Silent and unexpected, Sudden Infant Death Syndrome (SIDS) robs seemingly healthy babies of their lives, leaving parents and families haunted with guilt, loss, and grief. But, over the past 15 years — with the introduction of the nation’s “Back to Sleep” campaign — experts have introduced proactive steps parents can take to reduce their baby’s risk, while researchers are unraveling the mysteries of this disorder.

By Mary Best

Cloaked in mystery and superstition, SIDS has claimed the lives of babies for centuries. As medical science has advanced, scientists have ruled out a host of theories—from curses and murder to disease and suffocation. In 1969 the National Institutes of Health applied the term SIDS as a specific medical disease.

The reasons why a baby dies of SIDS, however, remain a diagnosis of exclusion.

“Most babies who die of SIDS appear perfectly normal,” says Rachel Y. Moon, M.D., FAAP, a pediatrician at Children’s National Medical Center, in Washington, D.C., and a member of the American Academy of Pediatrics’ SIDS Task Force. “We do know that there are demographic and environmental risks,” she adds, including African American and American Indian babies, infants who are born to women who smoked during pregnancy, very young women, and preterm and low birth weight infants.

“But no baby is absolutely safe from SIDS,” says John Kattwinkel, M.D., FAAP, chair of the AAP’s SIDS Task Force.

What the Research Says

There is good news, however. Although SIDS still lurks in the nightmares of new parents, researchers are uncovering scientific evidence of its causes. The following are among the most significant.

According to research funded by the National Institute of Child Health and Human Development (NICHD), infants who die of SIDS have abnormalities in the brain stem, which controls heart rate, breathing, blood pressure, temperature, and arousal. The finding is the strongest evidence to date suggesting that differences in a specific part of the brain may place some infants at an increased risk for SIDS.

This research also explains why stomach sleeping and soft bedding increases a baby’s risk of re-breathing his or her own air. “When they aren’t getting enough oxygen, most babies will do something to change their environment — they’ll turn their heads, or they’ll sigh, or they’ll yawn,” says Dr. Moon. “But babies who die of SIDS don’t wake up when they get into trouble, and we don’t fully understand why.”

Another important medical study suggests SIDS babies suffer from a “triple-risk model.” According to the NICHD, infants who die of SIDS are in a critical stage in the development of their immune, cardiovascular, and respiratory systems; susceptible to risks during this stage because of an underlying muscular weakness or neurological defect; and affected by an environmental cause such as stomach-sleeping or soft bedding.

In addition, an Australian study found that bacterial infections, such as Staphylococcus aureus, might be a cause of SIDS. And a Rhode Island study revealed that babies whose hearing was worse in their right ears — at three different frequencies — were more likely to die of SIDS.

But while researchers make medical strides, parents need to do their parts to reduce the risk of tragedy — because SIDS can strike anyone, anytime, anywhere.

Sadly, I know.

Losing My Will

When my doctor told me I was pregnant in the fall of 2006, I was speechless. The only words I could utter were, “holy mackerel.” Contrary to what the doctor thought, I was overjoyed — shocked, but overjoyed.

I barely remember driving home. I had left a few hours earlier certain I had the flu, and now I was turning into our driveway.

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SIDS is...

- **A disease of the unknown.** SIDS is the sudden death of an infant younger than 1 year of age. The cause of death remains unexplained after a complete investigation. This includes an autopsy, examination of the death scene, a review of the infant’s health, any other important medical history. The cause of death is considered a diagnosis of exclusion. SIDS is a recognized medical disorder.

- **A major cause of death.** SIDS is one of the leading causes of death for infants 1 month to 1 year of age. Most deaths occur between ages 2 and 4 months; 90 percent of SIDS deaths occur before 6 months of age. Approximately 2,500 babies in the United States die of SIDS each year — seven babies each day. SIDS claims more lives each year than AIDS, cancer, heart disease, pneumonia, muscular dystrophy, cystic fibrosis, and child abuse combined. As a result of the national Back to Sleep Campaign, launched in 1994 as a joint effort between First Candle/SIDS Alliance, the American Academy of Pediatrics, and National Institute of Child Health and Human Development, SIDS rates have declined significantly. According to the National Center for Health Statistics, 4,890 infants died of SIDS in 1992; in 2004, 2,246 SIDS deaths were recorded in the United States.

- **Also called crib death.** Most SIDS deaths occur while infants are sleeping, so the disorder is also called “crib death” or “cot death.” But not all SIDS deaths occur in a baby’s crib. Many have died in car seats, public places, strollers, etc. Some infants have even died in their parents’ arms.

- **Like a thief in the night.** Most SIDS babies appear to be healthy prior to death. A SIDS death happens quickly and silently, with no signs of suffering.

- **Non-discriminatory.** While SIDS occurs in all socio-economic, racial, and ethnic groups, African American and Native American babies are two to three times more likely to die of SIDS than Caucasian babies.

- **More harmful to boys.** 60 percent of SIDS victims are male; 40 percent are female.

- **Affected by weather.** More SIDS deaths occur in the colder months.

- **Devastating to parents.** Nothing can be done to save the life of a SIDS baby.
SIDS is not …

- **Predictable.** There are no signs.
- **Painful.** SIDS is not a cause of pain and suffering for the infant.
- **New.** SIDS has been referenced throughout Western culture, including in the Old Testament.
- **The result of Shaken Baby Syndrome or child abuse.** Experts estimate that child abuse accounts for less than 5 percent of all the SIDS cases recorded each year.
- **An ill child.** Often the only thing that can be seen medically wrong with a child prior to a SIDS death is a slight cold or the sniffles. Some babies were unusually fussy in the hours preceding their death, but these babies had no serious medical conditions and their deaths are a shock not only to the family but also to the physicians looking after the babies.
- **Contagious or infectious.
- **Hereditary.
- **A true syndrome.** To call it a syndrome would mean it would have symptoms, and in the case of SIDS, death is the sole symptom.
- **A fatal condition of small, weak, or sickly babies.** SIDS occurs to healthy and robust babies.
- **Caused by the immunizations.** Most children get their immunizations at about four months of age, which coincides with the average age of a SIDS baby. Children who were never vaccinated have also died of SIDS. Deaths due to vaccine reactions or child abuse are not classified as SIDS deaths; however, this has been implicated as a possible factor in SIDS deaths.
- **Caused by smothering.** If a baby was found face down or with bedclothes over the face it might be thought that smothering was the cause of death. Sometimes babies are covered with bedclothes, but others are found uncovered and free of bedclothes entirely. While it is possible for an infant to smother accidentally — and the incidence of smothering appears to be increasing — this is still somewhat rare. Not uncommonly the child is lying undisturbed as when last put to bed.
- **Caused by allergies.
- **Caused by poor, bad, or uneducated parents.** SIDS happens to parents of all economic, social, educational, and racial groups. Some cultures do not report SIDS deaths or have no way to classify SIDS and this often leads some to say that there are no SIDS deaths in that area, which is misleading.
- **The cause of every unexpected infant death.**

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— searching for the right words. Any words. I parked the car, and my husband greeted me at the door.

“We need to talk,” I mumbled.

We sat down on the sofa, and through a rush of tears, I blurted out that he was going to be a dad. I’ll never forget the happiness that filled his face.

Even after telling our parents and siblings, I still couldn’t believe the news. Over the next week, I bought several home pregnancy tests — just to make sure.

Months passed. By Christmas, we had learned we were having a boy, and test after test indicated our son was healthy. We decided to name him after our fathers — James William. We would call him Will.

Will made his grand appearance in the world on May 8, 2006. Even though the delivery was difficult, my healthy little miracle weighed 8 pounds, 2 ounces, and James took us home about 36 hours later.

That summer was the happiest time of my life. James accepted a new job, enabling me to stay home with our little prince.

On September 12, I took Will for his four-month checkup and first series of immunizations. Will and our pediatrician were like old friends, and after their usual playtime, Dr. Patel bragged that our little guy was fit as a fiddle.

Two nights later, we followed our regular routine — a bath, grooming, pajamas, prayers, goodnight kisses, and bedtime. I checked on him around 11, and he was sleeping soundly on his back.

About 3:45 I woke up to check on him again, like I did every night. When I walked into his room, I sensed something was terribly wrong. Through the darkness, I could see he had rolled over and was face down in his crib. To my horror, he was not breathing. I applied CPR, woke my husband, called 911, and continued CPR. But he was gone.

A few hours after this hellish nightmare began, the police, detectives, EMTs, and coroner took my son away. Along with a part of me.

More than two years later, I still suffocate from grief and guilt. Nothing in my life will ever hurt as much as losing my son. ●
The following are recommendations from the American Academy of Pediatrics (AAP) and the National Institute for Child and Human Development (NICHD) for reducing your baby’s risk of suffocating or dying from SIDS.

**1. Back is best.** Always place your baby on his or her back to sleep, for naps and at night. The back sleep position is the safest, and every sleep time counts. Side and tummy positions are unsafe.

**2. Mattress and crib safety.** Place your baby on a firm sleep surface, such as on a safety-approved crib mattress, covered by a fitted sheet.

**3. Bed behavior.** Never place your baby to sleep on pillows, quilts, sheepskins, or other soft surfaces. This includes sofas, chairs, cushions, waterbeds, etc. Also, keep soft objects, toys, and loose bedding out of your baby’s sleep area. Don’t use pillows, blankets, quilts, sheepskins, and pillow-like crib bumpers in your baby’s sleep area, and keep any other items away from your baby’s face.

**4. Bed sharing.** Keep your baby’s sleep area close to, but separate from, where you and others sleep. Your baby should not sleep in a bed or on a couch or armchair with adults or other children, but he or she can sleep in the same room as you.

**5. Breast is best.** Experts recommend that mothers breastfeed through the first year of their baby’s life. According to the AAP, breastfeeding is thought to help protect infants.

**6. Beat the heat.** Overheating can increase your baby’s SIDS risk. To help keep your baby from overheating during sleep, dress your baby in light sleep clothing, and keep the room at a temperature that is comfortable for an adult.

**7. Smoking prohibited.** Do not allow smoking around your baby. Don’t smoke before or after the birth of your baby, and don’t expose your baby to secondhand smoke.

**8. Pacifier pleasers.** Research published in the *Archives of Pediatrics & Adolescent Medicine* indicates that pacifiers may help reduce the risk of SIDS. Use a clean, dry pacifier when placing your infant down to sleep, but don’t force the baby to take it. If you are breastfeeding, wait until your baby is one month old before using a pacifier.

**9. Air supply.** According to another study published in the *Archives*, having a fan in the room where your baby sleeps was found to reduce the risk of SIDS by 72 percent. More research is needed to confirm these results, and fans cannot take the place of your baby sleeping on her back.

**10. False confidence.** Avoid products that claim to reduce the risk of SIDS because most have not been tested for effectiveness or safety. If you have questions about using monitors for other conditions talk with your pediatrician.

**11. Tummy time.** Provide “tummy time” when your baby is awake and someone is watching — it’s a good way to help baby strengthen muscles. Change the direction that your baby lies in the crib from time to time.

### Spread the Word

According to the American Academy of Pediatrics, 32 percent of infants are in childcare full-time, two-thirds of U.S. infants younger than 1 year spend their days in non-parental childcare, and infants of employed mothers spend an average of 22 hours per week in childcare.

Sadly, the increased risk of an infant dying of SIDS while someone else is caring for him or her is as much as 18 times higher than when he or she is with his or her parents. Approximately 20 percent of SIDS deaths occur while an infant is under the watch of a nonparental caregiver. About one-third of SIDS-related deaths in childcare occurs during the first week, and one-half of these occur on the first day.

Why? No one is certain, but it is believed that childcare providers sometimes place infants on their tummies to sleep, even though they are accustomed to sleeping on their backs. This places the child at much greater risk for SIDS. This risk can be greatly reduced by talking with those who care for your baby, including childcare providers, babysitters, family, and friends, about placing your baby to sleep on his or her back at night and during naps.

### To Learn More

- American Academy of Pediatrics: [www.aap.org](http://www.aap.org)
- American SIDS Institute: [www.sids.org](http://www.sids.org)
- Association of SIDS and Infant Mortality Programs: [www.asip1.org](http://www.asip1.org)
- CJ Foundation for SIDS: [www.cjsids.com](http://www.cjsids.com)
- First Candle/SIDS Alliance: [www.firstcandle.org](http://www.firstcandle.org)
- National Institute for Child and Human Development: [www.nichd.nih.gov/sids/sids.cfm](http://www.nichd.nih.gov/sids/sids.cfm)