

Information about Sudden Infant Death Syndrome (SIDS) (FAQ)

What is SIDS?

From a scientific perspective, the term Sudden Infant Death Syndrome refers to the sudden and unexpected death of an apparently healthy infant, one whose death remains unexplained even after a complete post mortem investigation that includes a full autopsy, an examination of the circumstances of the death, and a review of the case history.

In reality, SIDS is not a diagnosis. It simply refers to a group of infants who, although they looked healthy, died suddenly and for no apparent reason. In other words, the cause of death cannot be established.

What does the autopsy show in SIDS?

As mentioned, the autopsies of babies who die of SIDS show no cause of death. Even very experienced pathologists who perform autopsies on these babies can find no adequate explanation. Their respiratory tract may be mildly inflamed. A slight excess of fluid may appear in the air spaces of their lungs (although not enough to account for the death). It is also likely that pinpoint hemorrhages, called petechiae, will show up in the thymus gland and the membranes covering the lungs. But these did not cause the baby to die.

In perhaps 15% to 20% of all infants who have died suddenly, the cause of death may prove to be an unsuspected cardiac malformation or a severe, rapidly developing infection. A diagnosis of SIDS, however, is reserved for those deaths that cannot be explained.

An autopsy can answer the family's questions about whether a baby's death was due to a known cause. If the cause is known, the death, by definition, cannot be placed in the category known as Sudden Infant Death Syndrome.

What causes SIDS?

No one knows why a seemingly well baby dies so suddenly, so unexpectedly. Each year new theories arise as to what causes SIDS. But as yet, no single theory has yielded the answer that will enable us to prevent these tragic deaths. Ongoing research continues to shed new light on the processes involved. We need to remember, however, that all findings must be scrutinized to ensure that all factors have been taken into consideration. Many theories, highly plausible at first glance, have been rejected after more detailed studies.

What do we know about SIDS from research?

A pattern of recurring features has emerged from the results of many SIDS research studies underway around the world. We know that these sudden deaths are most likely to happen between the ages of 2 and 4 months, although both older and younger babies also die of SIDS. Usually the babies seem healthy or perhaps just recovering from a cold. Yet they are found dead unexpectedly. When we compare babies who died of SIDS with those who died suddenly of any other condition, or with healthy alive babies, two key factors emerge: babies who sleep on their stomach or their side and babies whose mothers smoked during pregnancy are both at greater risk for SIDS.

Studies from several countries worldwide have reported a dramatic lowering of SIDS rates for all infants when the "tummy down" sleeping position is avoided. These results of research led to the present recommendations:

- Place babies to sleep on their back on a firm, flat surface.
- Provide a smoke-free environment before and after birth.
- Keep a baby's crib free of such clutter as pillows, pillowlike items, comforters or duvets.
- Breastfeed, if possible.

How are SIDS deaths identified?

Detailed investigations have indicated several possible causes of death when a baby dies suddenly and unexpectedly. Sudden deaths in infants, therefore, are temporarily assigned to the broad category of Sudden Unexpected Death in Infancy (SUDI, or a similar term) until the results of the investigation are available. Often, parents receive a temporary diagnosis of SIDS and are referred to associations and support groups for help during the difficult months ahead.

Investigations into the cause of death take time, and all participants have an important role to play. Usually, the final autopsy report is the last piece of information to be obtained. The pathologist performing the autopsy carefully examines all organs and regions of the body, searching for abnormalities that can explain the tragedy of an infant's death. If after receiving the reports of all investigation parties the coroner or medical examiner still cannot determine the cause of death, a diagnosis of SIDS is likely to be retained. Although not a true diagnosis, SIDS in effect recognizes our ignorance as to the cause of the tragedy. Naturally, when a cause of death is identified during the investigation, the final diagnosis will pertain to that cause (for example, infection, heart malformation, and genetic disease).

Why are some babies who die suddenly, unexpectedly and with no identified cause of death not called SIDS victims?

For decades, SIDS was a total mystery. And in many cases, not much was done to try to solve that mystery. However, as more sophisticated investigations were gradually undertaken into the causes of those unexpected deaths, many diseases and conditions were identified as causes of sudden deaths in infants, even with no prior manifestation of illness. Unfortunately, some of those investigations are costly - the identification of genetic or metabolic diseases, for instance - and are still not done in all cases.

In the past, too, the risk factors that today are modifiable and well known were not always recognized. Now that so much has been learned about diseases and risk factors, scientists try to classify all sudden, unexpected deaths into categories according to the presence or absence of various disease manifestations and risk factors. At times, too, scientists separate the deaths occurring at the extremes of the age ranges typical for SIDS from the others. Yet while scientists may find this practice useful for their research, it has caused much confusion for the investigators of these deaths (coroners, medical examiners, pathologists) as well as for the parents.

Some investigators, despite a thorough investigation that reveals no cause of death, are reluctant to use the term SIDS when risk factors such as sleeping on the stomach or bedsharing with another person are present. Others eliminate the diagnosis of SIDS when elements of uncertain significance appear in either the history or circumstances of death; or when autopsy findings emerge that, while important, cannot explain the death. Still others do not use the term SIDS if certain specialized tests that might have identified rare genetic or metabolic diseases were not done. Today, investigators use the diagnosis of Sudden Unexplained Death (SUD) or a similar term for such cases; *in the past, however, those deaths were all called SIDS.*

Is the information about SIDS applicable to other unexplained deaths?

To date, very few scientific studies have explored the risk factors and characteristics of deaths not classified by investigators as SIDS. Nevertheless, the recommendations for avoiding SIDS risk factors constitute good general recommendations for childcare practices and are endorsed by health authorities around the world. They apply to the care of all babies.

In many ways, the stories of SUD and SIDS victims are identical. The pain of the parents is no less and the grieving process is similar. The Canadian Foundation for the Study of Infant Deaths recognizes that parents of babies dying suddenly and unexpectedly in infancy need help, whether in the form of specialized care for bereavement, support for families, or actual research. Similar organizations throughout the world have identified this need as well. As more research focuses on the diverse types of sudden unexpected deaths, we hope to learn more about the causes of this tragedy and, eventually, to prevent it.

Was the baby's death anyone's fault?

No one is at fault. When a baby dies as the result of a car accident or a known disease, we can understand what has happened. But in the case of SIDS, when even doctors cannot explain the cause, the death seems mysterious. Many parents blame themselves, or even each other at first; they feel they must have done, or failed to do, something. While it is understandable that parents feel this way, such guilt is inappropriate.

Families sometimes blame a caregiver or their doctor. Frequently the baby was examined shortly before death, and the doctor found no signs that would lead anyone to suspect that the baby might die. But SIDS cannot be predicted. Many doctors and nurses have lost their own babies to SIDS. It can happen to infants even in the hospital.

Even with accurate information about SIDS, some family members find it difficult to accept these facts. They may continue to search for answers or blame themselves or others.

Can anyone tell which infants are at risk of dying of SIDS?

While much has been learned about SIDS, we are still baffled as to its cause or causes and how to prevent it. Researchers are now able to identify certain common elements about the babies who die, about their parents, and even about the death itself. These are referred to as "risk factors." But this does not mean that the majority of SIDS cases have several or even one of these elements in common - only that they have been seen more frequently in infants dying due to Sudden Infant Death Syndrome than in other infants.

It is important to remember that associations and risk factors are not causes. Clearly, the vast majority of SIDS babies were well nourished, well cared for, and in apparent good health prior to death.

Many researchers think that what we now call SIDS will one day be found to be a number of disease processes that, on the surface, appear to be similar. Because we cannot pin down a cause of SIDS, no definitive tests are available that would enable doctors to identify a baby at special risk. Since we know of no particular condition that exists prior to death, parents as yet have no treatment, let alone a sure preventive measure.

Pregnant mothers, though, should be encouraged to decrease the risk of infant problems by taking good care of themselves and by following the latest prenatal health advice. Maternal smoking, as well as the inhalation of second-hand smoke, is discouraged. It is also recommended that babies sleep on their backs. Breastfeeding is recommended as well.

Did the baby suffer?

Most of the SIDS babies appear to die undisturbed in their sleep. Usually, at the time no one is even aware of the event. It is likely that such deaths are without pain or suffering; no outcry or struggle has been reported.

Did the baby choke on vomit?

Sometimes stomach contents or blood-tinged froth may be found around the infant's mouth and nose, or on the bedding. This does happen during a rapid death process, but it is not the cause of death. Rather it is the result of the act of dying. Note, too, that babies who sleep on their backs are not at greater risk of choking.

Would it have helped if the baby had been breast-fed?

Breast-feeding, although recommended for many reasons, provides no guarantee against SIDS. SIDS occurs in both breast-fed and bottle-fed infants. Indeed, unexpected sudden deaths have occurred since ancient times, when all babies were breast-fed.

Is SIDS infectious or contagious?

Other family members are not at risk. Whatever the cause of SIDS, it is not transmitted from the infant who died to other babies or children. Parents and caregivers do not need to take special precautions when caring for other children or adults in the family.

Is SIDS a rare occurrence?

SIDS is rare before one month of age, peaks at 2 to 4 months, and is also rare after one year of age. It takes the life of 1 of every 2,000 live-born babies in Canada. Babies of aboriginal background are at greater risk of SIDS.

Three babies die of SIDS every week in Canada. The rate varies from place to place and from year to year.

SIDS also occurs throughout the world.

Why do the coroner and police investigate?

These parties are obliged by law to investigate all unexpected deaths to ensure that they are due to natural causes. A thorough investigation that includes police involvement is therefore undertaken. Later on, parents are usually relieved that everything possible was done to discover the cause of death.

Would home monitors help?

Many people have heard about the home apnea monitors that can be attached to the baby or mattress to track heart rate and breathing. A monitor is not a treatment; it can only alert the caregiver to a potential problem. Although some parents may be reassured to know that their baby's breathing is being continuously assessed, some families find the full-time commitment to operating the device and the psychological stress that can result a heavy burden. These should be balanced against any possible benefits. Babies die even while on a monitor. Unfortunately, the research of the last 30 years provides no evidence that the incidence of SIDS decreases with the use of monitors.

What are the effects of SIDS on the family?

Whenever someone we love dies, we go through a period of grieving and mourning. It is a natural and necessary process. People grieve in many different ways. After the first shock and numbness have worn off, most parents feel depressed and have difficulty concentrating; they are excessively anxious about the safety of their other children or worry about caring for them. Sometimes parents feel they may be losing their minds.

Anger, while often denied, is another common grief reaction. It may be directed at the other parent, the doctor, the babysitter, the other children, even the SIDS baby or society in general. Anger may be expressed or suppressed; each individual copes with it in a personal way. Sometimes parents begin to argue as a result of the anger or to feel distant from each other.

These and other upsetting symptoms are normal reactions. With time, however, they become less intense and, eventually, they go away. It is good for parents to express their feelings, both to others and to each other. When they feel low and depressed, it often helps to talk to another parent who has had a baby die from SIDS. People who have had a similar experience can understand and reassure the grieving parents. They can explain that things do eventually improve. The SIDS Foundation is able to put bereaved parents in touch with each other.

Other people such as clergy, health professionals, and professional counselors may be able to help. Often, too, the parents' families and friends can be supportive; they can help by allowing the parents to talk about their baby, by listening without trying to "fix" the parents' pain. If the parents' grief seems excessive or prolonged, further professional help may be needed.

How should the baby's death be discussed with the other children?

Children are affected by a death in the family as well. But, because they don't always understand or talk about death in the same way as an adult, they may deny it or appear unconcerned. The youngest ones, who cannot tell of their fears or may not understand explanations, mostly need to be reassured of their parents' continuing love and affection and of their own safety. Older children should be told that the baby died of SIDS. They must be allowed to express their emotions and discuss their fears.

Just as parents feel the loss and have doubts, guilt, and sorrow, so do children. Children need an honest explanation; they need to know they were not responsible for the baby's death. They need reassurance that they will not die in the same way. Children may not show their grief in the

same way as adults. They may act out, have nightmares, revert to bedwetting, or become clingy. They may also have problems at school.

What if other people were caring for the baby?

Sometimes relatives, babysitters, or professional childcare providers were in charge of the baby when the death occurred. All caregivers should receive the same information about SIDS as do the parents. They should have an opportunity to express their feelings and speak to a counselor if they so wish. Parents may tend to blame the caregiver or themselves for having left the baby with someone else. And the caregivers may blame themselves.

Grandparents should be included in those who receive information about SIDS. They often have a special relationship with the baby as well as with the parents.

It is important that everyone understands the facts about the syndrome. No blame should be laid on anyone. Often, the distribution of accurate literature will help to explain the tragic situation.

Should the parents have another baby?

This decision is one that only the parents can make. It is wise for parents to take their physical health and emotional state into consideration. Some people decide to have another baby soon after the loss of their child; others may decide to wait. The decision should be made when both partners feel ready. It is important to remember that the next baby cannot replace the one who has died. The next baby is a new and unique person.

Can it happen again to the same family?

According to the best available information, SIDS is not hereditary. Moreover, it is very rare for it to occur more than once in a family. Many, many parents have brought up healthy children both before and after their baby has died of SIDS.

What about information from the media?

Many people are misinformed about SIDS. Well-meaning friends sometimes repeat misinformation to parents, causing them needless distress.

Articles and items about SIDS frequently appear in the news media. They often imply that "the cause" has been discovered, or a "breakthrough" has occurred. Television programs may sensationalize SIDS in presenting a story. If you read anything in the newspapers or hear anything on television or radio that is misleading, notify The Canadian Foundation for the Study of Infant Deaths. Its members will attempt to clarify the accuracy of the report.

What research is happening?

Medical researchers are working to discover the cause of SIDS so that it can be eliminated. They are also trying to identify which babies are at special risk, so that customized preventive approaches can be applied. Specific areas of study include the investigation of the many factors that control such basic functions as heart rate, breathing, temperature control, and other automatic functions. Other research examines how best to help grief-stricken families adjust to such a tragedy.

One key task of current research involves examining the normal development of healthy infants so that we can better understand how SIDS babies differ. Many SIDS investigators feel that these infants are born with some problem or defect that makes them more vulnerable to situations encountered in daily life. SIDS, however, probably has more than one overriding, single explanation.

Today, we hold many pieces of the puzzle. But we must piece together the total picture if we are to understand, and eventually prevent, Sudden Infant Death Syndrome.

Facts you should know about SIDS

SIDS cannot be predicted or prevented at this time.
SIDS is not caused by neglect or child abuse.

SIDS does not appear to cause a baby suffering.

SIDS is not contagious or infectious.

SIDS is not considered hereditary.

SIDS is not caused by vaccinations or by toxic gases.

SIDS is not a new medical problem.

SIDS occurs rapidly and silently, usually during periods of sleep.

SIDS probably has more than one cause, although the final death mechanisms appear to be similar.

SIDS is not anyone's fault.