

# Sudden Infant Death Syndrome and Safe Infant Sleep

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## LOVE LOST

By Rayne Frey

How can we know, what tomorrow will bring?  
Is today real, or is it a dream?  
This pain that I'm in, is it all a mistake?  
Will I find that it's true, every time I awake?

A love has been lost, so deep and so pure,  
The sickness I feel, has no kind of cure.  
My baby is gone, and no one knows why.  
My body is numb, endless tears I have cried.

What was the reason? Why was he taken?  
My heart has been shattered, my world has been shaken.  
I keep wandering around, without any purpose.  
I am trying to be strong, but right now I am worthless.

Was he part of a plan, or a reason divine?  
How I wish that I knew, why it had to be mine.  
There's a hole in my heart, that can never be mended.  
I will cherish his life, until the day mine has ended.

*A poem written by the father of Redford Elliot Frey.  
Born April 14, 2016. Died May 29, 2016.*



## Sudden Infant Death Syndrome<sup>1</sup>: Exploring the Medical Mystery

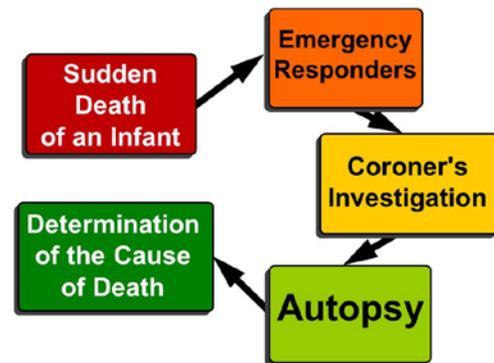
Thomas G. Keens, M.D.

“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 often 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 sudden infant death syndrome (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.<sup>2</sup>

<sup>1</sup> Other terms are sometimes used to describe babies who die suddenly and unexpectedly during sleep in whom the cause can not be determined. These terms include SIDS, SUID, SUDI, Undetermined, and some Accidental diagnoses. In this presentation, the term “SIDS” or “Sudden Infant Death Syndrome” will be used to describe all of these babies. These terms all mean the same thing: the death was *unexpected* and *unexplained*.

<sup>2</sup> Krous, H.F., J.B. Beckwith, R.W. Byard, T.O. Rognum, T. Bajanowski, T. Corey, E. Cutz, R. Hanzlick, T.G. Keens, and E.A. Mitchell. Sudden infant death syndrome (SIDS) and unclassified sudden infant deaths (USID): A definitional and diagnostic approach. *Pediatrics*, 114: 234-238, 2004.

## Sudden Infant Death Syndrome and Safe Infant Sleep

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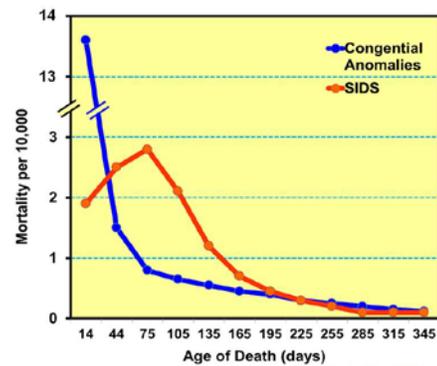
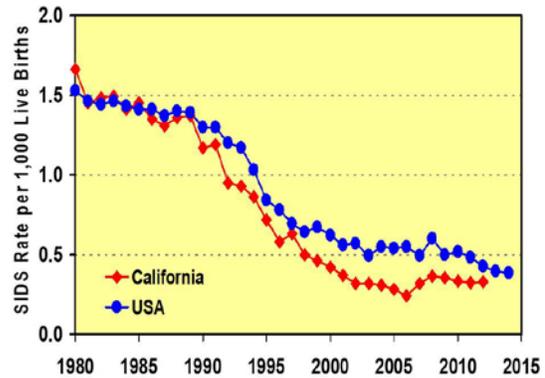
Thomas G. Keens, M.D.  
Penny F. Stastny, R.N., B.S.N., P.H.N.

There is some variation in the diagnoses which are used to define the cause of death in infants who die suddenly and unexpectedly during sleep. 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 use “SIDS”.

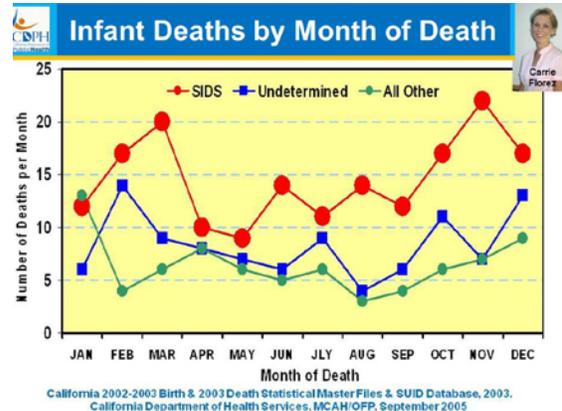
The key features are that the death is unexpected on the one hand, and unexplained on the other. SIDS is the most common cause of death between the ages of one-month and one-year, yet its cause remains unknown. As shown on the right, prior to 1990, the SIDS rate was that one out of every 600 babies born would die from SIDS. The SIDS rate has fallen to less than ~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 occurring 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. SIDS is up to five-times more common in infants born prematurely. The more premature the infant, the higher the risk.

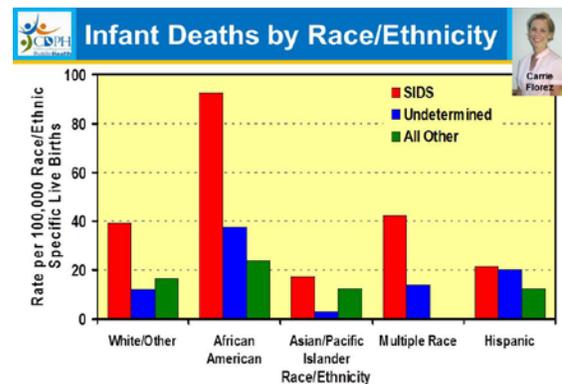
By definition, the autopsy does not indicate a cause of death. In general, SIDS babies were otherwise healthy, they did not show signs of



Gunteroth, W.G., and P.S. Spler. *Pediatrics*, 110: 110;e64, 2002.



California 2002-2003 Birth & 2003 Death Statistical Master Files & SUID Database, 2003. California Department of Health Services, MCAH/OPF, September 2005.



California 2002-2003 Birth & 2003 Death Statistical Master Files & SUID Database, 2003. California Department of Health Services, MCAH/OPF, September 2005.

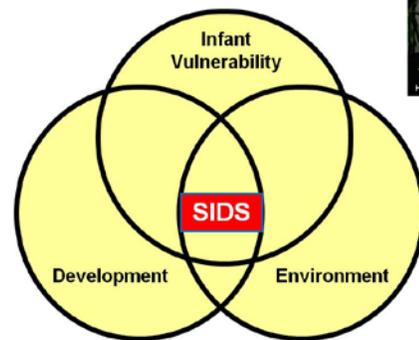
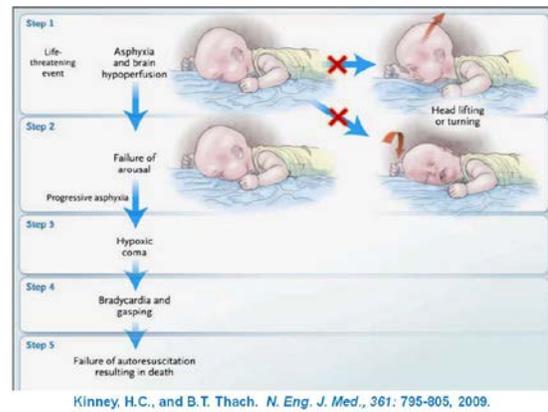
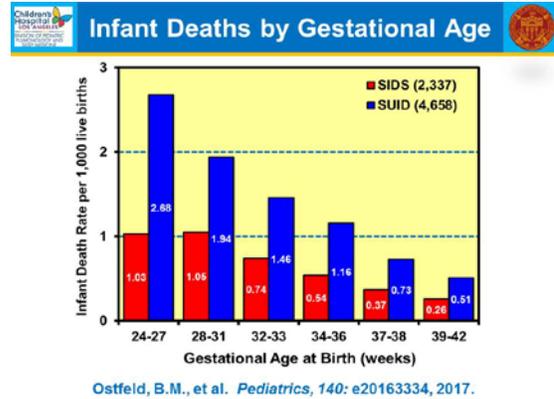
severe illness, and they did not show signs of significant stress. SIDS is a diagnosis of exclusion, which means that the diagnosis is only made if no other cause of death can be identified by autopsy or death scene investigation.

**Research into Possible Causes.**

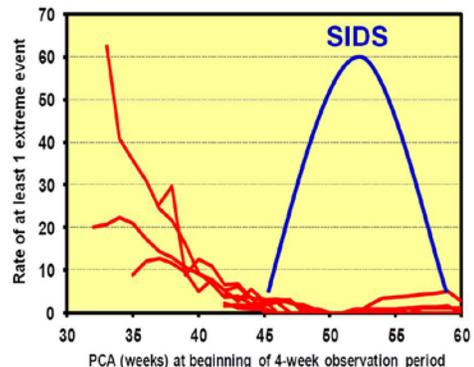
The cause of SIDS is unknown. There has been over 4½ four decades of research into potential causes. However, the cause has not been easy to discover. How are we to understand SIDS? Let us consider an analogy. Imagine a car going up a steep mountain road. The car has stopped. Why can't the car continue up the mountain road? In the traditional medical model, we might get out of the car, walk around it and see that two 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, J.J., and H.C. Kinney. *Biol. Neonate*, 65: 194-197, 1994.



Ramanathan, R., and CHIME. *J. Amer. Med. Assoc.*, 285: 2199-2207, 2001.

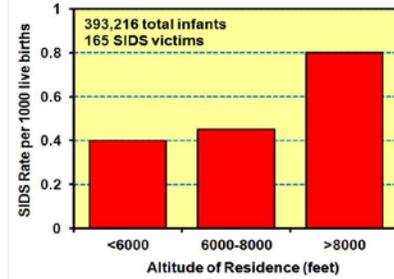


Filiano and Kinney proposed the *Triple Risk Model* of SIDS in 1994. There are three overlapping circles representing Development, Infant vulnerability, and Environment. The size of the overlap is the chance of an infant dying from SIDS. Each circle can change in size, depending on the relative contribution of the effect. For example, SIDS is most common between 2-4 months of age, so a 3-month old infant would have a larger developmental circle than an 11-month old. Similarly, the other circles can change in size. Let's explore each aspect of the *Triple Risk Model*.

**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 have long apneas and low oxygen (hypoxia) during sleep, which was previously unexpected. SIDS deaths are also increased in babies who reside at altitude over 8,000 feet, suggesting that hypoxia may be a contributor to SIDS. Is SIDS due to a catastrophic physiologic crisis? If normal infants do not precisely control breathing, heart rate, and oxygenation during sleep, then SIDS may not have to be a catastrophic physiological crisis. Maybe, there just needs to be a small problem which nudges or pushes a vulnerable infant over the edge.

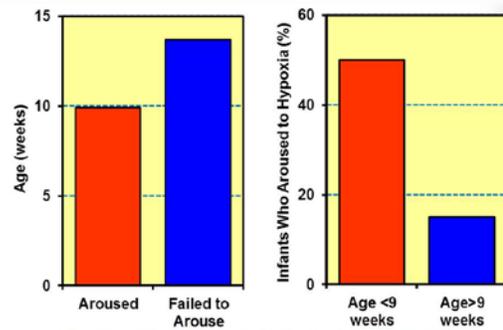
If an infant has a potentially dangerous apnea or hypoxia during sleep, probably the best thing he or she could do is to wake up and deal with the threat. Ward and colleagues showed that normal infants over 9-weeks of age were less likely to arouse (wake up) in response to a hypoxic challenge than

**SIDS at High Altitude**



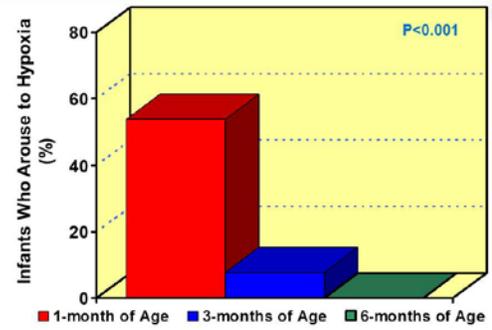
Katz, D., et al. *Pediatrics*, 135: DOI 10.1542/peds.2014-2697, 2015.

**Normal Hypoxic Arousal Response**



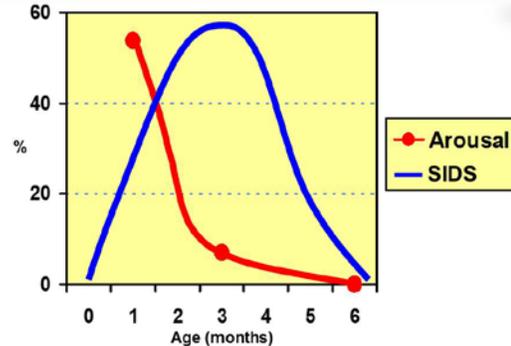
Davidson Ward, S.L., et al. *Pediatrics*, 89: 860-864, 1992.

**Normal Hypoxic Arousal Response**



Hamutcu, R., et al. *Am. J. Respir. Crit. Care Med.*, 163(5): A953, 2001.

**Normal Hypoxic Arousal Response**

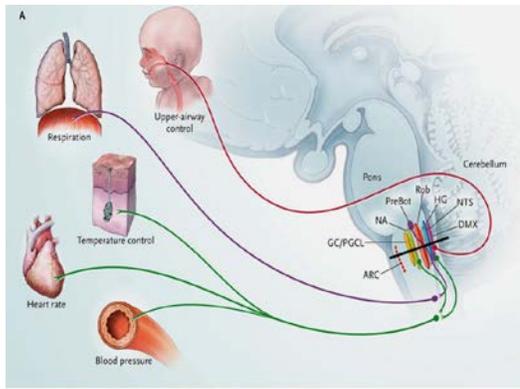


Hamutcu, R., et al. *Am. J. Respir. Crit. Care Med.*, 163(5): A953, 2001.

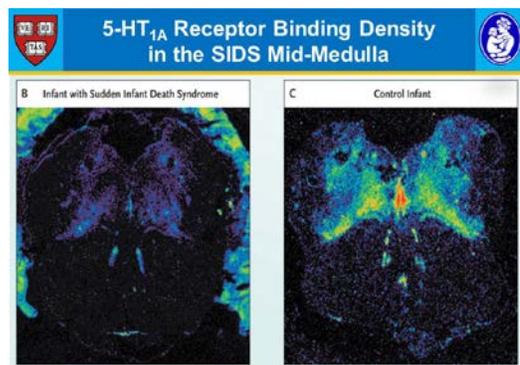
infants under 9-weeks of age. This was surprising. Hamutcu and colleagues studied the same normal infants longitudinally at 1-month of age (before the peak incidence of SIDS), 3-months of age (at the peak incidence of SIDS), and 6-months of age (after the peak incidence of SIDS). She found that 50% of 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 even to 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?

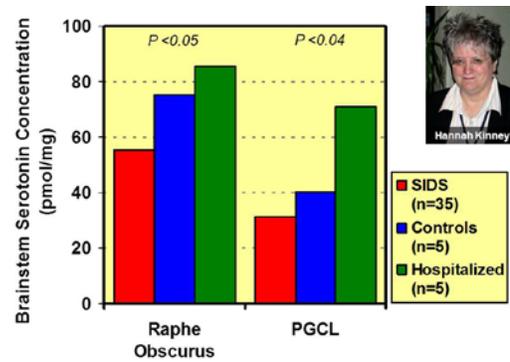
Kinney and colleagues studied the brainstems of babies who died from SIDS, and compared them to babies who died from other causes. The brainstem is the life-support portion of the brain. It controls breathing, heart rate response to environmental changes, blood pressure, body temperature, arousal (sleep-wakefulness), 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



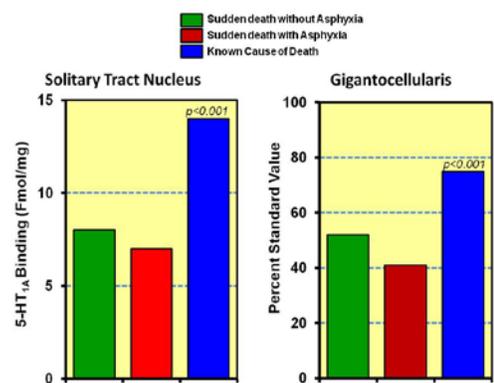
Kinney, H.C., and B.T. Thach. *N. Eng. J. Med.*, 361: 795-805, 2009.



Paterson, D.S., et al. *J. Amer. Med. Assoc.*, 296: 2124-2132, 2006.



Duncan, J.R., et al. *J. Amer. Med. Assoc.*, 303: 430-437, 2010.

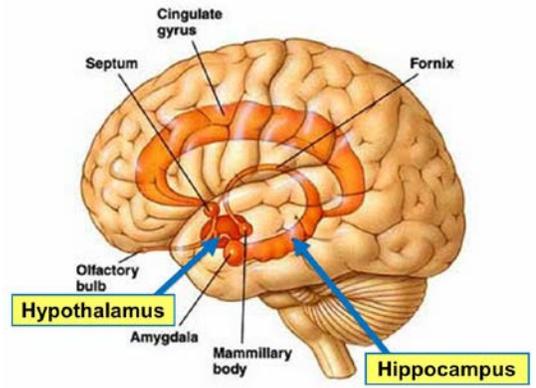


Randall, B.B., et al. *Pediatrics*, doi: 10.1542/peds.2013-0700. 2013.

able to rescue themselves (unless the asphyxia was severe), whereas those who died may have been more vulnerable. Because of a brainstem neurotransmitter deficit, they may not have been able to mount a normal response to rescue themselves.

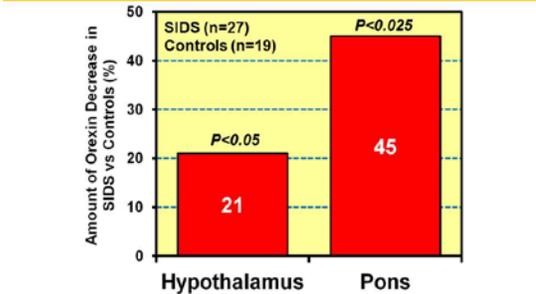
Other areas of the brain also contribute to control of breathing and sleep-wakefulness. Studies have been performed on the hippocampus and the hypothalamus in SIDS babies. There is a group of children over one-year of age, who die suddenly and unexpectedly, in whom a cause of death can not be identified; sudden unexpected (or unexplained) death in childhood (SUDC). A significant proportion of these SUDC children have a history of febrile convulsions, and this is often associated with structural abnormalities in the hippocampus. There is a subset of SIDS victims who also have a history of febrile convulsions and the same hippocampal structural abnormalities. Researchers hypothesize that if an infant has a seizure when in a potentially dangerous environment, the seizure would prevent the infant from rescuing himself or herself, and therefore go down the path to failure of arousal, hypoxic coma, and death. While this postulated mechanism does not apply to all SIDS deaths, it does describe a way in which some babies are more vulnerable to an unsafe sleeping environment because a seizure may prevent them from responding.

Orexin, also called hypocretin, is a neuropeptide that regulates arousal, wakefulness, and appetite. It is produced by neurons important in sleep/wakefulness and maintaining apnea-free breathing during sleep. The most common form of narcolepsy, in which the patient briefly loses muscle tone (cataplexy), is caused by a lack of orexin in the brain due to destruction of the cells that produce it. Australian researchers measured orexin in neurons in the hypothalamus and pons (brainstem) in SIDS vs controls (infants who died from a known cause of death). The amount of orexin was decreased 21% in the hypothalamus and 45% in the pons (brainstem) of SIDS babies compared to controls. This is yet another way in which variations in a substance in

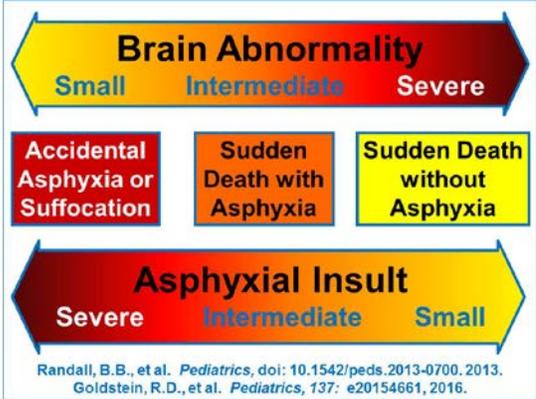


Kinney, H.C., and B.T. Thach. *N. Eng. J. Med.*, 361: 795-805, 2009.  
Kinney, H.C., et al. *Pediatr. Dev. Pathol.*, 12: 455-463, 2009.  
Smith, C. *Forensic Sci. Med. Pathol.*, 12: 202-203, 2016.

**Orexin in SIDS Hypothalamus and Pons**



Hunt, N.J., et al. *Acta. Neuropathol.*, 130: 185-198, 2015.  
Hunt, N.J., et al. *Mol. Neurobiol.*, DOI 10.1007/s12035-016-0234-3, 2016.



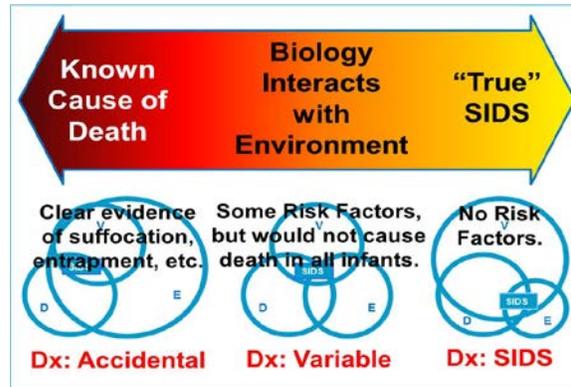
Randall, B.B., et al. *Pediatrics*, doi: 10.1542/peds.2013-0700. 2013.  
Goldstein, R.D., et al. *Pediatrics*, 137: e20154661, 2016.

the brain may cause an infant to be less able to deal with environmental challenges, thus making these infants more vulnerable to SIDS. Again, this is likely not an abnormality severe enough to cause death by itself, but another mechanism that may make some babies increasingly vulnerable.

Thus, we can envisage a continuum of brain abnormality from small or intermediate to severe. In order for an infant with normal brainstem serotonin, normal hippocampus, or normal hypothalamic and pontine orexin to die, the asphyxial insult must have been severe. In order for an infant to die without any asphyxial insult, the brain neurotransmitter or structural 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.

Using the Triple Risk Hypothesis for SIDS, some babies can die from a clear cause detected at the death scene investigation, such as strangulation. Here the environmental circle would be large, and the cause of death probably signed out as asphyxia. Some babies die without any environmental risk factors or dangers. Here the vulnerability circle would be largest, as these babies likely have significant brain dysfunction, and the diagnosis may be SIDS. The majority of babies dying suddenly today are found in a sleep environment with some risk factors, but not enough to cause death in every baby. Here, biology interacts with the environment, requiring some increased vulnerability or inability to deal with environmental dangers in order for death to occur.

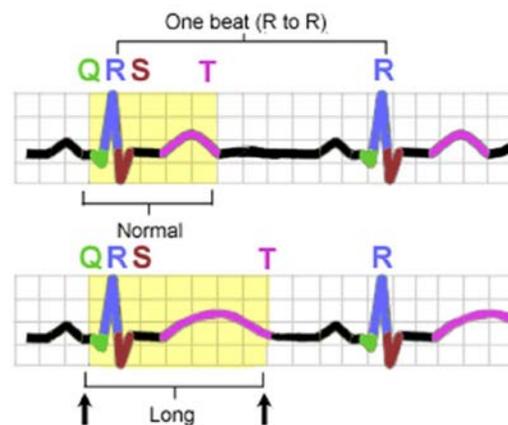
Can any of these abnormalities predict babies at high risk of dying prior to death? Decreased brainstem serotonin is likely a developmental problem which may exist at birth, allowing the theoretical possibility that it could be detected at birth, and thereby action taken to reduce the chance that this high risk baby will die. However, the research results described were measured in the brainstem, and blood levels do not reflect brainstem serotonin. The hippocampal abnormality is likely present at birth, but this is a microscopic finding which would require brain tissue to detect. Decreased orexin is likely a secondary change in the brain due to chronic or repetitive hypoxia, and therefore would not be present at birth, and therefore would not be a



**Brain Abnormalities in SIDS**

↓ Brainstem Serotonin	Possibly Developmental
Hippocampal Abnormality	Possibly Developmental
↓Orexin in Pons and Hypothalamus	Probably due to Chronic Hypoxia

**Each may increase infant vulnerability, but not be a cause of SIDS by itself.**



## Sudden Infant Death Syndrome and Safe Infant Sleep

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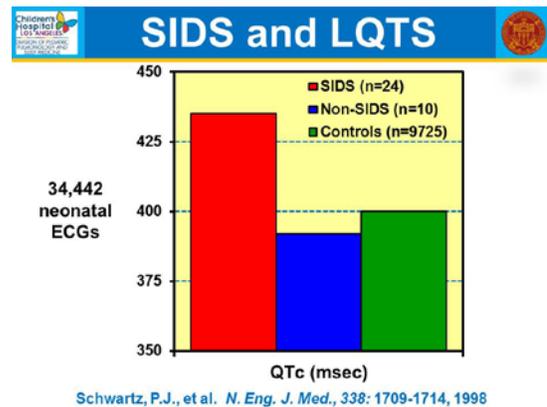
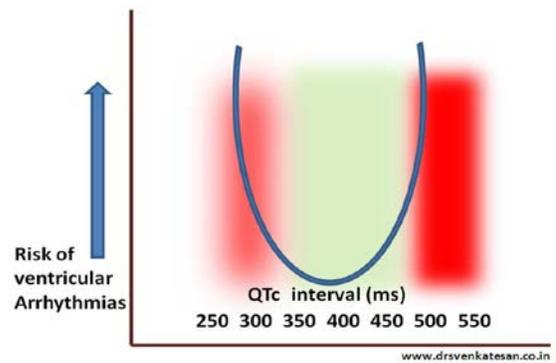
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possible predictive test. Each of these abnormalities may increase an infant's vulnerability for SIDS, but not be a cause by itself. There may be additional abnormalities, yet to be discovered, which could also increase an infant's vulnerability for SIDS.

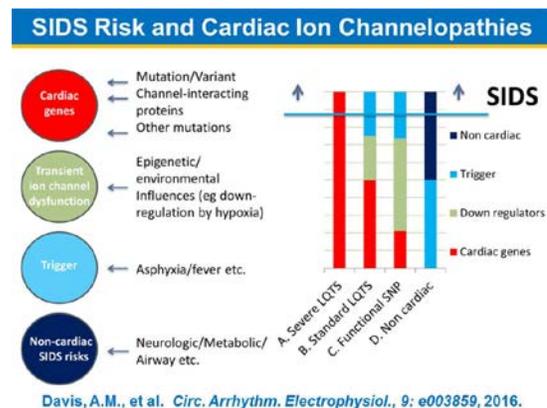
Aside from abnormalities in the brain, certain cardiac disorders may also cause or contribute to death and increase an infant's vulnerability to SIDS. Cardiac arrhythmias may cause sudden unexpected death, yet not be detected at autopsy. The prolonged QT interval syndrome (LQTS) is a condition, usually genetic in origin, which can cause a fatal ventricular arrhythmia. In LQTS, the heart takes longer to repolarize after a contraction. If the next heartbeat comes before repolarization is complete, it can cause a ventricular arrhythmia. The longer the time required for repolarization, the greater the chance of an arrhythmia. In 1998, Peter Schwartz reported on a study of neonatal ECGs performed in 34,442 infants. 34 subsequently died; 24 from SIDS. The QT interval (QTc) was prolonged in the SIDS babies compared to babies who died from known causes or from controls who did not die. This study suggested that some SIDS babies may have died from LQTS.

There are three phenotypes of LQTS, as shown above. LQT3 is the mutation associated with death during sleep, and would be the most likely form of LQTS to cause SIDS. However, this is rare.

Genetic mutations severe enough to cause SIDS by themselves are rare (Group A RIGHT). Some of these babies could potentially be detected by neonatal genetic studies, or possibly neonatal ECGs, but this would account for only a small portion of those babies who die from cardiac ion channel dysfunction. Hypoxia and other stresses can downregulate cardiac ion channels, causing cardiac ion channel dysfunction (Groups B & C ABOVE). Thus a hypoxic infant, without overt LQTS, could develop a ventricular arrhythmia due to an induced cardiac ion channel dysfunction. As this would occur as a consequence of hypoxia, it would not be present at birth, and neonatal screening would miss it. Of course, the majority of



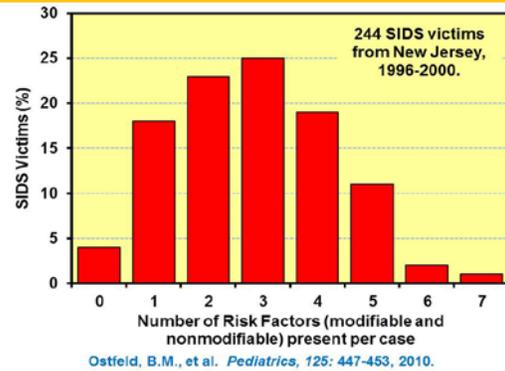
LQTS Type	Phenotype
LQT1	In boys, events triggered by sports or swimming.
LQT2	In girls, events triggered by startle, emotion, or at night.
LQT3	Sudden death at night (during sleep). SIDS most likely.



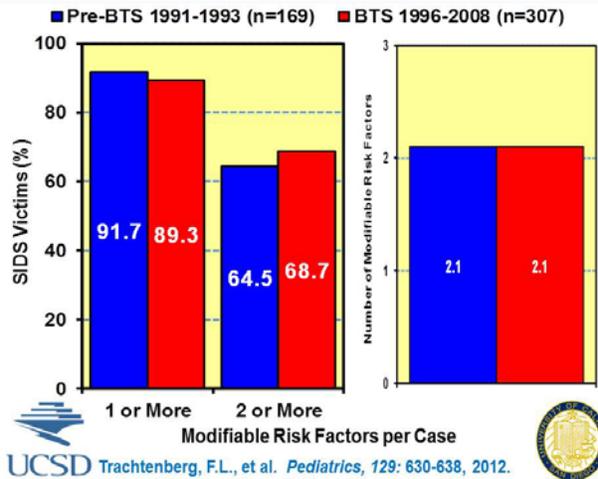
SIDS deaths do not involve abnormal cardiac ion channels at all (Group D ABOVE). Thus, neonatal gene screening for cardiac ion channelopathies or ECGs are not likely to significantly decrease SIDS deaths. Nevertheless, cardiac ion channel dysfunction, genetic and/or acquired, may be another mechanism to increase an infant's vulnerability toward death.

**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? We will review these recommendations below.

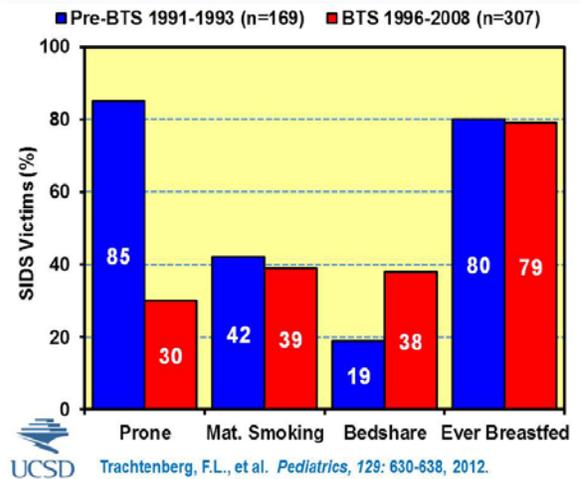
**The majority of SIDS victims have ≥1 Risk Factor**



**The majority of SIDS victims have ≥1 Risk Factor**



**The majority of SIDS victims have ≥1 Risk Factor**



It is important to remember that Safe infant sleep recommendations have decreased the SIDS rate. But SIDS has not been eliminated. Some babies still die in the absence of risk factors. Not all risk factors will cause death. First responders should not be too quick to assume death is due to the presence of one or more risk factors.

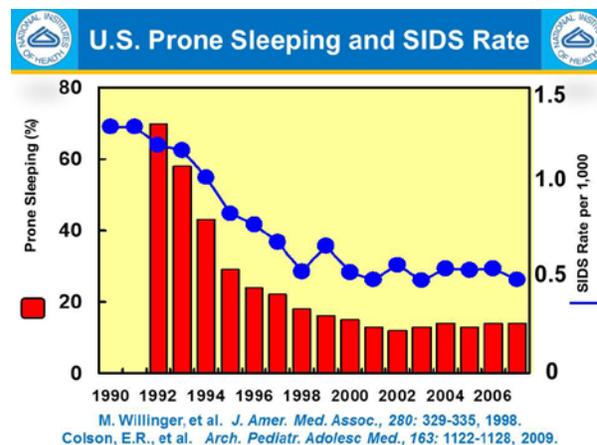
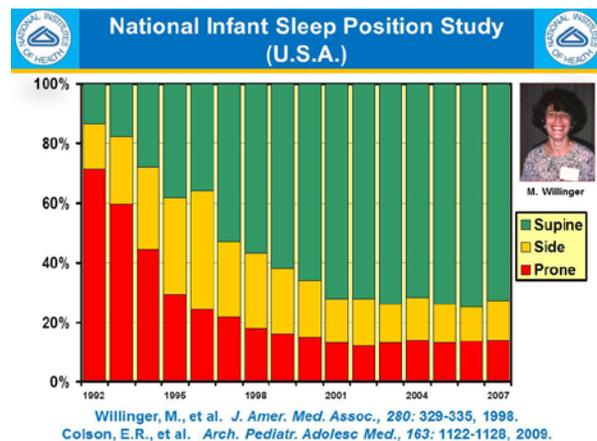
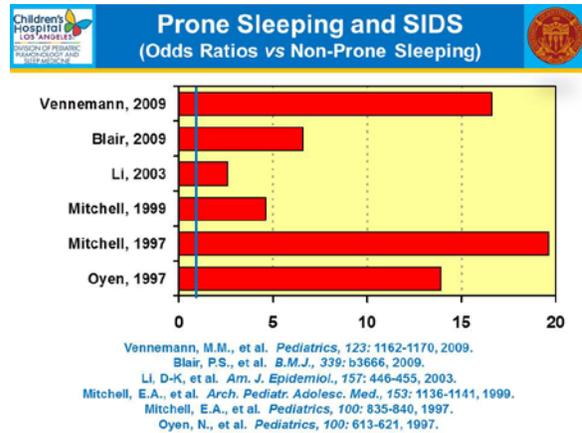
## Safe Infant Sleep Recommendations.

Thomas G. Keens, M.D.

In 2016, the American Academy of Pediatrics identified a number of risk factors which increase the risk of SIDS. Avoiding these risk factors has resulted in a fall in the SIDS rate and number of babies dying from SIDS. We review the important recommendations<sup>3,4</sup>.

**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 the child reaches 1 year of age. 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 spits up, the material would simply drain out the mouth, and the baby would not aspirate. However, if one



<sup>3</sup> Moon, R.Y., and AAP Task Force on Sudden Infant Death Syndrome. SIDS and Other Sleep-Related Infant Deaths: Updated 2016 Recommendations for a Safe Infant Sleeping Environment. *Pediatrics*;138: ce20162938, 2016

<sup>4</sup> Moon RY and AAP Task Force on Sudden Infant Death Syndrome. SIDS and Other Sleep-Related Infant Deaths: Evidence Base for 2016 Updated Recommendations for a Safe Infant Sleeping Environment: Technical Report. *Pediatric*, 138: e20162940, 2016.

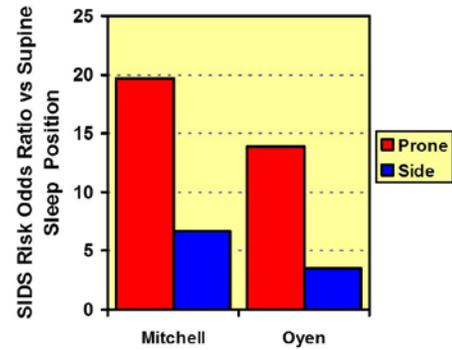
## Sudden Infant Death Syndrome and Safe Infant Sleep

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. The supine sleeping position does not increase the risk of choking or aspiration, even in the presence of gastro-esophageal reflux disease, where the supine sleep position is still recommended. There is no evidence to suggest that infants receiving nasogastric or orogastric feeds are at an increased risk of aspiration if placed in the supine position. Elevating the head of the infant's crib is ineffective in reducing gastro-esophageal reflux, and it is not recommended; in addition, elevating the head of the crib may result in the infant sliding to the foot of the crib into a position that may compromise respiration.

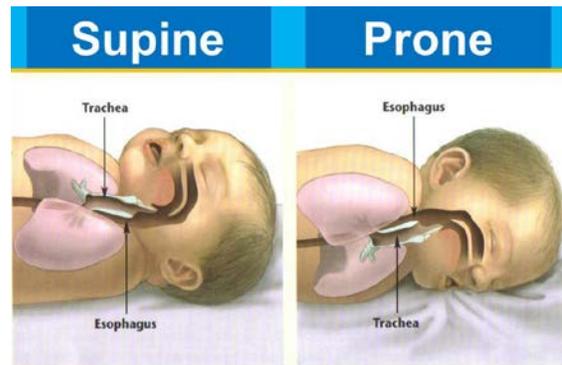
As stated in the AAP clinical report, "skin-to-skin care is recommended for all mothers and newborns, regardless of feeding or delivery method, immediately following birth (as soon as the mother is medically stable, awake, and able to respond to her newborn), and to continue for at least an hour." Thereafter, or when the mother needs to sleep or take care of other needs, infants should be placed supine in a bassinet. There is no evidence that placing infants on their side during the first few hours after delivery promotes clearance of amniotic fluid and decreases the risk of aspiration. Infants in the newborn nursery and infants who are rooming in with their parents should be placed in the supine position as soon as they are ready to be placed in the bassinet.

Once an infant can roll from supine to prone and from prone to supine, the infant can be allowed to remain in the sleep position that he or she assumes. Because rolling into soft bedding is an important risk factor for SIDS, parents and caregivers should continue to keep the infant's sleep environment clear of soft or loose bedding.

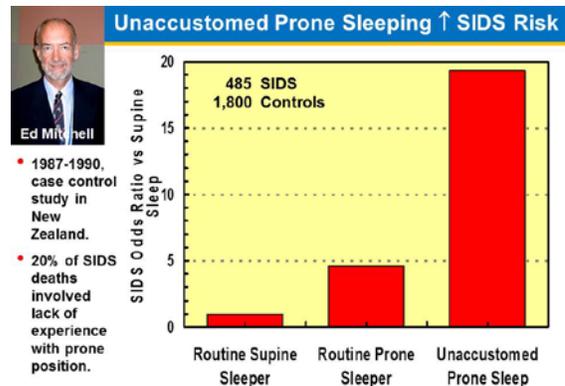
A particularly dangerous situation is babies who are accustomed to sleeping supine, but are placed prone. These unaccustomed prone sleeping infants



Mitchell, E.A., et al. *Pediatrics*, 100: 835-840, 1997.  
Oyen, N., et al. *Pediatrics*, 100: 613-621, 1997.



SIDS Risk Reduction: Curriculum for Nurses, NICHD, 2006.  
NIH Publication No. 06-6005.



Mitchell, E.A., et al. *Arch. Pediatr. Adolesc. Med.*, 153: 1136-1141, 1999.



Maternal and Infant Health Assessment Survey Prepared by: Maternal, Child and Adolescent Health Program, Center for Family Health, California Department of Public Health  
<http://www.cdph.ca.gov/data/surveys/MIHA/MIHAComparisonMaps/CompareRegSleepPos2012.pdf>

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.

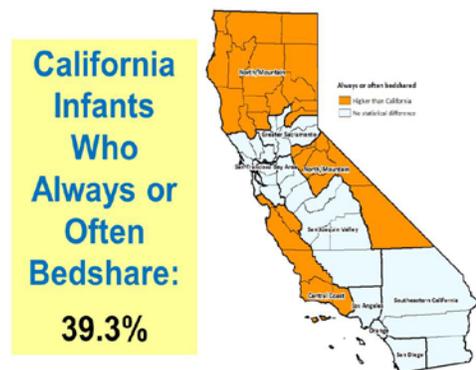
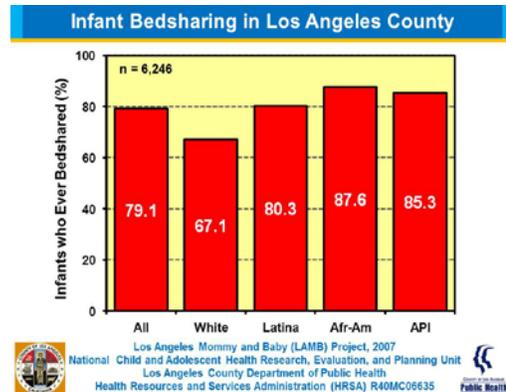
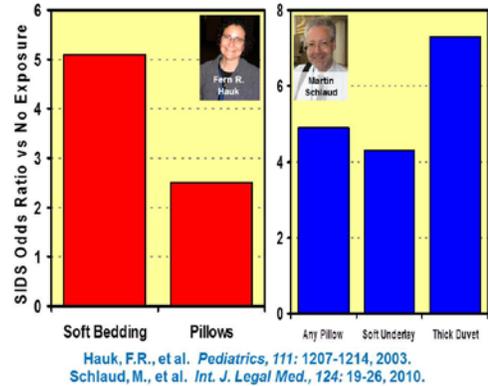
**Use a firm sleep surface.** Infants should be placed on a firm sleep surface (e.g., mattress in a safety-approved crib) covered by a fitted sheet with no other bedding or soft objects to reduce the risk of SIDS and suffocation. Soft bedding and items in the crib increase the risk of SIDS 4-8 times.

Soft materials or objects, such as pillows, quilts, comforters, or sheepskins, even if covered by a sheet, should not be placed under a sleeping infant. If a mattress cover to protect against wetness is used, it should be tightly fitting and thin. Infants should not be placed for sleep on beds, because of the risk of entrapment and suffocation. In addition, portable bed rails should not be used with infants, because of the risk of entrapment and strangulation.

Sitting devices, such as car seats, strollers, swings, infant carriers, and infant slings, are not recommended for routine sleep in the hospital or at home, particularly for young infants. Infants who are younger than 4 months are particularly at risk, because they may assume positions that can create a risk of suffocation or airway obstruction or may not be able to move out of a potentially asphyxiating situation. Infants should not be left unattended in car seats and similar products, nor should they be placed or left in car seats and similar products with the straps unbuckled or partially buckled.

**Breastfeeding is recommended.** Breastfeeding is associated with a reduced risk of SIDS. Unless contraindicated, mothers should breastfeed exclusively or feed with expressed milk for 6 months. The protective effect of breastfeeding increases with exclusivity. However, any breastfeeding has been shown to be more protective against SIDS than no breastfeeding.

**It is recommended that infants sleep in the parents' room, close to the parents' bed, but on a separate surface designed for infants, ideally for the first year of life, but at least for the first 6 months.**



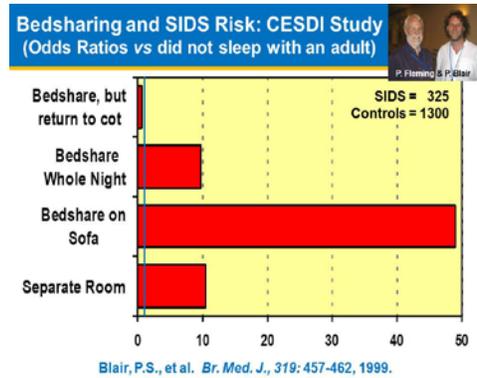
Data Source: Maternal and Infant Health Assessment Survey Prepared by: Maternal, Child and Adolescent Health Program, Center for Family Health, California Department of Public Health  
<http://www.cdph.ca.gov/data/surveys/MIHA/MIHAComparisonMaps/CompareRegBedshare2011.pdf>

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 obtunded 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. In Los Angeles County, 79% of parents of infants admitted to “bedsharing ever”, and 39% of California parents of infants admitted to “bedsharing always or often”. 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. 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.

Bedsharing has an increased risk of SIDS, and it is not recommended. Bedsharing is *especially unsafe* with:

- Infant <4-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.

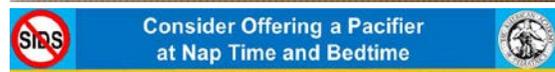
The safety and benefits of cobedding for twins and higher order multiples have not been established. It is prudent to provide separate sleep surfaces and avoid cobedding for twins and higher order multiples in the hospital and at home.

What if parents insist on bedsharing? There is no *safe* way to bedshare. Public Health messages should not be altered because some people do not want to comply. Remain firm in what is advised and what is safe. Work individually with families who insist on bedsharing: compromise, etc.

In 2016, the AAP made recommendations about skin-to-skin care and rooming in for healthy term infants after birth<sup>5</sup>. Skin-to-skin care is encouraged right after birth and during subsequent days. However, the mother should be awake and able to respond to her infant. The mother-infant dyad should be monitored during skin-to-skin care to assure that it is being done safely. Rooming-in for normal newborn nurseries is also encouraged, but bedsharing should be avoided when the mother is sleepy or not alert and able to respond to her infant. Providing safe infant sleep education to parents of newborn infants prior to discharge.

**Keep soft objects and loose bedding away from the infant's sleep area 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.

**Consider offering a pacifier at nap time and bedtime.** Although the mechanism is yet unclear,



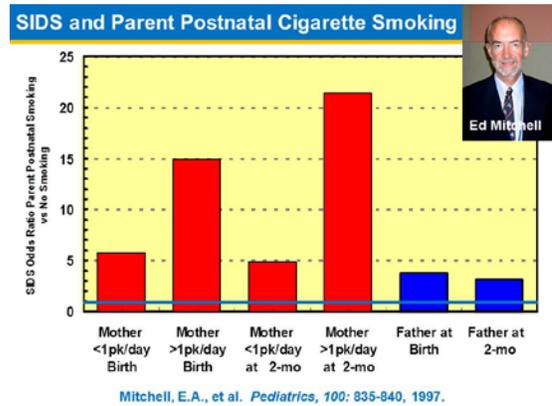
AAP Policy Statement. *Pediatrics*, 138: e20162938, 2016.

<sup>5</sup> Feldman-Winter, L., J.P. Goldsmith, AAP Committee on Fetus and Newborn, and AAP Task Force on Sudden Infant Death Syndrome. Safe sleep and skin-to-skin care in the newborn period for healthy term infants. *Pediatrics*, 138: e20161889, 2016.

studies have reported a protective effect of pacifiers on the incidence of SIDS. The protective effect of the pacifier is observed even if the pacifier falls out of the infant's mouth. The pacifier should be used when placing the infant for sleep. It does not need to be reinserted once the infant falls asleep. If the infant refuses the pacifier, he or she should not be forced to take it. In those cases, parents can try to offer the pacifier again when the infant is a little older. Because of the risk of strangulation, pacifiers should not be hung around the infant's neck. Pacifiers that attach to infant clothing should not be used with sleeping infants.

**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. Mothers should not smoke during pregnancy or after the infant's birth. 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. Second hand e-cigarette smoke (vaping) is perhaps even more dangerous than tobacco smoke, as the vapor gets further into the lungs than particulate tobacco smoke.



**Avoid alcohol and illicit drug use during pregnancy and after birth.** There is an increased risk of SIDS with prenatal and postnatal exposure to alcohol or illicit drug use. Mothers should avoid alcohol and illicit drugs periconceptionally and during pregnancy.

**Avoid overheating and head covering in infants.** Although studies have shown an increased risk of SIDS with overheating, the definition of overheating in these studies varies. Therefore, it is difficult to provide specific room temperature guidelines to avoid overheating. In general, infants should be dressed appropriately for the environment, with no greater than 1 layer more than an adult would wear to be comfortable in that environment. Parents and caregivers should evaluate the infant for signs of overheating, such as sweating or the infant's chest feeling hot to the touch. Overbundling and covering of the face and head should be avoided. There is currently insufficient evidence to recommend the use of a fan as a SIDS risk-reduction strategy.

**Pregnant women should obtain regular prenatal care.** There is substantial epidemiologic evidence linking a lower risk of SIDS for infants whose mothers obtain regular prenatal care. Pregnant women should follow guidelines for frequency of prenatal visits.

**Infants should be immunized in accordance with recommendations of the AAP and Centers for Disease Control and Prevention.** There is no evidence that there is a causal relationship between immunizations and SIDS. Immunized infants have about half the SIDS rate as those who are not immunized.

**Avoid the use of commercial devices that are inconsistent with safe sleep recommendations.** Be particularly wary of devices that claim to reduce the risk of SIDS. Examples include, but are not limited to, wedges and positioners and other devices placed in the adult bed for the purpose of positioning or separating the infant from others in the bed. These have not been proven to be safe or effective. Some have been associated with strangulation of infants.

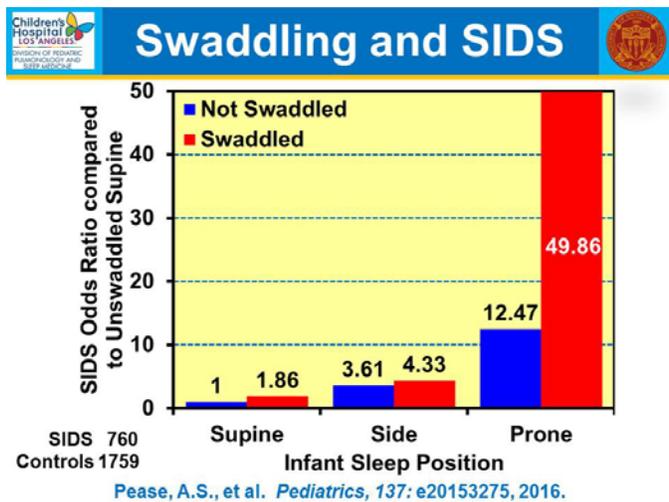
**Do not use home cardiorespiratory monitors as a strategy to reduce the risk of SIDS.** The use of cardiorespiratory monitors has not been documented to decrease the incidence of SIDS. These devices are sometimes prescribed for use at home to detect apnea or bradycardia and, when pulse oximetry is used, decreases in oxyhemoglobin saturation for infants at risk of these conditions. In addition, routine in-hospital cardiorespiratory monitoring before discharge from the hospital has not been shown to detect infants at risk of SIDS. There are no data that other commercial devices that are designed to monitor infant vital signs reduce the risk of SIDS.

**Supervised, awake tummy time is recommended to facilitate development and to minimize development of positional plagiocephaly.** Although there are no data to make specific recommendations as to how often and how long it should be undertaken, a certain amount of prone positioning, or ‘tummy time,’ while the infant is awake and being observed is recommended to help prevent flattening of the head and to facilitate development of the upper shoulder strength. Some infants develop a flat head from supine sleep. However, this goes away spontaneously by 2-years of age.



AAP Policy Statement. *Pediatrics*, 128: 1030-1039, 2011.  
<http://www.medscape.com/features/slideshow/safe-sleep-principles?>

**There is no evidence to recommend swaddling as a strategy to reduce the risk of SIDS.** 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 18<sup>th</sup> century, and it has had a major resurgence recently as a way to curb excessive crying. 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.

Pease and colleagues performed a meta-analysis of published studies on SIDS and swaddling. Infants swaddled sleeping supine had an insignificant increase in SIDS compared to babies not swaddled supine. Side sleeping was associated with an increased SIDS risk compared to supine sleep, and infants swaddled on the side had a slightly higher risk than unswaddled infants sleeping on their side. Unswaddled infants sleeping prone had a 12-times increased SIDS risk compared to unswaddled supine sleepers, but swaddled babies sleeping prone had a 50-times increased risk. If a supine swaddled baby turned from supine to prone, the SIDS risk increased 12-times, compared to only 3-times for unswaddled babies. Thus, babies swaddled prone is extremely dangerous.

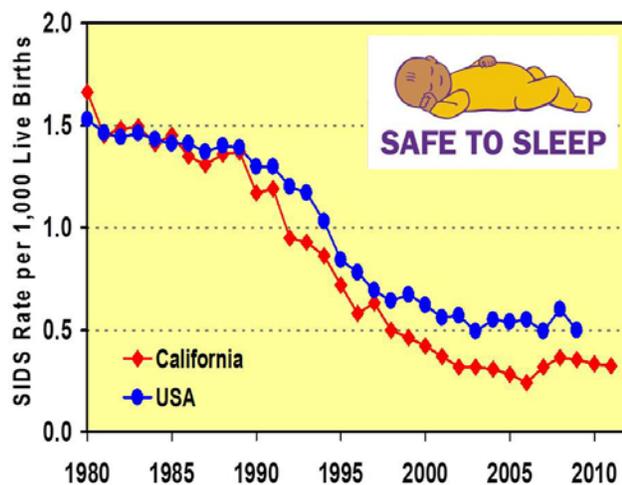
Swaddling should be avoided if:

- Prone sleeping position.
- Thick blankets (danger of overheating).
- The face is covered,
- Infants over 2-3 months of age. There is a danger that when infants begin to roll from supine to prone, the swaddled infant can not regain the supine position.

In summary, *Swaddling Prone* is associated with a 50-times increased SIDS risk compared to unswaddled supine sleeping babies, and it should be avoided. If babies are swaddled, this should be discontinued at 2-3 months of age, when they may roll from supine to prone, placing them in a dangerous sleeping situation.

### **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



## Sudden Infant Death Syndrome and Safe Infant Sleep

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.

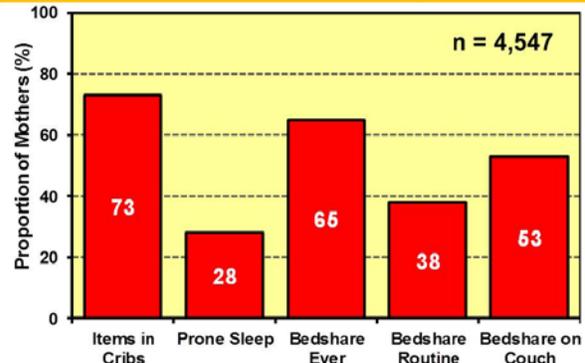
### But, Do Parents Follow these Recommendations, and What can We do About It?

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 NICUs, and child care providers should endorse and model the SIDS risk reduction recommendations from birth..**

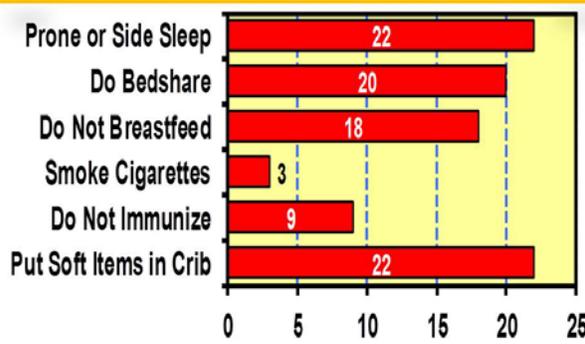
Yet, despite this recommendation, primary care physicians know that behavior changes can reduce the risk of SIDS, and they know that they should discuss safe infant sleep with parents of their newborn infants. However, they do not discuss SIDS risk or distribute written materials on safe infant sleep. 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.

#### Parents Ignore Safe Infant Sleep Recommendations



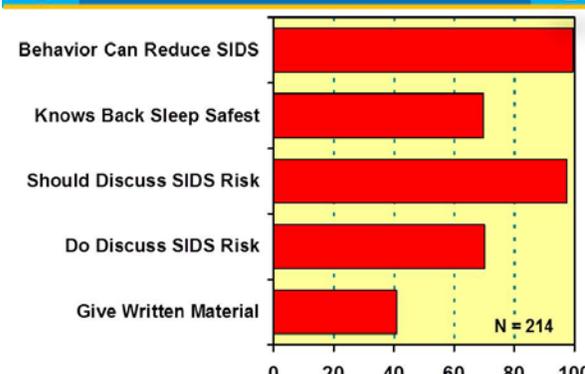
Dreisbach, S. *American Baby Magazine*, March, 2014, issue. <http://www.parents.com/baby/safety/nursery/how-safe-is-your-babys-sleep/?page=3>

#### Many Parents Do Not Follow Safe Infant Sleep Recommendations



Varghese, S., et al. *J. Perinatol.*, doi:10.1038/jp.2015.111, 2015.

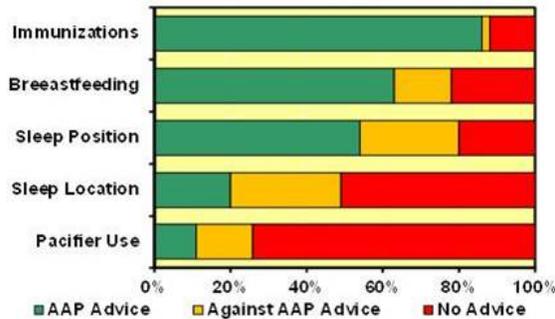
#### Primary Care Physicians Do Not Discuss SIDS Risk Reduction



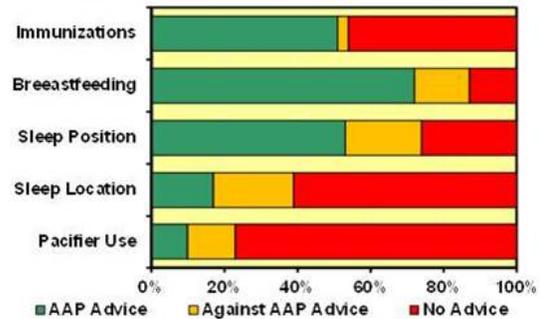
Eron, N.B., et al. *Health Promot. Pract.*, 10: 1-9, 2009.

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

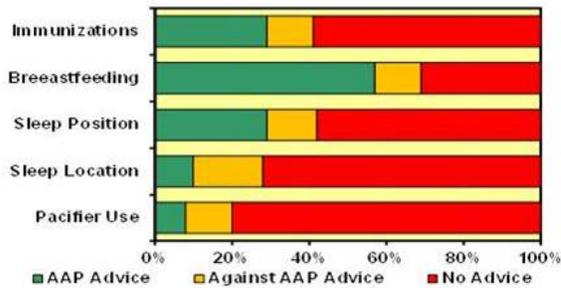
**Advice from Physicians**



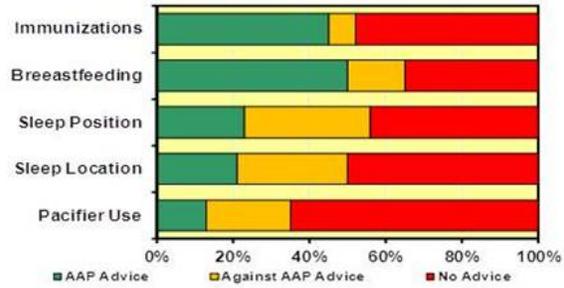
**Advice from Nurses**



**Advice from Media**



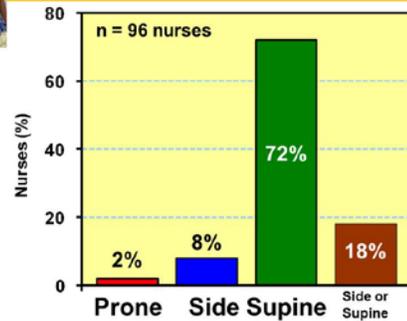
**Advice from Family**



Eisenberg, S.R., et al. *Pediatrics*, 136: DOI: 10.1542/peds.2015-0551, 2015.

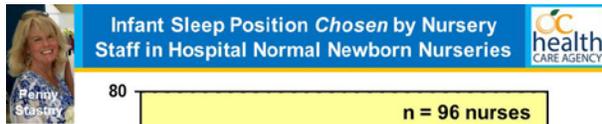
Stastny and colleagues studied hospital normal newborn nurseries. Most (72%) of 96 nurses working in these units knew that the supine sleeping position was the safest in terms of reducing the risk for SIDS. Yet 68% preferred the side sleeping position for normal newborn infants in the hospital nurseries. 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

**Safest Sleeping Position to Reduce the Risk for SIDS Cited by Nurses**

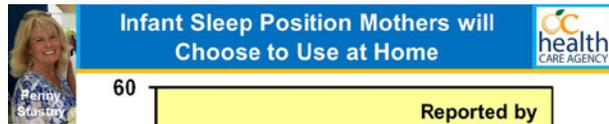


Stastny, P.F., et al. *Nursing Research*, 53: 122-129, 2004.

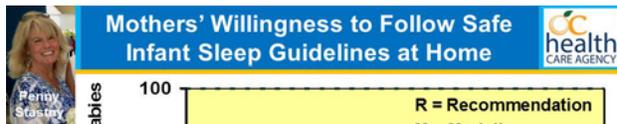
recommended supine sleep. Thus, hospital normal newborn nursery nurses have a great influence on mothers' willingness to have their babies sleep supine if they both model and recommend supine sleep in the hospital. 91% of nurses who placed babies to sleep on their side did so because they feared aspiration 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



Stastny, P.F., et al. *Nursing Research*, 53: 122-129, 2004.



Stastny, P.F., et al. *Nursing Research*, 53: 122-129, 2004.



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Stastny, P.F., et al. *Nursing Research*, 53: 122-129, 2004.



Tablizo, M.A., et al. *Arch. Pediatr. & Adolesc. Med.*: 161: 507-510, 2007.



Tablizo, M.A., et al. *Arch. Pediatr. & Adolesc. Med.*: 161: 507-510, 2007.

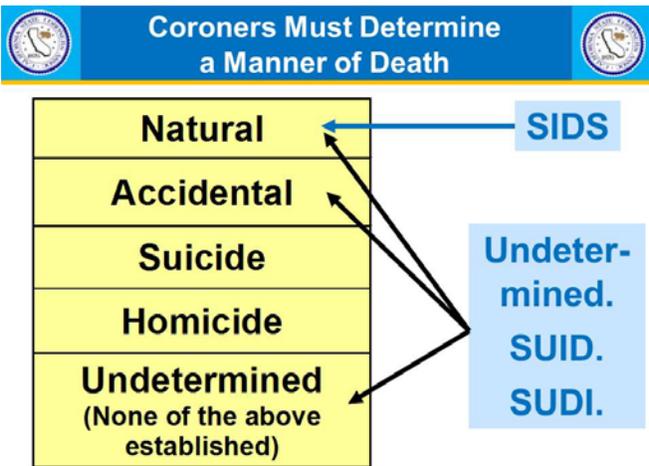
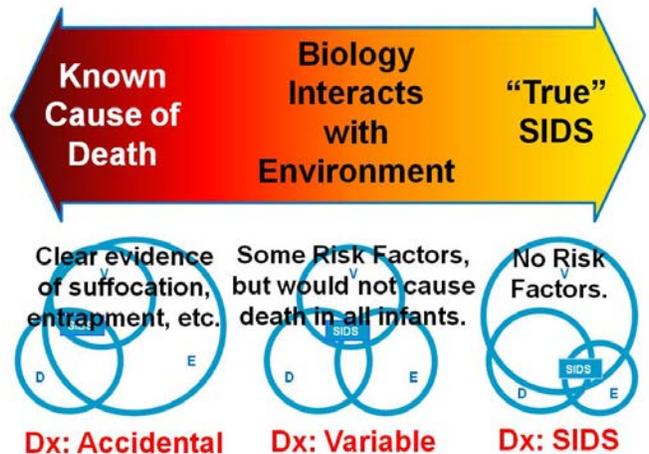
transfer to the NICU, or died. Thus, it is safe for normal newborn infants to be placed on their backs to sleep from birth.

Thus, part of the reason why parents do not follow safe infant sleep recommendations may be that health care professionals do not make these recommendations to parents routinely, and/or they do not model them during hospitalizations as would be appropriate. Part of the solution to improving parent adherence to these recommendations is consistent counseling from health care professionals.



**SIDS, SUID, SUDI, Undetermined: Does It Matter?**

In California, and in the rest of the country, infants who die suddenly and unexpectedly during sleep, 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 brain or brainstem problem. Most are in the middle. They have some risk factors, suggesting the possibility of an asphyxial contribution to the death, but the environmental hazard may not be enough to cause death in all infants. These infants may have some asphyxial contribution, combined with some brain or 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* or *Undetermined* 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?



Why do coroners use different diagnoses for the “same” thing?

## Sudden Infant Death Syndrome and Safe Infant Sleep

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 during sleep 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 findings to determine the best cause and manner of death. But, it was 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. When Coroners decide not to refer families

### SIDS Summit 2011

#### “Pristine SIDS” Case

Cause of Death	%	Manner of Death	%
SIDS	56	Accidental	0
Undetermined	22	Homicide	0
SUID	16	Natural	63
Asphyxia	6	Undetermined	38

Some pathologists were persuaded to use “SUID” because it is recommended by the Center for Disease Control and Prevention.

California State Coroners Association.  
SIDS Summit 2011. Studio City, California. October 19, 2011.

### Challenge to the California SIDS Community



PHNs reach out to your Coroners

### SIDS Summit 2

**“It is almost criminal to not make that referral to the SIDS Coordinator and PHNs, let us make the choice to meet or not meet with a PHN, seek grief support and resources; that should be our choice, it is our choice, do not make it yours.”**

Maureen Rubalcaba  
SIDS Parent



SIDS Summit 2. California State Coroners Association.  
Indian Wells, California. September 22-23, 2016.

of babies dying suddenly and unexpectedly to county public health nursing for education and support, they deprive those families of receiving this critically important information and help.

The challenge to the California SIDS community is to learn the lessons from *SIDS Summit I*, which was confirmed and extended in *SIDS Summit II*. Infants will be given different diagnoses in different jurisdictions: SIDS, SUID, SUDI, Undetermined, etc. In the minds of those making the diagnoses (Coroners and Medical Examiners), these all mean the same thing: the death is *unexpected* and *unexplained*. California law requires Coroners to refer “SIDS” or “Presumed SIDS” babies to public health nurses for follow-up, SIDS education, and grief support. However, these referrals may not be made if the diagnosis is other than “SIDS”. Public health services should be provided to all. Thus, PHNs should reach out to their local Coroner, establish a contact, and facilitate referral of all of these babies so services can be provided. Further, PHNs and Parents should be counseled that these diagnoses all mean the same thing. Having the diagnosis of “SIDS” is no *better* than a diagnosis of “SUID”, “SUDI”, or “Undetermined”.

### **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.

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**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.**

**Deborah R. Gemmill**  
SIDS Parent



## **Impact of a SIDS Death on the Family, Grief, and Guilt <sup>6</sup>**

Penny F. Stastny, B.S.N., R.N., P.H.N.

The death of an infant is one that is never expected. When you become a parent, you instinctively 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, unexpected, 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 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

### **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.**

Darcie D. Sims. American Grief Academy, 1998



### **“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)**

<sup>6</sup> Stastny, P.F., T.G. Keens, and A. Alkon. Supporting SIDS families: the public health nurse SIDS home visit. *Public Health Nursing*,33: 242-248, 2016.

thoughts are normal, but they should decrease with time and with support from all of those around them including family, friends, and health care providers, and other SIDS 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 that they think 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 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

## 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*



## 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*

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.

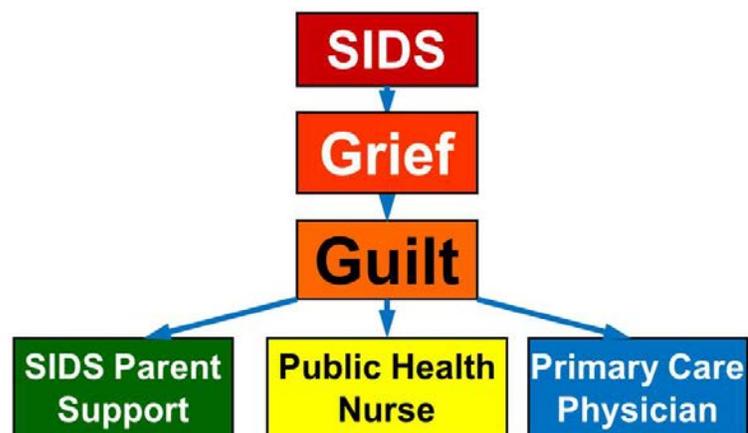
In the immediate aftermath of the infant's death, parents are devastated and often have difficulty "putting one foot in front of the other." The best thing the public health nurse can do is just listen. Avoid trying to explain the death to parents, invoking religious platitudes, or reassuring the parents 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).

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, 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

## 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.**



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Ostfeld, B.M., et al. *Devel. Behav. Pediatr.*, 14: 156-162, 1993.  
Vance, J.C., et al. *Pediatrics*, 96: 933-938, 1995.  
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Stastny, P.F., et al. *Publ. Health Nurs.*, 33: 242-248, 2016

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 Southern and Northern 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 child care providers with other child care providers who have experienced a death in their care is also 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 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 from it. I have to feel this way now.

Maybe you could just listen.

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