

Facts and Feelings









CALIFORNIA

SIDS
PROGRAM
SUDDEN INFANT
DEATH SYNDROME

Sudden Infant Death Syndrome

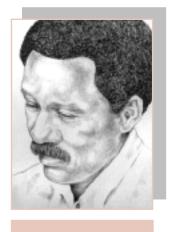
What is Sudden Infant Death Syndrome (SIDS)?

SIDS is the sudden and unexpected death of a baby who seems perfectly healthy. Even after an autopsy, the reason for the baby's death is unexplained.

SIDS happens quickly and quietly. The baby is put to bed for a nap or for the night. When the baby is checked some time later, it is discovered that the baby has died while sleeping.

Most babies have no sign of serious illness before the SIDS death. Some babies may have a slight cold or other mild illness. The autopsy may find little breaks in blood vessels of the lungs or some swelling of the airway. None of these things would account for the death.

SIDS is the number one cause of death among babies between the ages of one month and one year. Most babies who die of SIDS are between 2 and 4 months of age. A few thousand babies die of SIDS every year in the United States alone. SIDS happens in families of all social, economic, and ethnic groups. SIDS happens everywhere in the world.



What causes SIDS?

No one really knows what causes SIDS. A great deal of research is going on. Scientists are studying babies and how their brains, hearts, and lungs work. They are learning about breathing and sleeping pat-

terns. They are also looking into autopsy findings, among many other things.

SIDS is a natural cause of death.

- SIDS is not due to infections.
- It is not caused by immunizations.
- SIDS is not contagious.
- It is not hereditary.

Researchers are beginning to believe that SIDS may have something to do with how all babies normally breathe while asleep. However, the reason or the way babies die of SIDS is not yet understood. At this time, there is no way to predict or prevent SIDS.

I feel so guilty and angry at the same time. Was anyone at fault?

No one is to blame for SIDS. Almost all parents or caregivers feel in some way to blame for the baby's death until they begin to understand the facts about SIDS. Sometimes parents blame each other. Sometimes families blame the caregiver, or the doctor who said the baby was healthy.

It is important to know that:

- No one can tell ahead of time whether a baby will die of SIDS.
- No one can stop SIDS from happening.

Nothing you did caused the baby's death. Nothing you could have done would have prevented it.



Did our baby suffer?

SIDS happens very suddenly and all at once. The baby may move a little in the last few seconds. This would account for the crumpled covers or unusual positions in which babies are sometimes found.

Babies do not cry out and show no sign of having been disturbed in their sleep. They simply stop breathing and die very peacefully.

Could the baby have vomited and choked?

SIDS is not caused by vomiting or choking. Sometimes milk or a blood-tinged froth is found around the baby's mouth, nose, or on the bedding. This happened after the baby died. The autopsy shows that the airway was not blocked by this fluid.

I have heard that the *Back to Sleep* recommendations could have prevented my baby from dying of SIDS. Is this true?

There is no way to prevent a SIDS death. Researchers have learned that parents can reduce the risk of SIDS by placing babies to sleep on their back, avoiding cigarette smoke, breastfeeding, not letting their babies get too hot, keeping soft blankets and pillows out of the crib, and not sleeping in the same bed with their baby.

Sleeping on the stomach, exposure to cigarette smoke, over bundling, etc. are risk factors for SIDS, but they do not cause SIDS. By avoiding these risk factors, parents have greatly decreased the overall number of babies dying from SIDS. However, there are still babies that die from SIDS, even those who have avoided the risk factors. We do not know why.

Current research is looking at why these risk factors increase the risk of SIDS; hopefully this will lead to finding the cause(s). For now, there is nothing a parent could have done to prevent their baby from dying of SIDS. Parents can only reduce the risk.



Our baby had just gotten her DTP shot. Is SIDS caused by DTP?

SIDS is not caused by the DTP shot or any other immunization. This has been shown by several studies. SIDS happens in babies

who have never had shots of any kind. SIDS happens at the same rate in countries where DTP is given at a later age or not at all.

Is SIDS contagious? Could our older children get it?

SIDS is not contagious. It cannot be spread from person to person. There is no need to be afraid of touching the clothing, bedding, or furniture of the baby who died of SIDS. SIDS only happens to babies. Older children do not die of SIDS.

My baby seemed so bruised. Could SIDS have been caused by child abuse?

SIDS is not caused by child abuse or neglect. Sometimes a SIDS death may not be discovered for a few hours. The changes that happen in the baby's body after the death may make it look like the baby was injured. But everyone, the police, paramedics, parents and caregivers should realize that these changes after death are normal.

Would it have helped if our baby had been breastfed?

Breastfeeding does not prevent SIDS. SIDS has happened all through recorded time even when nearly all babies were breastfed. SIDS happens to both breastfed and bottle-fed babies.

What about babies we might have in the future?

SIDS is not hereditary. Most future babies (over 999 out of 1000) will not die of SIDS. You can learn more about it by talking to your doctor or by calling the California SIDS Program.



Grieving people go through many difficult feelings.

After the shock and numbness of the first few days begin to wear off, you may be left with depression. This can be brought on by thoughtless or innocent remarks

from people who do not understand SIDS. You may go through these low points when it is the day of the week or the date your baby died. At times like these, it may help to talk to another SIDS parent or a public health nurse who understands SIDS.

You may find it hard to concentrate. It may be hard for you to read or write or make decisions. You may feel dizzy or have headaches. You may worry that you are losing your mind. These feelings are all normal for people in grief.

You may not be able to sleep. Bad dreams may replay over and over in your mind. You may become overtired. Even with sleep, you may always feel exhausted. You may have muscular problems or other physical symptoms, especially around your heart or stomach. You may have no appetite. You may feel "tied in knots" inside. Your arms may ache to hold your baby.

You may feel like just running away. You may be afraid of being alone. You may worry that you or those you love are in danger. If you have other children, you may feel overwhelmed with fear for their safety. At the same time, you may not want the responsibility of caring for them. You may be irritated or impatient with the children's behavior.

You may lean on your family and friends for help. But at the same time, you may resent that help or feel guilty. If your friends and neighbors don't know about SIDS, they may end up saying the wrong thing. You just may not feel comfortable around these other people.

At times your grief may seem unbearable. You may feel that you can't go on. Call your local SIDS group or your public health nurse for support.



Brothers and sisters will also be affected deeply by the death of the baby.

Smaller children need love and affection. They may have some very frightening thoughts that they cannot express: Did I cause the

baby to die? Will I die, too? Will Mommy and Daddy die? Who will take care of me now? They may cling to their parents and do other things to get attention. It is very important for them to know that they are loved and secure.

Older brothers and sisters will go through their grief in different ways depending on their ages and past experiences. Sometimes they feel guilty because they think they may have caused the baby's death. They may be very sad or may not show their feelings at all.

Children should be told as much about the death as they are able to understand. It's a good idea to be open in talking about thoughts and feelings.

As adults talk freely, children will better be able to talk about how they feel. They will feel free to ask questions about the death. It is best to be clear about the baby's death, as children can worry and be confused about statements like: "The baby went away" or "The baby is sleeping in peace." It is important to explain that SIDS happens only to babies and not to older children or adults.

Many children have been sources of strength for their families. They have written poetry and often show an amazing faith and understanding of the pattern of life and death. They may also show their sorrow in other ways. They may have nightmares, wet the bed, or have a hard time in school. A doctor or counselor may have good ideas for helping children through this difficult time.

Even years after the baby's death, children will need to talk about what happened. As they grow up and have new questions, they will need more information.

Sometimes the baby is with another caregiver when SIDS happens.

It is important for that person to get help and support, too. SIDS groups have volunteers who can give that kind of help. Literature and counseling can be very reassuring for anyone going through this.

Everyone goes through their grief in different ways.

Some people may need to "talk out" their grief. Others may keep their feelings to themselves. Some parents may even take on extra work to keep from thinking about the loss all the time. Some parents find it hard to ask for help and support from others.

Often the loss of the baby is the first loss either parent has gone through. Grief is very intense and each person's experience is different. This may cause tension and a feeling of being all alone. It may be a struggle to find ways to understand and support each other. It helps to be able to talk about feelings openly, even though that can be difficult.

Where can I call for the help and information I need?

The California SIDS Program can help:

- Connect you with your local SIDS support group or your local public health nurse.
- Answer questions you may have.
- Assist you with helpful booklets and pamphlets.

If you live in California call the: **CALIFORNIA SIDS PROGRAM 800-369-SIDS (7437)**

Throughout the United States you can call the: First Candle/SIDS Alliance 800-221-SIDS (7437) "Facts and Feelings, Sudden Infant Death Syndrome" is designed especially for families and caregivers experiencing a SIDS loss. It is based on information published by the U.S. Department of Health, Education and Welfare in a booklet entitled "Facts About SIDS".

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