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# Frequently Asked Questions about SIDS: A Doctor's Response

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*The following information was excerpted from a speech entitled, "Using Accurate Information," presented on January 29, 1983 at a workshop for parent contacts, "Healing Grief: Helping the Survivors of Sudden Infant Death." The information was updated by Dr. Beckwith in January 1997.. Beckwith is a pediatric pathologist and was a principal member of the SIDS Research Team at Children's Hospital and the University of Washington, Seattle, from 1964 to 1984. He has authored or co-authored numerous research publications on SIDS. He is currently Head of the Division of Pediatric Pathology at Loma Linda University, Loma Linda, CA*

## I. WHAT IS THE CAUSE OF SIDS?

It is common for the daily media to gleefully report that "the cause" for SIDS has been discovered. Over the years I have worked with SIDS, literally hundreds of such reports have appeared, and to date not one of them has passed the test of time. One of the most common causes for misunderstanding is the failure to distinguish *risk factors* from *causes*. For example, maternal smoking, viral infections, tummy sleeping, or prematurity have all been touted as "causes" for SIDS. Yet, most infants exposed to these risk factors will live, and many SIDS victims will have none of these risk factors.

I think of SIDS, not as a disease, but as a manner of dying. It is the result of an episode that likely occurs very rapidly, perhaps over just seconds or minutes, that results in death of the infant. This episode seems to be something to which the developing human is at risk over a relatively short period of time, perhaps related to critical maturational stages that the infant passes through after the neonatal period, but during the early months of postnatal life.

I have long believed that the answer to SIDS will come, not by looking at predisposing factors, but by working backwards from the moment of death. What exactly is the *mechanism* of death? Is it due to airway obstruction, cessation of the drive to breathe, stoppage of the heart, or some catastrophic event in the developing brain? By answering the question about exact mechanism of death, we can work backwards more efficiently to causes for that type of event, and from those to predisposing factors.

I spent many years presenting evidence that suggests the mechanism of death may be a sudden internal obstruction of the upper airway, probably at the very end of a breath. The sleeping baby lets out air, and something closes down inside the throat that prevents the intake of the next breath. The infant cannot cry out, but may change position as a result of this event. The baby may get into situations suggesting external suffocation during this episode-- the face becomes straight down into the bedding, or wedged into a corner of the crib, or blankets are pulled up over the face. This findings may lead to a false suggestion that the cause of death is external suffocation. But they are not the *cause* of death, they are the *result* of the dying episode.

If the autopsy suggests airway obstruction, how can we so confidently rule out external suffocation as the cause for SIDS? One of the most compelling arguments is that the autopsy findings are identical in babies dying of SIDS with the face entirely uncovered to those where the face is covered.

The main evidence for airway obstruction is the presence of tiny hemorrhages, called *petechiae*, which are present over the surfaces of the organs inside the chest cavity, but not elsewhere, in the great majority of SIDS victims. Such petechiae are present in nearly 90% of SIDS victims. They are far less common in infants or children dying of external suffocation. Our research indicates a potential reason for this -- the hemorrhages seem to be the result of suction pressures inside the chest that can only achieve the required force when obstruction occurs at the instant of full expiration (letting out of a breath). At this moment, the respiratory muscles are in a position to generate strong efforts to breathe in, which can generate high suction pressures in the chest cavity. Strangulation, or external suffocation, will occur at random points in the respiratory cycle, only occasionally happening at the instant when we suspect the obstruction of SIDS may occur.

In conclusion, I do not know the *cause* of SIDS, though I believe the *mechanism* may be a sudden internal obstruction of the upper airway during sleep. There may never be a single "cause" that can be identified.

## II. WHY CAN A HEALTHY BABY DIE SO SUDDENLY?

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Why would the airway become obstructed during sleep in a healthy and thriving baby? Nobody knows for sure. If one accepts that we understand how they die, the next question is why do they die? A concept that I have found appealing for many years is that this stoppage, or obstruction, of the airway is not due to a disease process or abnormality of the baby, but is a reflection of the fact that babies at this time of life are undergoing an incredibly rapid state of growth and maturation.

Many important changes are occurring at the age when most SIDS occur. The infant is, among other things, coming into an age where he is beginning to sleep through the night. That's not just a simple change in habit pattern, but a change that is very fundamental and has to do with control mechanisms in the brain. Centers that are beginning to be active in the baby's brain didn't even exist when that infant was born. Virtually all of brain growth occurs in the first two years of life and the growth rate in the first six months is the most rapid of any time in life. During the time when these important control centers are in a period of transition, abnormal messages might come down to the organs of respiration, one of which is to "close off" rather than "open up." Normally, at the end of a breath, the throat collapses or closes, then opens up prior to a new breath being taken. But, if the wrong message comes down from the brain, the throat may stay closed instead of opening. That wrong message isn't necessarily a result of this baby being abnormal, but occurs in a normal baby whose brain is growing at a tremendously rapid pace.

This view of SIDS is certainly one person's view; it's not shared by everybody who works in SIDS. It's a view which I find very reasonable and helpful; the concept is that the baby was normal when it dies, not abnormal. There is no way for anyone to predict that a normal baby is going to have this kind of abnormal event. Many factors may contribute to that event. Minor irritation of the airway may, by increasing the sensory input coming up the nerves from the throat to the brain, increase the

likelihood of abnormal messages to come down. Thus, perhaps we have a connection with the minor respiratory infections which are present in many cases.

### III. HOW IS THE SIDS DIAGNOSIS MADE?

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In doing a post-mortem examination, we don't see the lethal mechanism directly. After death, muscles relax, so the pathologists don't find the throat muscles clamped shut. There are little things that we find consistently, such as the pinpoint hemorrhages I mentioned earlier, but none of those things account directly for death. They are only clues to the way the baby died, and helpful to the pathologist in diagnosing the case as SIDS.

The SIDS victim did not die of nothing. The baby died of a very distinctive entity. Any of you who are familiar with sudden infant death will know that the typical case falls into a narrow age range, and seemed to be okay except maybe for a cold, ate his last meal normally, was put to bed and was later found dead. You know when you hear that story what the pathologist is going to say. But when the story is different, then you really want to know what the pathologist found. When there are some unusual features to the case, the post-mortem becomes especially important, as there are many conditions other than SIDS which can kill infants and young children suddenly.

If we take all babies under one year, who have (1) died unexpectedly, (2) during sleep, with (3) no history of alarming symptoms, such as seizures, temperature over 105°, and (4) no external findings to allow one to suspect a cause of death (like a fractured skull or a skin rash), 92% of cases will be diagnosed as SIDS after autopsy. If, for some reason, it is not possible to get an autopsy, one can usually do an x-ray examination to add to these four criteria. With the presence of a normal, full-body x-ray, the chances the death was due to SIDS goes from 92% to 98.2%.

### IV. MY BABY WASN'T A TYPICAL SIDS CASE

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Each of you who has personally experienced SIDS probably feels that, in some ways, your baby doesn't fit the classical profile. You read about "high risk" babies and it's very easy to confuse the concept of "high risk" with "typical." For example, a "high risk" baby might be born weighing less than three pounds to a disadvantaged family in the winter months. The risk to that baby is perhaps one in 50. The risk to a random baby is probably in the order of one in 500. If your baby was a full-term, 8-lb. baby who died in the summertime, and was a girl, it doesn't sound typical of the "high risk" baby that you hear about. But, in fact, most SIDS babies are not drawn from the "high risk" population. There are many more babies in our society who are in the "low risk" population, and the majority of SIDS babies are from this "low risk" population.

Thus, the 8-lb. baby is a more "typical" SIDS victim than is a 3-lb. premie, even though that premie had a higher individual risk of dying. Because there are so many full-term babies, they constitute the majority of SIDS babies. The same principal applies to the other so-called "high risk" factors. Therefore, these things you read about "high risk" SIDS babies often lead to confusion and it is important to understand that "high risk" and "typical" are very different concepts.

Any one case is a single dot on the bell-shaped curve and it could fall anywhere on that curve. The description of a population as a whole does not describe each individual member of that population. That's an idea that's often difficult to get across. I don't know if the totally typical case of SIDS ever has occurred. Every baby that ever died was an individual, and every person who has lost a baby identifies SIDS with that particular individual-- the hair color, behavioral patterns, and the medical history of that baby is the profile of SIDS to that parent and family.

It's important for families to be able to appreciate that because that baby seemed different than the other children in that family, it doesn't mean that difference was in any way related to the death. My experience has made it very clear that there is no typical pattern of behavior, for example, in babies who later die of SIDS.

#### V. MY BABY CRIED OUT DURING THE NIGHT HE DIED, AND I FEEL SO GUILTY BECAUSE I DIDN'T RESPOND.

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This was a death caused by airway obstruction and babies can't cry when their airway is obstructed. So, when that baby was crying, he could not have been dying. He cried, went to sleep, and then died later. Not responding to that cry had nothing to do with the fact that the baby died. Babies do not die from crying.

#### VI. SINCE SIDS ONLY OCCURS DURING SLEEP, IF I HAD AWAKENED MY BABY, WOULD HE HAVE DIED?

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My answer has to be, "No, he wouldn't have died then." But, how in the world could anybody know at what moment it was going to happen? The way to prevent SIDS would never be to let a baby sleep, and that's obviously impossible.

#### VII. IS SIDS CONTAGIOUS?

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Again, the answer is "no." My personal experience with over 1,200 cases includes not one example where a SIDS victim was closely in contact with another SIDS victim (except for three cases of twin SIDS incidences). There are times in every community when there are more SIDS than other times. When viral diseases of certain kinds are sweeping through the community, the incidents of SIDS will climb. But there is no "crib death virus."

#### VIII. WILL IT HAPPEN AGAIN IN MY FAMILY?

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**SIDS IS NOT A HEREDITARY DISEASE.** Early literature on SIDS suggested that subsequent siblings of SIDS babies had a modestly increased risk of SIDS. However, subsequent experience has shown that nearly all cases of apparent familial SIDS, when carefully studied, can be attributed to other causes. Certain genetic or environmental factors can result in sudden death in infancy, and some such deaths have been mistakenly attributed to SIDS in the past. Careful studies of families with more than one case of "SIDS" usually reveals other factors.

Any apparent SIDS victim who has siblings or other close relatives who have died similar deaths should be investigated with great care to exclude genetic or environmental factors. Many of the genetic causes of sudden death will be suggested by the wider age range, and atypical circumstances of death (such as death while awake) of some infants or children.

Since SIDS is one of the most common causes of infant mortality, affecting one in every 1,000 infants, it can rarely strike twice in the same family on random chance alone. However, present evidence suggests that subsequent siblings of true SIDS victims are at no higher risk of this phenomenon than any other babies. When nonspecific risk factors such as prematurity are also present, these will raise the risk of subsequent siblings of SIDS victims to the same degree they do for other infants.

(See appendix for more information on risk of multiple SIDS deaths in a family)

## IX. WHAT CAN I DO TO PROTECT MY NEXT BABY FROM SIDS?

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While there is nothing now that will guarantee protection of an infant from SIDS, a number of studies suggest that rates of SIDS may be decreased by some simple, inexpensive and safe changes in infant rearing habits:

(1) Place your baby on its back to sleep during the SIDS age period, as now recommended by the American Academy of Pediatrics. Populations where most infants sleep on their backs seem to experience significantly lower SIDS rates than those where most infants sleep in the prone (tummy) position. Intervention studies in several countries suggest that a change from prone or the less stable side sleeping position for infants reduces SIDS rates.

(2) Don't expose your baby to tobacco smoke. There is now substantial evidence that SIDS rates are higher in infants whose parents or other persons in the household smoke.

(3) Don't let your baby get overheated during sleep. This is perhaps the most controversial recommendation, but several studies have suggested that infants who cannot get rid of body heat because of excessive clothing, blankets or unusually warm room temperature may be at higher risk of SIDS. Until this issue is settled, I feel it is prudent to avoid excessive layers and unusually warm sleeping environments for infants in the SIDS age range.

NONE OF THESE SUSPECTED RISK FACTORS IS THE CAUSE OF SIDS. The vast majority of babies who sleep on their tummies, are exposed to tobacco smoke, or have relatively warm sleeping conditions do not die in infancy, and numerous infants with none of these risk factors have died of SIDS. These recommendations are intended to reduce the risk for your baby, but they cannot guarantee freedom from this tragedy.

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## **Appendix: Results of Subsequent Sibling Risk Studies**

*Edited by Nora Davis, MD, medical advisor to the SIDS Foundation of Washington*

“If we have more children, what are the chances of or losing another baby?” This question has been asked by virtually every parent of a SIDS infant.

In a 1984 study of 1,311 SIDS families, Dr. Donald Peterson of the University of Washington and his colleagues found that the SIDS families had no more risk of losing another child during infancy than comparable families who had not lost an infant. But, has research since then changed that statement?

The April 1990 *Journal of Pediatrics* contained a study by Dr. Warren Guntheroth and colleagues from the University of Washington. To determine the risk of recurrence of sudden infant death syndrome in families, they studied 251,124 live births by linked birth and death certificates from Oregon over a 10-year period. They found five recurrences among 385 subsequent siblings, for a rate of 13/1000 live births. Families with infant deaths from causes other than SIDS had similar recurrence rates, suggesting that the phenomenon was not specific to sudden infant death syndrome. The overall mortality rate for subsequent siblings after a sudden death event totaled 20.8/1000. The researchers believe that a risk of 2%, although small in the design of studies of infants at risk for sudden infant death syndrome, is not trivial in the counseling of parents.

Two studies on SIDS and siblings were reported in the December 1992 *Clinics in Perinatology*. The first, by Dr. Daniel Shannon at Massachusetts General Hospital in Boston, indicated that the risk is only slightly increased in the subsequently born sibling. The study found no factors that discriminate the baby at risk of death from SIDS, but among infants who have sustained an ALTE (Apparent Life Threatening Episode), there are several identifiable causes or factors associated with high risk for a repeated event.

The second '92 study was done by pediatric epidemiologist Dr. Susan Beal of Adelaide Children's Hospital in Australia. She concluded that SIDS is not a genetic disorder, so for most families, the risk of another death from SIDS is very low. The conclusion was based on the overall low recurrence rate of SIDS (<2%) and the fact that SIDS rarely happens to both twins; in fact, multiple studies on twins show no genetic influences, even in identical twins. The most likely explanations for an increased incidence in siblings are (1) that SIDS constitutes a mixed group of disorders, including some genetic diseases and some disorders that are known to be recurrent but not genetic, (2) that some recurrences occur in families whose prior birth experiences might increase the risk of SIDS, e.g. a previous baby had a low birth weight and (3) that some recurrences occur in families whose infant care practices might increase the risk of SIDS, e.g. one or both parents is a smoker.

A Norwegian study reported in the August 1, 1996 *American Journal of Epidemiology* analyzed data for 352,475 mothers whose first and second single births were reported between 1967 and 1988. The data suggested that previous SIDS was associated with an increased risk of all other types of loss: asphyxia, immaturity-related infant deaths, congenital malformations and other causes. In contrast, previous late stillbirth and previous asphyxia and immaturity-related infant deaths were associated with a reduced risk of subsequent SIDS.

An article in the August 4, 1998 *Seattle Times* newspaper examined the part that race plays in infant mortality rates. Infants and children of all ethnic backgrounds have particular medical issues, but research shows that African-American babies die before their first birthdays at more than twice the rate of white, Hispanic and Asian babies, and at nearly twice the rate of native-American infants. The Federal Centers for Disease Control and Prevention speculate that black women must overcome factors such as poverty, lack of health insurance and access to care, early life experiences such as diet or illnesses, stress that may be different somehow from that experienced by white women, and finally, susceptibility to an infection called bacterial vaginosis, linked to premature delivery.

For families planning to have more children, an absolute number cannot be given, but more recent data suggest less than a 1% chance of a SIDS recurrence, which is an encouraging sign. Revised September 1998