



NATIONAL SIDS RESOURCE CENTER

WHAT IS SIDS?

Sudden Infant Death Syndrome (SIDS) is the “sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history” (Willinger, et al., 1991).

What Are the Most Common Characteristics of SIDS?

Most researchers now believe that babies who die of SIDS are born with one or more conditions that make them especially vulnerable to stresses that occur in the normal life of an infant, including both internal and external influences. SIDS occurs in all types of families and is largely indifferent to race or socioeconomic level. SIDS is unexpected, usually occurring in otherwise apparently healthy infants from 1 month to 1 year of age. Most deaths from SIDS occur by the end of the sixth month, with the greatest number taking place between 2 and 4 months of age. A SIDS death occurs quickly and is often associated with sleep, with no signs of suffering. More deaths are reported in the fall and winter (in both the Northern and Southern Hemispheres) and there is a 60- to 40-percent male-to-female ratio. A death is diagnosed as SIDS only after all other alternatives have been eliminated: SIDS is a diagnosis of exclusion.

What Are Risk Factors for SIDS?

Risk factors are those environmental and behavioral influences that can provoke ill health. Any risk factor may be a clue to finding the cause of a disease, but risk factors in and of themselves are not causes.

Researchers now know that the mother’s health and behavior during her pregnancy and the baby’s health before birth seem to influence the occurrence of SIDS, but these variables are not reliable in predicting how, when, why, or if SIDS will occur. Maternal risk factors include cigarette smoking during pregnancy; maternal age less than 20 years; poor prenatal care; low weight gain; anemia; use of illegal drugs; and history of sexually transmitted disease or urinary tract infection. These factors, which often may be subtle and undetected, suggest that SIDS is somehow associated with a harmful prenatal environment.

How Many Babies Die From SIDS?

According to the Center for Health Statistics (NCHS), each year from 1983 to 1991, the number of SIDS deaths reported in the United States ranged from 5,000 to 6,000. In April of 1992, the American Academy of Pediatrics announced that healthy infants should sleep on their back to reduce the risk of SIDS. Beginning that year, SIDS deaths began to decline somewhat, to 4,890. In June of 1994, the Back to Sleep campaign began, and SIDS deaths declined even more. This decline continued throughout the 1990s, and, according to the NCHS, final figures for SIDS deaths in 1999 were approximately half of what they were in 1991 (2,648 versus 5,349). (NCHS, Telephone Interview, November 2001)

When considering the overall number of live births each year in the United States, SIDS remains the leading cause of death in infants between 1 month and 1 year of age, and the third leading cause of death in infants birth to 1 year of age, behind congenital abnormalities and short gestation/low birth weight. (National Vital Statistics Report, June 26, 2001)

How Do Professionals Account for the Significant Recent Decline in SIDS Deaths?

According to most professionals, the significant decline in SIDS deaths starting in the mid-1990's can be attributed to results achieved from health messages promoted in the public health campaign known as the "BACK TO SLEEP CAMPAIGN" (BTS).

In April of 1992, the American Academy of Pediatrics, Task Force on Infant Sleep Position (AAP), issued a statement recommending that infants be placed on their back or side to sleep to reduce the risk of SIDS. In 1994, in response to the 1992 AAP announcement, a national campaign was initiated. This campaign was a joint effort of the U.S. Public Health Service (National Institute of Child Health and Human Development and the Maternal and Child Health Bureau), the AAP, the SIDS Alliance, and the Association of SIDS and Infant Mortality Programs. In 1996, it was reported at the 4th SIDS International Conference that infants who sleep on their side have a greater risk of dying of SIDS than infants who sleep on their back. As a result, the AAP changed its message to pediatricians and parents to recommend the supine sleep position as the preferred sleep position for healthy infants. Even though the side position is safer than sleeping on the stomach, infants who sleep on their side can roll over onto their stomach—the sleep position that carries the greatest risk of SIDS. (Pediatrics, March 2000)

The BTS Campaign expanded to become a nationwide public health effort. Major responsibility for disseminating information and educational materials on this crucial health topic was assigned to the National Institute of Child Health and Human Development (NICHD). NICHD adopted the following recommendations to implement this nationwide effort to increase awareness of the critical importance of infant sleep position as a risk factor for SIDS:

- preparation and dissemination of several publications on infant care practices targeted at both consumer and health professional audiences;
- establishment of a toll-free hotline as a contact point for obtaining these publications; and
- design of a Web page with current information about activities of and resources available from the BTS Program.

Largely as a result of the public awareness raised by BTS campaign messaging, the number of SIDS deaths declined by approximately 50 percent between 1991 and 1999. (NCHS, Telephone Interview, November 2001)

How Do Professionals Diagnose SIDS?

Often the cause of an infant death can be determined only through a process of collecting information, conducting sometimes complex forensic tests and procedures, and talking with parents and physicians. When a death is sudden and unexplained, investigators, including medical examiners and coroners, use the special expertise of forensic medicine (application of medical knowledge to legal issues). SIDS is no exception.

Health professionals make use of three avenues of investigation in determining a SIDS death:

1. the autopsy,
2. death scene investigation, and,
3. review of victim and family case history.

The Autopsy

The autopsy provides anatomical evidence through microscopic examination of tissue samples and vital organs. An autopsy is important because SIDS is a diagnosis of exclusion. A definitive diagnosis cannot be made without a thorough postmortem examination that fails to point to any other possible cause of death. Also, if a cause of SIDS is ever to be uncovered, scientists will most likely detect that cause through evidence gathered from a thorough pathological examination.

A Thorough Death Scene Investigation

A thorough death scene investigation involves interviewing the parents, other caregivers, and family members; collecting items from the death scene; and evaluating that information. Although painful for the family, a detailed scene investigation may shed light on the cause, sometimes revealing a recognizable and possibly preventable cause of death.

Review of the Victim and Family Case History

A comprehensive history of the infant and family is especially critical to determine a SIDS death. Often, a careful review of documented and anecdotal information about the victim's or family's history of previous illnesses, accidents, or behaviors may further corroborate what is detected in the autopsy or death scene investigation.

Investigators should be sensitive and understand that the family may view this process as an intrusion, even a violation of their grief. It should be noted that, although stressful, a careful investigation that reveals no preventable cause of death may actually be a means of giving solace to a grieving family.

What SIDS Is and What SIDS Is Not

SIDS Is:

- the major cause of death in infants from 1 month to 1 year of age, with most deaths occurring between 2 and 4 months
- sudden and silent—the infant was seemingly healthy
- currently, unpredictable and unpreventable
- a death that occurs quickly, often associated with sleep and with no signs of suffering
- determined only after an autopsy, an examination of the death scene, and a review of the clinical history
- designated as a diagnosis of exclusion
- a recognized medical disorder listed in the International Classification of Diseases, 9th Revision (ICD-9)
- an infant death that leaves unanswered questions, causing intense grief for parents and families

SIDS Is Not:

- caused by vomiting and choking, or minor illnesses such as colds or infections
- caused by the diphtheria, pertussis, tetanus (DPT) vaccines, or other immunizations
- contagious
- child abuse
- the cause of every unexpected infant death

Any sudden, unexpected death threatens one's sense of safety and security. We are forced to confront our own mortality (Corr, 1991). This is particularly true in a sudden infant death. Quite simply, babies are not supposed to die. Because the death of an infant is a disruption of the natural order, it is traumatic for parents, family, and friends. The lack of a discernible cause, the suddenness of the tragedy, and the involvement of the legal system make a SIDS death especially difficult, leaving a great sense of loss and a need for understanding.

FOR ADDITIONAL INFORMATION ON SIDS, CONTACT:

American SIDS Institute, 2480 Windy Hill Road, Suite 380, Marietta, GA 30067, (770) 612-1030

Association of SIDS and Infant Mortality Programs (ASIP), c/o Minnesota Sudden Infant Death Center, Children's Hospitals and Clinics, Suite 605-C, 2525 Chicago Avenue South, Minneapolis, MN 55404, (612) 813-6285, (612) 813-7344 (fax), kathleen.fernback@childrenshc.org (e-mail), <http://www.asip1.org> (Web site)

National Sudden Infant Death Syndrome Resource Center (NSRC), 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182, (703) 821-8955, (703) 821-2098 (fax), <http://www.sidscenter.org> (Web site)

Southwest SIDS Research Institute, Inc., Brazosport Memorial Hospital, 100 Medical Drive, Lake Jackson, TX 77566, (409) 299-2814, (800) 245-7437, (409) 297-6905 (fax)

Sudden Infant Death Syndrome Alliance, 1314 Bedford Avenue, Suite 210, Baltimore, MD 21208, (800) 221-7437, (410) 653-8226, (410) 653-8709 (fax)

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