

Information about Sudden Death Infant Syndrome (SIDS)



Office of the Chief Coroner
Nunavut

WHAT RESEARCH IS HAPPENING?

Medical research attempts to discover the cause of SIDS so that it may be eliminated, and to identify a baby who may be at special risk, so that some preventative approach may be applied to that particular baby. Specific areas of study may include investigation of possible risk factors or the many factors that control such basic functions as heart rate and breathing. An additional area of research is to determine how best to help a grief-stricken family adjust to such a tragedy.

One task of future research will be to examine the normal development of a healthy infant so that we can better understand how the SIDS baby differs. Many of those who study SIDS feel that these infants may be born with some problems or defect that make them more vulnerable to this syndrome. Probably SIDS will have more than one complete explanation.

We have many pieces of the puzzle. Now we must find their place in the total picture in order to understand and eventually prevent Sudden Infant Death Syndrome.

FACTS YOU SHOULD KNOW ABOUT SIDS

- SIDS is leading cause of infant deaths under the age of one year of age.
- SIDS can not be predicted nor prevented at this time.
- SIDS is not caused by neglect or child abuse.
- SIDS is not contagious or infectious.
- SIDS is not caused by a fault in the design of the baby's crib.
- 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.

It is possible for a baby to die even while on a monitor. There has been no evidence that the incidence of SIDS decreases with the use of a monitors. Scientists are still trying to develop research approaches which will determine the appropriate role of home apnea monitors.

SHOULD PARENTS HAVE ANOTHER BABY?

This decision is one which can only be made by the parents. It would seem wise for the parents to take into consideration their physical health and emotional state. It is recommended that the mother not become pregnant until she has had an opportunity to deal adequately with her grief from the loss of her previous child. Many parents feel that it is appropriate to consult with other health professionals as well as a doctor or physician. It is important to remember that the next baby cannot replace the one who had died. This 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 and any future babies born to that family may run a very slightly increased risk. 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 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 Baby's Breath Flower which will attempt to clarify whether or not the report is accurate.

WHAT IS SIDS?

Sudden Infant Death Syndrome (SIDS), often called "crib death", refers to the sudden and unexpected death of an apparently healthy infant, whose death remains unexplained even after a complete post mortem investigation which includes an autopsy, an examination of the circumstances of the death and a review of the case history.

WHAT DOES THE AUTOPSY SHOW AS THE CAUSE OF DEATH?

Even when very experienced pathologists perform autopsies on the children, they find no adequate explanation for the death. Pathologists may find the respiratory tract to be mildly inflamed or there may be a slight excess of fluid in the airspace of the lungs, not sufficient to account for the death. Pinpoint hemorrhages, called "petachiae", are probably found in the thymus gland and the membranes which cover the lungs, but these did not cause the baby to die.

In about 10-20% of cases of all infants who die suddenly, the cause of death may prove to be an unsuspected congenital malformation or a very rapid virulent infection. A specific diagnosis is made when there is recognized cause of death. SIDS is reserved only for those deaths which cannot be explained. An autopsy can answer the family's questions about whether a baby's death was due to SIDS or some known cause. If the cause is known, by definition it cannot be called Sudden Infant Death Syndrome.

WHAT CAUSES SIDS?

No one knows why a baby that seems well can die so suddenly and unexpectedly. Each years brings new theories about what causes SIDS but, as yet, no single theory has yielded the answer that will enable us to prevent this tragic death. Ongoing research will continue to shed new light on the processes involved, but it necessary to bear in mind that all findings must be assessed with critical eye to be sure that all factors have been taken into consideration. Many theories which seemed highly plausible when originally suggested have been rejected after more detailed study.

WHAT DO WE KNOW ABOUT SIDS FROM RESEARCH?

There do seem to be some recurring features which have emerged from the results of many research studies around the world. The death is most likely to happen between the ages of 2 and 4 months, often close to 12 weeks, although both older and younger babies also die of SIDS. The majority of SIDS deaths occur during the winter months. The baby usually appears healthy or may be just recovering from a cold. The baby is unexpectedly found dead, usually in bed.

The risk of SIDS is higher in low birth weight babies, in multiple births and in boys slightly more than girls. Fewer than 5% of the babies who died were observed to have had the temporary stoppages in breathing known as apnea. The older the mother, the lower the risk, with infants of teenage mothers being at the greatest risk. There is a higher rate of SIDS among infants whose mothers did not receive prenatal care and who smoked or abused drugs during pregnancy.

Of special interest is the discovery that some babies who have died of SIDS may have had less oxygen delivered to their bodies tissues, brain or lungs, for a relatively long period of time before death, probably even before birth. Why this happens is poorly understood.

Recent research suggests an association between the prone (stomach) sleeping position and SIDS. Studies report a lowering of SIDS rate by avoiding the prone sleeping position, avoid overheating the baby and encourage a smoke free environment.

WAS THE BABY'S DEATH ANYONE'S FAULT?

No one is at fault. If a baby dies as the result of a car accident or a known disease, we can understand it. But when even doctors cannot explain the cause of SIDS, the death seems very mysterious. Many parents blame themselves, or even each other at first, feeling that the cause was something they did, or failed to do. It is understandable that parents feel this way, but there is no reason for this guilty feelings.

In the same way that parents feel the loss and have doubts, guilt and sorrow, so do children. They need an honest explanation that they were not responsible for the baby's death and be reassured that they will not die in the same way. Children may not show their grief in the same way as an adult. They may act out by being naughty, having nightmares, reverting to bedwetting or having problems at school and at home.

WHAT IF OTHERS WERE CARING FOR THE BABY?

Sometimes relatives, babysitters, or professional child care providers were in charge of the baby when the death occurred. All caregivers should have the opportunity to express their feelings, and to speak to a counsellor if they wish. Parents may tend to blame themselves for having left the baby with someone else. Caregivers may blame themselves.

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

It is important that everyone understand the facts about the syndrome and that no blame is laid on anyone. Often, the distribution of accurate literature helps to explain.

WOULD HOME MONITORS HELP?

Many people have heard about home apnea monitors which can be attached to a baby to track heart rate and breathing. However, a monitor is not a treatment, it can only alert the caregivers to a potential problem. Monitors can be useful for small, select group of infants who have exhibited breathing problems. Although the knowledge that their baby's breathing is continuously assessed may be reassuring to some parents, the full-time commitment to operating the device and the psychological stress which could result to the family may have serious consequences. These should be balanced against any possible benefits.

These and other oppressive symptoms are normal reactions and, with time, they become less intense and eventually go away. Mothers may be able to talk about their grief easily than fathers, but it is good for both parents to express their feelings. Time heals. Life returns to normal, leaving a sad memory of the event but with a healthy personal adjustment to it.

When parents feel low and depressed, it often helps to talk to another parent who has had a baby die from SIDS. Someone who has had a similar experience can understand and reassure the grieving parents, explaining that things do eventually improve.

The Baby's Breath Flower (formerly the Canadian Foundation for the Study of Infant Death) is able to put bereaved parents in touch with each other. Other people who may be able to help are clergy, health professionals and other counsellors. Often the parents' families and friends can be supportive.

If grief reaction seems excessive or prolonged, professional help may be needed.

HOW SHOULD THE BABY'S DEATH BE DISCUSSED WITH THE OTHER CHILDREN?

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

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

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

CAN ANYONE TELL WHICH INFANTS ARE AT RISK OF DYING OF SIDS?

While much has been learned about SIDS, final knowledge as to its cause or causes and a means of prevention still baffles us. Research has been able to identify certain common elements about the babies who die, their parents and the death itself. These are often referred to as "risk factors", but this does not mean that the majority of SIDS cases had several or even one of these common, only that they were seen more frequently in infants dying due to Sudden Infant Death Syndrome than in other infants.

Even Though we have a profile of the typical SIDS infant, this only gives us a clue as to which babies might be at special risk, but as yet we are unable to identify which specific child might die of SIDS.

It is important to remember that associations and risk factors are not causes. 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 call SIDS will one day be found to be a number of disease processes which lead to deaths which appear, on the surface, to be similar. Because we are unable to pin down a cause of SIDS, there are as yet no definitive tests that doctors can give to identify if a baby is at special risk. Since we do not know of any particular conditions that exist prior to death, there is as yet no treatment or sure preventative measures which parents can take.

Pregnant mother should be encouraged to take good care of themselves and to follow the latest prenatal health advice in order to decrease their risk for any infant problems. Maternal smoking, is discouraged. It is advisable to use a flat, firm mattress, not soft sleeping materials and to avoid the prone position for the baby. Breastfeeding is highly recommended.

DID THE BABY SUFFER?

Most of these babies appear to die undisturbed in their sleep. Usually, no one is aware of the event at the time. Observers of SIDS deaths have reported that there was no outcry or struggle, so it is most likely that such a death is without pain or suffering.

DID THE BABY SUFFOCATE OR SMOTHER?

If the baby was found face down or covered over with blankets, it is natural to worry that the baby may have been unable to breathe. However, many babies often sleep in the ways with no harmful effects. Many SIDS cases occur where the face is clear.

DID THE BABY CHOKE ON VOMIT?

Sometimes stomach contents or blood tinged froth may be found around the mouth and nose or on the bedding. This happens during a rapid death process, and is not the cause of death, but the result of the act of dying.

WOULD IT HAVE HELPED IF THE BABY HAD BEEN BREAST-FED?

Breast-feeding is recommended for many reasons, but cannot provide a guarantee against SIDS. SIDS occurs in both breast-fed and bottle-fed infants. Unexpected sudden infant 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 baby who died to other babies or children. Parents and caregivers do not need to take special precautions in caring for other children or adults in the family.

IS SIDS A RARE OCCURRENCE?

SIDS is the single leading cause of death of babies in developed countries from the age of about one week to one year. It takes the life of approximately one out of every 1000 live born babies in Canada. The rate varies from place to place and from year to year. SIDS is not likely to occur after one year of age, but is not unknown then. It occurs in all parts of the world.

WHY DO THE CORONER AND POLICE INVESTIGATE?

They are obligated by law to investigate all unexpected deaths to make sure that they are due to natural causes. Later, parents will find it a relief that their baby's death had been investigated.

WHAT ARE THE EFFECTS OF SIDS ON THE FAMILY?

Whenever someone we love dies, we go through a period of grieving and mourning, which 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, have difficulty concentrating, are excessively anxious about the safety of their children or are fearful about caring for them. Sometimes parents feel that they may be losing their minds.

Anger is a common grief reaction, and is often denied. 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 as each individual copes with it in a personal way.