SIDS and SUID: The PHN’s Role in Reducing the Risk and Supporting Families

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- How can an apparently healthy baby die suddenly without explanation?
- Is there anything we can do to prevent it?
- If there were easy ways to reduce the risk of SIDS, would parents follow these recommendations?
- How does a SIDS death affect surviving family members?
- How can PHNs or SWs best educate, console, and provide grief counseling to families who have experienced a SIDS or SUID death?

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SIDS and SUID: The PHN’s Role in Reducing the Risk and Supporting Families.

Sudden infant death syndrome (SIDS) is the most common cause of death in infants between the ages 1-month and 1-year, yet its cause remains unknown. The usual story is that an apparently healthy infant is put down to sleep, and the parent or caregiver comes back some time later to find that the infant has died suddenly and unexpectedly. In general, there was no sign that this infant was sick, or that he or she would die. By law, all such infants undergo a death scene investigation and autopsy. For most babies who died suddenly and unexpectedly, the cause of the death remains unexplained. What is the cause of this medical mystery? Most SDS researcher believe that SIDS does not have one single cause, but it is due to an interaction of a developmental window of vulnerability, some intrinsic vulnerability in the infant decreasing the ability to respond to environmental challenges, and an unsafe environment during sleep. Since 1992, public health measured aimed at reducing unsafe infant sleep environments have resulted in a dramatic decrease in the number of babies dying from SIDS. However, this approach has not completely eliminated SIDS, and many families still grieve the death of their precious babies from SIDS. The public health nurse has important roles to educate, console, and provide grief counseling to families of SIDS victims. The PHN is also at the forefront or providing public education about safe infant sleep recommendations and reducing the risk of SIDS.
SIDS Definition, Research, and Risk Reduction
Thomas G. Keens, M.D.

“And this woman's son died in the night ...”
1 Kings 3: 19 (950 B.C.)

For over 3,000 years, people have known that apparently healthy babies could die swiftly, silently, and unexpectedly during their sleep. Throughout most of history, it was believed that mothers inadvertently rolled over on them, suffocating them, or that they strangled in their bedclothes. Now, we do not think this is a common cause of SIDS.

The clinical story is usually something like this. The parent or caregiver places the baby down to sleep for an overnight sleeping period or a daytime nap. Sometime later, they come back to find that the infant has died. Generally, these infants were healthy, and there was no sign that something was wrong with the baby, or that death would occur. The baby was thought to have been asleep when death occurred. In some cases, the baby has been in the next room, within hearing distance of the parents, who have come back to the baby within 30-minutes to find that the baby has died during that short period of time. Yet there was no noise, sound of struggle, or any indication that something was happening. Thus, SIDS appears to be something that happens swiftly and silently. There is no indication that the baby suffered.

When a baby dies suddenly, it precipitates a cascade of first responders. 911 is called. Police, Fire, and Paramedics arrive rapidly. In most cases, the baby is obviously dead. A Coroner’s investigator performs an examination of the death scene. By California law, an autopsy must be performed. All of these are used to determine the cause of death. National statistics suggest that in ~15%-20% of infant deaths, an identifiable cause of death can be found. This leaves the majority in whom no identifiable cause of death is found, and this is the group of babies called sudden infant death syndrome (SIDS), which is defined as:

The sudden unexpected death of an infant, under one-year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy, and review of the circumstances of death and the clinical history.1

There is some variation in the diagnoses which are used to define the cause of death in infants who die suddenly and unexpectedly. Medical examiners and coroners may use diagnoses such as Sudden unexpected or unexplained infant death (SUID), Sudden unexplained death in infancy (SUDI), Undetermined, etc. However, these all mean the same thing; that the death was unexpected on the one hand, and unexplained on the other. In this presentation, the terms SIDS, SUID, SUDI, and Undetermined all mean the same thing, and we will generally use “SIDS”.

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The key features are that the death is unexpected on the one hand, and unexplained on the other. SIDS is the most common cause of death between the ages of one-month and one-year, yet its cause remains unknown. As shown on the right, prior to 1990, the SIDS rate was one out of every 600 babies born would die from SIDS. The SIDS rate has fallen to ~0.5 SIDS deaths per 1,000 live births, but it is still the most common cause of post-neonatal death.

SIDS has a unique age distribution. SIDS peaks at 2-4 months of age, with 95% of SIDS occur before 6-months of age. Other natural causes of infant death peak near birth and fall off exponentially after that. This unique age distribution has led some epidemiologists to suggest that SIDS is not just a collection of babies who died from causes that could not be figured out, but rather, they seem to have died from a similar mechanism. SIDS deaths are more common in winter months, and less common in summer. The reason is unclear, but it may be due in part to the nonspecific stress of viral respiratory infections or cold. SIDS is about 2½ more common in African-Americans than in Caucasians or Hispanics. SIDS is lowest in Asian-Pacific Islanders.

By definition, the autopsy does not indicate a cause of death. In general, SIDS babies were otherwise healthy, they did not show signs of severe illness, and they did not show signs of significant stress. SIDS is a diagnosis of exclusion, which means that the diagnosis is only made if no other cause of death can be identified in autopsy or death scene investigation.

**Research into Possible Causes.**

The cause of SIDS is unknown. There has been over 4½ four decades of research into potential causes. However, the cause has not been easy to discover. How are we to understand SIDS? Let’s consider an analogy. Imagine a car going up a steep mountain road. The car has stopped. Why can’t the car continue up the mountain road? In the traditional medical model, we might get out of the car, walk around it and see that all four tires are flat. We have discovered a cause. We could replace the
tires, and presumably continue our journey. This is the traditional medical model of disease. Using this approach, scientists have determined that cardiac causes, respiratory causes, arousal disorders, metabolic causes, infections, vitamin deficiencies, environmental toxins, etc., are not important causes of SIDS. Thus, we need a new way of thinking about SIDS.

So, how are we to understand SIDS? Let us return to our car analogy. Perhaps the car can not continue up the steep mountain road because the engine is not powerful enough, maybe we have too many passengers in the car. Maybe the road is too rocky, or the road is too steep. You can see that any of these could be reasons why the car can not continue to go up the road, but in no case is there actually anything wrong with the car. So, we need to think of SIDS in a new way.

Most SIDS researchers believe that SIDS occurs when an infant is in a potentially life-threatening situation, such as sleeping prone on soft bedding. The infant can lift or turn the head to avoid suffocation. If the infant does not or can not rescue himself, then he can progress through failure of arousal, hypoxic coma, slow heart rate, and death. Most infants appear to rescue themselves, but some apparently do not, and they can die.

Filiano and Kinney proposed the Triple Risk Model of SIDS in 1994. There are three overlapping circles representing Development, Infant vulnerability, and Environment. The size of the overlap is the chance of an infant dying from SIDS. Each circle can change in size, depending on the relative contribution of the effect. For example, SIDS is most common between 2-4 months of age, so a 3-month old infant would have
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Development: SIDS is most common in infants between 2-4 months of age. The cardiorespiratory system is rapidly developing during the first 6-months of life. From an engineering point of view, any system in transition is intrinsically unstable. An unstable respiratory system can cause infants to stop breathing (apnea) during sleep. Central apneas occur when an infant makes no respiratory effort. Obstructive apneas occur when the upper airway occludes during inspiration, preventing air movement. In the 1990’s, the CHIME Study showed that apneas in babies did not occur at the same age as SIDS. Therefore, SIDS is not as simple as babies stopping breathing during sleep. However, the CHIME Study did show that even normal infants could have long apneas and low oxygen (hypoxia) during sleep, which was previously unexpected. SIDS deaths are also increased in babies born at altitude over 8,000 feet, suggesting that hypoxia may be a contributor to SIDS. If an infant has a potentially dangerous apnea or hypoxia during sleep, probably the best thing he or she could do is to wake up and deal with the threat. Ward and colleagues showed that normal infants over 9-weeks of age were less likely to arouse (wake up) in response to a hypoxic challenge than infants under 9-weeks of age. This was surprising. Hamutcu and colleagues studied the same normal infants longitudinally at 1-month of age (before the peak incidence of SIDS), 3-months of age (at the peak incidence of SIDS), and 6-months of age (after the peak incidence of SIDS). She found that 50% of infants at 1-month of age aroused in response to hypoxia, compared to only ~10% at 3-months of age, and none at 6-months of age. She postulated that infants were born with a protective arousal response to respiratory stimuli (hypoxia), which was lost at 3-months of age. This coincides with the peak incidence of SIDS. While we do not believe that this is the cause of SIDS, something seems to happen to even normal infants, which decreases this
potentially protective physiologic response at the same age that the incidence of SIDS increases. This may be a partial explanation for the increased risk of SIDS at 3-months of age.

**Infant Vulnerability:** Why do some infants arouse and turn or lift their heads in response to potentially dangerous conditions during sleep, and others do not? Kinney and colleagues studied the brainstems of babies who died from SIDS, and compared them to babies who died from other causes. The brainstem is the life-support portion of the brain. It controls breathing, heart rate response to environmental changes, blood pressure, body temperature, arousal (sleep-wakefulness), etc. She found that the neurotransmitter serotonin (a chemical nerve cells use to talk to each other) was decreased in SIDS brainstems compared to those of babies dying from other causes. Serotonin receptor binding sites were also decreased in SIDS. Serotonin is an important neurotransmitter in the brainstem, which controls life-support functions. This suggests that SIDS victims have abnormal control of breathing, heart response to environment, and arousal. Even more important, Kinney found that serotonin was decreased both in SIDS infants who had no evidence of possible asphyxia or suffocation contributing to the death, and in those in whom the death scene investigation suggested that asphyxia or suffocation might be present. This suggests that normal infants, with normal brainstem serotonin, would likely have been able to rescue themselves (unless the asphyxia was severe), whereas those who died may have been more vulnerable. Because of brainstem neurotransmitter deficit, they may not have been able to mount a normal response to rescue themselves. Thus, we can envisage a continuum of brainstem abnormality from small or normal to severe. In order for an infant with normal brainstem serotonin to die, the asphyxial insult must have been severe. In order for an infant to die without any asphyxial insult, the brainstem neurotransmitter deficit must have been severe. For most infants, who increasingly die in the presence of one or more SIDS risk factors or unsafe sleep environments, there is probably some brainstem dysfunction, though not enough to have caused death in the absence of environmental stressors.
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Environment: There are parts of the sleep environment which can be dangerous. The majority of babies who die suddenly and unexpectedly have a number of risk factors identified at the time of death. This research has identified a number of potentially modifiable risk factors for SIDS. Identifying and eliminating these modifiable risk factors has been associated with decreased SIDS deaths, and a reduced risk of SIDS. It is important to note that risk factors are not causes. Most babies with risk factors will not die. Some patients without risk factors will die. But, those babies with risk factors have an increased risk of dying. How can we reduce the risk of SIDS in infants?

Public Health Interventions Decrease SIDS Deaths.

In 2011, the American Academy of Pediatrics identified a number of risk factors which increase the risk for SIDS. Beginning in 1992, the American Academy of Pediatrics recommending avoiding these risk factors, as this has resulted in a fall in the SIDS rate and number of babies dying from SIDS. We review the important recommendations.

Back to Sleep for every sleep—To reduce the risk of SIDS, infants should be placed for sleep in a supine position (wholly on the back) for every sleep by every caregiver until 1 year of life. Side sleeping is not safe and is not advised. Many studies have been performed over many years in many countries, which show that prone sleeping is associated with an increased risk of dying from


SIDS. This is not controversial. Consequently, in 1992, the American Academy of Pediatrics first recommended that babies should not sleep on their stomachs. The prone sleeping rate has fallen from ~70% in 1992 to ~12% in 2010. The SIDS rate has fallen in parallel fashion with the fall in prone sleeping. Thus, most SIDS researchers equate the fall in SIDS deaths with the decrease in prone sleeping. Side sleeping is also associated with an increased SIDS risk compared to the supine position, which is the safest. Side sleeping is unstable. Thus, in order to keep a baby sleeping on the side, one will need to prop the baby. Where will they place the prop? Usually on the back, which just insures that the baby will roll onto the stomach, which is the most dangerous position. Prone sleeping was initially thought to be a good idea because if a baby spit up, the material would simply drain out the mouth, and the baby would not aspirate. However, if one looks at the anatomy, in the prone position, the esophagus (food tube) is above the trachea (windpipe). Thus, if a baby spits up, the material will go by gravity into the trachea. In the supine position, the esophagus is below the trachea. So, spit up material would have to defy gravity to get into the trachea. A particularly dangerous situation is babies who are accustomed to sleeping supine, but are placed prone. These unaccustomed prone sleeping infants have ~four times the SIDS risk as routine prone sleepers, which is already higher than those babies who sleep supine. Therefore, the number of babies dying from SIDS has been profoundly reduced by having babies sleep on their backs.

Use a firm sleep surface—A firm crib mattress, covered by a fitted sheet, is the recommended sleeping surface to reduce the risk of SIDS and suffocation. Use safe firm mattresses, free of hazards, not in adult beds. Sitting devices are not recommended for routine sleep. Soft bedding and items in the crib increase the risk of SIDS 4-8 times.

Room-sharing without bedsharing is recommended --- There is evidence that this arrangement decreases the risk of SIDS by as much as 50%. In addition, this arrangement is
most likely to prevent suffocation, strangulation, and entrapment that might occur when the infant is sleeping in an adult bed. In 1892, a Scottish Police Surgeon, Doctor Templeman, described 258 cases of what he called “suffocation in babies”. These babies had been sleeping in the same beds as their parents. More than half of the deaths occurred on Saturday nights, and he postulated that obtund parents from alcohol rolled onto their babies and suffocated them. Thus, there has been concern for over 100 years that babies could be suffocated by sleeping in the same bed with their parents. Consequently, the American Academy of Pediatrics recommends roomsharing, but not bedsharing.

Nevertheless, bedsharing is common. Some have suggested that bedsharing has a survival advantage for babies. Considerable research has been performed in this area. Bedsharing does increase the frequency and duration of infant breastfeeding when compared to babies sleeping in another room. However, when compared to babies who roomshare with their mother, but do not bedshare, there is no difference in the frequency or duration of breastfeeding. Bedsharing does not improve an infant’s breathing or decrease infant apnea. There appear to be no physiologic benefits of bedsharing. On the other hand, there are many epidemiological studies which show an increased risk of bedsharing compared to roomsharing without bedsharing. A number of commercially available infant beds or cribs can be placed next to the mother’s bed, to facilitate interaction, but provide the safety of a different sleep surface.
In general, bedsharing has an increased risk of SIDS, and it is not recommended. However, bedsharing is especially unsafe with:

- Infant <3-months of age.
- Parent cigarette smoking, even if they do not smoke in bed.
- Parent is excessively tired; such as sleep deprivation (<4-hours sleep the previous night).
- Parent depressant medication or alcohol use.
- Bedsharing with a non-parent or multiple persons.
- Soft or unsafe bed.
- Duvets, pillows, or soft covers.
- Sleeping on a sofa, armchair, or couch. This is extremely dangerous, and it is associated with a 50-70 times increased risk of SIDS.

Thus, the American Academy of Pediatrics specifically recommends:

- Room-sharing, with the infant in a crib in the parents’ room next to the adult bed, is safest, and is safer than bedsharing.
- Infants brought to bed for breastfeeding should return to a separate crib.
- Do not bedshare if parents smoke cigarettes.
- Do not bedshare if the parents’ arousal is depressed (alcohol, drugs, sleep deprived <4-hours sleep the night before).
- Do not sleep with an infant on a sofa or chair.

**Keep soft objects and loose bedding out of the crib to reduce the risk of SIDS, suffocation, entrapment, and strangulation.** Babies should sleep in an empty crib, without blankets or pillows, with nothing covering the head, and without bumper pads.

**Avoid smoke exposure during pregnancy and after birth — Both maternal smoking during pregnancy and smoke in the infant’s environment after birth are major risk factors for SIDS.** Maternal cigarette smoking during pregnancy is associated with a 3-15 times increased risk of SIDS. The more cigarettes the mother smokes per day during pregnancy, the higher the risk. After the baby is born, exposure to second-hand cigarette smoke is also associated with an increased risk for SIDS. Because mothers spend more time with infants than fathers, maternal smoking after birth carries 6-22 times increased
risk of SIDS, and paternal smoking after pregnancy carries a 3-4 times increased risk. The more hours/day a baby is exposed to second hand cigarette smoke, the higher the SIDS risk. Babies exposed to 8-hours/day of cigarette smoke have a 10-times increased risk of dying from SIDS. No mother should ever smoke during pregnancy, and no one should ever smoke around a baby.

**Breastfeeding is recommended.** The protective effect of breastfeeding increases with exclusivity. However, any breastfeeding has been shown to be more protective against SIDS than no breastfeeding. Infants who ever breastfeed have 40% the SIDS rate as those who formula feed. Thus breastfeeding is protective, and should be encouraged.

Infants should be immunized in accordance with recommendations of the AAP and CDCP --- There is no evidence that there is a causal relationship between immunizations and SIDS. Infants should also receive regular well-child check-ups. Because SIDS is most common between 2-4 months of age, and because infants receive baby shots at 2, 4, and 6 months of age, there was concern that immunizations cause SIDS. Research has shown that there is no causal relationship between SIDS and immunizations. SIDS infants are less likely to have received their immunizations than those who do not die. Immunized infants have about half the SIDS rate as those who are not immunized.

**Avoid alcohol, and drug exposure during pregnancy and after the baby is born.** These are associated with an increased risk for SIDS.

**Offer a pacifier during sleep.** While it was once thought that using a pacifier would cause orthodontic abnormalities (crooked teeth), this is not true. There is a modest protective effect against SIDS, though pacifiers should not be forced on infants who do not want to use them.

**Avoid overheating.** Babies should sleep in a light sleeper without blankets, not over-bundled, and not swaddled with thick blankets. Infants should sleep in a room temperature which is comfortable for a lightly clothes adult.

**Avoid commercial devices claiming to prevent SIDS.** These have not been proven to be safe or effective. Some have been associated with strangulation of infants.

**Supervised Tummy Time while awake.** Some infants develop a flat head from supine sleep. However, this goes away spontaneously by 2-years of age. When babies are being observed while awake, they can be on the stomachs to improve development and trunk motor tone.

**Infant Swaddling:** Though not an official AAP Safe Infant Sleep recommendation, a great deal of attention has been paid to infant swaddling. Swaddling has gone on for millennia, and *The Bible* specifically describes the baby Jesus as “wrapped in swaddling clothes” (*Luke*, 2: 12). Infant swaddling was nearly universal before the 18th century, and it has had a major resurgence recently as a way to curb excessive crying. But is it safe? Does it reduce or increase the risk of SIDS? In one study, 62% of parents were unwilling to comply with a recommendation “not to swaddle their baby”. Parents swaddle their babies because they believe that it makes them more comfortable and warmer. Research studies show that swaddling increases sleep continuity, decreases startles during sleep, decreases cortical arousals, decreases auditory arousal thresholds, increases tactile arousal thresholds, but does not change oxygenation. Swaddling decreases wakefulness, but has no effect on respiratory rate, heart rate, central or obstructive apneas, or oxygenation.
Infant swaddling has been associated with deaths. Twelve infant deaths were described when loose swaddling material became wrapped around the face and neck. When using commercial swaddlers, fasteners should be securely fastened so infants cannot undo them.

Two studies suggest an increased SIDS risk with infant swaddling. Blair and colleagues showed that swaddling was associated with a 31-times increased SIDS risk compared to not swaddling, but sleep position was not accounted for. Ponsonby found that babies swaddled supine actually had a slightly decreased SIDS risk compared to supine non-swaddled babies. However, babies swaddled prone had a 9-times increased SIDS risk compared to unswaddled babies sleeping prone. If a supine swaddled baby turned to prone, the risk increased 12-times, compared to only 3-times for unswaddled babies. Thus, babies swaddled prone is extremely dangerous.

Swaddling should be avoided if:
- Prone sleeping position.
- Thick blankets (danger of overheating).
- The face is covered,
- Infants over 3-months of age.

The AAP says “Although swaddling may be used as a strategy to calm the infant and encourage use of the supine position, there is not enough evidence to recommend it as a strategy for reducing the risk of SIDS.”

In summary, Swaddling Prone may increase some SIDS risk factors. It may prevent infants from head lifting or turning to avoid a potentially asphyxial environment. The SIDS rate increases 12-times increase when prone in swaddled vs not swaddled babies. On the other hand, Swaddling Supine may reduce some SIDS risk factors. It may prevent infants from rolling to prone position. It may prevent infants from crawling to dangerous asphyxiating environment. It may prevent infants from pulling blankets over their heads.
Success of Safe Infant Sleep in Reducing SIDS Deaths: Since 1992, these Safe Infant Sleep recommendations have been phenomenally successful at reducing the SIDS rate. In the U.S., the SIDS rate fell from 1.5 SIDS deaths per 1,000 live births in 1980-1990, to 0.5 SIDS deaths per 1,000 live births in 2010. Only one-third as many babies are dying now as they once did. In California, the SIDS rate fell from 1.5 SIDS deaths per 1,000 live births in 1980-1990, to 0.3 SIDS deaths per 1,000 live births in 2010. Only one-fourth as many babies are dying now as they once did. The Safe to Sleep campaign is comprised simply of an aggressive and consistent educational campaign. Informing parents about SIDS, and how the risks can be reduced, has been a huge success story in modern health care.

But, Do Parents Follow these Recommendations, and What can We do About It?

The Safe to Sleep public education campaign has been extremely successful in reducing the number of babies dying from SIDS. However, parents ignore safe infant sleep recommendations. One-fourth of California families do not have their babies sleep on their backs. 80% of families have ever bedshared with their infants, and 40% do so regularly. The American Baby Magazine survey of 4,547 mothers indicated that 73% had items in the crib, 28% had infants sleep prone, 66% bedshared ever, 38% bedshared routinely, and 63% bedshared on a couch or sofa. In addition, many parents of newborn infants are unwilling to comply with Safe Infant Sleep recommendations. Thus, the American Academy of Pediatrics recommends:

Health care professionals, staff in newborn nurseries and neonatal intensive
care nurseries, and child care providers should endorse the SIDS risk reduction recommendations from birth. Yet, despite this recommendation, primary care physicians know that behavior changes can reduce the risk of SIDS, and they know that they should discuss safe infant sleep with parents of their newborn infants. However, they do not discuss SIDS risk or distribute written materials on safe infant sleep. Eisenberg and colleagues showed that mothers of newborn infants often receive no advice on infant care practices, and in many cases they receive advice which goes against the AAP recommendations on safe infant sleep. This includes advice from physicians, nurses, media and their families. Thus, health care professionals, in general, do not give new mothers appropriate safe infant sleep information.

**Mothers Commonly Receive No Advice on Infant Care**

**Advice from Physicians**

- **Immunizations**
- **Breastfeeding**
- **Sleep Position**
- **Sleep Location**
- **Pacifier Use**

**Advice from Nurses**

- **Immunizations**
- **Breastfeeding**
- **Sleep Position**
- **Sleep Location**
- **Pacifier Use**

**Advice from Media**

- **Immunizations**
- **Breastfeeding**
- **Sleep Position**
- **Sleep Location**
- **Pacifier Use**

**Advice from Family**

- **Immunizations**
- **Breastfeeding**
- **Sleep Position**
- **Sleep Location**
- **Pacifier Use**

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Infant Sleep Position Modeled by Nursery Staff in Hospital Normal Newborn Nurseries

Infant Sleep Positioning in the Hospital as Observed by Researchers

Infant Sleep Position Mothers will Choose to Use at Home

Mothers’ Willingness to Follow Safe Infant Sleep Guidelines at Home

Why Did Some Nurses Choose the Side Sleeping Position?

Infants who “Spit-up”
Stastny and colleagues studied hospital normal newborn nurseries. Most (72%) of 96 nurses working in these units knew that the supine sleeping position was the safest in terms of reducing the risk for SIDS. Yet 68% preferred the side sleeping position for normal newborn infants in the hospital nurseries. Only 37% of nurses modeled placing infants to sleep in the supine position, compared to 49% on the side and 14% on the side or back. When researchers observed newborn babies in these nurseries, 48% were sleeping on their side, and 52% were sleeping supine. Of 579 mothers, 50% planned to place their babies to sleep on their sides at home, and only 36% planned to place them supine to sleep. If nurses both recommended and modeled supine sleep in the nursery, 80% planned to place their babies to sleep supine at home. Only 61% would place their babies supine at home if nurses recommended, but did not model supine sleep in the hospital nursery. Only 55% would place babies to sleep supine at home if nurses modeled but did not recommend supine sleep. Only 7% of mothers would place their babies supine to sleep if nurses neither modeled nor recommended supping sleep. Thus, hospital normal newborn nursery nurses have a great influence on mothers’ willingness to have their babies sleep supine if they both model and recommend supine sleep in the hospital. 91% of nurses who placed babies to sleep on their side did so because they feared aspiration in the supine position. Tablizo and colleagues studied 3,240 normal newborn infants in the first 24-hours of life. 3.4% spit up at least once during sleep. Most infants were in the supine sleep position in the hospitals. No spit up episode required significant intervention to revive the baby, developed pneumonia or aspiration, required transfer to the NICU, or died. Thus, it is safe for normal newborn infants to be placed on their backs to sleep from birth.

SIDS, SUID, SUDI, Undetermined: Does It Matter?
In California, and in the rest of the country, infants who die suddenly and unexpectedly, in whom there is no identifiable cause of death, even if the autopsy and death scene are identical, may not be given the same diagnoses. Some are called SIDS, SUID, SUDI, or undetermined. There is a spectrum of infants who die suddenly and unexpectedly. For some, there is clear evidence of an accidental asphyxia, strangulation, or entrapment, though this is relatively rare. For some, there is no evidence of any asphyxial contribution, and these babies presumably died of “true SIDS”, primarily due to a brainstem problem, such as deficient serotonin. Most are in the middle. They have some risk factors, suggesting the possibility of an asphyxial contribution to the death, but
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the environmental hazard may not be enough to cause death. These infants may have some asphyxial contribution, combined with some brainstem deficit, resulting in the death. Further, Coroner’s must not only decide on a cause of death (diagnosis), but also a manner of death. SIDS is usually considered to be a Natural manner of death, whereas Undetermined, SUID, or SUDI could be determined as Natural, Accidental, or Undetermined. Why do coroners use different diagnoses for the “same” thing?

In October, 2011, the California State Coroner’s Association convened SIDS Summit 1, a working conference for coroners and medical examiners to explore whether greater consistency in the diagnoses of babies dying suddenly and unexpectedly could be achieved. Attendees were shown doll re-enactment photos of death scenes, given the history and autopsy findings, and asked to determine a cause and manner of death. The first case was a “Pristine SIDS” baby in a 3-month old male without any risk factors. While most called the baby SIDS, others used Undetermined and SUID. Other cases had a variety of risk factors in the sleeping environment, which may or may not have contributed to the death. It was clear that all in attendance struggled with the finding to determine the best cause of manner of death. But, it is not possible to come to a definitive conclusion, to which all in attendance agreed. Thus, it is difficult to put together a story about what happened to a baby based on circumstantial evidence alone. All agreed that they were determining “probable cause”, but not “certainty”.

The lessons from SIDS Summit 1 were that these diagnoses are not made capriciously, and everyone involved is trying to do the best they can to determine a cause of death. However, certainty is not possible, Consensus will not be achieved between jurisdictions. However, in the minds of those making the diagnoses, SIDS, SUDI, SUID, and Undetermined all mean the same thing: that the death was unexpected and unexplained. It is now incumbent on the SIDS community to counsel SIDS parents that these diagnoses all mean the same thing, and that SIDS education and grief support services should be provided to all of these families, regardless of the specific diagnoses made.
Medical/Scientific Summary:

In summary, SIDS is the most common cause of death in infants between the ages of 1-month and 1-year, yet its cause remains unknown. The cause is best understood as an interaction between development, infant vulnerability, and environmental challenges. This triple risk model, and recent research, suggests that SIDS deaths occur when these three elements coincide. Some vulnerable babies may never die if they were never challenged by adverse environmental situations. A SIDS death can not be predicted prior to death. However, public health interventions have successfully decreased the number of babies dying from SIDS. The success of public health campaigns has been phenomenal at decreasing the number of babies who die. However, some parents and health care professionals do not provide education about safe infant sleep. SIDS has not been eliminated, and we still are faced with addressing the needs of parents of SIDS victims and surviving family members.

Impact of a SIDS/SUID Death on the Family, Grief, and Guilt.

The death of an infant is one that is never expected. When you become a parent, you instinctually assume that your child will outlive you. For this reason, a parent losing a child is the most traumatic loss any person can experience. This trauma is then intensified by the final cause of death diagnosed as Sudden Infant Death Syndrome (SIDS) or some other unknown etiology such as Sudden Unexpected Infant Death (SUID) or “Undetermined”. All of these diagnoses mean the same thing: the infant’s death was sudden, expected, and unexplained. The lack of an explanation for the death of a presumably healthy baby leaves parents, family members, and caregivers with intense feelings of grief, guilt, and confusion. Most parents experience profound and intense guilt and blame themselves for their baby’s death. These parents are forever changed. One SIDS parent, Rachel Strickland, says this: “We all are changed by the loss of a child or grandchild. Our grief becomes a part of who we are now, hence the name of my group, A New Normal.”

Grief is a natural and normal reaction to loss. It is a response that is physical, emotional, spiritual, and psychological.

Grief: The Price We Pay For Love

- Anger and guilt are common emotions. Parents may feel angry with God, their spouse, their children or with others, either involved or totally separate from the death. Parents often think they are going crazy.
Grief is also very personal and it is a complex process guided by our past experiences, our religious beliefs, our socio-economic situation, and our physical health. Although every parent’s grief experience is different, some natural grief reactions and feelings may include: shock and disbelief, hopelessness, obsessive thoughts, indecisiveness, lack of concentration or interest, anger, feelings of going crazy, guilt, shame, and just about every emotion and crazy or irrational thought. They need to know that all of these feelings and thoughts are normal, but they should decrease with time and support from all of those around them including family, friends, and health care providers, and other SIDS/SUID parents.

Because the SIDS death is unexplained, parents often search the pregnancy and the baby’s brief life for things they may have done to cause the death, or at least not prevent it. Almost always, these things have no relation to their baby’s death.

In addition, SIDS parents may also experience “If onlys,” or thoughts of scenarios of what they think that they could have done differently to prevent their baby’s death. Some examples are:

• “If only I had not taken him to the caregivers and stayed home …. he would be alive”
• “If only I had placed my baby in the crib instead of having him sleep with me … he would be alive”
• “If only I had placed her on her back instead of her stomach or side …. she would be alive”

“If Onlys”: Usually a part of the GUILT process SIDS parents experience because there is no cause of death

• “If Onlys” usually continue (sometimes months or even years) until parents finally come to a place of acknowledgement and acceptance where nothing they did or didn’t do would have changed the final outcome of their baby’s death.
• Having a final cause of death as SIDS can greatly intensify the grief and guilt felt by parents and child care providers especially since a complete autopsy was done and nothing was found. (diagnosis of exclusion)

How to Help

• Acknowledge the loss; Use deceased’s name
• Avoid judgments; Avoid cliches
• Don’t minimize or depersonalize loss
• LISTEN (Listen=information) (hear=emotions)
• Don’t rush the grief process. Self regulating time clock.
• Be Patient. Grief lasts far longer than anyone assumes!
• Share feelings, but DO NOT COMPARE losses
• If you sense substance abuse or dependency, quietly offer support. Never use the SHOULD statement.
• Break the ISOLATION by encouraging others to interact.
• Remember Important Days if known
• Keep in check your impulse to GUIDE the process
• Don’t try to find something positive in the loss. LOSS HURTS!

Darcie D. Sims. American Grief Academy, 1998
• “If the caregiver had checked on her sooner or left the door open so she could have heard her cry … she would be alive”

In California, public health nurses or social workers are mandated to visit newly bereaved SIDS families and caregivers to provide SIDS information, counseling, support services, and referrals as necessary.

The Coroner’s Office and their Investigators can be of great support and provide much information to the PHN before and after she makes her phone call and home visit. In addition to gathering important information about the family and the death of the baby, communicating with the coroner’s investigator allows the PHN and the coroner’s investigator to develop an understanding of each other’s roles, to share resources and information, and to work as a team. (see Table 1).

In the immediate aftermath of the infant’s death, parents are devastated and often have difficulty “putting one foot in front of the other.” The best thing the public health nurse can do is just listen. Avoid trying to explain the death to parents, invoking religious platitudes, or reassuring the parents they can have another child. These comments are not comforting to parents, and are more often viewed as insensitive and hurtful. When in doubt about what to say, just be quiet and listen. Do not feel obligated to break an “awkward silence.” Parents will remember that you were there with them and for them, even when you are not saying anything. (See Could You Please Just Listen, by Deborah R. Gemmill).

### Health Department Responsibilities

- Contact family, childcare provider and/or foster parent within 3 days after coroner notification.
- Provide SIDS Information, Counseling, Support Services, and Referrals as necessary.
- Consult with infant’s physician of record if one.  

*SB 362, Statute of 1991*

### Linking Up Parents and Caregivers with other SIDS Parents Is Key

- It allows parents and caregivers to have someone who has experienced a similar infant death … they can identify and semi understand them!
- It allows them to have someone to talk and cry with when needed, and during hours that a PHN, SW, or even clergy may not be available.
- It gives the new SIDS parent hope that their normal “highly emotional crisis state” is temporary, and there is “light at the end of the tunnel”.
- They can see other SIDS parents laughing and moving on; it shows them that their life will not always be this sorrowful and hard.
The Public Health Nurse provides a critically important healing function with the SIDS home visit. These parents need the nurse’s help. They need the education nurses will give them about SIDS/SUID, and they need grief support. The PHN should never underestimate the importance of what they are doing to improve the lives of the surviving family members and caregivers after a SIDS death. They can help to show them the way, when they are otherwise directionless in their new world after SIDS.

There is a tremendous community of parents who have experienced the death of their baby to SIDS, who work tirelessly to support one another through one on one meetings, online support groups, text messaging, in person support groups, and at events such as the California Regional SIDS Councils, and the Annual California SIDS Conference. Newly bereaved SIDS parents are best healed by speaking with another parent who has gone through the same thing, and who has survived one of the greatest tragedies, if not the greatest tragedy, a family can experience.

In summary, a SIDS death has a devastating effect on surviving family members and caregivers. The death is sudden, so parents are not able to “prepare” for the death. There is no known etiology, so parents experience guilt about what they might have done or not done to contribute to the death or not prevent the death. SIDS parents are in desperate need of support. The public health nurse or social worker has a crucially important role in providing grief support, SIDS education, and offering resources and referrals. Reassuring families that they did not cause their baby’s death has a tremendous impact on relieving guilt. Putting newly bereaved SIDS parents in contact with other SIDS parents is one of the most helpful things a public health nurse can do to help families. Similarly, linking up newly bereaved caregivers with other caregivers who have experienced a death in their care is extremely helpful and supportive.

Public Health Nurses and Social Workers should never underestimate the importance of what they can do to improve the lives of the surviving family members after a SIDS death. It is never too late to reach out to SIDS parents and make a call and home visit months after the death is better than no call or home visit at all. PHNs can and do have an opportunity to make a tremendous difference by helping SIDS families and caregivers work through their grief and mourning.
COULD YOU PLEASE JUST LISTEN?
by Deborah R. Gemmill

My baby has died. Please don't tell me you know how I feel. You don't. You can't. I hope you never do. Don't tell me that he's with God and I should be happy. How can I be happy when every time I go into his nursery all I see is an empty crib and toys that will never be played with? How can I be happy when my arms ache to hold him?

Please don't tell me God needed another angel. It's hard for me to understand why God would take away this little one who was so loved. Maybe I'll understand later. But for right now.... let God find another angel. Please, please, please don't tell me I'll have other children. Maybe I will... but my son was not a puppy that ran away.... he cannot be replaced.

Maybe you could just listen when I remember out loud all the things we did together... the walk, the early morning feedings, the first time he rolled over. Maybe you could just sit with me while I cry over all the things we'll never do together.

Please don't tell me it could be worse. How?

I really don't want to hear about your grandfather's death. It's not the same. Don't think my pain will be eased by comparison. Of course I'm glad that he didn't suffer, but I'd be a lot happier if he hadn't died at all.

I know it must be hard for you, but would you mind looking at his picture just one more time, we don't have many of him and I'm just a little bit afraid that I may forget what he looked like. He wasn't here that long, you know.

Could you please just listen?

Don't tell me I'll get over it. There is no "over it", only through it. Maybe you could just be with me while I take my first steps through it. Please don't tell me I should be glad he was just a baby, or that at least I didn't get to know him. I knew him before I ever saw him. He is a part of me. And now he is gone. I haven't just lost a seven-month old baby. I have lost a part of myself.

I know you mean well, but please don't expect me to tell you how to help me. I'd tell you if I knew, but right now I can hardly put one foot in front of the other. Maybe if you looked around, you could find some things to do, like taking my daughter for a walk, or doing the dishes, or making some coffee. Please don't try to remove my pain or distract me form it. I have to feel this way now.

Maybe you could just listen.

REFERENCES


Table 1: Questions to Ask the Coroner’s Investigator Before the Home Visit

1. Get to know the Coroner Investigator, if possible, and establish a working relationship.
2. Was the family informed that a supportive PHN would be calling the parents to offer a home visit?
3. What information was told to parents about possible or probable causes of death?
4. What are the preliminary death scene investigation and autopsy results?
5. Were there any unusual circumstances to the death?
6. Where did the death occur? Home, child care facility, other?
7. Are there any other locations where the family may be residing, such as relatives’ homes?
8. How were the parents coping when you left the home or hospital?
9. Was the infant sick or on medications? If so what illness and what medications?
10. Was the infant’s pediatrician, primary care physician, or health care facility informed of the death? Do you have contact information?
11. Was the mother’s obstetrician informed of the death? Do you have contact information?
12. What information or educational materials were given to the parents?
13. Does the family have a support system (family, friends, church, etc.)?
14. Are there other children in the family?
15. What language is spoken by the parents in their home?
16. Is there anything else the PHN should know before making the call or home visit?
Table 2: What to Consider When Interviewing the SIDS/SUID Family

1. Be an active listener, and listen for clues indicating guilt or self-blame. Encourage parent(s) to express their feelings.

2. Avoid asking questions which reinforce the parent’s guilt, such as “Did you feed your baby regularly?” Avoid “why did you do that?” questions, which may invoke judgment.

3. Assess where each family member is in the grief process including young children. Each family member will pass through the grief process in their own way. Encourage family members to be patient and understanding of one another.

4. Validate feelings and reassure parent(s) they are not going crazy, but this is part of the normal grieving process.

5. Identify and emphasize family strengths.

6. Remember that people who are grieving do not always hear or remember what has been said. Be prepared to repeat what you say.

7. If probable SIDS or SUID, emphasize the triple risk theory.

8. If the death involved possible suffocation, asphyxiation, entrapment or overlay, emphasize that the baby’s death was accidental, not intentional.

9. Discuss common symptoms of grieving for anticipatory guidance. Be aware of possible physical manifestations of grief.

10. Include the father in the home visit, if appropriate. Fathers are also grieving and have emotions that need to be validated.

11. Offer the parents the opportunity to invite extended family members to the home visit if they want them present.

12. Help the parents to connect with other SIDS parents and/or the local SIDS parent support group.

13. Before you leave, give the parents your contact information. Ask if they would like you to set-up another home visit. Invite them to call you if they have questions. Thank the parents for their time.