

# Patient education: Sudden infant death syndrome (SIDS) (Beyond the Basics)

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## SUDDEN INFANT DEATH SYNDROME OVERVIEW

Sudden infant death syndrome (SIDS), also called crib or cot death, is defined as the sudden death of an infant younger than one year of age that remains unexplained after a thorough investigation.

SIDS is the leading cause of death in infants between one month and one year of age in the United States, where approximately 2500 children per year die as a result of SIDS.

This topic review will discuss the possible causes of SIDS, ways to reduce the risk of SIDS, and what to expect if an infant dies unexpectedly. More detailed information about SIDS, written for healthcare providers, is available by subscription. (See 'Professional level information' below.)

# WHAT IS SIDS?

Sudden infant death syndrome (SIDS) is the term used to describe the sudden and unexplained death of an infant who is between one month and one year of age. Most infants

who die from SIDS are between two and four months of age, and 90 percent are less than six months old. Most such infants die during sleep, often between midnight and 6 AM, and have no signs that they suffered.

Other terms that overlap with SIDS are "sudden unexpected infant death" (SUID) and "sudden unexpected death in infancy" (SUDI). These can then be subdivided into the following categories:

- "Explained SUID/SUDI" "Explained" means that a clear cause of death was identified, such as injury, suffocation, or underlying medical problem.
- "Unexplained SUID/SUDI" This category generally includes those cases considered SIDS by the medical examiner, as well as some cases that are not considered SIDS but lack a clear explanation for cause of death. In general, the term unexplained SUID/SUDI has the same meaning as SIDS.

Before a child is determined to have died of SIDS, all other possible causes of death must be investigated. (See 'Determining the cause of death' below.)

# SIDS CAUSE

Because SIDS is defined as an "unexplained" death, the cause of SIDS is unknown. However, studies that examined the records of children who died of SIDS have provided a better understanding of how SIDS might occur.

The most likely theory is that infants who die of SIDS have an underlying vulnerability (such as a genetic pattern or a subtle brain abnormality) and are exposed to a trigger (eg, unsafe sleeping position or sleeping environment, maternal smoking, infection, or other stress) at an early stage in the development of the brain or immune system. However, it is not yet possible to know in advance if a child has one or more of these vulnerabilities.

Vaccines do not cause SIDS — There is **no** evidence that childhood vaccinations increase the risk of SIDS. Although there are anecdotal reports of infants dying a few days or weeks after vaccination, this is because most infants in the age range at risk for SIDS are receiving routine vaccines.

Studies of large numbers of children have shown no increased risk of dying as a result of

childhood vaccines. Furthermore, the number of cases of SIDS has fallen by more than 50 percent since the mid-1980s, whereas the number of vaccines administered since that time has continued to rise. (See "Patient education: Why does my child need vaccines? (Beyond the Basics)".)

### REDUCING THE RISK OF SIDS

No monitoring system, test, or combination of symptoms can accurately predict whether an infant might die from SIDS. However, there are several strategies that can effectively reduce the risk of SIDS.

During pregnancy — Pregnant people should receive regular prenatal care and should not smoke during pregnancy. Both of these factors reduce the risk of SIDS after the infant is born.

### After birth

Safe sleep practices — After the infant is born, the following practices help to reduce the risk of SIDS:

• Infants should sleep on their backs – All infants, including infants who were born prematurely, should be placed on their backs for every sleep ( figure 1). Even though children may be able to roll from the back to the stomach, infants should be placed on their backs to sleep. The American Academy of Pediatrics (AAP) began an advertising campaign in 1992 called "Back to Sleep," which informed parents of the importance of placing infants to sleep on their back. The rate of SIDS fell by over 50 percent following this campaign.

Side-sleeping is not recommended, and infant "sleep positioners" or pillows should not be used to prop the infant, because these devices can be dangerous. Prone positioning ("tummy time") is encouraged when the infant is awake and can be monitored by an adult. If the infant is swaddled for sleep (wrapped tightly to restrict movement), swaddling should be discontinued as soon as the infant is old enough to attempt to roll over. It is particularly important that a swaddled infant sleep only on his or her back.

• Infants should not share a bed with adults or other children during sleep – Infants sharing a bed with adults or other children during sleep have a higher risk of SIDS and

for accidental death from suffocation. For the first six months, the safest place for an infant to sleep is in a crib (cradle, bassinet) in the parents' room. Infants should **not** sleep (alone or with an adult) on an adult bed, sofa, recliner, armchair, or other type of cushioned chair.

For parents who want to sleep closely with their infant, a variety of cribs and bassinets are available. These provide a safe sleeping surface for the infant that is separate but near the parents' or caregiver's bed ( figure 2). "Co-sleeper" devices that are placed within an adult bed are not recommended.

- **Firm sleep surface** Infants should be placed to sleep on a firm and flat surface. Infants should never sleep on surfaces that are soft, such as sofas, polystyrene-filled cushions, waterbeds, and sheepskin bedding. Infants should also never sleep on air mattresses, even if they are fully inflated.
- Car seats should not be used for sleep Car seats, strollers, or swings should not be routinely used for sleep, because young infants do not breathe as well in the sitting position. Use of a car seat for car travel has safety benefits that clearly outweigh the small risk of SIDS associated with sleep in these devices. Therefore, we recommend against routine use of car seats for sleep outside of a car but strongly recommend their use for car travel.
- Avoid soft objects in bed Soft objects, accessories (eg, pillows, quilts, comforters, stuffed animals), and blankets should not be inside the infant's crib, bassinet, or cradle. Bumper pads should not be used [1]. The infant's head should remain uncovered during sleep. Infant sleep clothing ("sleeper" or "sleep sack") is a safe alternative to a blanket, provided that the sleep clothing is appropriately sized and selected to avoid overheating.
- **Do not smoke** The infant's caregivers and other household members should quit smoking. Parents who cannot quit are encouraged to cut down and to avoid smoking inside the child's home and in enclosed spaces such as a car.
- **Breastfeed** In addition to having other health benefits, breastfeeding helps to protect against SIDS. Protection against SIDS increases with more months of breastfeeding but does not require exclusive breastfeeding.

- **Other factors** Other factors that might help to protect against SIDS but are not as well proven include:
  - **Avoid overheating** Overheating should be avoided; the infant should be lightly clothed for sleep, and the bedroom temperature should be comfortable for a lightly clothed adult (approximately 65°F [18°C]). If the infant is dressed in a sleeper, no more than a thin blanket is necessary. Infants should not sleep next to a radiator or heater or in direct sunshine. A fan in the infant's room might reduce the chances of overheating and help to circulate the air.
  - **Pacifiers** The use of a pacifier ("dummy" or "soother") during sleep may reduce the risk of SIDS. However, the AAP suggests delaying the introduction of the pacifier in breastfed infants until breastfeeding is firmly established.

Home monitors do not prevent SIDS — Home monitors that measure heart rate and oxygen level (known as cardiorespiratory monitors or apnea monitors) are available. This includes medical devices that require a prescription and commercially available devices that are sold directly to consumers. Some of these devices have sensors built into infant clothing or socks that can send data to a smartphone. None of these devices have been shown to reduce the incidence of SIDS, so they are not recommended for this purpose.

In the past, home monitors were used in infants thought to be at increased risk for SIDS because experts believed that SIDS was related to episodes in which an infant stops breathing (apnea) and has a slowed heart rate (bradycardia). However, studies have failed to confirm a relationship between SIDS and apnea or bradycardia.

In addition to being unproven with regard to reducing SIDS risk, home monitors can give inaccurate results. So, instead of using these devices, parents should focus on practices that are proven to improve sleep safety, as discussed above.

Special considerations — Parents and health care providers often have special concerns and questions about SIDS risk for infants who are siblings of SIDS victims, or those who have experienced a brief episode that resolved itself:

Siblings of SIDS victims — Siblings of SIDS victims have a five- to sixfold increased risk of dying of SIDS. Twin siblings have a twofold increased risk of SIDS. However, the risk that a second child will die as a result of SIDS remains less than 1 percent for most families.

Parents who have lost a child to SIDS are usually counseled to use the measures discussed above (see 'After birth' above). Other measures, including home apnea monitors or more frequent health care provider visits, have not been proven to reduce the risk of SIDS.

Infants who have an acute event reported by their parent or caregiver — Some infants have a sudden unexpected change in breathing, appearance, or behavior that quickly resolves. After evaluation by a doctor or nurse, in most cases, this type of episode can be classified as a "brief resolved unexplained event," or "BRUE." BRUE is not a specific diagnosis but a description of a sudden, brief, and now resolved episode in an infant that includes one or more of the following features:

- Stop in breathing, or irregular breathing
- Cyanosis (blue-tinged lips or skin) or pallor (skin that looks paler than normal)
- Marked change in muscle tone (usually limpness or, rarely, rigidity)
- Altered level of responsiveness (being harder to wake up than usual)

Most but not all infants with BRUE are at low risk for recurrence or for having a serious underlying problem. BRUE replaces the term "apparent life-threatening event" (ALTE), which is no longer used because it was broad and included a wide range of events and prognoses.

In the past, children who experienced these events were believed to be at risk for SIDS. However, the vast majority of infants who die of SIDS do not experience such events prior to death. Studies over the past two decades have failed to find any evidence that children who experience these events are at increased risk of SIDS. Infants who have experienced these events are typically evaluated by a doctor after the event. Some of these infants are found to have an underlying medical problem.

# WHAT TO EXPECT IF AN INFANT DIES

Determining the cause of death — Following the unexpected and sudden death of an infant, it is important to try to determine the cause of death. This usually involves reviewing the infant's recent health, behavior, diet, sleeping habits, and general appearance. There will also be a review of the child's sleeping environment, including the type of bed or crib, the amount and position of clothing and bedding, the room temperature, and the type of ventilation and heating. Examining the scene can help to exclude accidental, environmental, and unnatural causes of death.

A postmortem examination (autopsy) of the infant is performed in most cases; autopsy is necessary to detect some congenital abnormalities (birth defects), injuries, infections, and some genetic diseases in which the body cannot properly turn food into energy (known as inborn errors of metabolism).

It is difficult for many parents to face this type of investigation while struggling to cope with an infant's death. However, these procedures will enable the parents and health care provider to understand why the infant died and how other children in the family, including subsequent children, might be affected. This type of examination may also advance our understanding of the cause of SIDS and help to prevent future deaths of infants in other families.

Remaining in contact with the child's health care provider can help parents to cope during this time; the health care provider can discuss the results of the investigation, answer any questions, and provide emotional support. Parents are also encouraged to seek support from their religious group, a SIDS support group, or a grief counseling center.

Coping with the death of an infant — The death of a child can be an overwhelming experience filled with anger, guilt, blame, fear, anxiety, sorrow, grief, and feelings of failure. Immediately following a child's death, parents often experience feelings of numbness, shock, and disbelief. Intense feelings of sadness, yearning for the child, anxiety about the future, disorganization, and emptiness commonly develop in the weeks after the death.

"Searching behaviors," including visual and auditory hallucinations of the child, are common and may lead the parent to fear that he or she is "going crazy." Despair and sadness are common as the parent comes to accept that the child will not return. Sleeplessness, changes in appetite, agitation, chest tightness, sighing, and exhaustion are common. Grief comes in waves that are often precipitated by reminders of the child; the parent may feel fine one moment and be overcome with sadness and grief the next moment.

Normally, feelings of grief gradually diminish in intensity over a period of months.

Anniversaries and important events often trigger waves of sadness, although the severity of the sadness usually diminishes over time. However, the grief may never go away entirely.

Grief versus depression — It is often difficult to differentiate grief from depression. Signs of depression include feelings of hopelessness, helplessness, worthlessness, and guilt. Parents whose grief is complicated by depression often benefit from an antidepressant medication in

addition to individual or group psychotherapy. In contrast, parents suffering with grief but not depression are more likely to benefit from counseling or psychotherapy rather than antidepressant medication.

Treatment of depression is discussed in a separate topic review. (See "Patient education: Depression treatment options for adults (Beyond the Basics)".)

Counseling or psychotherapy — Counseling or psychotherapy can be helpful in coping with the loss of a child. Several types of health care providers provide counseling, including social workers, psychologists, nurses, and psychiatrists. Some people prefer to meet one-on-one with a counselor, while others prefer to meet in a group setting with other people who have had similar experiences.

- One-on-one counseling usually includes a discussion of emotional responses to the loss, coping methods, and ways to maintain personal relationships.
- Group psychotherapy allows people to compare their experiences, overcome their tendency to withdraw or become isolated, and support one another's attempts at coping and recovering. SIDS support groups are available in the United States and elsewhere ( table 1).
- Relaxation techniques can help to relieve feelings of anxiety and may include meditation, progressive muscle relaxation, yoga, clinical hypnosis, or biofeedback.

# WHERE TO GET MORE INFORMATION

Your child's health care provider is the best source of information for questions and concerns related to your child's medical problem.

This article will be updated as needed on our website (www.uptodate.com/patients). Related topics for patients, as well as selected articles written for health care professionals, are also available. Some of the most relevant are listed below.

Patient level information — UpToDate offers two types of patient education materials.

The Basics — The Basics patient education pieces answer the four or five key questions a patient might have about a given condition. These articles are best for patients who want a general overview and who prefer short, easy-to-read materials.

Patient education: Sudden infant death syndrome (SIDS) (The Basics)

Patient education: Secondhand smoke and children (The Basics)

Patient education: Brief resolved unexplained event (BRUE) in babies (The Basics)

Beyond the Basics — Beyond the Basics patient education pieces are longer, more sophisticated, and more detailed. These articles are best for patients who want in-depth information and are comfortable with some medical jargon.

Patient education: Why does my child need vaccines? (Beyond the Basics)

Patient education: Depression treatment options for adults (Beyond the Basics)

Professional level information — Professional level articles are designed to keep doctors and other health professionals up-to-date on the latest medical findings. These articles are thorough, long, and complex, and they contain multiple references to the research on which they are based. Professional level articles are best for people who are comfortable with a lot of medical terminology and who want to read the same materials their doctors are reading.

Sudden infant death syndrome: Risk factors and risk reduction strategies
Sudden unexpected infant death including SIDS: Investigation and family care
Acute events in infancy including brief resolved unexplained event (BRUE)
Use of home cardiorespiratory monitors in infants

Other resources — The following organizations also provide reliable health information about SIDS:

- National Library of Medicine: Sudden Infant Death Syndrome (www.medlineplus.gov/suddeninfantdeathsyndrome.html)
- National Center for Education in Maternal and Child Health: SUID/SIDS Gateway (www.ncemch.org/suid-sids)
- American Academy of Pediatrics: Safe Sleep (www.aap.org/en/patient-care/safe-sleep)
- The Nemours Foundation: Sudden Infant Death Syndrome (SIDS)

(www.kidshealth.org/en/parents/sids.html)

• First Candle

(www.firstcandle.org)

• Lullaby Trust (United Kingdom)

(www.lullabytrust.org.uk)

• Red Nose (Australia)

(www.rednose.org.au/section/education)

[1-5]

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