

What is Sudden Infant Death Syndrome (SIDS)?

SIDS is the diagnosis given for the sudden death of a baby under one year of age that remains unexplained after a complete investigation, including an autopsy, examination of the death scene and review of the symptoms or illnesses the baby had prior to dying and any other pertinent medical and family history. A SIDS diagnosis falls under a broader classification of infant deaths call SUID (Sudden Unexpected Infant Death). There are 4,500 SUID in the United States each year, including more than 2,200 SIDS deaths. Of these SIDS/SUID deaths, statistics indicate that as many as 80-90 percent may be the result of unsafe sleep practices.

What causes SIDS?

There is mounting evidence that suggests many SIDS babies are born with brain abnormalities that make them vulnerable to sudden death during infancy. Studies of SIDS victims reveal abnormalities in the “arcuate nucleus,” a portion of the brain that controls most of the baby’s major bodily functions such as heart rate, breathing, temperature and the ability to wake from sleep. This abnormality makes babies unable to cope with challenges in their environment that a healthy baby would be able to overcome. These challenges include tummy sleeping, bed sharing, use of soft bedding, overheating and tobacco exposure.

When is SIDS most likely to occur?

SIDS is the leading cause of death in babies one month to one year of age. Most SIDS deaths occur when a baby is between two and four months. Ninety percent of SIDS victims die before six months. The risk of SIDS diminishes after six months. The diagnosis of SIDS is not commonly used after one year of age. However, some babies older than one year do die suddenly and unexpectedly.

Is there anything parents can do to prevent SIDS/SUID?

Currently there is no way to predict which newborns will die from SIDS and no way to prevent it in all cases. However, there are lifesaving steps parents and caregivers can take to help protect their baby from SIDS, suffocation and accidents during sleep:

- **Back Sleeping.** Placing babies on their backs to sleep is the single most important step that parents and caregivers can take to reduce the risk of SIDS. Since the Back to Sleep campaign started in 1994, SIDS deaths have declined by more than 50 percent. This means that more than 25,000 babies’ lives have been saved during the last decade alone with this simple step. It is important to note that placing babies to sleep on their sides is not safe. Babies that roll from their side to their tummy are 18 times more likely to die of SIDS.
- **Bedding.** Babies should sleep in a crib that meets current safety standards. The mattress should be firm, fit snugly in the crib and be covered with only a tight-fitting crib sheet. Play yard style cribs are also a good choice. There should be no soft, fluffy or loose bedding or other objects in the crib, including blankets, pillows, quilts and stuffed animals. Bumpers are not necessary - soft or pillow-like bumpers should not be used. Use a wearable blanket or other sleep clothing instead of blankets to keep babies warm. Infants under one year of age should not be placed to sleep on an adult bed, waterbed, sofa, cushion, pillow or sheep-skin.

Never use wedges or positioners to prop your sleeping baby up or keep him on his back. These devices have not been tested for safety and have not been shown to be effective at keeping babies on their backs. These devices are particularly dangerous when your baby starts wiggling around during sleep.

- **Head Covering.** Make sure your baby's head remains uncovered during sleep. Babies are at an increased risk for SIDS if their head becomes covered during sleep. Avoid using a blanket or other covering over your baby's face as a sun or weather screen, or to block out distractions or sounds while your baby is sleeping. The blanket will cause a build-up of exhaled air around the baby's face. This exhaled air does not have enough oxygen, which can lead to a SIDS or suffocation death.
- **Bed Sharing/Sofa Sharing.** Do not share a sleep surface with your baby. Sharing a sleep surface is especially dangerous for babies less than 12 weeks old and premature or low birth weight babies. It's okay to bring your baby into bed to feed and cuddle, but when it's time to go to sleep, place the baby alongside your bed in a separate, safe sleep space. In addition to the known hazards caused by pillows and comforters in the family bed, there is also increased risk for accidental suffocation or overly. Never bring your baby into bed with you if you or your partner is exhausted, smoke or impaired by drugs or alcohol. Sofas and chairs are particularly dangerous places to fall sleep with your baby.

It is important to note that bed sharing has not been found to be protective against SIDS, in fact current research indicates that bed sharing increases a baby's risk to die by as much as 40 times. Research does, however, suggest that room sharing is protective against SIDS. Keep your baby next to where you sleep in her own separate space for at least the first six months. This provides greater safety for the baby and makes it easier to breastfeed and share closeness with your baby.

- **Pacifiers.** Recent research shows that pacifiers can greatly reduce a baby's risk for SIDS. Experts recommend giving your baby a pacifier EVERY time he or she is placed down to sleep. If you are breastfeeding, wait until nursing is going well (usually one month) before offering a pacifier.

While the exact safety mechanism is not yet known, there are many possibilities for this finding. One is that the presence of a pacifier in the mouth may discourage babies from turning over onto their stomach during sleep. Because moving or turning may dislodge the pacifier, it may encourage babies to stay on their backs. Another is that the pacifier and/or sucking reflex helps keep the tongue positioned forward, keeping the airways open. Pacifier use can also help quiet a restless infant who might otherwise move more aggressively around the crib. Because pacifiers stimulate the upper airway muscles and saliva production, it is felt that pacifier use may keep babies from falling into a deep sleep, which is protective against SIDS. Regular pacifier use is protective against SIDS even if the pacifier falls out of the baby's mouth when he or she falls asleep.

- **Smoking.** Babies whose mothers smoke during pregnancy are three times more likely to die from SIDS. Exposure to second-hand smoke by mothers, fathers, grandparents and others after the baby is born also greatly increases the risk of SIDS. Studies have found that the risk of SIDS increases with each additional smoker in the home, the numbers of cigarettes smoked a day, and the length of the infant's exposure to cigarette smoke. New research now warns of the dangers of third-hand smoke – the chemicals left behind on clothing and in homes and cars. Babies should always be kept in a smoke-free environment to protect against SIDS and other respiratory illness.
- **Room Temperature.** Babies should be kept warm, but they should not be allowed to get too warm. An overheated baby is more likely to go into a deep sleep from which it may be hard to wake up. Keep the temperature in the baby's room at a level that feels comfortable to a lightly clothed adult and avoid overdressing the baby.
- **Prenatal Care.** Good prenatal care, including proper nutrition, abstinence from alcohol, drugs, and smoking, and frequent medical checkups beginning early in pregnancy, is critical to your baby's overall health and well-being. Early and good prenatal care can also help prevent a baby from developing an abnormality that could put him or her at risk for sudden death.

- **Breast Feeding.** Breast feeding has been shown to be good for babies by building their immunity against illness and infections, in addition to other benefits. Recent research provides the strongest evidence to date that breastfeeding may also reduce the risk of SIDS. Mothers should be encouraged to breastfeed for the first 12 months and exclusively for at least the first six months if possible.

Data analyzed by scientists at the National Institute of Environmental Health Sciences suggest that breastfeeding can reduce the risk of death for infants in their first year of life. Looking at infants between 28 days and one year of age, researchers concluded that promoting breastfeeding could potentially prevent up to 720 post-neonatal deaths in the U.S. each year. Researchers compared CDC records of 1,204 children who died between 28 days and one year of causes other than congenital anomalies or cancer with those of 7,740 children still alive at one year.

- **Proper Health Care.** Take your baby to the doctor for all regular well-baby checkups and make sure that your baby receives his or her immunizations on schedule.
- **Childcare.** Babies who usually sleep on their back are at a significantly increased risk of SIDS when placed to sleep on their stomach by a well intentioned but ill-informed relative or caregiver. Be sure to share your safe sleep rules with baby sitters, child care providers, grandparents and anyone who cares for your baby. Since childcare practices have changed a lot since you were a baby, do not assume that everyone knows about important safe sleep practices in preventing SIDS, suffocation and accidents during sleep.

What is the Back to Sleep campaign?

This campaign is aptly named for its main recommendation to place healthy infants on their backs to sleep to reduce the risk of SIDS. The lead partners in this campaign include the National Institute of Child Health and Human Development (NICHD), American Academy of Pediatrics (AAP), First Candle/SIDS Alliance and the Association of SIDS and Infant Mortality Programs. Based on a recommendation made by the AAP in 1992, the campaign was launched in 1994 with an effort to reach every parent and caregiver in the country.

Has the campaign been successful?

The campaign has been very successful in reaching parents and other caregivers with the Back to Sleep message. We have seen a change from 70 percent of babies placed on their stomachs to sleep in 1992 to 15 percent in 2005. Rates of SIDS have declined by more than 50 percent during that time, resulting in the most significant impact on our nation's high rates of infant mortality in history. However, we have not reached all families and all populations. Of the more than 2,200 SIDS deaths each year, more than 70 percent were placed on their stomach to sleep. Thousands of other SUID occur as a result of bed sharing, soft bedding use and other unsafe sleep practices.

As a result, experts are recommending expanding the campaign beyond Back to Sleep to Safe Sleep to save as many lives as possible and continue have an impact on our nation's high rates of infant mortality.

Are some babies more at risk for SIDS than others?

Yes, babies in the following categories are at a higher risk for SIDS:

- Babies born to mothers who smoke during or after pregnancy
- Babies placed to sleep on their stomach or side
- Babies who share a sleep surface
- Babies who are premature or low birth weight
- Multiples
- Babies born to mothers who are less than 20 years old at the time of their first pregnancy
- Babies born to mothers who had no or late prenatal care
- Babies born to mothers with too short an interval between pregnancies

Are any ethnic groups more prone to SIDS?

African American babies are nearly two-and-a-half times more likely to die of SIDS/SUID than Caucasian babies, and Native American babies are nearly three times more likely to die of SIDS/SUID. The Back to Sleep campaign is being stepped up, with a special effort to get the message out to these two populations with the help of community, civic and religious groups.

Can SIDS be inherited?

At this time there is not direct link to SIDS and genetic predisposition. Metabolic disorders, which can be inherited, have at times been mistaken for SIDS. One such disorder, medium chain acylCoA dehydrogenase deficiency (MCAD), prevents the infant from properly processing fatty acids. A build up of these acid metabolites could eventually lead to a rapid and fatal disruption in breathing and heart functioning. If there is a family history of this disorder or childhood death of unknown cause (especially more than one case within a family), genetic screening of parents by a blood test can determine if they are carriers of this disorder. If one or both parents are found to be a carrier, the baby can be tested soon after birth at little cost.

This is another reason why the autopsy is so important. Tests can be done on the tissues of an infant to identify known metabolic disorders. Other research studies into possible genetic links to SIDS are ongoing.

I have heard that the side sleep position is effective against SIDS.

In 1992, the AAP recommended both the side and the back sleeping position to reduce the risk of SIDS. In 1996, however, after reviewing data from various new studies, they revised their recommendation to back sleeping as the only safe sleep position for babies. These reports indicated that the risk for SIDS is greater for babies placed on their sides versus those placed on their backs, perhaps because babies placed on their sides have a higher likelihood of rolling onto their tummies. In 2005, the AAP began recommending against side sleep position for babies.

Won't my baby choke on spit-up or vomit if he sleeps on his back?

Many parents place babies on their stomachs to sleep because they think it prevents them from choking on spit-up or vomit during sleep. In fact, the opposite is true – babies are less likely to choke when sleeping on their backs. When babies sleep on their back, the esophagus (food pipe) is below the trachea (wind pipe.) As a result, the spit-up or vomit cannot be breathed into the wind pipe. When a baby sleeps on his stomach, the food pipe is above the wind pipe. Gravity would then allow for the spit-up/vomit to be breathed in, causing the baby to choke. Since babies have been sleeping on their backs, studies worldwide have not found any increase in the incidence of aspiration, choking, pneumonia or other problems.

Won't my baby be more comfortable sleeping on her tummy?

Many parents place their baby on his or her stomach because they think the baby will be more comfortable. This may be true, but tummy sleeping is very dangerous and increases the risk of SIDS and suffocation. It appears sleep position preference is a learned behavior during the first four to six months of life. If babies are placed to sleep on their backs from birth, they will not know any other sleep position and will be comfortable sleeping that way.

What about swaddling?

Some experts feel that swaddling in the early weeks can help newborns sleep more comfortably on their backs. This can help minimize the startle reflex and ease colic symptoms in some babies. If you choose to swaddle, take time to learn how to swaddle properly before you leave the hospital. Take care not to swaddle too loosely, as the blanket can come loose and accidentally suffocate your baby. Take care not to swaddle too tightly as this can compress your baby's chest and make it difficult to breathe. Tight swaddling can also cause problems with your baby's hips and legs. Once your baby starts to wiggle around during sleep, it is probably time to stop swaddling.

Can't back sleeping make my baby's head flat?

Since babies started sleeping on their backs, there has been an increase in parents reporting a flat spot on the back of their baby's head. Experts say that this is normal and will disappear after the baby has begun to sit up and crawl.

There are simple steps parents and caregivers can take to avoid flat spots: alternate the end of the crib where you place your baby's head for sleep; alternate the arm in which you hold your baby for feedings; give your baby lots of tummy time when he or she is awake and being supervised (see below); and make sure that your baby does not spend too much time in car seats, carriers, swings and other similar products.

Should babies ever be placed on their tummies?

Yes, you should give your baby as much "tummy time" as possible when he or she is awake and being supervised. This will help strengthen your baby's neck and upper body muscles. Begin by laying your newborn on his or her tummy, across your lap. As your baby gets stronger, place him or her on a quilt on the floor with toys within reach. This is also a great chance for the two of you to spend quality time together, on the floor playing! Tummy time can also help prevent flat spots from developing on the back of your baby's head. Never leave your baby unattended during tummy-time. If your baby tires or is sleepy, change activities or place her in her crib, on her back, for a nap.

What research is being conducted to further explain the cause of SIDS?

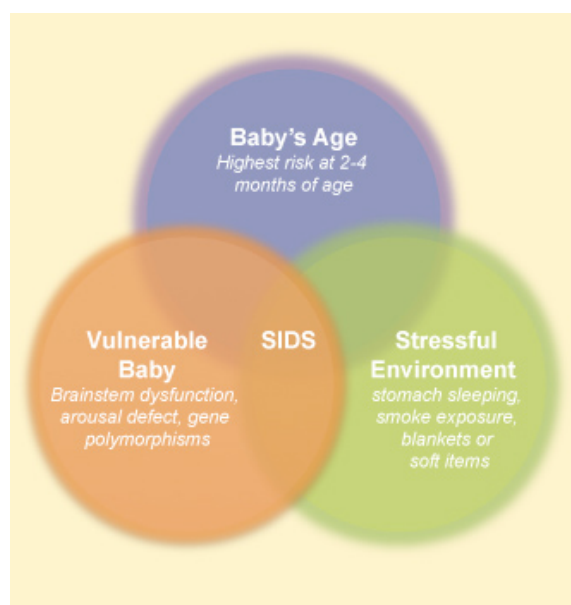
A recent major breakthrough in SIDS research has provided the most concrete evidence to date that SIDS is not the mystery we once thought. Ongoing research studies by Dr. Hannah Kinney at the SIDS Center of Excellence at Harvard University have identified abnormalities in the part of the brain that controls most of a baby's major bodily functions, including heart rate, breathing, temperature and sleep/wake patterns. Babies with this defect are not able to respond to challenges in their environment. (See Triple Risk Model below)

In addition, scientists continue to explore the development and function of the brain, nervous system, heart, breathing, sleep patterns, body chemical balances, autopsy findings and environmental factors. SIDS, like other medical disorders may eventually have more than one explanation – and more than one means of prevention. More needs to be done to uncover what causes SIDS, who is at risk for the disorder and ways to lower the risk of sudden infant death. In addition to research funding provided by the NICHD, First Candle maintains its own national research program and conducts grassroots advocacy programs that help ensure Congressional allocation of adequate funding for issues related to SIDS and other sudden, unexpected infant deaths (SUID).

What is the "Triple Risk Model" for SIDS?

Recent advances in medical research shows us that babies that die of SIDS may not be as healthy as we once thought. Scientists have uncovered an abnormality in the brainstem of SIDS victims that make them vulnerable to sudden, unexpected death.

While there is still much we do not know about SIDS, a triple-risk model is often used to describe the series of events that takes place when a baby dies of SIDS:



- The first element of the model is the critical development period, which is the first six months of life where the baby is growing and developing very rapidly. This rapid growth can make a baby's system become unstable.
- The second element, the vulnerable infant, represents an infant with this underlying abnormality in an area of their brainstem that controls respiration, heart rate, temperature, arousal from sleep and other major bodily functions during early life.
- The third element involves external or environmental challenges that a normal baby can easily overcome and survive, but that an already vulnerable baby might not. Challenges such as tobacco exposure, tummy sleeping, soft bedding, bed sharing or an upper respiratory infection alone do not cause death for healthy infants, but could trigger a sudden, unexpected death in an infant with this defect.

According to this model, all three of these elements must come together for SIDS to result (some experts now feel that even two elements could trigger a sudden death.) Unfortunately, at this time, there is no way to identify which babies are at increased risk as a result of this brainstem abnormality.

Can home monitors help prevent SIDS?

Much research has been done to investigate the effectiveness of monitors in preventing SIDS. In the 1970's and early 1980's, it was thought that monitoring had promise in identifying infants at risk for SIDS and signaling caregivers when infants have life-threatening events that may proceed to SIDS. In September of 1986, the NICHD held a consensus conference titled, "Infantile Apnea and Home Monitoring." After examining all available research, the consensus panel determined that monitoring is effective only in some cases to manage infantile apnea. For the normal newborn, the risks, disadvantages, and costs of monitoring outweigh the potential of identifying infants at risk for SIDS.

There are many home monitors now on the market that claim to help prevent SIDS. It is important to note that while these devices may be helpful at monitoring sound and activity in your baby's room, they are not effective at predicting or preventing a SIDS death. These monitors can also cause great stress due to the high incidence of false alarms. The best defense against SIDS is placing your baby to sleep on his or her back, in a safety-approved crib with a firm mattress covered with only a tight-fitting crib sheet and removing all soft and fluffy bedding and other objects from the crib.

Are there state or national guidelines for investigating the sudden death of infants?

A death scene investigation is an integral part of a SIDS/SUID diagnosis to rule out accidental, environmental and unnatural causes and to provide information to researchers on risk factors. In 2004 the CDC launched an initiative to improve the investigation and reporting of SIDS/SUID, in collaboration with other federal agencies and organizations representing medical examiners, coroners, death scene investigators, emergency medical personnel, law enforcement officials, SIDS researchers, infant death review experts, and SIDS parents. As part of this effort, on March 1, 2006, CDC released the *Sudden, Unexplained Infant Death Investigation (SUIDI) Reporting Form* for state and local use in infant death scene investigations. The SUIDI Reporting Form replaces the Investigation Report Form that accompanied the 1996 *Guidelines for the Death Scene Investigation of Sudden, Unexplained Infant Death*.

Currently, approximately half of the states have mandatory autopsy legislation for the sudden death of an infant that, in many cases, includes support for the administration of compassionate bereavement services for families. Other states are in the process of establishing similar legislation. SIDS/SUID families, at the guidance of First Candle, have been at the forefront of efforts urging the funding of research, adoption of mandatory autopsy legislation, and thorough, but compassionate death scene investigations. Broader, standardized implementation of autopsy and death scene mandates is crucial to efforts to differentiate cases of SIDS from cases of child abuse, and to expand our medical knowledge about SIDS.

How does a SIDS death affect the family?

A SIDS/SUID death is a tragedy that prompts intense emotional reactions among surviving family members. After the initial disbelief, denial, or numbness begins to wear off, parents can fall into a prolonged depression. This depression can affect their sleeping, eating, ability to concentrate, and general energy level. Crying, weeping, incessant talking, and strong feelings of guilt or anger are all normal reactions.

Many parents experience unreasonable fears that they, or someone in their family, is in danger. Over protection of surviving children and fears for future children are common reactions. As the finality of the child's death becomes a reality for the parents, recovery can occur. As healing begins, parents are able to begin to take a more active part in their own lives, which begin to have meaning once again. The pain of their child's death becomes less intense but not forgotten. Birthdays, holidays, and the anniversary of the child's death trigger periods of intense pain and suffering.

Children will also be affected by the baby's death. They may fear that other members of the family, including themselves, will also suddenly die. Children often also feel guilty about the death of a sibling and may feel that they had something to do with the death. Children may not show their feelings in obvious ways. Although they may deny being upset and seem unconcerned, signs that they are disturbed include intensified clinging to parents, misbehaving, bedwetting, difficulties in school, and nightmares. It is important to talk to children about the death and explain to them that the baby died because of a medical problem that only occurs rarely and only in babies.

What kind of support is available for families who have lost a baby to SIDS/SUID?

Families are encouraged to seek counseling and support. First Candle offers a bilingual, 24/7 crisis hotline and provides grief materials and resources to all those affected by the death of a baby at 1.800.221.7437 or www.firstcandle.org.