weight **premature babies** will not die of SIDS. It should be stressed that very few infants are born this small. For instance, in the 1980's in our hospital in Los Angeles, California, almost 17,000 babies were born each year, but only 250 were very low birth weight infants. For a baby who is born prematurely but who weighs more than 3 lbs 4 oz, the risk of SIDS is less, approximately four in 1000.

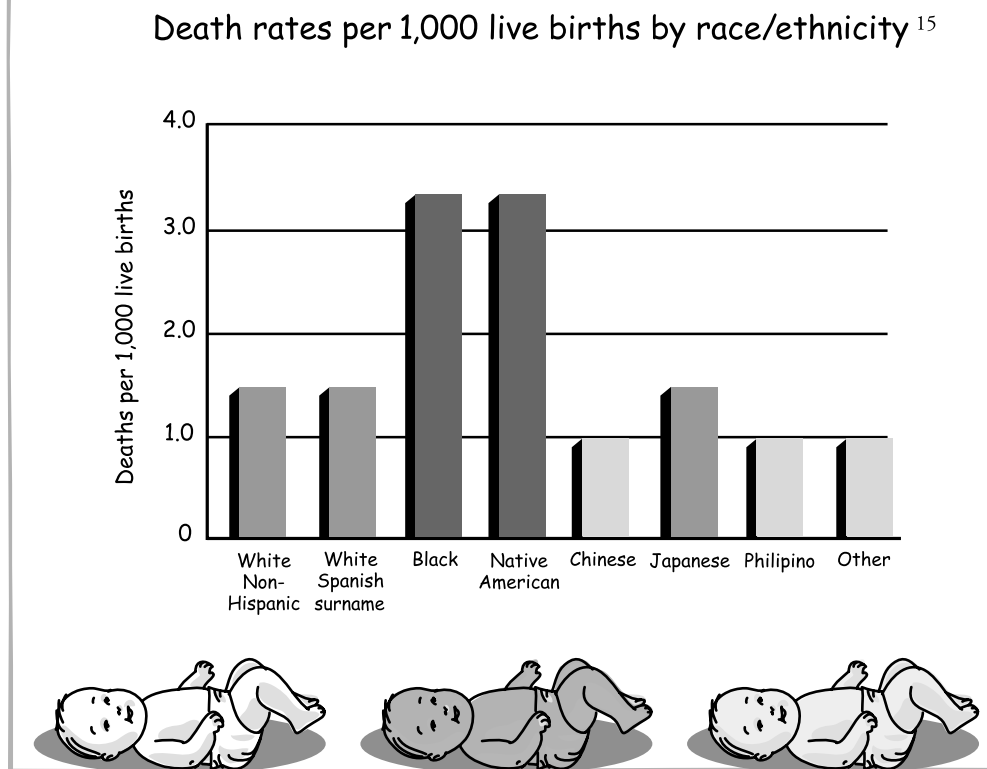
#### 2. ONE OF TWINS

Although SIDS is statistically more likely to happen to a twin than to a single baby, SIDS in twins is still not very common, occurring in four per 1000 twin births. Strangely enough, it is not necessarily the smaller, frailer twin who dies; rather it can be the larger, healthier baby. If one twin dies, the risk for the other twin is only slightly increased compared to a single birth.

#### 3. SUBSEQUENT SIBLINGS OF SIDS

If a family loses a baby to SIDS, chances are remote that it will ever happen to another infant in that family. Studies indicate that the risk is only slightly higher in babies born to families who have already experienced a SIDS.

Figure 10



It is practically certain that SIDS is not something that is inherited. Thousands of women every year become pregnant with another baby after one has died. They experience, understandably, quite a bit of fear during their pregnancy and the baby's first year. However, practically all of these babies reach their first birthday without serious problems.

#### 4. BABIES WITH AN ALTE

A small number of infants, probably less

than five per thousand, may stop breathing and turn limp, blue or white. These ALTE's used to be called a **near miss SIDS** or **aborted crib death**, terms that have now been discarded. Parents, caretakers or paramedics have **resuscitated** these infants, and rushed them to the hospital.

##### a. Ruling out known causes

To try to determine the cause of an ALTE, doctors will consider the following possibilities:

<sup>15</sup> See page 56.

- **Pneumonia** can cause difficulty in breathing and apnea. An **x-ray** is typically taken to examine the condition of the lung.
- **Convulsions** or **seizures** may cause apnea. To detect these doctors may recommend a brain wave test, called an **electroencephalogram** or EEG.
- **Gastro-esophageal reflux** may happen when stomach contents are regurgitated into the **esophagus**. This is a common event in babies, but it may cause apnea if the material gets into the lung. Doctors often test for reflux from the stomach by placing a tube (**endoscope**) into the baby's esophagus to examine the condition of the esophageal lining. Another method is placing a **pH probe** down

the throat that measures acidity from the stomach during sleep. Sometimes an infant is given barium to swallow so that an x-ray can show the outline of the stomach and esophagus. At present, doctors do not agree as to how important reflux is as a cause for apnea. Surgery to correct reflux in these babies is rarely needed.

- **Inborn errors of metabolism** are suspected in some instances. In these cases, blood and urine from the infant will be tested for accumulations of abnormal substances produced when an enzyme transforming food into energy (**metabolism**) is missing. As discussed in Part 3, Section C2, page 50, an inborn error of metabolism can cause sudden death that may be mistaken for SIDS.

If, after the proper tests are done, the cause of the ALTE is still unknown, the diagnosis of **apnea of infancy** (AOI) is made. This means that the apnea cannot be explained. Most infants with apnea of infancy will never have such an episode again. Some will have one or more additional episodes. Most of these take place within six weeks of the first apnea. Occasionally, an apnea that requires resuscitation may happen a few

months later. As a group, these infants seem to be at a higher risk for SIDS. However, most infants have developed normally after such episodes.

#### **b. Münchausen by proxy**

On rare occasions, mothers try to suffocate an infant and bring the baby to the doctor with a list of complaints. The following excerpt gives a further description:



*“Pediatricians, and I am one of them, need to learn to recognize Munchhausen by proxy. We owe it to our patients. These children cannot protect themselves.”*

*“Typically, a mother will bring her child to the physician and relate some specific complaints. Doctors take these complaints seriously and initiate a number of tests. The child is sent home and several weeks pass. The tests yield no clear results and the mother returns with the child.”*

*Perhaps the mother has given the child the medicines that were prescribed. Perhaps she has gagged on them; perhaps the child has developed new symptoms that suggest to the doctor that other tests should be run. The doctor hesitates because the child is still so young and these tests are difficult to perform in young children. Children strenuously resist swallowing a balloon. They seem to fear that they are suffocated. Perhaps the doctor considers a tonsillectomy. “That might reduce the breathing problems,” he silently argues with himself. “That’s one of the signs the mother talks about after all.” A few weeks later, the doctor examines her again in his office. She clings to her mother, thumb in her mouth. “What do these droopy eyelids mean?” A sudden sadness in the child’s eyes meets his own tiredness. He shakes it off brusquely and turns to the mother.*

*“No, the previous tests yielded no definite diagnosis, but.... since she has not improved, I would like to do some other ones. For these the child will have to remain in the hospital for a night. I’ll write the appropriate documents and requests,” he says. “Please contact the hospital within the next few days.” He motions to the door while he forces himself to smile. His eyes follow the frail body that seem to lack the vitality of his own two children, while she slips out of the door.*

*“It is our responsibility as physicians to recognize what is happening.” I hear the speaker say. “The child cannot take care of herself. If continued tests fail to reveal a diagnosis, sooner or later, but preferably sooner, the doctor must begin to entertain the diagnosis of Munchhausen by proxy. I cannot stress enough the importance of this,” she asserts. “We as pediatricians have in the past too often failed such a child. We are inclined to give the parents the benefit of the doubt. We don’t like to entertain this most awful of diagnoses, that the mother intentionally makes the child sick to fulfill her own needs.”*

*And now the speaker’s lighted pointer goes to the board. She reads off the means that are most often used by mothers who make their child ill. Young babies can be suffocated; older children may be fed their own feces. It is very quiet in the auditorium. Off at a distance, kitchen personnel drop a glass that crashes on the tile floor. There is the zoom of the slide projector and the now monotonous drone of the speaker’s voice.*

*“What prompts these mothers to initiate these drastic, almost unthinkable measures?” She asks rhetorically. “We can only speculate. The need for the doctor’s attention?”*



## 5. COLDS

Colds are not more common in SIDS infants than in other infants who do not die. However, respiratory infections are more common during cold weather when most SIDS deaths occur. In the lungs of 60% of the infants who died of SIDS, pathologists have found some evidence that the babies had a cold prior to death. While it is not believed that a common cold in and of itself causes death, it may cause abnormal cells to be present in the lungs at autopsy. This is sometimes mistaken for pneumonia. Of course, colds are common in infants, especially after the age of two months. A cold has been considered a contributing factor because it may lead to troubled sleeping for an infant.

It is a commonly held belief that newborn babies cannot breathe through their mouths. Therefore, the thinking goes, breathing troubles accompany a stuffy nose. One study, however, shows that many babies can indeed breathe through their mouths when airflow through their nose is obstructed. Physicians, scientists and parents do agree nonetheless, that stuffy noses bother babies as they do adults.

There is a resurgence of interest in how infections either in the mother during pregnancy or in the baby after birth might contribute to SIDS. **Infections** stimulate the production of a group of organic chemicals called **cytokines**. These substances are produced by the **lymphocytes** and **plasma cells** in the infant's body, cells that control

the immune response to infection. In addition to cytokines, the body responds to an infection by producing **antibodies**. How can this process be related to SIDS? We will discuss this in Part 4, Section C3c, page 84.

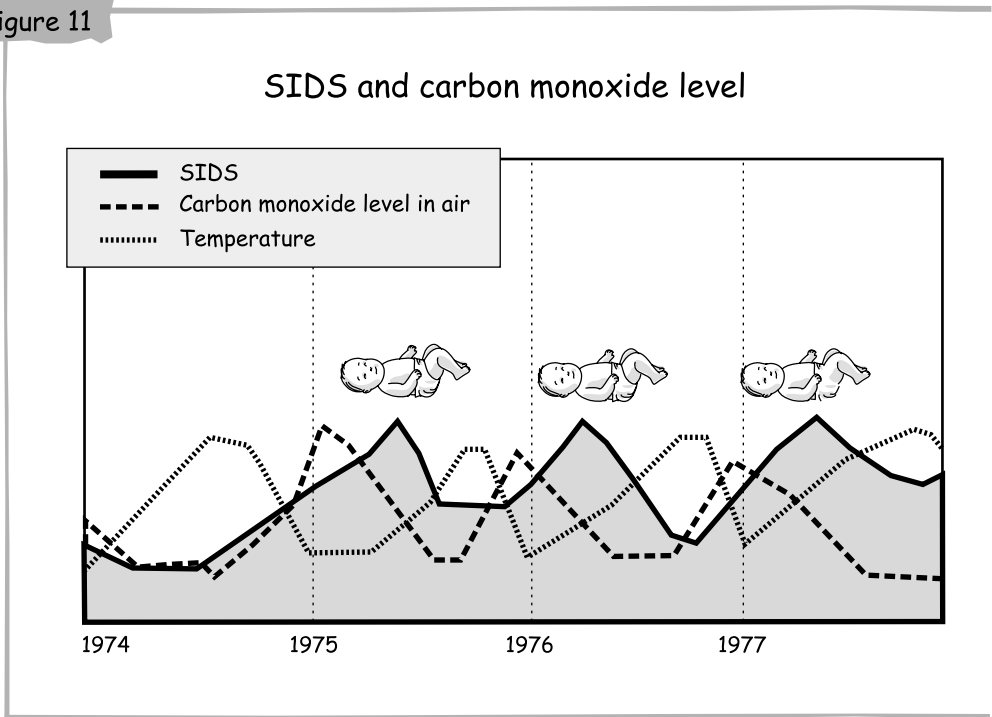
## G. OTHER RISK FACTORS

### 1. SMOKING

Maternal smoking during pregnancy has been one of the factors most consistently found to increase the risk that an infant will die of SIDS.

The more the mother smokes, the greater the risk. A study from Sweden showed that maternal smoking up to 9 cigarettes per day doubled the risk, while 10 or more tripled it. Smoke contains a number of chemicals that harm the fetus. Nicotine causes constriction of blood vessels, possibly interfering with delivery of oxygen and nutrients to the fetus across the **placenta**. Elevated levels of carbon monoxide decrease the amount of oxygen that can be carried in the blood to the placenta, possibly contributing to a mild lack of oxygen also called **hypoxia** and growth failure in the fetus. Exposure to second hand smoke from any person in the household after birth also increases the risk, especially when infants are surrounded for hours by cigarette smoke. The risk of dying from SIDS, however, is highest if the mother smokes.

Figure 11



## 2. AIR POLLUTION

In the 1970's we carried out studies of ambient **air pollution** and SIDS. One of the known facts about SIDS is that deaths increase in the winter. Certain invisible pollutants such as carbon monoxide rise in the winter months in Los Angeles. Research has shown that these pollutants cause **hypoxic** changes in animal brains. Our studies indicated that the occurrence of SIDS increased seven weeks after these ambient pollutants began to rise in the Los Angeles basin. While pollution from indoor sources such as smoking is the most dangerous, exposure from outdoor sources for instance from sitting in a car in very slow freeway traffic should not be underestimated

(see figure 11). Smoking is, however, the pollutant most directly under the control of the family

## 3. MATERNAL DRUGS

An increase in SIDS deaths was first reported in infants whose mothers during pregnancy took heroin or methadone, both opiates. Since then, with the increase in its use cocaine, especially 'crack', has been added to the list of drugs that can increase the risk for SIDS up to tenfold.

How the opiates and cocaine affect the fetus is not entirely clear. Cocaine causes constriction of the blood vessels and may interfere with oxygen delivery across the **placenta**.



The relationship between other drugs of abuse and SIDS is uncertain. While alcohol during pregnancy can cause **fetal alcohol syndrome**, a relationship with SIDS has not been established in the majority of cases. However, Native American women who drink before becoming pregnant and early in their pregnancy increase the risk for SIDS. In general, when mothers drink excessively after birth, the risk for SIDS increases as well. This may be a result of the mother forgetting to put the baby on her back, or not noticing a baby's illness for instance. The effects of single drugs are difficult to define because many mothers who abuse drugs use more than one. Also it is hard to separate the effects of the drugs from those associated with the life these women lead. Poor eating habits, a lack of prenatal care and poverty are often simultaneously present. Maternal **caffeine** intake does not seem to influence the risk for SIDS.

There is no evidence that drugs for epilepsy, asthma, heart disease and mental disorders such as depression or anxiety are in any way associated with SIDS.

## ***H. DIAGNOSIS AND TREATMENT OF THE INFANT AT RISK FOR SIDS***

### **1. ARE THERE DIAGNOSTIC TOOLS TO IDENTIFY AN INFANT AT RISK?**

Unfortunately, there are no diagnostic tests that can identify ahead of time the infant who will die.

**Pneumograms** record breathing and heart rate. These were first used in the seventies with the hope that individual infants at risk could be identified and the death prevented. Apneic pauses lasting more than 20 seconds, more than five percent of time breathing periodically, and shorter apnea accompanied by drops in heart rate have all been considered in the past as signs of risk. It has become clear that apnea, periodic breathing and drops in heart rate occur regularly in normal infants and do not identify infants at risk (see figures 2, 3 and 5, pages 52 and 54). Unfortunately, 20 years of experience has shown that the individual infant who will die of SIDS cannot be identified by changes on the pneumogram.

For an infant at increased risk for SIDS, a sleep study called a **polysomnogram** is frequently recommended. In addition to the breathing and heart rate patterns, this polysomnogram records body motion, oxygen levels, obstructive breathing and the infant's sleep state such as rapid eye movement or quiet sleep. The study is typically performed in a sleep laboratory, either overnight or during a nap. Such an elaborate study occasionally reveals abnormalities such as prolonged obstructive apnea; however, such abnormalities have not identified the individual infant who will die of SIDS.

### **2. HOME MONITORING AS TREATMENT**

The home monitor is an electronic instrument that is connected to the infant to pick up

breathing movements and the heart beat. When the baby stops breathing for a predetermined amount of time for instance 20 seconds, an alarm sounds. This signals to a parent the need to attend to the baby. The monitors will also sound an alarm when the heart rate slows. Occasionally the doctor will prescribe an additional piece of equipment that monitors oxygen levels in the baby's blood.

Home monitoring was introduced more than 25 years ago in response to the theory that SIDS was the result of sleep apnea, a now discredited theory. Despite a lack of evidence that home monitoring was effective in preventing SIDS, its use spread rapidly. It was championed by both physicians and parent groups and recommended for infants at increased risk for SIDS such as subsequent siblings and premature babies. In the intervening 25 years it has become obvious that home monitoring does not prevent SIDS.

What have been the past indications for home monitoring? One approach has been based on the results of **pneumograms** and **polysomnograms** as described above. However, most findings of apnea, periodic breathing and drops in heart rate that in the past were considered worrisome have been observed in normal infants. The individual infant at risk to die cannot be identified from these tests. Brief apneic pauses of 20 seconds that have been used in the past as an indication for monitoring are so numerous in all infants that they should be considered normal and not worth recording.

A second approach is based on the risk group in which the baby is born such as a premature baby or a subsequent sibling. In 1987, a panel of doctors at the National Institutes of Health (NIH) published a consensus statement about home monitoring.<sup>16</sup> The use of monitors was suggested for infants following an ALTE. Such a treatment plan seemed sensible for a baby who had been found not breathing and had thoroughly frightened the parents. Routine monitoring for premature infants was not recommended and the decision to monitor subsequent siblings was left up to the individual doctors and parents.

In 1990, the NIH initiated a nationwide study about monitoring in which six academic centers participated: in Toledo, Honolulu, Cleveland, Chicago, Boston and our site. In Los Angeles, the Newborn Division of the LAC+USC Medical Center, the Children's Hospital of Los Angeles and the Good Samaritan Hospital were all three involved in the study. It was called the Collaborative Home Infant Monitoring Evaluation (CHIME).<sup>17</sup> Parents were asked to use a very sophisticated computer driven-monitor once their infants were discharged from the hospital. This monitor preserves the recording of apnea and bradycardia whenever such events happen as well as the simultaneous oxygen levels and the baby's sleeping position.

In this study we essentially counted the serious events that happened sponta-

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<sup>16</sup> Consensus Development on Infantile Apnea and Home Monitoring, published in *Pediatrics* volume 79, 1987, pages 292-299.

<sup>17</sup> Ramanathan and colleagues published an article about this study in the *Journal of the American Medical Association (JAMA)* volume 285, 2001, pages 2199-3207

neously in infants once they were discharged from the hospital. More than 700,000 hours of monitoring were obtained in over 1000 infants. Ten percent of the infants showed at least one serious event defined as a stop breathing episode (apnea) longer than 30 seconds, a heart rate drop to lower than 80 beats per minute in the newborn and to lower than 60 beats per minute in the older infant.

What have we learned from this study? There was no difference between normal infants born at term, term born subsequent siblings and infants after an ALTE in the frequency of these serious events. Premature babies monitored between 36 weeks of conception (2-4 weeks before they were supposed to be born) and 43 weeks (3-5 weeks after they were supposed to be born) had more of these than babies born at term. However, once the preterm infants reached 43 weeks after conception, they had no increase in these events.

In summary, we learned that normal babies have “serious” events that we previously thought were abnormal. Premature babies have more of these early, but by the age of increased risk for SIDS, they have no more of such events than normal term babies. What to expect after the baby has had a serious event? The study revealed that subsequent events in infants, if they happened at all, tended to happen within six weeks of the first one.

In 2003, the American Academy of Pediatrics introduced a policy statement on

Apnea, SIDS and Home Monitoring.<sup>18</sup> The recommendations were based on the results of the CHIME and other studies as well as the fact that 25 years of home monitoring had not reduced the incidence of SIDS. The first recommendation stated clearly that home cardio-respiratory monitoring should not be prescribed to prevent SIDS. The CHIME study did not establish the benefit of monitoring premature infants after hospital discharge. Additional studies are required to determine which premature infants might benefit. If the premature infant is monitored, monitoring should be limited to 43 weeks postconceptional age.

There is agreement at the present that far too many monitors are being used. The most current recommendation states that home monitoring does not prevent SIDS. While this is a position taken by the majority of physicians who have studied the problem thoroughly, you will still find others who recommend monitors.

The decision whether to monitor or not is essentially up to the parents and their babies’ physicians. Parents who do not choose to use such a machine should not be made to feel guilty. Some newer monitors on the market are called event monitors because they provide a record of the changes in the heart rate and breathing when the monitor alarms. They have the advantage that when doctors review the tracings, they can tell whether the event was real or a false alarm.

<sup>18</sup> American Academy of Pediatrics, Policy Statement, *Pediatrics* volume 111, 2003, pages 914-917.

The CHIME study used **Respiratory inductance plethysmography (RIP)** that detects obstructive apnea, events not detected by conventional impedance monitoring. It may be important to know about these additional events in some infants. If you choose to use an apnea monitor, it should be the newer event monitor. Ongoing support from the people who sell or rent the equipment is important and the parents or caregivers should carefully follow instructions. Parents must be given the telephone number of a doctor or a nurse who will respond should monitor alarms cause concern about the baby. Whether or not you decide to monitor your baby, it is wise to learn CPR in case you need to resuscitate your infant. Small children should be kept away from the monitors because they could harm themselves or the baby by playing with the cord connecting the baby to the monitor or plugging it into an electric outlet the wrong way.

When should monitoring be discontinued? After you have heard no alarms for one month? After 3 months? After the first half year of life? The CHIME study has shown that monitoring can be discontinued far earlier than previously believed. If infants have had a serious event, they will in all likelihood have outgrown these within six weeks of the event. It certainly is wise to stop monitoring when the baby begins to pull off the sensor or chews on the wires.

**a. Reasons not to monitor**

Home monitoring of infants has not proven to prevent death from SIDS. Infants have died even while on a monitor. In the 20 years that home monitors had been widely used in the United States prior to the **Back to Sleep** Campaign (see Part 3, Section I 2a, page 71), no drop in SIDS rates occurred.

There are no reliable ways to determine which infants if any would benefit from a monitor. As stated above, results from pneumograms would erroneously place many normal babies on machines at home. And, despite the fact that results of the polysomnogram are being used to recommend home monitoring, there is no evidence that these results can tell which infants might benefit from home monitoring.

These monitors are not without their flaws. There is evidence that monitors cause severe family stress. Alarms tend to go off when no serious apneas have occurred, or less frequently, may not alarm when something serious does happen. In other words, parents or caretakers might panic unnecessarily or be lulled into a false sense of security.

Also, these monitors can easily begin to rule family life. For instance, it is more difficult to get a baby-sitter, going out with the baby and the monitor is cumbersome and all the children have to be better supervised. These are only a few of the adaptations that families who monitor must make.

### b. Reasons to monitor

Monitoring has provided some parents with a feeling of security even though there are no guarantees. For some parents this is far better than staying up all night, bending over the crib, and listening for every breath of their child. Perhaps, home monitoring treats parental anxieties, while the effect for the baby is less certain.

The monitor does not seem to affect

the baby's future development. In one study in Europe, babies who had been monitored were entirely normal at ten years of age. In a new study from Holland where monitoring is not as popular as in the United States, two thirds of parents chose not to monitor their subsequent babies. Stress levels were not different in those who did or did not monitor and none of the babies died.<sup>19</sup>

Here is the account of one mother:



*Many parents face the dilemma of whether or not to monitor their subsequent child. It's an individual decision of the parents, with possible input from the family physician. The important thing is to be comfortable with the decision made. From talking to other subsequent parents it seems that either decision causes anxiety. My decision was to monitor Matthew. I was comfortable with my decision, but I found myself constantly defending my decision to neighbors, coworkers etc. I heard remarks such as "why didn't you monitor your first baby?" or, At least this baby will be safe from SIDS". I had to constantly explain that a monitor would not save my baby if he was destined to die from SIDS, and it was mostly a peace-of-mind measure for me. If it didn't go off, I knew Matt was alive. I could sleep at night. I attempted to educate these people about SIDS, but there are many misconceptions out there.*

From: One mother's reaction to her subsequent child by Liz Berthold.<sup>11</sup>



### 3. TREATMENT WITH DRUGS

Doctors sometimes prescribe medicines such as **theophylline**, or **aminophylline** that are caffeine-like substances known to stimulate breathing. It is currently not certain that

these drugs effectively decrease severe apnea in all babies. They probably work best in young prematurely born babies. To date there is no evidence that these drugs will prevent SIDS.

<sup>19</sup> Dr. L'Hoir's work can be found in the *European Journal of Pediatrics*, volume 153, 1994, pages 694-699 and in the same Journal in 1998

<sup>11</sup> See page 41.

## ***I. MINIMIZING THE RISK FOR SIDS***

Since the cause of SIDS remains unknown, we know of no specific treatments or techniques to prevent it. This is difficult for both the parent who has lost a baby to SIDS as well as a parent who has not, but worries about SIDS. There are, however, common sense suggestions that can foster the birth and growth of a healthy infant even though they cannot guarantee that your baby will not die of SIDS.

In the eighties, doctors in England reported some very encouraging findings. They identified and followed mothers who delivered infants at risk for medical problems. By providing well-baby care through a nurse-visitor, the number of infant deaths declined, including the number of SIDS. If every expectant mother would follow these suggestions we should be able to save more lives (see Appendix 5 for guidance).

### **1. WHAT YOU CAN DO BEFORE THE BABY COMES**

#### **a. Family Planning**

By waiting to have a baby until after your teenage years you reduce the risk. Also the risk is less when you space your pregnancies so that at least one or more years pass after you have had a baby, before you become pregnant again.

Three months after birth is the peak

age of risk for SIDS. By planning for babies to be born in spring, you might be able to decrease the chance for SIDS since its incidence is lowest in the summer, three months later.

#### **b. Health Education**

Community support and education in general promote healthy babies. We believe our young people should learn in school how the unborn child and the newborn baby benefit from healthy ways of living. They should learn what to expect about babies' behavior during different developmental stages. Parenting skills foster healthy growth. Just as they are now cautioned about smoking, drugs and alcohol, counseling all our young men and women about the risks of teenage pregnancies should be part of the school curriculum. It is not just the chance of SIDS that would be reduced, but also the chance of prematurity, birth defects, mental retardation and a host of other illnesses.

#### **c. Diet and Drugs**

Eating regular, balanced meals and not taking any unnecessary drugs during pregnancy benefits the unborn baby. Cigarettes and other recreational drugs such as cocaine and heroin have a bad effect on the unborn baby.

#### **d. Prenatal Care**

Regular check-ups with your doctor or in the clinic during your pregnancy are a strong recommendation.

A doctor may be able to spot some abnormalities early. Prenatal care started early in pregnancy, preferably by the second month, has been shown to improve the health of the infants born to mothers who received this care. Parenting classes given at local colleges and as part of community efforts are also invaluable in preparing new parents for successful parenthood.

## 2. AFTER THE BABY HAS ARRIVED

Just as we can give some common sense suggestions for mothers during pregnancy we can also give some recommendations for after the baby is born.

### a. Sleeping position: “Back to Sleep”

Infants should be put to sleep on their back.

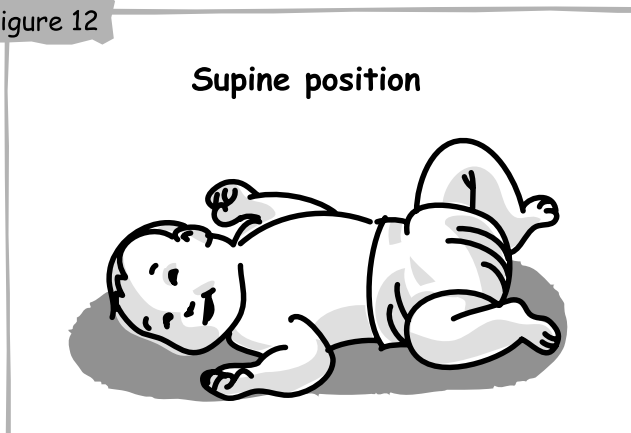
Babies in the United States usually have been put to sleep on their abdomen in the **prone position**. In 1992, the American

Academy of Pediatrics issued a strong statement recommending that infants be put to sleep on their backs, in the **supine position** (see figure 12) or on their sides. The reason for this change was the growing body of information from other countries that sleeping in the supine position reduced the incidence of SIDS by about half. A study from Britain that came out in the summer of 1996 indicated that even placing infants on their side involves an extra risk for SIDS.

All the studies showed that the supine position is safe for healthy babies. In the past, babies were placed prone because of the common problem of gastro-esophageal reflux where stomach content is regurgitated into the throat. Fears that sleeping on the back might lead to choking and aspiration of stomach content into the lungs, turned out to be unfounded. This is not surprising, as healthy babies do not aspirate in this manner no matter what position they sleep in. The supine position is now also recommended

for most premature babies except those with breathing and swallowing problems. The campaign called **Back to Sleep** has met with success. Most doctors and nurses now advise parents to place their babies on their back for sleeping. About 80% of mothers place their infants on their back. The rate of SIDS has come down in all racial groups, although less in African-American babies. There is still room for improvement.

Figure 12



We recommend starting very early to place healthy infants in the supine position for sleeping. We follow this policy in the normal newborn nurseries of our hospital where infants are placed on their backs from the very first day.

Since babies are being put to sleep on their backs there has been increasing concern that the back of the baby's head will flatten. This can happen because the baby's bones are soft and malleable. In extreme cases this condition is called **positional plagiocephaly** and can be treated. For most babies simple precautions started in the first

month will prevent this from happening. For example the baby should be placed on the tummy while awake and being watched.

The flattening resolves spontaneously usually by six months as the infant becomes more active. The use of helmets or surgery is rarely needed.

Not all infants will sleep on their backs. Some will fuss until turned to their stomachs and some will change position during sleep. Boys whose motor development is faster than that of girls may spontaneously turn over at an earlier age. Once infants have learned to turn over and they show strong preferences, nothing but frustration will be gained by trying to change them. In the Netherlands, a baby sleeping sack (figure 13) has proven useful for keeping babies in the supine position.<sup>19</sup>

If the baby is used to sleeping on the back, then it is dangerous to put the baby to bed on its abdomen in the prone position. This is called inexperienced prone and increases the risk for SIDS.

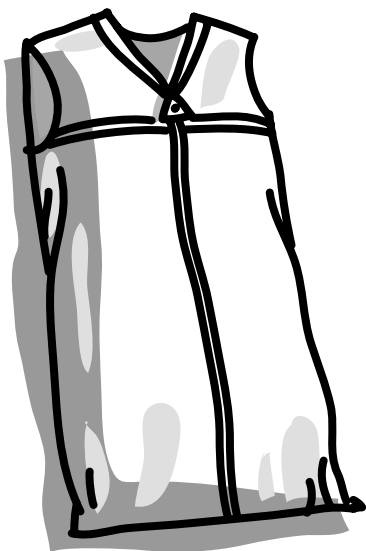
This issue becomes particularly important during daycare, where one out of five SIDS occurs, sometimes during the first day at the center. Parents must make sure that the caregiver is placing their baby on the back.

#### **b. Bedding**

It is strongly recommended that infants be put to sleep at night or for naps on a firm mattress with a smooth sheet and without a pillow. Waterbeds, sheepskins, feather beds

**Figure 13**

**Baby sleeping sack**





and pillows are not designed for infants. Even covers such as comforters or loose blankets are best avoided. Infant pajamas usually should be adequate to keep the infant warm.

Firm mattresses with porous coverings have been developed and are being advertised as protective against SIDS regardless of sleep position (Baby Air/Kidsafe, Breathe Easy, Bumpabed, Halo Sleep System, Sleep Guardian). The idea behind these special mattresses with porous covering is to prevent pockets of stale air from developing around the baby's face. Two products currently on the market (Halo Sleep System, Sleep

Guardian) even have a pump in the mattress to move air. None of these mattresses have been clinically tested to show whether or not they can decrease SIDS.

A recent study testing these products in the laboratory has shown that only one (Halo System) protects against the re-circulation of stale air containing increased levels of CO<sub>2</sub>.<sup>20</sup> However there is no data that shows that this mattress prevents SIDS. Once again, current recommendations are to place babies on their backs on firm mattresses. Soft objects such as stuffed animals, pillows and quilts should be removed from the crib.

#### Safe Sleeping

- Baby should be placed on the back
- Firm mattress (no waterbeds); pillows and quilts should be removed
- Babies should be sleeping preferably in their own crib

#### In case of co-sleeping,

- No alcohol, cigarettes or drugs should be used,
- Parents should not be obese,
- Mattress should be firm

#### c. Temperature

Some parents are inclined to overdress and over-wrap their infants for fear of exposing the baby to cold. Infants are efficient at producing body heat and do not require extra clothing or bedding.

Babies do not require a warmer environment than other members of the family. They should be dressed similarly to older children or adults in the same surroundings.

Keep in mind that while some infants may be able to kick off a blanket, they cannot remove excess clothing. Any temperature excess, be it hot or cold affects the baby's ability to deal with a lack of oxygen.

#### d. Breast-feeding

Breast-feeding is recommended for almost all infants as the most healthful way to feed an infant.

<sup>20</sup> This study, performed by Dr. Carolan and colleagues was reported in *Pediatrics*, volume 105, 2000, pages 774-779.

Although SIDS may not occur as often in breast-fed babies, breast-feeding does not completely protect against SIDS. Breast-feeding, however, gives the mother a good opportunity to observe the baby closely, it helps to protect the infant from getting infections and decreases the chances of **botulism** (Part 3, Section C2, page 49).

**e. Pacifiers**

The use of pacifiers seems to improve the infant's ability to arouse from sleep. Some reports suggest the risk of SIDS is reduced by as much as 50% in babies who use pacifiers. However, we cannot conclude that pacifiers prevent SIDS. The effect may be the result of an associated finding such as infants are sleeping on their backs (see Part 3, Section C4, page 51, association does not mean cause).

**f. Well Baby Care**

Regular care will help to protect your baby. This should include regular visits to a doctor or clinic and routine immunizations.

There is no reason to be afraid of immunizing your baby, as **immunizations** have never been shown to cause SIDS (Part 4, Section A5, page 78).

Your baby will get the best care if you can provide her with a regular place where she receives well baby care, immunizations and where you can take her when she is sick. This has been called a "medical home". The advantage of one place is that the doctors and nurses get to know your family and the

baby's records are there. A clinic or doctor's office with on-call service for 24 hours a day is the best choice. If you have health insurance this care should be covered. All insurance policies in California and most other states are required by law to include preventive care for children.

If you can afford private care, you can select your own regular physician. All health plans called HMO's or managed care will provide care for babies and children. If you do not have insurance or a health plan and cannot afford to pay for care, you may be eligible for Medicaid. This is a program paid for by the United States Federal Government and the state in which you live. Many doctors who care for children will accept Medicaid fees. You should not hesitate to discuss payments for your baby's care with your doctor. For example, if you can't afford the immunizations that are recommended, the doctor or the nurse can arrange for these to be given in the office or by the Public Health Department at little or no cost.

Health Department clinics, including WIC clinics and Children's or Pediatrics departments of city and county hospitals are dependable sources for information about health care. Many have programs in which you can enroll and all should be able to help you obtain care for your baby that you can afford. All of these places have social workers that know what is available for you. You can ask for an appointment with the social worker when you call or visit the clinic or hospital. As a last resort, you can take your

baby to an emergency room when she is sick. This is a place to find immediate help, but does not provide the regular care that every baby needs.

**g. Recognizing when your baby is sick**

In the English study mentioned earlier, nurses visited the homes and taught young mothers to recognize when the baby needed more care. The nurses helped parents evaluate problems and urged them to seek help when they thought the baby could benefit from seeing the doctor. In Appendix 5, we are including the recommendations that parents in England receive that have been shown to be effective.

**h. Medicines**

We suggest that you DO NOT give babies drops for helping them sleep without the advice of a doctor. It has been shown that such drops can cause apnea.

**i. Sleeping with the baby**

Whether sleeping with the baby is protective or contributes to SIDS is controversial. This topic will be discussed in more detail in Part 4, Section B 1a, page 79.



## Theories about SIDS

### A. *DISCARDED THEORIES*

- Sleep Apnea Theory
- Allergies
- Thyroid hormone
- Vitamin deficiencies
- Immunizations
- Overwhelming viral infection

Because SIDS is so tragic and incomprehensible, the urgency to solve it has led to many incorrect answers and false hopes. Several times a year we may read or hear on TV that the breakthrough is around the corner, but the sad truth is that SIDS is still the unexplained death of what appears to parents and professionals alike to be a healthy infant. Here are some of the wrong guesses.

#### 1. SLEEP APNEA THEORY

In 1972 it was proposed that repetitive apnea during sleep could result in a prolonged apnea from which the infant would not awaken. This theory, although untested, was

received with great enthusiasm by both parents and physicians. It offered the promise of prevention of SIDS by home monitoring for apnea. Unfortunately with further study it has become clear that apnea occur regularly in healthy infants and are not a marker for SIDS. After more than twenty-five years of home monitoring the incidence of SIDS remained unchanged. The sleep apnea theory as a cause for SIDS should be discarded; however, prolonged apnea remains a potential explanation for the mechanism of death.

#### 2. ALLERGIES

Some doctors have proposed that babies who have died of SIDS may have been highly allergic. If so, death would result from an overwhelming response by the blood vessels and the heart to the presence of allergens such as cow's milk. The blood vessels would dilate causing a dangerous drop in blood pressure called **shock**. A search for allergens in babies who died from SIDS showed no differences when compared to living babies and babies who died from other causes. At present it is considered very unlikely that SIDS is due to an allergy.

### 3. THYROID HORMONE

One report accompanied by much media attention suggesting that SIDS babies have a lack of thyroid hormone called **triiodothyronine** turned out to be wrong when further tests were made.

### 4. VITAMIN DEFICIENCIES

Lack of Vitamin D or E in mothers or babies was once proposed as a factor in SIDS. This theory was discarded because there is no evidence showing that infants who died of SIDS had a lack of specific vitamins.

### 5. IMMUNIZATIONS

In 1978 three infants in Tennessee died within a day or two after their DPT (diphtheria, pertussis [whooping cough], and tetanus) shots. Since then, parents have been concerned whether immunizations may contribute to death from SIDS. Most shots are given during the first six months of life that correspond to the time of highest risk for SIDS. Therefore, one would expect that in some babies a shot would be given close to the time of death. Several extensive studies have shown that the cause of death in SIDS is not from DPT shots. In countries where DPT shots are given after six months of age, the number of babies dying of SIDS is not less. These studies indicate that the shots do not contribute to SIDS. However, there are real dangers in *not* giving babies their shots in time. In England many people were concerned about shots and decided not to have their baby immunized. As a result in the 1980's a whooping cough outbreak

developed and more than a 100,000 babies got sick. Thirty of these babies died of whooping cough. Although there are minor risks in having the shot (SIDS is not one of them), the disease, whooping cough can cause death. Clearly, the risk of the disease outweighs the risk of the shots.

### 6. OVERWHELMING VIRAL INFECTION

Mothers pass their antibodies to their babies through the placenta before they are born and in breast milk after birth. This makes the babies immune to certain **viruses** and **bacteria** for the first month or two. The lowest level of antibody in the baby's system occurs at about three months of age, the time of the peak incidence of SIDS. The infant is least protected against infection at this time. After their second month of life, infants must develop their own antibodies in order to survive. If they fail to do so, they could die of infection. In the past, scientists have thought SIDS was due to an overwhelming infection by a virus. After extensive research, no special virus has been identified and this guess has not been proven correct.

## B. CONTROVERSIAL THEORIES

- Sleeping Environment
- Heart problems such as a prolonged QT interval
- Lack of lung surfactant

## 1. SLEEPING ENVIRONMENT

### a. Co-sleeping/Suffocation from overlying

The benefits and dangers of co-sleeping when an infant shares an adult's bed have been argued for centuries. Until the early 1970's smothering was considered a cause for SIDS. Overlaying of an infant in bed by an adult was considered to cause smothering of the infant with death resulting from **asphyxia**. Nobody really knows for sure, but it is now believed that a healthy infant when threatened to be pushed aside by the weight of an adult, will struggle and cry, thereby waking the adult. Thus smothering would be prevented. Of course, if this baby had already died silently of SIDS, the parents would not be aroused from sleep if they rolled over on the infant.

The controversy has been rekindled by a recent publication by the Consumer Product Safety Commission. The commission reported the hazards of bed sharing in a respected medical journal. This report was accompanied by a warning from the First Candle/SIDS Alliance suggesting again that smothering is a cause of SIDS. In this publication, five hundred fifteen infant deaths were reported over an eight-year period, 120 of which were considered caused by smothering from overlying. The remainder was believed due to entrapment of the infant's head in various parts of the bed. This controversy will be hard to settle, as neither smothering nor SIDS produce pathologic

changes that can differentiate the two conditions at autopsy.

It is important to distinguish safe and unsafe environments for bed sharing. Parents who have been drinking or have taken drugs, parents who are smoking or who are severely overweight provide an unsafe environment and should avoid co-sleeping. Since we do not know the answer, at present the safest course is to keep the baby next to the parents but in a separate bassinet.

To illustrate the confusion in SIDS research, we now describe another theory which, rather than warning against sleeping with the baby in one bed, concludes that the baby may benefit from sleeping in bed with the parents. According to this theory, if the baby were to stop breathing, by hearing and feeling the parent's breathing, he might be helped to start breathing again. Another scientist has tested a breathing bear, an electronic crib toy. Snuggling against this bear would presumably help the baby begin breathing again as well. While these are ideas that may be pursued further, there is no proof at this time that a mechanical bear or parents for that matter, by being close to their baby can make their babies begin breathing once they have stopped.

### b. Suffocation from bedding

Whether or not an infant can suffocate in bed remains unclear. If the nose and mouth of healthy infants are covered accidentally, most infants will move their heads and fight successfully for air. Even newborn term

infants when placed face down on a firm mattress will raise and turn their heads. However, doctors have studied animals face down on soft surfaces and discovered pockets around their faces with stale air. This air contained an excess of carbon dioxide from the animals' breathing, air they then inhaled. Excess carbon dioxide is poisonous and depresses breathing. It appears that animal findings apply to human babies as well. Therefore, infants should be put to sleep on their backs on a firm surface without pillows or loose covers. (See also Part 3, Section I 2b, page 72).

## 2. HEART PROBLEMS SUCH AS A PROLONGED QT INTERVAL

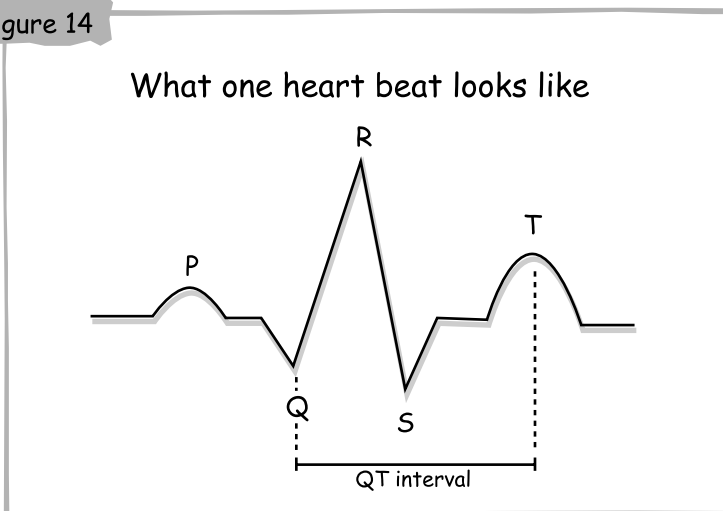
In cardiology, the nervous conduction across the heart is described by the letters P,Q,R,S,T (figure 14). The interval between the Q at

the start of the nervous impulse to the **ventricles** (two of the four heart chambers) and the T that represents the relaxation of the ventricles after contraction is called the QT interval. On few occasions, infants are born with a defect in the heart's intrinsic conduction system. This results in a lengthening of the time a nervous impulse takes to travel through the heart ventricles, **prolonging the Q-T interval**. This condition can result in death from arrhythmia.

This rare condition is not the same as the prolonged QT interval found at birth in half of the infants who subsequently died of SIDS by physicians in Italy.<sup>21</sup> It is hard to accept the prolonged QT interval at birth as a marker for SIDS. Several previous large studies have *not* shown a prolonged QT interval in newborn infants at risk for SIDS or who subsequently died of SIDS. In addition,

there are drugs that may prolong the QT interval, for instance a steroid salve that is put on the mother's nipple to prevent soreness, or cisapride given to the infant to treat gastro-esophageal reflux. Perhaps the mothers in this Italian study had taken these drugs. Lastly, there is no evidence that the QT interval was prolonged when the baby actually

Figure 14



<sup>21</sup> Article by Dr. Peter Schwartz, published in the *New England Journal of Medicine*, volume 338, 1998, pages 1709-1714.



died making it unlikely that a prolonged QT interval was immediately responsible for death. Whether the QT interval is prolonged closer to the time of death will determine the importance of this finding.

### 3. LACK OF LUNG SURFACTANT

Normal lungs produce a detergent called **surfactant** that lines the air passages. It stabilizes the lungs and prevents their collapse when breathing out. A study has shown that babies who have died of SIDS have had not only less surfactant but in addition the surfactant present was different from that of normal infants.<sup>22</sup> The investigators propose that death might have occurred from sudden collapse of the lungs. Since the lung is necessary to supply oxygen to the blood, collapse of the lung could cause hypoxia and threaten the baby's life. It is difficult to explain how this change in surfactant could occur suddenly and without prior symptoms. This theory deserves further study.

## C. CURRENT THEORIES

### Mechanisms of death

- Respiratory failure
- Heart failure

We will organize this section around the two mechanisms of death discussed in Part 3, Section C5, page 51, respiratory failure, following abnormally prolonged apnea or

airway obstruction and heart failure due to arrhythmia or shock. It is impossible to study the mechanism of death in babies unless we catch the rare death of a baby on an event monitor. To date there are just three published reports of such deaths in the literature with less than two dozen cases total, worldwide. These reports have not yet resolved how babies die.

### 1. RESPIRATORY FAILURE

SIDS is presumed to happen when babies are asleep. If babies stop breathing during sleep (apnea), they usually arouse and start breathing again. In effect, they revive themselves. A **failure to arouse** is one of the current theories of the cause of SIDS that we will discuss in more detail below.

What might happen if the baby does not arouse in time, which is referred to as a failure of arousal? If this protective response fails, there is a second line of defense, gasping. The infant's brain stimulates slow, deep, labored breaths that temporarily restore his oxygen supply. If this mechanism also fails, the infant will die from a lack of oxygen.

### 2. HEART FAILURE

If the heart slows dangerously (severe bradycardia) or stops during sleep as a result of either an arrhythmia or shock, the blood will not deliver oxygen to the heart itself or any of the body tissues including the brain and the muscles for breathing. Arousal and gasping cannot be effective because the heart has stopped pumping the blood to the baby's

<sup>22</sup> Various studies performed mostly in Britain

organs. In this case the baby will also die from a lack of oxygen but this is caused by a different mechanism, heart failure.

What these mechanisms have in common is an acute or sudden lack of oxygen. Death happens so quickly that the effects of this acute **hypoxia** do not produce visible changes in the cells of the body at autopsy. There is no proof that one or the other of these mechanisms is more likely to cause death from SIDS. At present some investigators lean toward thinking that the final mechanism is heart failure. A recent report from Germany discusses the death of nine babies who were on an event monitor. All of the infants developed gasping which failed to resuscitate them. In the majority of cases, bradycardia was seen rather than apnea.<sup>23</sup>

### 3. THEORETICAL CAUSES FOR BREATHING AND HEART FAILURE

The important question is what could be the cause of these failures: failure to arouse, failure to gasp, heart failure, arrhythmia or shock.

- What is the contribution of mild chronic hypoxia?
- What may cause a failure to awaken from sleep or an arousal failure?
- How can an overwhelming response to infection cause heart failure?

#### a. The potential contribution of mild chronic hypoxia

There is some evidence that infants who die of SIDS have been exposed to a reduced amount of oxygen during pregnancy and their first months of life, a condition called **mild chronic hypoxia**. This lack of oxygen is comparable to that due to living at high altitude or flying in an airplane. Continuous or chronic exposure to mild hypoxia or episodes of sudden hypoxia in babies who died of SIDS is supported by five findings, see next page.

In a cumulative fashion, this lack of oxygen could affect the brain centers that regulate arousal, gasping and control of heart rate and blood pressure. Consequently, mild chronic hypoxia could predispose to either respiratory or heart failure.

Not everyone embraces this idea. Investigators question whether the changes in the brain and body are indeed caused by lack of oxygen or by something else. Secondly they question whether such small changes in availability of oxygen can lead to the catastrophic regulatory failures seen in SIDS.

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<sup>23</sup> Dr. Poets and colleagues reported this finding in *Pediatric Research*, volume 45, 1999 pages 350-354

- When SIDS babies are carefully studied after death by special tests, mild scarring can be found in the brain (**gliosis**). This can be caused by hypoxia. A study published in 2003 revealed **apoptosis** in the brain. This is cell death without damage or scarring in the surrounding tissues. Significant cell death was found in 79% of SIDS cases in the brainstem. These results suggest that SIDS victims suffered one or more acute hypoxic insults at least several hours before death.
- In 60% of the infants changes are found in blood forming organs, blood vessels and infant fat (**brown fat**) indicative of chronic exposure to mild hypoxia.
- Some SIDS infants showed fetal hemoglobin for a longer period of time than babies who did not die from SIDS. Hemoglobin in the blood helps bring oxygen to the brain and other organs. Right after birth, infants have fetal hemoglobin that holds onto oxygen tighter than adult hemoglobin. As a result less oxygen is released in the tissues. Between two and three months of age, fetal hemoglobin normally converts to an adult type. If it does not convert in a timely manner, the tissues receive less oxygen. Not every study has confirmed this finding so its significance remains unclear.
- The rate of SIDS is clearly elevated in infants of mothers who smoke and it is also increased following times of high air pollution. Both of these decrease oxygen availability to the fetus and infant thus causing mild chronic hypoxia.
- Studies of the brains of infants dying of SIDS have revealed increased levels of **vascular epithelial growth factor** (VEGF). The gene for this cytokine is highly sensitive to oxygen levels in the tissue (see below for the role of cytokines and infection). This suggests that hypoxia was a frequent event that preceded death in these infants.

**b. Failure to awaken from sleep or arousal failure/neurotransmitters**

This theory describes a potential cause of SIDS that would lead to respiratory failure. It proposes that some infants fail to wake up and take a deep breath to end a prolonged apnea. As a result the oxygen level in their

brain continues to go down, making it increasingly more difficult for them to wake up and breathe. In the **brainstem** are centers that regulate breathing and stimulate arousal. A recent study reports abnormalities in the arcuate nucleus of the brainstem, one of the centers for breathing. An unresponsive

center that controls breathing could cause apnea from which the baby does not arouse.

Scientists now have developed special tests to study the chemicals that are necessary for the brain cells to work properly. These are called **neurotransmitters**<sup>24</sup>. Such studies are not done on a routine basis when an autopsy is performed but could be done. Careful study of the brain in a number of babies has revealed that in SIDS there may be abnormalities in these neurotransmitters. At present this is a very promising area of research for the cause of SIDS

New studies have identified yet another aspect of neurotransmitters in SIDS: changes in a specific gene region that controls transport of neurotransmitters. If confirmed these gene changes could possibly identify infants at risk.

### c. **Overwhelming response to infection.**

In section 4, under Discarded Theories we discussed an overwhelming infection by a virus as a cause of death. In this section we discuss the theory of an overwhelming *response* of the body to infection. This theory describes a potential cause of SIDS that would lead to heart failure rather than respiratory failure. The presence of bacteria, viruses or toxins produces a response of the body called the **inflammatory cascade**. This means that when bacteria or viruses are present, specific white blood cells, lymphocytes and plasma cells produce chemical

substances called **cytokines**. Some of these cytokines produce inflammation that is designed to fight the infection. These inflammatory substances do so by increasing blood flow to the infected area. They widen the local blood vessels supplying healing oxygen and nutrients. Other cytokines are anti-inflammatory and are designed to balance the response. The process is controlled by the **adrenal gland**. It is possible that the 2-4 months old infant is vulnerable to an over-active inflammatory response to infection accompanied by an under-active anti-inflammatory response. If this inflammatory process gets out of control it can lead to **shock** in the infant. Shock is a sudden decrease in blood pressure due to excessive widening of local vessels that results in decreased blood flow to vital organs such as the heart and brain. This leads to lack of oxygen or hypoxia and ultimately death. The actual cause of death would *not* be the infection but the inflammatory *response* to the infection. Such a condition would not produce changes found on **autopsy** thus fulfilling the definition of SIDS. The inflammatory cytokines are under genetic control. Studies of parents of SIDS have shown they produced higher levels of inflammatory cytokines than parents who did not lose an infant to SIDS.

A recent study in lambs from Australia revealed that bacterial infection increased steroid hormones in the brain by 50 percent. The lambs became drowsy and difficult to

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<sup>24</sup> Dr. Kinney and her colleagues have performed most of this work. One of her newest studies can be found in the *American Journal of Respiratory and Critical Care*, volume 166, 2002, pages 1530-1531.

awaken. If the same occurs in humans, even a mild infection could cause a failure to arouse from sleep as discussed above.

In conclusion, at the beginning of the new millennium the two most promising theories about the cause of SIDS are a failure to arouse because of abnormal neurotransmitters and an overwhelming bodily response to infection. At present these are receiving the most attention in the scientific community.

#### **D. NEW DIRECTIONS/ RESEARCH TOOLS**

##### **1. MOLECULAR BIOLOGY**

In the last decade a branch of science, called **molecular biology** has drawn a great deal of attention and has much to offer medical research. One of the major accomplishments has been the mapping of all the human **genes**, the **Genome Project**. Genes are made up of **DNA protein molecules** that determine our body characteristics such as eye color and functions such as breathing. The genes are inherited from our parents. Sometimes a person is born with defective genes that can cause a disease like diabetes. As far as we know the cause of SIDS is **not** a defective gene that is inherited. SIDS follows no known inherited pattern and no single gene is expected to cause SIDS. However, genes in all the body cells regulate proteins such as neurotransmitters and

cytokines. Under certain circumstances the gene's action can be up regulated or down regulated. This process increases or decreases the amount of the proteins that they control. For example, a lack of oxygen can either up or down regulate a specific gene that produces a protein such as a cytokine. Molecular biology is important for the study of SIDS because it may explain why some babies have respiratory or heart failure. Because genes are responsible for the regulation of breathing, some research groups are currently studying mice whose breathing genes have been artificially altered in order to understand what these specific genes do. Results of such studies should give us clues for eventual study of babies. Sophisticated research is currently underway to help understand the complexity of cellular function as it relates to SIDS.

##### **2. BRAIN SCANS**

New, but costly, instruments can examine normal babies while they are sleeping to determine whether areas in the brain seem to be using more oxygen and glucose than other areas. This information can tell the doctors something about how certain areas of the brain function in a young infant. As far as we know, studies which use new machines with names as **nuclear magnetic resonance imaging (MRI)** or **spectroscopy (MRS)**, **positron emission tomography (PET)** or even **lasers**, seem to be without risk for the baby. They are, however, expen-

sive and found in only a few centers in the world. These techniques become especially valuable when we want to find out whether infants died as a result of failing to awaken from sleep. In the future investigators might look at two areas in the brain, the brainstem and the **cortex**, because abnormalities in each of these areas could cause an infant not to awaken. The same techniques can be used to find out whether a mild chronic lack of oxygen affects the development of these areas.

#### **E. CONCLUSIONS: THE FUTURE OF THE SIDS PUZZLE**

The study of SIDS continues to be difficult because we do not know in advance which baby will die and therefore we cannot be certain which babies to study. Despite this we are determined to continue our quest to solve SIDS. There are at least five ways to further our knowledge by studying:

- Babies after they have died.
- Parents of SIDS victims
- Groups of babies at increased risk
- Development of normal babies.
- Young animals during development. Studies of breathing and the brain in rabbits, mice and rats cannot tell us about human babies, but they may give us useful clues.

#### **F. HOW YOU CAN HELP WITH SIDS RESEARCH**

You can help by giving financial donations for continued research. This booklet has been written in part to help raise money for that purpose. Of every booklet sold, one dollar will go toward research. As long as SIDS has not been solved we wish to continue our efforts. While the Federal Government has supported SIDS research including our own in the past, many worthwhile research efforts are not funded because the money available is not enough for the very expensive new research techniques.

Other suggestions: In the past people have sent us monetary gifts in memory of an infant who died. That is another way to help us continue. You can send a contribution to:

#### **The Newborn Service, SIDS Research Project**

Room 9L19  
Women's and Children's Hospital,  
LAC/USC Medical Center  
1240 Mission Road  
Los Angeles, 90033  
Telephone 323 226 3406  
Fax 323 226 3440;

Checks should be made out to *The Newborn Service*. We would like you to include the name of the infant who died, and your own name and address so that we can write to tell you that we received your donations and thank you. Some people are in a position to give in a different way.

Sometimes we receive a gift through United Way when an individual has stipulated that their contribution should go to our SIDS research project. One woman told us:

*“My grandchild died of SIDS and I happen to be the president of a foundation that supports medical projects. It occurred to me that I would like to support SIDS research; I plan to bring this before the board, will you provide me with the necessary information how we can help?”<sup>25</sup>*

People, not in the position to give money, may mention in their will that a gift should go to this research. We are confident that large and small contributions will enable us, together with scientists all over the world, to continue pooling our research efforts. Just as was the case of tuberculosis, we will ultimately resolve the riddle of SIDS.

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<sup>25</sup> Ms. Rose LeVantine, past president of the Arthur Zimtbbaum Foundation, New York.





# Glossary

**Aborted Crib Death** – An old term for ALTE (see below).

**Adrenal gland**– among other things responsible for regulating sugar, fat and salt metabolism

**Air pollution** – contamination of air by smoke and harmful gases, mainly oxides of carbon, sulfur and nitrogen coming from automobile exhausts, industrial plants, burning rubbish, etc. Smog is air pollution characterized by a hazy and often highly irritating atmosphere resulting from a mixture of smoke and other air pollutants, with fog.

**Airway Obstruction** – Something blocking air from passing through the throat and larynx to the lungs.

**Aminophylline** – drug used to stimulate breathing and prevent pauses in breathing or apnea

**Anemia** – low levels of hemoglobin, the substance in the red blood cells that carries oxygen

**Antibiotic** – a drug used to treat bacterial infections

**Antibodies** – substances produced by the body that protect it from infection

**Apnea** – pauses in breathing

**Apnea Monitor** – an instrument that sounds an alarm when the baby has a long pause in breathing

**Apnea of Infancy (AOI)** – a prolonged pause in breathing for which no explanation can be found

**Apoptosis** – the death of a cell without damage or scarring of the surrounding tissue

**Apparent Life Threatening Event (ALTE)** – when the infant is found pale or blue, limp and not breathing, and probably would have died without stimulation or resuscitation

**Arrhythmia** – an abnormal heart rate that is either too fast, too slow or irregular

**Asphyxia** – technical term for lack of oxygen, too much carbon dioxide and too much acid in the blood. When present for long enough, organs of the body, including the brain suffer damage.

**Autopsy** – an examination of the internal organs of the body after death to find out why the baby died.

**Back-to-Sleep** – a program sponsored by the American Academy of Pediatrics recommending that babies be put to sleep on their backs to reduce the risk for SIDS

**Bacteria** – a microscopic (invisible) bug that causes infection.

**Bacterium Clostridium botulinum** – a bacteria that grows in fields and gardens and produces spores that may cause paralysis in young infants. These spores can be found in honey.

**Botulism** – a poison that comes from a special kind of bacteria, Clostridium botulinum – and causes paralysis.

**Bradycardia** – too slow a heart rate

**Brainstem** – the lowest part of the brain, which connects with the spinal cord. It controls basic functions like breathing, the heart rate, and blood pressure. It also controls awakening from sleep.

**Brown fat** – fat found in newborn infants that yields more heat and energy than normal fat. It should gradually disappear over the first few months of life.

**Caffeine** – a drug that stimulates breathing (the active ingredient in coffee)

**Carbon Dioxide** – waste gas formed in the body and breathed out by the lungs. It depresses breathing if it is retained in high levels in the blood.

**Central Apnea** – pauses in breathing where the chest muscles do not move because the brain has sent them no messages.

**Cerebral hemorrhage**– bleeding into the brain

**Chromosomes** – the structures in every body cell that contain the genes that control body function

**Circadian Rhythm** – repetitive daily changes that occur in many physiological systems depending on the time of day and night.

**Coma**– loss of consciousness

**Convulsions** – violent spasms or jerking of the muscles with loss of consciousness (also called seizures).

**Coroner** – an official whose duty is to investigate sudden, suspicious, or violent death to determine the cause.

**Cortex (cerebral cortex)** – the outer portion of the brain

**Cot Death** – another term for SIDS, mostly used in England

**Cremation** – burning of the remains before burial

**Crib Death** – another term for SIDS, because the baby is usually found in the crib

**Cytokines** – proteins produced in response to infections. These stimulate the appearance of leucocytes, lymphocytes and plasma cells that fight the infection.

**Death scene investigation** – check of the condition of the crib, bed and room in which the infant died to help establish the cause of death. This includes ruling out infanticide

**DNA protein molecules** – these are the building blocks of the genes

**Down Syndrome** – Mental retardation associated with abnormalities of the face, hands and feet, often with heart or bowel defects as well. An extra chromosome in the egg or the sperm causes it.

**Electroencephalogram (EEG)** – a record of the brain waves

**Endoscope** – an instrument with a flexible tube that can be put down the esophagus to diagnose problems.

**Enzyme** – a complex protein that takes part in the conversion of food into energy in the body

**Esophagus** – the tube leading from the throat to the stomach

**Etiology** – the cause(s) of disease

**Failure to Arouse** – inability to wake up from sleep

**Fatty acid oxidation** – metabolism of certain fatty substances

**Fetal Alcohol Syndrome** – a condition of abnormal appearance and mental retardation caused by excessive maternal alcohol intake

**Fetal Hemoglobin** – hemoglobin is a substance in the blood that carries oxygen to the organs of the body. The fetus makes a special kind that gives up oxygen to the tissues more slowly than adult hemoglobin. It is still present at birth but disappears within the first 2–3 months.

**Gastroesophageal Reflux (GER)** – Acid stomach content regurgitated (vomited up) into the throat

**Genes** – are made up of DNA protein molecules that determine all our inherited characteristics including metabolic processes in all our body cells

**Genome Project** – study of the map of genes found in every cell of the body

**Gliososis** – scarring in the brain

**Hemoglobin** – a substance in the red cells of the blood that carries oxygen to all the tissues of the body such as the muscles, the brain and the heart.

**Hypotonic** – limp, having less than normal muscle tone

**Hypoxia** – lower than normal levels of oxygen in the body

**Hypoxic** – too little oxygen

**Immune System** – cells in the body that fight infection

**Immunizations** – shots to prevent specific infections such as whooping cough

**Inborn error of metabolism** – the lack of an enzyme inherited from the parents that is needed for metabolism

**Infanticide** – killing of an infant

**Infections** – the body's response to invading bacteria or viruses

**Inflammatory cascade** – the multiple effects in response to infection that include production of cytokines that in turn stimulate cells such as lymphocytes and plasma cells

**Interstitial Pneumonia** – technical term referring to the location of inflammation within the lung.

**Irritant fumes** – gases breathed into the lungs causing inflammation

**Jaundice** – yellow staining of the skin and eyeballs that can be caused by several diseases

**Laryngospasm** – spasmodic closure of the airway

**Larynx** – the upper part of the tube that carries air from the throat to the lungs and contains the voice box

**Lasers** – devices that concentrate high energies into a narrow beam of light

**Leucocytes** – white blood cells that respond to and fight an acute infection.

**Lymphocytes** – one type of cell produced in the bone marrow that helps fight infection

**Magnetic resonance imaging (MRI)** –see NMRI

**Magnetic resonance spectroscopy (MRS)** –see NMRS

**Medical Examiner** – a medical doctor who acts as a coroner

**Meningitis** – infection causing inflammation of the covering of the brain or spinal cord

**Mental Retardation** – mental deficiency, a slow or limited development.

**Metabolism** – the complicated process of the burning of food substances to eventually produce energy for the body. This process requires the presence of specific enzymes that stimulate the appropriate chemical reactions

**Mild chronic hypoxia** – low levels of oxygen in the blood that persist over time

**Molecular biology** – the study of cellular processes such as gene activity

**Mortuary** – a place where the burial or cremation of the body is arranged

**Near Miss SIDS** – another old term for ALTE

**Neonatal Intensive Care Unit (NICU)** – a place in a hospital where very sick newborn infants are cared for

**Neurotransmitters** – chemical substances in the brain needed for normal brain function

**Nuclear Magnetic Resonance Imaging (NMRI)** – a way to make images of the brain by using a strong magnetic field to measure the response of nuclei in the cells. This process gives sharp, three-dimensional pictures of structures in the brain. With this technique there is no exposure to radiation.

**Nuclear Magnetic Resonance Spectroscopy (NMRS)** – a way to measure the activity in structures of the brain, using a strong magnetic field as described in NMRI, see above. It is also referred to as functional MRI or fMRI.

**Obstructive Apnea** – breathing pause caused by closure of the airway

**Oxygen** – the part of air needed for metabolism and survival

**Paralysis** – total loss of muscle strength

**Pathologist** – a doctor who specializes in the study of causes of death

**Periodic Breathing** – a repetitive series of short pauses in breathing

**Petechiae** – small amounts of blood leaking outside of the blood vessels

**pH probe** – a piece of equipment that can be put down the esophagus to check the acidity of its contents

**Pneumogram** – a recording of heart rate and respiration by the impedance technique done while the infant sleeps or naps

**Pneumonia** – an inflammation of the lung

**Positional plagiocephaly** – flattening of the back of the head in early infancy as a result of babies lying on their backs.

**Placenta** – the organ that grows in the pregnant mother's uterus to nourish the fetus

**Plasma cells** – another type of cell produced in the bone marrow that helps to fight infection

**Polysomnogram** – a recording of breathing, heart rate and some brain functions during sleep

**Positron Emission Tomography (PET)** – a device that reveals the place of a radioactive tracer in the brain. Doctors can then determine which part of the brain is the most active during specific activities such as eating, speaking and the like.

**Postmortem** – an examination of the body after death, also called an autopsy

**Post-mortem lividity** – discoloration produced by blood settling in the lower parts of the body after the heart has stopped.

**Preterm/Premature Baby** – an infant born at least one month early

**Prolonging the QT interval** – lengthening of the time an electrical impulse travels through the heart ventricles

**Prone position** – on the abdomen or belly

**Respiratory Impedance technique** – measurement of breathing by recording contraction of respiratory muscles. This technique has the disadvantage of not being able to capture obstructive apnea.

**Respiratory Inductance plethysmography** – measurement of breathing by recording change in the volume of the chest and the abdomen. This technique has the advantage of identifying obstructive apnea

**Resuscitated** – restoring heart rate and breathing

**Rh Factor** – a protein that is normally present in red blood cells but absent in about 15% of people.

**Seizure** – another word for convulsion

**Shock** – a medical term to mean a serious decrease in blood supply to the heart and brain that can result in death

**Spores** – dried part of a plant which may carry bacteria

**Streptomycin** – an antibiotic that is active against the tubercle bacillus

**Sudden Infant Death Syndrome (SIDS)** – sudden and unexplained death of an apparently healthy infant for whom no cause can be found at autopsy, by a death scene investigation and a review of the clinical history

**Suffocation** – preventing breathing

**Supine position** – on the back

**Surfactant** – detergent substance that coats the lining of the lung in contact with the air

**Theophylline** – a drug used to stimulate breathing

**Thymus** – a gland located in the neck that is part of the immune system

**Toxin** – a poisonous substance

**Tri-Iodothyronine** – a hormone made by the thyroid gland.

**Tubercle Bacillus** – the bacteria that cause tuberculosis

**Tuberculosis** – an inflammation of the lung caused by the tubercle bacillus

**Vascular epithelial growth factor (VEGF)** – a cytokine that regulates growth of blood vessels.

**Ventricles** – two muscular heart chambers that pump blood into the arteries of the lungs and the body

**Viruses** – ultra small infectious agents that do not respond to antibiotics

**X-Ray (Roentgen ray)** – rays that penetrate the body to reveal internal organs and bones

# Appendix 1: Burial Information

In Los Angeles County, a person in the Coroner's office works specifically with cases of children under the age of 12. SIDS cases take precedence. Ms. Barbara Nelson, R.N. goes out to the home and works with families to assist them to find the most suitable place and way to bury the infant if they so choose. When recently contacted, Ms. Nelson told us that the cost of burying a baby should not exceed \$1,000. This is a minimal service and does not include a limousine. A cremation by itself should cost approximately \$125. She is most helpful to talk to (323) 343 0714; her office hours are Tuesday through Friday 7:00 am to 5:30 pm. Grieving parents can benefit from help, she told us. She heard of a family who was charged \$3,500 recently. Ms. Nelson will always refer parents who are concerned about how to pay for a burial to Heather Atkins.

Since her son died of SIDS, Heather has established the **Little Heroes, the Chad Aitkins Foundation**. Heather offers assistance in dealing with the mortuary and cemetery. If the family is in financial hardship, she will see if she can negotiate a deal for them. Forest Lawn, for instance, is willing to work with her. Heather Aitkins does not speak Spanish, so she asks for somebody to be available for translation.

Heather Aitkins  
Home: 818 593 3033  
Office: 818 887 6529  
Pocket Talk 888 463 3849

If the family is not able to find burial or cremation funds from any source, the body of the baby will be sent to the County Morgue and cremated. The ashes will not be released unless the family can pay the cremation fees of about \$500. The ashes will be held for three years so that the family can try to raise the money. If ashes are unclaimed after three years, they will be buried in a common grave with all other unclaimed ashes from the same year.

As can be seen, there are no standards for burial expenses in Los Angeles County but families in need can find both practical and financial assistance. Whether similar assistance is available in other cities in California, other states or other countries is unknown to us. The agencies listed in Appendix 2 can be consulted for this kind of information.

## Appendix 2: Public Health Programs

### **Alabama**

*Alabama Department of Public Health*

434 Monroe Street  
Montgomery, AL 36130  
(334) 242-5760  
(800) 654-1385 (in AL)  
(334) 269-4865 (fax)

### **Alaska**

*Alaska Department of Health  
and Social Services*

1231 Gambell Street, Suite 302  
Anchorage, AK 99501  
(907) 272-1534  
(907) 274-1384 (fax)

### **American Samoa**

*LBJ Tropical Medical Center*

Pago Pago, AS 96799  
9-011-684-633-4604  
9-011-684-633-5379 (fax)

### **Arizona**

*Arizona Department of Health Services*

1740 West Adams Street, Room 200  
Phoenix, AZ 85007  
(602) 542-1875

### **Arkansas**

*Arkansas Department of Health*

4815 West Markham Street, Slot 17  
Little Rock 72205  
(501) 661-2727  
(800) 482-5400 (in AR)  
(501) 661-2055 (fax)

### **California**

*California SIDS Program*

5330 Primrose Drive, Suite 231  
Fair Oaks, CA 95628  
(916) 536-0146  
(800) 369-7437 (in CA)  
(916) 536-0167 (fax)

### **Colorado**

*Colorado SIDS Program*

6825 East Tennessee Avenue  
Building 1, Suite 300  
Denver, CO 80224  
(303) 320-7771  
(800) 332-1018 (in CO)  
(800) 214-1863 (anywhere in USA)  
(888) 285 7437  
(303) 322-8775 (fax)

### **Connecticut**

*Connecticut Department of Health Services*

150 Washington Street  
Hartford, CT 06166  
(203) 566-1178  
(203) 566-8401 (fax)

### **Delaware**

*Division of Public Health*

Cooper Building  
Federal and Waters Street  
Dover, DE 19903  
(302) 739-4785  
(800) 464-4357  
(302) 995 8617 (Kathy Frost contact person)  
(302) 739-6617 (fax)

### **District of Columbia**

*Commission of Public Health*

800 Ninth Street, 3rd Floor  
Washington, DC 20004  
(202) 645-5620  
(202) 645-0525 (fax)

### **Federated States of Micronesia**

*Government of the Federated States of Micronesia*

PO Box PS 70 Palikir Station  
Pohnpei, FM 96941  
9-011-691-320-2619  
9-011-691-320-5263 (fax)

### **Florida**

*Florida SIDS Program*

1317 Winewood Boulevard  
Tallahassee, FL 32399  
(904) 488-2834 x 125  
(904) 488-2341 (fax)

### **Georgia**

*Georgia Department of Human Resources*  
2600 Skyland Drive, Room 5  
Atlanta, GA 30301  
(404) 679-0531  
(404) 679-0686 (fax)  
SIDS Alliance  
(800) 221-SIDS

### **Government of Guam**

*Department of Public Health and Social Services*  
PO Box 2816  
Agana, GU 96910  
9-011-671-734-7116  
9-011-671-734-5910 (fax)

### **Hawaii**

*Kapiolani Children's Medical Center*  
1319 Punahou Street, Room 741  
Honolulu, HI 96826  
(808) 983 8387  
(808) 949-4232 (fax)

### **Idaho**

*Idaho Department of Health and Welfare*  
450 West State Street, 5th Floor  
PO Box 83720  
Boise, ID 83720  
(208) 334-5957  
Idaho Care Line (800) 983 8387  
Compassionate Friends (208) 343 6553  
SIDS SUPPORT group (208) 455 5300

### **Illinois**

*Illinois Department of Public Health*  
535 West Jefferson Street  
Springfield, IL 62761  
(217) 785-4528  
(217) 782-4890 (fax)

### **Indiana**

*Maternal and Child Health Services*  
2 North Meridian, Suite 700  
Indianapolis, IN 46204  
(317) 233-1243  
(800) 433-0746 (in IN)  
(317) 233-1299 (fax)  
SIDS Support group (800) 433 0746

### **Iowa**

*Iowa SIDS Program*  
Lucas State Office Building  
Des Moines, IA 50319  
(515) 281-4911  
(515) 242-6384 (fax)

### **Kansas**

*Kansas Department of Health and Environment*  
900 SW Jackson  
Topeka, KS 66612  
(913) 296-1307  
(913) 296-4166 (fax)

### **Kentucky**

*Maternal and Child Health Bureau*  
275 East Main Street  
Frankfort, KY 40621  
(502) 564-3236  
(502) 564-8389 (fax)

### **Louisiana**

*Department of Health and Hospitals*  
Capitol Area Services District, Region II  
1772 Wooddale Blvd.  
Baton Rouge, LA 70806  
(504) 925-3611  
(504) 925-7245 (fax)

### **Maine**

*Maine SIDS Program*  
Division of Public Health Nursing  
11 State House Station  
Augusta, ME 04333  
(207) 287-3259  
(207) 287-4631 (fax)

### **Mariana Islands**

*Department of Public Health & Environmental Svcs*  
Northern Mariana Islands  
P.O. Box 409 CK  
Saipan, MP 96950  
(670) 234-8950



**Marshall Islands**

*Republic of Marshall Islands*  
 P.O. Box 16  
 Majuro, MH 96960  
 9-011-692-625-3355  
 9-011-692-625-3432 (fax)

**Maryland**

*University of Maryland School of Medicine*  
 650 West Fayette Street, Room 50684  
 Baltimore, MD 21201  
 (410) 706-5062  
 (800) 808-7437 (in MD)  
 (410) 0146 (fax)

**Massachusetts**

*Boston Medical Center*  
 Boston Medical Center Place  
 Boston, MA 02118  
 (617) 534-7437  
 (800) 64107437 (in MA & RI)  
 (617) 534-5555 (fax)

**Michigan**

*Michigan SIDS Center*  
 North Tower, 9th Floor  
 1200 Sixth Street  
 Detroit, MI 48226  
 (313) 256-2153  
 (800) 359-3722 (in MI)  
 (313) 256-1844 (fax)

**Minnesota**

*Children's Health Care*  
 2525 Chicago Avenue South  
 Minneapolis, MN 55404  
 (612) 813-6285  
 (800) 7323812 (in MN)  
 (612) 813-7344 (fax)

**Mississippi**

*Mississippi State Department of Health*  
 2423 North State Street  
 P.O. Box 1700  
 Jackson, MS 39215  
 (601) 960-7441

**Missouri**

*SIDS Resources, Inc.*  
 \*\*75 James Blvd.  
 Poplar Bluff, MO 63901  
 (573) 840-9720  
 (800) 421-3511 (in MO)  
 (573) 840-9727 (fax)  
 Boothill Healthy Start (573) 472 4949

**Montana**

*State Department of Health  
 and Public Services*  
 Cogswell Building  
 Helena, MT 59620  
 (406) 444-2660  
 (406) 444-2606 (fax)

**Nebraska**

*Nebraska SIDS Foundation*  
 5015 Dodge Street, Suite 5  
 Omaha, NE 68132  
 (402) 551-9975  
 (402) 551-7198 (fax)

**Nevada**

*Nevada State Division of Health*  
 505 East King Street, Room 205  
 Carson City, NV 89710  
 (702) 687-4885

**New Hampshire**

*New Hampshire Division of Public Health Service*  
 Bureau of MCH  
 6 Hazen Drive  
 Concord, NH 03301  
 (603) 271-4536  
 (800) 852-3345) x 4536 (in NH)  
 (603) 271-3745 (fax)

**New Jersey**

*New Jersey SIDS Resource Center*  
 254 Easton Avenue  
 New Brunswick, NJ 08903  
 (908) 249-2160  
 (800) 545-7437 (in NJ)  
 (908) 249-6306 (fax)

**New Mexico**

*University of New Mexico*  
School of Medicine  
Albuquerque, NM 87131  
(505) 277-3053

**New York**

*Office of the Medical Examiner*  
520 First Avenue, Room 506  
New York, NY 10016  
(212) 686-8854  
(212) 447-2716 (fax)

**North Carolina**

*Department of Environment, Health,  
and Natural Resources*  
P.O. Box 29597  
Raleigh, NC 27626  
(919) 715-3401  
(800) 662-7030 (in NC-ask for SIDS Program)  
(919) 715-3401 (fax)

**North Dakota**

*State Department of Health Division of Maternal  
and Child Health*  
600 East Blvd Avenue  
Bismarck, ND 58505  
(701) 328-4533  
(701) 328-4727 (fax)

**Ohio**

*Ohio Department of Health*  
P.O. Box 118  
Columbus, OH 43216-0118  
(614) 466-5332  
(614) 466-8924  
(614) 644-8661 (fax)

**Oklahoma**

*State Department of Health Pediatric Division*  
1000 NE 10th Street  
Oklahoma City, OK 73117  
(405) 271-4477  
(800) 248-7437 (in OK)  
(405) 271-1011 (fax)

**Oregon**

*Center for Child and Family Health*  
Child Health Section  
Suite 825  
800 NE Oregon Street, # 21  
Portland, OR 97232  
(503) 731-4016

**Palau**

*Bureau of Health Services*  
Republic of Palau  
P.O. Box 771  
Koror, PW 96940  
9-011-680-488-2420  
9-011-680-48-3115 (fax)

**Pennsylvania**

*Pennsylvania SIDS Center*  
Benjamin Franklin House  
834 Chestnut Street Suite 200  
Philadelphia, PA 19107  
(215) 955-1400  
(800) 258-7434 (in PA)

**Puerto Rico**

*Puerto Rico Department of Health*  
Call Box 70184  
San Juan, PR 00936  
(809) 754-9580  
(809) 76-1945 (fax)

**Rhode Island**

*Department of Health*  
Free Capitol Hill, Room 302  
Providence, RI 02908  
(401) 277-2312  
(401) 277-1442 (fax)

**South Carolina**

*South Carolina Department of Health  
and Environmental Control Division  
Of Children's Health*  
Robert Mills Complex, Box 101106  
Columbia, SC 29211  
(803) 737-4061  
(800) 868-0404 (in SC)  
(803) 734-3255 (fax)

**South Dakota***Health and Medical Services*

445 East Capitol  
 Pierre, SD 57501  
 (605) 773-4476

**Tennessee***Department of Health*

Tennessee Tower, 10th Floor NE  
 312 Eighth Avenue North  
 Nashville, TN 37247  
 (615) 741-0358  
 (615) 532-1886 (fax)

**Texas***Harris County Health Department*

PO Box 25249, 2501 Dunstan  
 Houston, TX 77265  
 (713) 620-6895

**Utah***Utah Department of Health*

Division of Community and  
 Family Health Services  
 288 N. 1460 W.  
 Box 144450  
 Salt Lake City, UT 84114  
 (801) 538-99200 (Melanie Wallentine)  
 (800) 826-9662 (in UT)  
 (801) 538-6510 (fax)  
 Also, Troy and Lisa Hughes (801) 973 8533

**Vermont***Vermont Department of Health*

108 Cherry Street  
 PO Box 70  
 Berlington, VT 05402  
 (802) 863-7333  
 (800) 464-4343 (in VT)  
 (802) 863-7425 (fax)

**Virgin Islands***Charles Harwood Hospital*

North 3500 Estate Richmond  
 St. Croix, VI 00820  
 (809) 776-1311

**Virginia***Virginia Department of Health*

1500 East Main Street, Suite 136  
 Richmond, VA 23218  
 (804) 786-5916  
 (800) 523-4019 (in VA)  
 (804) 371-6031 (fax)

**Washington***Department of Health*

PO Box 47880  
 Olympia, WA 98504  
 (360) 753-6060  
 (360) 586-7868 (fax)

**West Virginia***Bureau of Public Health*

1411 Virginia Street, East  
 Charleston, WV 25301  
 (304) 558-7996  
 (800) 642-9704 (in WV)  
 (304) 558-2183 (fax)

**Wisconsin***Children's Hospital of Wisconsin*

PO Box 1997  
 Milwaukee, WI 53201  
 (414) 266-2743  
 (414) 266-2653 (fax)

**Wyoming***Division of Public Health*

Hathaway Building, 4th Floor  
 Cheyenne, WY 82002  
 (307) 777-7166  
 (307) 777-5402 (fax)  
 Cheyenne Children's Clinic (307) 635 7916

## Appendix 3: Addresses and Web Sites

### **Association of SIDS and Infant Mortality Programs**

Tel: 612 813 6285  
Fax: 612 813 7344  
c/o Minnesota SIDS center,  
Children's Hospitals and Clinics  
2525 Chicago Ave South  
Minneapolis, MN 55404  
E-mail: Kathleen.fernbach@childrenshc.org;  
www.asipl.org

### **National Center for Education in Maternal and Child Health**

Tel: 202 7849770  
Fax: 202 784 9777  
2115 Wisconsin Ave NW, Suite 601  
Washington DC 20007-2292 (street address)  
Georgetown University, PO Box 571272,  
Washington DC 20057-1272 (mailing address)  
E-mail: mchlibrary@ncemch.org  
www.ncemch.org

### **U.S. Department of Health and Human Services**

Tel: 301 443 2170  
Fax: 301 443 1296  
Parklawn Building, Room 18-0,  
5600 Fishers Lane, Rockville, MD 20857  
www.mchb.hrsa.gov

### **First Candle/ Sudden Infant Death Syndrome Alliance**

Tel: 800 221 7437  
410 415 6628  
Fax: 410 653 8709  
1314 Bedford Ave, Suite 210  
Baltimore, MD 21208  
E-mail: sidshq@charm.net,  
info@sidsalliance.org or  
info@firstcandle.org  
www.sidsalliance.org

### **National Sudden Infant Death Syndrome Resource Center/Circle Solutions**

Tel: 866 8667437 (toll free)  
703 821 8958  
Fax: 703 821 2098 (c/o Olivia Cowdrill)  
2070 Chain Bridge Road, Suite 450  
Vienna, VA 22182  
E-mail: sids@circlesolutions.com  
www.sidscenter.org

### **Back to Sleep Campaign**

Tel: 800 505 2742  
www.nichd.nih.gov

### **National SIDS & Infant Death Support Center**

Tel: 800 638 7437  
410 4156628  
Fax: 410 415 5093  
1314 Bedford Ave, Suite 210  
Baltimore Maryland 21208  
E-mail: sidspsc@aol.com  
www.sids-id-psc.org

### **Guild For Infant Survival of California**

awellsRN@aol.com

### **KIDS/SIDS**

E-mail: badrat@msn.com

### **SIDS Alliance of Northern California**

Tel: 877 938 7437  
925 274 1109  
1324 Bodega Place  
Walnut Creek, CA 94597  
E-mail: info@sidsnc.org  
www.sidsnc.org

### **SIDS Foundation of Southern California**

Tel: 800 9 SIDS LA  
310 558-4511  
Fax: 310 558 7075  
3428 Motor Ave, West Los Angeles, CA 90034  
E-mail: idsfsc@aol.com  
www.sidsfoundationofsoutherncalifornia.org

**American SIDS Institute**

Tel: 800 232 7437

[www.sids.org](http://www.sids.org)

**CJ Foundation for SIDS**

Tel: 888 8CJSIDS

201 996 5111

Fax: 201996 5326

The Don Imus-WFAN Pediatric Center,  
Hackensack University Medical Center  
30 Prospect Ave, Hackensack, NJ 07601  
[www.cjsids.com](http://www.cjsids.com)

**Alliance of Grandparents Against  
SIDS Tragedies (AGAST)**

Tel: 888 774 7437

**California Sudden Infant Death  
Syndrome Program**

Tel: 800 369-SIDS

916 536 0146

Fax: 916 536 0167

3164 Gold Camp Drive, Suite 220  
Rancho Cordova, CA 95670-6052  
E-mail: [info@californiasids.com](mailto:info@californiasids.com)  
[www.california.sids.com](http://www.california.sids.com)

**Department of Health Services /  
Maternal and Child Health Branch**

Tel: 916 657 1374

Fax: 916 657 3069

Ben Carranco, Program Consultant,  
Office of Perinatal Health  
714 P Street Rm 750, Sacramento, CA 95814  
E-mail: [bcarranc@dhs.ca.gov](mailto:bcarranc@dhs.ca.gov)

**Black Infant Health Program (BIH)** is part of the Maternal and Child Health Program of the State of California. One of its goals is to reduce deaths of African-American infants, including deaths due to SIDS. The Maternal and Child Health Branch should be able to route messages to this program.

**Canadian Foundation for the Study  
of Infant Deaths**

568 Eglinton Ave East, Suite 308,  
Toronto, Ontario  
Mailing Address: PO Box 190 Station R.  
Toronto, Ontario, Canada M4G 3Z9  
Tel: 416 488 3260

**The Foundation for the Study of Infant  
Deaths**

35 Belgrave Square, London SW1X 8QB,  
United Kingdom  
071 235 0965 or 071 823 2216

**SHARE** (for parents who have lost children)  
St Elisabeth Hospital, 211 S. Third Street,  
Belleville, IL 62222  
Tel: 618 234 2415 or  
618 234 2120 ext 1430

**The Compassionate Friends**

(for grieving parents)  
PO Box 3696, Oak Brook, IL 60522  
Tel: 312 990 0010

## Appendix 4: Dos and Don'ts when talking to parents who lost a baby to SIDS.

- |  |   |
|--|---|
| DO let your genuine concern and caring show  | DON'T let your own sense of helplessness keep you from reaching out to a bereaved parent                        |
| DO be available  |   |
| DO call or write to the family if it feels right   | DON'T avoid them because you are uncomfortable  |
| DO say that you are sorry about what happened to their child and about their pain  | DON'T say you know how they feel (unless you have lost a child yourself you probably do not know how they feel) |
| DO allow them to express as much grief as they are feeling at that moment and are willing to share   | DON'T say "you ought to be feeling better by now" or anything else that implies a judgment about their feelings |
| DO encourage them to be patient with themselves, not to expect too much of themselves, and not to impose any 'shoulds' on themselves   | DON'T tell them what they should feel or do   |
| DO allow them to talk about the child they have lost as much and as often as they want to  | DON'T change the subject when they mention their dead child   |
| DO talk about the special, endearing qualities of the child they have lost   | DON'T avoid mentioning the child's name   |
| DO give attention to the surviving siblings  | DON'T try to find something positive about the child's death (for instance a moral lesson, closer family ties)  |
| DO reassure them that they did everything that they could  | DON'T point out that at least they have their other children  |
| DO share your personal experiences of death and grieving if it seems useful and normal but realize that the death of an infant, of grandparents and uncles is not the same as the death of a young child | DON'T say that they can always have another child   |
|  | DON'T suggest that they should be grateful for their other children   |

*From Abby Wasserman, MD  
modified from copyrighted material  
by Lee Schmidt, RN, MN  
Parent Bereavement Outreach Pediatrics  
74:323-329, 1984*

# Appendix 5: How to recognize whether your baby is ill

## ***WHEN TO CALL AND TALK TO A DOCTOR OR CLINIC ABOUT YOUR BABY:***

- If you think your baby is ill even without any obvious symptoms contact your doctor or clinic.
- If your baby shows any of the following symptoms, especially if he has more than one, your doctor would expect you to ask for advice

## ***ALWAYS URGENT-CONTACT A DOCTOR IMMEDIATELY IF THE BABY:***

- has a fit or convulsions, or turns blue or very pale
- has quick, difficult or grunting breathing
- is exceptionally hard to awaken or unusually drowsy or does not seem to know you

## ***SOMETIMES SERIOUS:***

- croup or a hoarse cough with noisy breathing
- cannot breath freely through his nose
- cries in an unusual way or for an unusually long time or you think your baby is in severe pain
- refuses feeds repeatedly, especially if unusually quiet
- vomits repeatedly
- frequent loose bowel movements, especially if watery (diarrhea). Vomiting and diarrhea together can lead to excessive loss of fluid from the body and this may need urgent treatment
- unusually hot, cold or floppy.

Even if you have consulted a doctor, a health visitor or nurse, If your baby is not improving or is getting worse, **TELL YOUR DOCTOR AGAIN THE SAME DAY.**

*From the Foundation for  
the study of Infant Death, England*

# Appendix 6: Recommended Reading

**Sudden Infant Death Syndrome, Medical Aspects and Psychological Management.**

Jan L. Culbertson, Henry Krous and Debra Bendell (Editors) The John Hopkins University Press, 1989. This book is written for Physicians and other Health workers who come in contact with SIDS and SIDS parents.

**When a Baby Suddenly Dies; Cot Death the Impact and Effects.**

Janet Devison Lord. Hill of Content, Melbourne, Australia 1987. For parents and people who wish to help them.

**The SIDS Survival Guide, Information and Comfort for grieving family and friends and professionals who seek to help them**

by Joani Nelson Horchler and Robin Rice Morris. SIDS Educational Services, Inc Hyattsville, 1994

**Sudden Infant Death Syndrome and Child Care Practices**

by Tony Nelson. Lamarr Offset Printing Ltd, Hong Kong 1996

**Sudden Infant Death, Patterns Puzzles and Problems.**

This book is based on a large survey of British families who lost an infant to SIDS. The authors are Jean Golding, Sylvia Limerick and Aidan Macfarlane. University of Washington Press, Seattle 1985

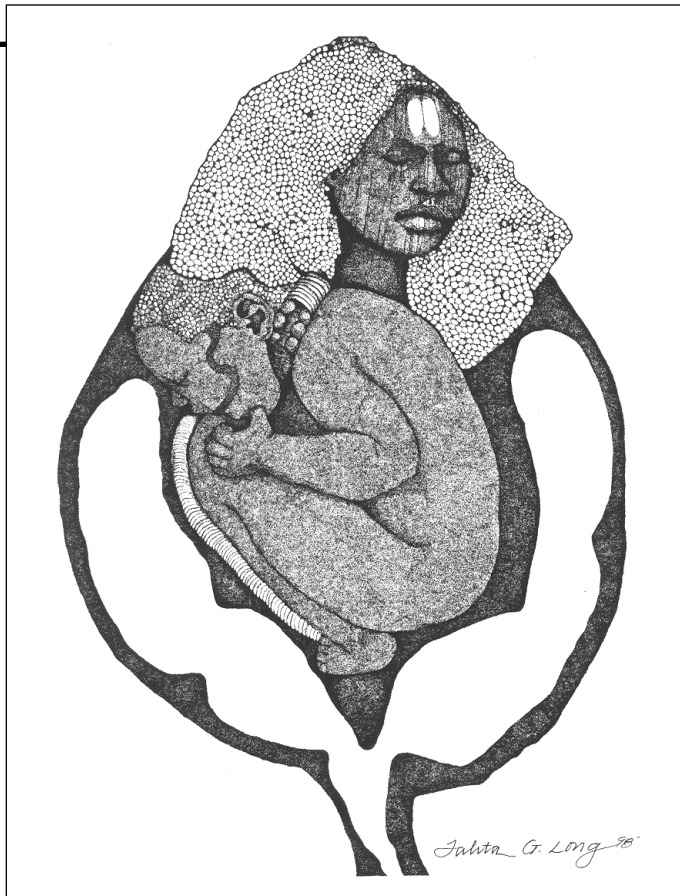


## About the authors:

**Toke Hoppenbrouwers** did her undergraduate work at the University of Utrecht, The Netherlands. She received her Ph.D. in Physiological Psychology from the University of California, Los Angeles where she also studied Clinical Psychology. She is Clinical Professor at the University of Southern California, Keck School of Medicine, in Los Angeles where she has been doing research on SIDS since 1972. Between 1990 and 2000 she was principal investigator of the Collaborative Home Infant Monitoring Evaluation (CHIME), a multi-center study funded by the National Institute of Child Health and Human Development. She has taught in the Psychology Department of California State University, Northridge since 1980.

Website: <http://toke.hoppenbrouwers.net>

**Joan Hodgman** received her B.A. from Stanford University and her M.D. from the University of California, San Francisco. She served as Director of the Newborn Service at LAC+USC Medical Center from 1955 to 1987 and as Interim Director between 1990 and 1991. She is Professor of Pediatrics at the University of Southern California, Keck School of Medicine in Los Angeles. Dr. Hodgman is active with the American Academy of Pediatrics and in 1999 she was the recipient of the prestigious Virginia Apgar award.



**T**he incidence of SIDS is high in African-American babies. This original signed piece of art, made by the African-American artist Talita Long is an excellent reminder of the goals of the Black Infant Health Program:

- Reduce deaths of African-American infants, including deaths due to SIDS
- Increase first trimester prenatal care visits by pregnant African-American women
- Foster continuity of healthcare services during the perinatal period for African-American women and their children.

---

This poster (22.5" x 32") can be ordered through <http://toke.hoppenbrouwers.net>, the section SIDS has the details. You can also write and send a check to The Newborn Service at the address on page 86. The price of the poster is \$35 plus \$6.50 for tax, mailing and handling.

**S**udden Infant Death Syndrome (SIDS) occurs in infants throughout the world; its cause is unknown. In the United States an estimated 3,000 infants die every year of SIDS. In the early nineties parents in the Western world were urged to place infants on their back to sleep. This public health measure has reduced the rate of SIDS by nearly 50% but SIDS in African-American infants has remained at high levels.

Since 1972, the authors of this book have been involved with the care of newborns and SIDS research. This book reflects the current state of knowledge about SIDS from an integrated perspective: scientific, medical and counseling.

It is written in clear language with as little jargon as possible so that parents, day care workers, coroner's personnel and health care professionals can understand the health, medical, counseling and research issues brought together in one volume. In addition it contains practical information and resources that can be used by the reader.



Doctors Hoppenbrouwers and Hodgman who are pioneering Sudden Infant Death syndrome (SIDS) investigators, have made important contributions to our scientific understanding of SIDS. The book *SIDS* is a comprehensive manual for SIDS parents and professionals that brings you up to date on all the issues. In *SIDS*, the authors share insights gained from their 30-year research of this disorder. They explore this tragic loss from the parent's perspective, through explanation of current research theories and they provide information on how to survive. This book is an important resource for anyone who has been touched by SIDS.

***THOMAS G. KEENS, M.D.***

Professor of Pediatrics, Physiology and Biophysics  
Keck School of Medicine, University of Southern California  
Childrens Hospital Los Angeles

"In this booklet, Dr. Hoppenbrouwers and Dr. Hodgman share their experience with SIDS research and SIDS families in a helpful, easy to understand format. Long time SIDS family supporters, they offer helpful information about the grieving process and suggestions to families as they attempt to survive after SIDS. Both professionals and families will benefit from their work."

***DEBBIE GEMMILL***

SIDS Parent, Author

**Monte Nido Press**  
Calabasas, CA 91302  
<http://toke.hoppenbrouwers.net>  
US \$6.50

ISBN 0-9742663-0-2  
50650

