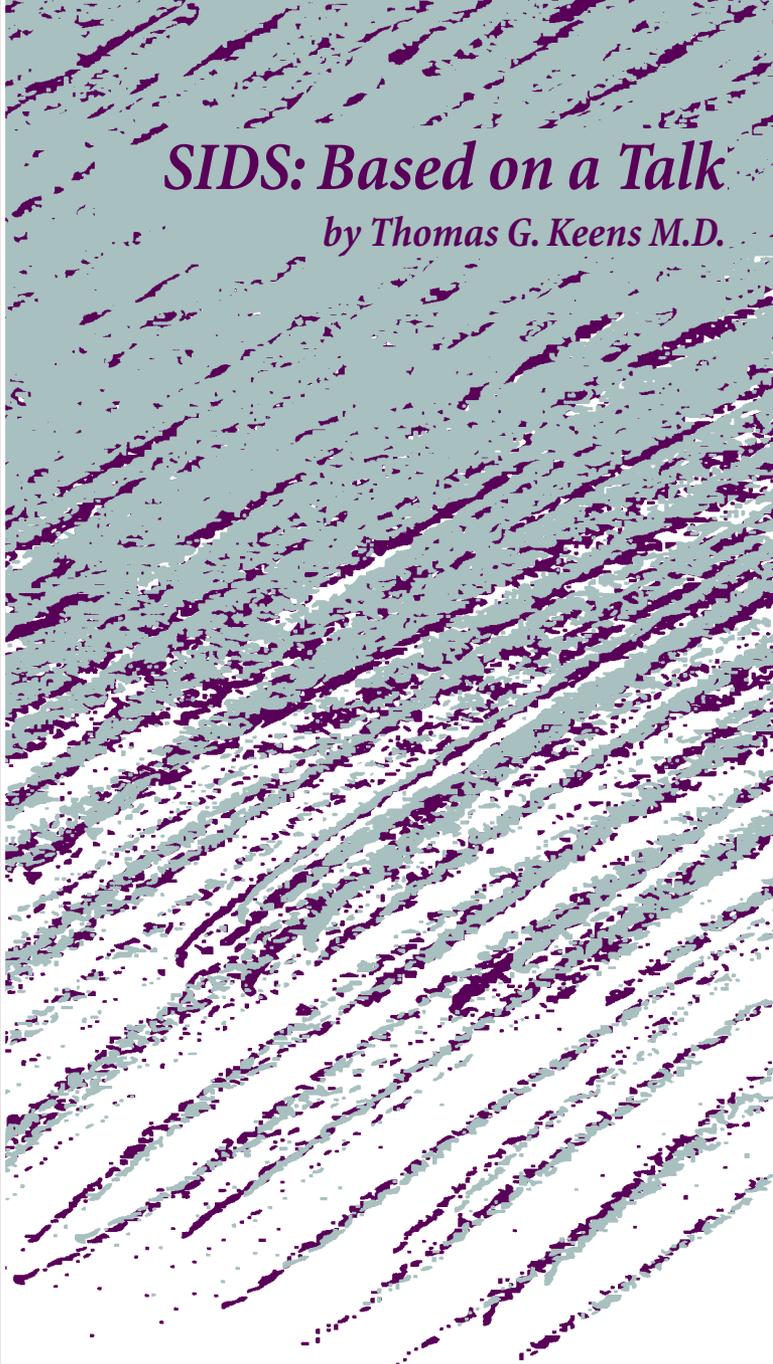




SIDS: Based on a Talk

by Thomas G. Keens M.D.



CALIFORNIA
SIDS
PROGRAM
SUDDEN INFANT
DEATH SYNDROME

CALIFORNIA DEPARTMENT
OF HEALTH SERVICES MCH

Sudden Infant
Death Syndrome



BASED ON A TALK



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Thomas G. Keens, M.D. Professor of Pediatrics, Physiology and Biophysics, Division of Pediatric Pulmonology, Childrens Hospital Los Angeles, has been involved in the SUDDEN INFANT DEATH SYNDROME (SIDS) community for over 20 years. He is a member of the California SIDS Advisory Council, serving as the American Academy of Pediatrics liaison. Dr. Keens served for many years as President of the Southern California Regional SIDS Council and remains an active member. He was the Co-Principal Investigator of the Collaborative Home Intervention Monitoring Evaluation (C.H.I.M.E.) Study and is internationally recognized for his SIDS research. He has authored numerous articles and continually serves as a guest lecturer in California, throughout the United States as well as internationally. His most notable accomplishment however is being named as a recipient of the Senator Daniel E. Boatwright Award for extraordinary public service on behalf of Californians touched by SUDDEN INFANT DEATH SYNDROME.

Many families and caregivers of babies who have died from SIDS want to hear as much as possible about it. This publication is based on a talk by Thomas G. Keens, M.D. We hope this gives you more of the information you seek.



What is Sudden Infant Death Syndrome (SIDS)?

SIDS is the sudden death of an infant under one year of age, which remains unexplained after performance of a complete postmortem investigation, including an autopsy, investigation of the death scene, and review of the case history.

This means that SIDS is the sudden and unexpected death of an infant who appears perfectly healthy. SIDS almost always happens when the baby is asleep. Even when the baby's death is completely analyzed, there is no known cause of death which can be found. However, from what we know, SIDS is a natural cause of death.

SIDS is the most common cause of death for babies between the ages of one month and one year. It happens to one baby out of every 2,000 births. About 3,000 babies die from SIDS every year in the U.S. There is one SIDS death in the U.S. every three hours.

Most SIDS deaths occur between two and four months of age. Nearly all SIDS deaths occur before six months of age, but about five percent can occur between six and 12 months of age.



We have never really heard of SIDS before our baby died. Is this something new?

SIDS is not a new disorder. A probable SIDS death is described in the Old Testament of the *Bible* (1 Kings 3:19). Historical records suggest that SIDS has been around for at least 3,000 years. However, it used to be thought that babies died from suffocation by tangling in their bedclothes or having someone roll over on them. Now we do not believe that these are common or important causes for SIDS. Because SIDS was not an official diagnosis which was used to describe a cause of death until 1974, many babies may have died from SIDS before that, but the official cause of death may have been listed as something else. Even though SIDS is an old disorder, no one knows what causes SIDS even to this day.

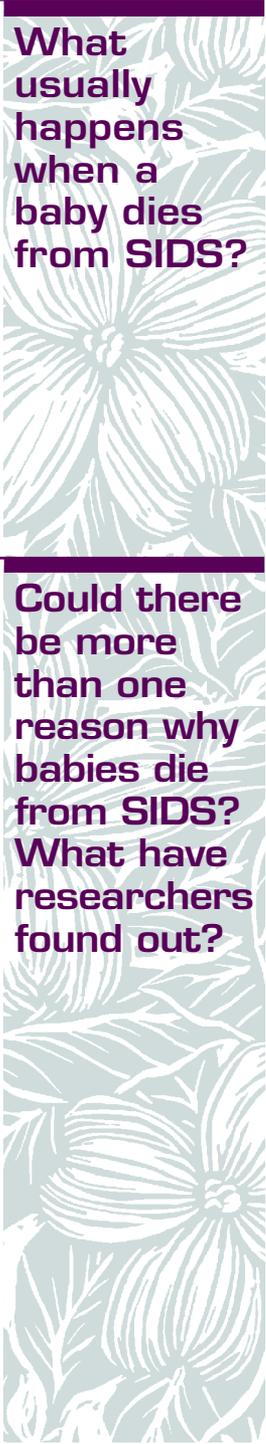
The parents or caregivers put a baby down to sleep at night or for a daytime nap. When they come back, sometimes as little as 20 minutes later, they find that the baby has suddenly died while sleeping. SIDS has also happened when a baby has been sleeping in a car seat, or even in the mother's arms. There is no warning. The baby makes no sound. SIDS happens quickly and quietly. We do not believe that babies who died from SIDS suffered or felt any pain.

Most of the time, SIDS babies seemed completely healthy prior to death. Some might have had a mild cold, but the cold was not the cause of SIDS. Other babies have had some other minor illness. However, these were not severe enough to make anyone think that the baby would die.

All babies who die suddenly and unexpectedly are examined by a Coroner to find the cause of death. For 15 percent to 20 percent of these babies, a reason for the death can be found. These are not SIDS deaths. But for 80 percent to 85 percent of babies who die suddenly and unexpectedly, no explanation for the death is found. These babies are said to have died from SIDS.

Since no one knows why babies die from SIDS, no one knows for sure whether or not all SIDS babies die the same way. There could be more than one reason for the deaths of these babies. As we begin to understand more and more, we may find other explanations for some deaths we now call SIDS. However, most SIDS babies do have some important things in common. This leads many researchers to conclude that there is probably one reason for most SIDS deaths. These are some of the things that make SIDS deaths different than other causes of infant death:

- Most babies die from SIDS between two to four months of age. SIDS is less common in the first one to two months of life, but it can occur. Other natural causes of infant death are most common near birth and fall off after that. The unique age distribution of SIDS suggests that most babies are dying from the same thing, which is different than other infant diseases.



What usually happens when a baby dies from SIDS?

Could there be more than one reason why babies die from SIDS? What have researchers found out?

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- Most babies die from SIDS in winter months. Other causes of infant death do not necessarily increase in any given season.
 - Most babies who die from SIDS are healthy. They are well nourished, well cared for, and have grown normally. They do not generally have serious illnesses.
 - Most babies who die from SIDS have similar autopsy findings. These include small breaks in the blood vessels around the heart and lungs, lung congestion, and swelling in the airway; though these are not severe enough to have caused the baby's death.

These suggest that there is a similar cause of death in nearly all SIDS deaths. Many researchers believe that at least 80 percent to 85 percent of SIDS deaths happen in the same way.

I've heard that some babies may be at higher risk for SIDS than others. Is this true?

Many researchers have tried to identify which babies might be at higher risk of SIDS. Some studies show that there may be a higher chance of SIDS in some babies. These include infants who were born prematurely, had low birthweight, and were born in poverty. However, these factors should not be thought of as *causes* for SIDS, but rather, they are *clues* which may help researchers to eventually find the cause of SIDS. Most babies who die from SIDS do not have any of these risk factors. And most babies who have many or even all of these risk factors do not die from SIDS. Even if all of these factors are added together, they cannot be used to predict which babies will die from SIDS.

Is SIDS a disease?

Researchers believe that SIDS is a natural process. It was not caused by something parents did or did not do. For many years, researchers have been searching for something that was wrong with the babies who died from SIDS, something which might explain why they died. We have not been able to find any such marker or cause. We cannot do any tests on babies which will predict if they will

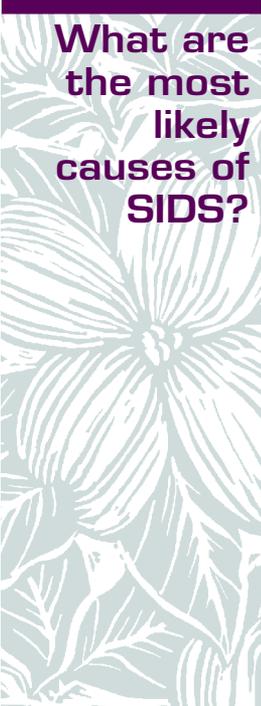
die from SIDS. This has led many researchers to believe that although SIDS is a natural process, it may not be a disease as we usually understand it.

Often, when researchers try to find the cause of something, they look for something which might be wrong. For example, imagine a car driving up a steep mountain road. All of a sudden, the car stops. Why did the car stop? You examine the car and find that all four tires are flat. You can fix the tires, and the car can continue up the mountain road. In this example, there was a cause for the problem, and by identifying the cause, this problem could be fixed. Researchers have looked for such a cause for SIDS for at least 20 years, but have not been able to find one. Therefore, SIDS may not be as simple as one cause.

Now imagine the same car which is not able to drive up the steep mountain road. However, the tires are not flat and the engine works. Maybe the car does not go up the mountain because there are too many people in the car, the road is too steep, the road is too rocky, or the engine is not powerful enough. There is really nothing wrong with the car. However, in the given situation or environment, it is not able to function. Many SIDS researchers are beginning to believe that SIDS is similar to this story. That is, SIDS results from an interaction of many things, including the maturity of the baby; the ability of the baby's heart, lungs, and brain to respond to changes in the environment; and some external factors, such as might be found in the environment.

Although SIDS researchers have these new thoughts about SIDS, we are still a long way from knowing the cause of SIDS. However, researchers are working hard to try to find the cause of SIDS.





What are the most likely causes of SIDS?

Most researchers think that SIDS relates to immaturity or the inability of the brainstem to respond to changes in the environment. The brainstem is the part of the brain which tells you how often and deep to breathe, how fast your heart should beat, whether you are awake or asleep, etc. When babies sleep, breathing is not regular. Babies have pauses in their breathing, and oxygen levels in the baby rise and fall. SIDS might be related to this irregular breathing. If you are asleep, and something dangerous happens to you (like stopping breathing), you often wake up to protect yourself. Many babies do not wake up from sleep to protect themselves from things like low oxygen, which might occur if a baby stops breathing. This inability to rescue yourself from a breathing pause may also be related to SIDS. However, we do not know for certain that these may be related to the cause of SIDS. Researchers are working hard to try to find the cause of SIDS.



Did I do anything to cause my baby to die from SIDS?

Based on our current understanding, there is nothing SIDS parents did to cause their baby's death, and there is nothing they could have done to prevent it. Because we cannot tell you why your baby died, it is natural to assume that it was due to something you did or did not do. However, this is not the case. SIDS is not due to anything you did, and there was nothing you could have done to prevent it.

Recently, you may have heard about a number of things parents can do which might reduce the risk of their baby dying from SIDS. These may reduce the risk of SIDS, but they have not completely prevented SIDS. These include the following:

- Place your baby to sleep on the back, **not** the side or stomach.
- Do not smoke cigarettes around any baby. Do not smoke cigarettes during pregnancy.
- Do not let your baby get too hot. Do not overdress your baby.
- Breastfeed your baby.

- Use a firm mattress for the baby in the crib. Do not put stuffed animals, bumper pads, sheepskins, or thick blankets in the crib with the baby. Do not place your baby to sleep on a bean bag, waterbed or couch.

While we recommend these for babies, even if all of these things are done, this will not prevent all SIDS deaths from occurring. Many babies who die from SIDS have not had any of the risk factors described. Most babies who have had some or all of these risk factors will not die. Therefore, these are not causes of SIDS. Even if you did one or more of these, that did not cause your baby to die. Again, SIDS is not due to anything you did, and there was nothing you could have done to prevent it.

We do not think that SIDS is hereditary. Most researchers believe that a future brother or sister of a baby who died from SIDS does not have an increased risk for SIDS. The chance of dying is the same as infants in the general population, which is less than one-in-one-thousand. There are no medical tests or sleep studies which will predict whether a baby is likely to die from SIDS or not.

There are some groups of babies who might benefit from special attention and evaluation. It would be important to get special medical help for a surviving twin if the other twin dies from SIDS, for a baby who stopped breathing and was found blue and limp, but who was able to be revived; or for a baby born into the rare family where there has been two or more SIDS deaths.

We believe that the average, otherwise healthy, sibling of one previous SIDS victim does not need any special study or treatment. But, it is normal to worry about the new baby. Home monitoring may help some parents feel more secure about their new baby's health. However, there are not scientific studies which show that a home monitor really protects babies from SIDS. Parents who may be interested in using a home monitor should discuss this with their baby's pediatrician.



**Will our
next baby
be in
danger of
SIDS?**

The grief over losing our baby overwhelms me. How can I get through it?

The parents, families, and caregivers of babies who die of SIDS are devastated by this tragedy. SIDS deaths are so unexpected. Parents don't have the chance to plan for the death or say "good-bye" to their baby. The baby they love so much is suddenly gone.

What makes it even worse is that the death cannot be explained. Doctors cannot tell parents exactly why their baby died. So, parents think about every little thing they did or did not do that could have caused the death. They feel terribly guilty.

For most people, the best and most important resource is a SIDS parent support group. This group has SIDS parents who are available to speak with other SIDS parents and caregivers. The chance to talk to someone who has been through it, who understands it, and who has survived it, is very reassuring.

How can I find the help I need?

If you live in California and you need the telephone number of your local SIDS parent support group and/or public health nurse, contact:

California SIDS Program
800-369-SIDS (7437)

Throughout the United States, you can call the national SIDS organization:

First Candle/SIDS Alliance
800-221-SIDS (7437)



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