



SECOND EDITION
REVISED & UPDATED

The SIDS Survival Guide

*Information and Comfort for
Grieving Family & Friends
& Professionals Who
Seek To Help Them*

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Chapter 17

Dreams and Premonitions

A young pregnant woman dreams that she is standing at a bay window holding her baby against her shoulder. Random bullets suddenly spray the baby in the back, killing him instantly. The same young woman delivers a healthy baby boy months after this dream. But her happiness doesn't last long. He dies of SIDS. She recalls the horror of her dream—what she believes was her premonition that her baby would die.

A lay minister dreams that he and his wife are in a fatal car accident. Even though they don't have a baby, he remembers asking over and over, "Does the baby have to die?" and hearing a voice, as if from God, respond, "Yes, the baby has to die." The minister is so upset by the dream that he can't sleep, and the next day, he checks in on his own grandchild. He almost faints when he is then told the news that his nephew, little Michael Carroll Hitch, has died of SIDS.

Two weeks before Christian died, Joani canceled a scheduled tubal ligation only hours before it was to be done. "I just had this feeling that everything was too perfect. I didn't focus on the baby because he seemed so healthy, but I had a feeling that something terrible was going to happen to someone in the family."

Denise Dickerson had recurring dreams throughout her life that she would have a baby who would die. In her dream, she was first in a hospital being told that her baby died (but never *why*) and later at the baby's funeral. Denise had always attributed this dream to the fact that her mother and father had lost a baby (a girl, Michelle) to an illness. But when her own baby (also named Michelle) died of SIDS, Denise had "a sense of *déjà vu*; that this had already happened to me." Since the death, Denise has never again had the dream.

After her baby died, Denise's brother had a vision of the baby surrounded by a white light and being cared for by a young woman and a young man. Her brother's description of the woman was very similar

to how Denise had always imagined her older sister would look. To Denise, this was a comforting sign that her baby was being cared for by her sister.

Interestingly, according to a new study, premonitions are more common among parents who eventually lose babies to SIDS than among parents who do not lose babies. Yet so rarely is this talked about, we were able to obtain only one contribution to this chapter. In this contribution, researchers present examples of the premonitions they uncovered in their recent study.

The Effect of Premonitions of SIDS on Grieving and Healing

by Patricia Christenson, Richard Hardoin, M.D., Judith Henslee, Frederick Mandell, M.D., Melvin Morse, M.D., and Carrie Griffin Sheehan in a study conducted through the Southwest SIDS Research Institute.

"If Only..."

"My baby had another monitor alarm... May I schedule a sleep study for next month?... I... I...", Wendi hesitated. She had lost an infant two years earlier to SIDS and had monitored her subsequent sibling from birth. From the sound of her voice, it was clear that she was still worried and concerned about the well-being of this infant. "I... Something happened... It's hard to talk about... Maybe I'm going crazy... Do you have a minute?" The poignant story that unfolded that summer afternoon would have a lasting effect on our approach to the anxious parents and SIDS families with whom we come in daily contact.

Two weeks before my baby died, I had a vision, a premonition of her death. I was wide awake, working in her closet, when I saw an image of my baby in a small white casket at the front of our church. The vision was horrible! I dropped what I was holding, and the image went away but recurred 10 minutes later. Everyone thought I was crazy... When my daughter died and we went to the funeral home, my baby was placed in a small white casket identical to the one I had seen. It was the only infant casket available... I knew!... If only I could have done something...

The agony in Wendi's voice revealed the depth of her pain, as she discussed the anger, confusion, guilt, and massive grief she continued to experience. Grief resolution was hindered by her belief that aggressive action, following the vision, might have prevented her daughter's death. Although anger is a normal part of the grieving process, Wendi's anger was intensified by the almost uniform lack of support she received from others when she discussed her premonition prior to the loss. Society's discomfort with death and inexplicable events made seeking help difficult. Wendi felt isolated and impotent to prevent her baby's death, leaving her with a deep sense of guilt and many "if onlys."

The Study

The Southwest SIDS Research Institute houses a nationwide database consisting of comprehensive prenatal, birth, neonatal, and developmental histories on babies who have died of SIDS and control infants. Information contained in this database was used to answer the following questions: Are premonitions a normal occurrence among SIDS parents? If common, what is their impact on grieving and healing? Can anything be done to help affected families cope with their losses? Do parents of healthy infants also experience death premonitions that do not come true?

To answer these questions better, SIDS and control parents, responding to a 273-field questionnaire, were asked if they ever "sensed" that something was going to happen to their infants. Parents who answered positively were asked to complete written questionnaires describing their experiences and the effects of these experiences on their lives. Telephone interviews were then conducted with these families to validate the questionnaire and expand upon their answers.

Two additional control populations consisted of 197 parents of healthy infants seen consecutively in a Seattle pediatric practice and 207 parents of every other healthy infant born in a hospital on the Texas Gulf coast. Both groups were asked if they felt that something was going to happen to their infants. Seattle parents were questioned at 2, 4, 6, 9, and 12 months of age. Texas parents were questioned when their infants were 2, 4, 6, 8, 12, 16, 20, and 24 weeks of age. As participants in a study of normal infant sleep physiology, the Texas babies were closely followed throughout their first year of life, all medical

records were obtained, and outcome was determined within two weeks of their first birthdays.

Results

In the database study group, 38 of 174 SIDS parents and 4 of 164 control parents stated that they did feel that they would lose their babies. Of the SIDS parents, 94.7% were contacted and agreed to be interviewed versus 75% of the control parents. Of the two SIDS parents who were not participants, one was lost to follow-up and one refused to participate.

Interestingly, three of the SIDS parents who had written about premonitions in the original questionnaire, completed shortly after their infant's deaths, could no longer recall their premonitions. Consequently, SIDS study results were based on responses from 33 parents, representing 34 SIDS deaths. Control study results for database participants were based upon responses of three parents. Follow-up with these parents revealed that two of the three children did develop problems considered to be potentially life-threatening. Review of their medical records showed polygraphic documentation of gastroesophageal reflux and apnea. Both children were treated with monitors and medication. One recovered completely, and one, though four years old, continues to have documented prolonged apnea with oxygen desaturations.

Five (2.5%) of the Seattle control parents stated that they did sense that something was going to happen to their infants, yet nothing had happened. Six (2.9%) of the 207 Texas control parents stated on a questionnaire administered during their infants' sleep studies that they felt that something was going to happen to their babies. Four of the six parents were available for verbal interview. One of these six infants developed significant cardiorespiratory control problems, documented by polygraphic evaluation and in-home recording. She required monitoring and use of theophylline, a respiratory stimulant. The mother of this infant reported concerns about her baby's well-being prior to the baby's birth.

Study findings suggest that premonitions of death are a common occurrence among SIDS parents and an uncommon occurrence among control parents. Statistically significant differences were observed between SIDS and control parents, with 21.8% of 174 SIDS parents

compared to 2.6% of 568 control parents sensing that something was going to happen to their infants. Of the 15 control infants whose parents reported a premonition, three (20%) did experience an event believed to be "life-threatening" in nature, and all three had significant cardiorespiratory abnormalities that were well documented.

The Impact

Despite requests for help, many of the SIDS parents were unable to obtain support before their infants' deaths. Anger and guilt were common, even years after the SIDS event.

The majority of SIDS parents experiencing a premonition described a "vague, uneasy feeling without any obvious cause." A few had observed a physical event, such as a choking or blue spell, or had personal knowledge of a SIDS loss, occurrences that may have triggered their uneasy feelings. More than half of those interviewed described a vivid dream or an auditory or visual hallucination while awake. Don, a physician in a large metropolitan area, experienced vague, uneasy feelings as well as auditory warnings about his son's impending death.

During the first trimester [of the pregnancy], I sensed that the happiness his birth would bring would not be long lasting. A few months before birth, I would, on occasions, find myself contemplating a nearby cemetery, now where my son is buried. The day he was born and [I] first held him in my arms, I felt, for no apparent reason, he, my son, was not supposed to be with us. Probably two to three weeks before his death, I would be awakened from my sleep and think about SIDS. The day before he died, a voice sounding very similar to my own, would repeatedly say, "Take a good look. This is the last time you will see him."

According to Don, his fears intensified when his wife planned to visit her parents and take the baby with her. Her parents lived in another state, and a flight was required. The night before she left they argued about whether the baby should go. Don stated that he desperately wanted his son to stay but still didn't relay his fears to his wife. When he took them to the airport, he was flooded with negative feelings. As they walked to security, he heard a clear voice warn him that he would never see his son again. Don stated that he knew that his baby would die while he was gone. Even as he walked to the parking lot, the voice kept

telling him to go back, to get his infant. As Don kept walking, the voice got softer, then stopped. His wife called early the next morning and was hysterical, relaying the fact that their baby was dead. Later, Don's aunt shared the fact that she had had similar feelings about the infant. When asked what effect, if any, the premonition had on the grieving process, Don replied:

The process has not been a shock to me since I knew beforehand this [death] was going to happen. The only thing I didn't know was when and where... I have no idea of its meaning. The only thing I can say is that perhaps if I would have listened to "my heart" many mishaps could have been prevented... I think people have the ability to perceive things and give it a purposeful meaning which can be used for any future event.

Another SIDS parent, Mary, described physical symptoms in her infant that triggered her fears. Her baby was frequently congested and colicky. Unlike most parents experiencing a sensation that something was going to happen to their infants, Mary repeatedly sought the assistance of physicians. Unfortunately, they all felt that the mother's concern was disproportionate to the infant's symptoms. Mary was consequently reassured and sent home, most likely dismissed as an overreactive, nervous mother.

He had trouble breathing and [was] congested since day one. [He] cried around the clock, and sometimes he seemed like he was in severe pain. We did let the doctor know all this, but he said that he was just an unhappy baby.

The night before their baby died, Mary and her husband took him to their local emergency room. Again they were reassured that he was fine. Prior to leaving the emergency room, Mary's husband told her that he would press for hospital admission if she didn't feel comfortable with the physician's assessment. Mary, with some misgivings, decided to take her baby home.

Mary continued to feel nervous and uneasy, with heightened concern for her infant. As she walked toward the baby's bedroom with the sleeping infant over her shoulder, she saw their reflections in a mirror. According to Mary, she knew, at that moment in time, that her child would die that night.

Frustrated by her attempts to obtain medical care for her son, Mary felt powerless to avert the impending tragedy. Unable to sleep, she cleaned the house until 3 am so that it would be clean for the family members she knew would attend her baby's funeral. Arousing from a fitful sleep early the next morning, Mary found her son dead, a victim of SIDS. The pathologist's report confirmed his healthy appearance.

This three-and-a-half-month-old boy was found dead in his crib... He had no significant prior illness and had been a healthy baby... [He]... had a minor upper respiratory infection for a week. He was a healthy infant from birth except for a few episodes of colic. On the early morning of August 26th, the parents found him dead in his crib. Clinical and pathological diagnosis: SIDS.

Did the special bond that exists between mother and child allow Mary to sense that her baby had a fatal condition? Certainly neither the doctors who examined the infant before his death nor the pathologists who performed the autopsy were able to document any significant abnormality. Yet Mary knew that her baby would die, with a certainty that defies understanding. Mary's experience strengthened her belief in trusting her own instincts.

Mary has subsequently had two children, a boy and a girl. Both, though beautiful, healthy appearing infants, had severe sleep apnea and gastroesophageal reflux documented by in-hospital sleep studies with esophageal pH measurements. Both children were placed on monitors that recorded breathing and heart rate patterns, and both required surgery because of reflux that was resistant to conventional treatment. These children are doing well, and all symptoms of apnea have disappeared. Mary continues to feel that medical intervention might have saved her son's life. "If only they had listened..." remains a daily thought.

The Role of the Medical Professional

How can a physician distinguish between the new parent who is simply nervous and the parent who strongly senses that he or she is going to lose the baby? Study findings suggest that only about 3% of parents of normal, healthy infants have premonitions about their baby's death. A significant percentage (17.6%) of the infants in this group did experience a life-threatening event during the first few months of life.

When questioned further, many of the control parents who "sensed" that something was wrong and reported a "vague, uneasy feeling" could pinpoint the cause of their fear. Previous knowledge of a SIDS event or direct observation of an unusual or frightening episode were commonly cited. Anxiety tended to be less diffuse than that observed in parents of SIDS infants, remaining relatively constant throughout the newborn period, then tending to decrease with time.

As seen in the control population, the majority of SIDS parents reported sensing an impending loss on multiple occasions; more than half experienced the premonition more than five times. In contrast to the control population, however, there was a strong increase in anxiety as the death approached. One-fourth of the parents reported a premonition during the pregnancy; three-fourths sensed the loss immediately preceding the death.

The majority of SIDS parents felt that the premonitions had a negative effect on the grieving process. Although interviews took place an average of four years following the death, SIDS parents continued to feel anger, fear, and guilt.

Feelings of guilt are common in SIDS parents. However, for the subgroup of parents who "sensed" that they were going to lose their infants, guilt feelings were intensified by their inability to save their children. A 30-year-old teacher said

I called the doctor's office Thursday afternoon, but he was out, and the nurse said if the baby wasn't crying not to worry... I wanted to [see the doctor], but the doctor was unavailable at the time. I was told to come in the next day if I was still worried—but my baby died the next day.

At first, I blamed myself for not taking him to another doctor. Then I was angry at the nurse who told me not to worry and at the doctor...

Another parent found herself looking for an excuse to contact her baby's physician. She was hesitant to contact him on the basis of her "feelings."

Brandi died on Friday. All day Thursday (Wednesday night, too) I just "felt" like something was wrong... She wouldn't eat, just wanted to sleep and seemed behind [delayed]. All evening

Thursday, I cried... Friday morning, I took her temperature a dozen times. I hoped she would have a fever or something so I would have an excuse to take her to the doctor.

It [the premonition of loss] has frightened me so that I cannot allow myself to lose control and cry. If I go on a crying jag, I might lose Michael, too...

Self-blame was common among respondents. A 28-year-old mother elaborates:

I told the doctors that B.J. didn't act right. I knew there was something wrong with my son. But the doctors said he was all right... I had B.J. in the doctor's office every week because he just wasn't right...

I blamed myself [for his death] for a long time. I should have made the doctors run more tests on B.J. and just maybe he would be here today.

This mother felt that support from the medical profession would have eased her pain, even if death was inevitable. When asked if others could learn from her experience, she replied:

Yes, if they feel like their child isn't right. Make the doctors run tests and if that doesn't work, cherish every day you have with that child, because one day he or she might not be there.

Parents who reported a premonition of impending death to a medical professional, spouse, or friend were rarely taken seriously. One-third of the SIDS parents visited their baby's physician following the premonition. Despite requests for medical intervention or evaluation, nonroutine medical follow-up was not recommended for any of the SIDS infants studied. This lack of follow-up probably resulted from the very normal appearance of the infant before death (confirmed at autopsy) and the tendency to downplay parental fears in an effort to reduce anxiety. Furthermore, the majority of parents did not report observable physical symptoms and, when done, physical examinations were within normal limits.

When, despite a normal exam, the parent expressed concern about the future death of the apparently healthy baby, responses ranged from outrage ("How could you say such a thing?") to denial ("Your baby's

perfectly fine! Relax and enjoy him!"). These reactions tended to inhibit further verbal communication about the premonition, both before and after the death. Although the premonition often resulted in intensified feelings of guilt ("I knew something was going to happen. I had the responsibility to do something to prevent it..."), respondents seemed relieved to discuss their feelings, and, as a group, were left with a strong belief in trusting their instincts.

Study findings suggest that caring, supportive health-care professionals, who are willing to listen to affected parents and who take their concerns seriously, have the potential to make a tremendous effect on the resolution of their grief. Whatever the outcome, this approach should diffuse the intense anger and guilt so often reported and should provide the parent with a peace of mind not found in the study population.

Those parents who also described some contact with their infants after death (dreams, visions, or feelings) were uniformly positive about the experience and were left with a firm belief that their infants are well cared for and in a better place. These findings, although not previously described in the medical or SIDS literature, are not entirely unexpected. Elizabeth Kubler Ross and Melvin Morse have presented clinical case studies documenting that acknowledgment of such premonitions, and using them to interpret the child's death, can be useful in grief therapy.

The health-care professional's reaction to parental feelings of impending death strongly influences the grieving process. Anticipatory grief, when allowed to occur, may positively affect the grieving family member. It must be understood that the subjective nature of such experiences makes it seemingly impossible to judge their objective reality, nor is it necessary to do so. Simply acknowledging that such premonitions are a natural and normal event can be comforting and validating to parents who have lost a baby to SIDS.