

# MCV/Q

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## SUDDEN INFANT DEATH SYNDROME

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For our issue on the Sudden Infant Death Syndrome Symposium held in Richmond in June 1979, the MCV QUARTERLY departs from its usual presentation of formal papers. In attempting to recapture some of the spontaneity of this remarkable and often moving conference, we have chosen to publish the taped remarks of the discussants with the minimal editing required.

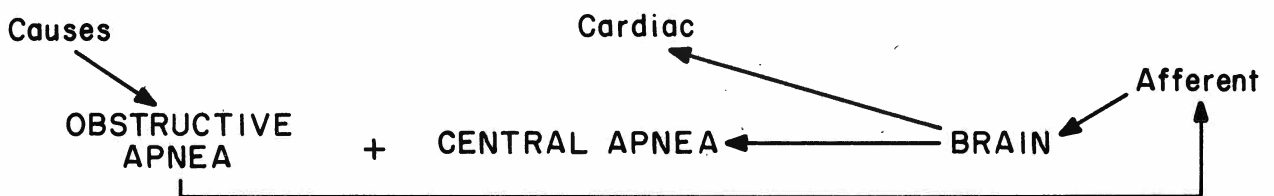
THE EDITORS

## INTRODUCTION

During my neurology training, one of my associates discovered his little son dead in the back of his car, after his daughter had cried out, "Why is brother so cold?" This was my first encounter with Sudden Infant Death. Since then I have been acutely aware of this tragic event which occurs in approximately 100 to 140 cases yearly in Virginia. It is amazing that with such frequency of incidence, this is only the second symposium held in Virginia. Hopefully, we will arouse more profound interest in the subject. Many theories have been expounded as to the cause of Sudden Infant Death, not the least of which are those reports in the newspapers. This symposium covers the problem of etiology, pathophysiology, and recognition of the at-risk infant, the management of the Sudden Infant Death victim, parents and the family, as well as efforts to prevent the occurrence of this event.

sult is yet to be discovered. (See Figure) If these brain derangements are in fact causative, it is essential to correlate clinical aspects with the pathological states. Neuropathological changes noted include impaired myelination of intrinsic and extrinsic nerve structures, leukomalacia of a specified area, dendritic abnormalities and astroglial proliferation, all affecting brain centers and resulting in dysfunction of the autonomic nervous system, respiratory and cardiac centers. The clinical correlates are the lack of respiratory drive, abnormal breathing patterns, and abnormal responses in organs under autonomic nervous system control, that is to say, the heart and gastrointestinal tract. Recently, a new syndrome in adults, sleep apnea, may well serve as a model for Sudden Infant Death in children.

At the Medical College of Virginia we have been aggressive in evaluating what we



There is a growing feeling among neurologists and neuropathologists that whatever the multitude of environmental factors, afferent stimuli and end organ failure that occur, in at least 50% of the infants with Sudden Infant Death Syndrome (SIDS), there has been or is an old or continuing dysfunction in brain structures. How much of this is cause or re-

have diagnosed as near-miss SIDS and we believe that in many of our cases we have established treatable precipitating causes for acute episodes.

EDWIN C. MYER, M.D.  
*Chairman, Child Neurology*

# The Nature of the Problem: Sudden Infant Death Syndrome

DAVID W. MARSLAND, M.D.

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The following is an overview of the Sudden Infant Death Syndrome (SIDS) and emphasizes salient features of its epidemiology, pathology, pathophysiology and management. Controversial points are not discussed.

## **Epidemiology**

SIDS is an increasingly common problem with a reported incidence of 2 to 3 per 1,000 live births. In the United States, there are approximately 10,000 deaths per year. For Virginia in 1976, there were 129 reported cases.

In the 1972 King County, Washington study, from one week to 11 months of age the leading cause of death is SIDS (45%), followed by congenital malformations (20%). From one week to 14 years of age SIDS is the third leading specific cause of death behind diseases of early infancy and accidents. SIDS is more common in males than females, 3:2. The syndrome is more common in the economically disadvantaged, with blacks having an incidence of 5 per 1,000 live births. Infants of lower birth weight and gestational age have a higher incidence of the problem. For example the risk for babies weighing 3 lbs 8 oz is 13.27 per 1,000 live births. Paradoxically, infants who weighed

less than 3 lbs 8 oz at birth have a decreasing incidence, but the lower incidence may reflect the high mortality from respiratory disease in the neonatal period. SIDS is most common at 2 to 4 months of life with few cases being reported before 2 weeks and after 12 months. Nasopharyngitis seems to accompany SIDS. In the northern hemisphere, SIDS tends to occur more frequently in winter; whereas in the southern hemisphere, the syndrome occurs more commonly in summer months. About 74% of all deaths are discovered during sleep in the early morning hours.

It should be remarked that nationally, there is considerable debate as to the true epidemiology of SIDS.

## **Pathology**

During the past ten years pathologists have assisted in bringing about a better understanding of the syndrome. SIDS is defined as, "The sudden death of any infant or young child, which is unexpected by history, and in which a thorough postmortem exam fails to demonstrate an adequate cause of death."\* By definition an autopsy is then necessary to rule out SIDS.

Beckwith reported a series of 500 autopsies in infants dying during the first year of life. In 15% a cause of death could be found (infection, trauma, major malformations and others). In 87% of the infants intrathoracic

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This is an edited transcript of the remarks by Dr. Marsland at the Sudden Infant Death Syndrome Symposium held June 1, 1979, at the Richmond Hyatt House, Richmond, Virginia.

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\* J. B. Beckwith: "The Sudden Infant Death Syndrome." *Pediatrics* 3:29, 1973.

petechiae were noted. A number of observations by investigators from pathological specimens would tend to indicate that infants dying of SIDS are chronically hypoxemic. These findings would include leukomalacia, demyelination of the brain, intrathoracic petechiae, decreased cytoplasmic granules in carotid chemoreceptors, increased muscle mass in the small pulmonary arterioles, extramedullary hematopoiesis and retention of brown fat. Other autopsy findings in SIDS would include normal nutrition and hydration, perhaps some blood-tinged sputum or frothy fluid at the mouth or nostrils, diapers wet or full of stool, clutched hands, pulmonary congestion or edema, perhaps some interstitial pulmonary lymphocytic infiltrate, normal size adrenal glands, normal thymus and no evidence of aspiration.

### **Pathophysiology**

Why do babies die of SIDS? What is a near-miss SIDS and how does it relate to SIDS? How does the physician identify the infant at risk for SIDS? Answers to these questions would be important to the child and the clinician. As yet there are no clear answers but many clues.

A near-miss infant is defined as a previously well infant who, during sleep, experienced an episode of apnea, limpness, cyanosis or pallor that was terminated by vigorous stimulation or mouth-to-mouth resuscitation. It has now been documented that a number of infants with near-miss SIDS die of SIDS. These near-miss infants need the following: 1) complete physical and neurological examination, 2) complete blood count, 3) urinalysis, 4) serum  $\text{Ca}^{++}$ ,  $\text{PO}_4^-$ ,  $\text{Mg}^{++}$ , glucose,  $\text{Na}^+$ ,  $\text{K}^+$  and amino acids, 5) capillary blood gases, 6) urine organic and amino acids, 7) chest and skull x-ray, 8) barium swallow, 9) 12-lead electrocardiogram, and 10) sleep and awake electroencephalogram. Included in the differential diagnoses are seizures, esophagopharyngeal reflux, sepsis and aspiration.

The control of ventilation is a very delicately balanced system. The near-miss SIDS and SIDS victim would appear to have abnormal control of ventilation especially during sleep. Study of ventilation in the small infant is difficult and not available except in research lab-

oratories. Sleep and awake electroencephalograms, ventilatory response to various inspired gas mixtures and thoracic and nasal movements are monitored in an integrated system. To date it has been demonstrated that the near-miss SIDS infant has hypoventilation, a depressed ventilatory response to  $\text{CO}_2$  breathing, prolonged sleep apnea, frequent short apnea, periodic breathing and apnea clustered in sleep. Apnea in near-miss infants has been demonstrated in REM and Quiet Sleep.

In addition to evidence for abnormal control of ventilation during sleep clinical investigations have hypothesized that obstructive apnea may occur during the terminal event. Tonkin demonstrated the anatomic vulnerability at the oropharyngeal level between the soft palate and the base of the skull in the small infant. In REM sleep with muscle relaxation this anatomic vulnerability may lead to oropharyngeal occlusion. In near-miss SIDS infants abnormalities of muscle tone have been demonstrated particularly shoulder hypotonia. In one case study, loss of electromyogram (EMG) activity of the genioglossus muscle with obstructive sleep apnea has been confirmed. Several family members had died from SIDS.

Therefore, the near-miss SIDS and SIDS patient would appear to have chronic hypoxemia, abnormal control of ventilation during sleep and possibly an obstructive asphyxial event. Despite all of the evidence, the pathophysiology is not completely explained and a simple test to identify the infant at risk has not been forthcoming.

### **Management**

Autopsies should be performed on all infants who are thought to have SIDS. The postmortem will rule out abuse and infanticide and other diagnoses. The parents can then with certainty be told that their infant died from SIDS and that they could not have prevented the death.

A common denominator for the family is guilt which when combined with grief and lack of knowledge can lead to major emotional stress, exacerbation of previous psychiatric conditions, and marital problems. To alleviate the guilt and grief the parents should be referred to a SIDS guild, and should be helped by many counseling visits to their pediatrician or family physician.

# Recognition of the At-Risk Child

DOROTHY KELLY, M.D.

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From 1959 to 1966, Dr. Richard Naeye, a pathologist at Hershey Medical School, participated in the Collaborative Perinatal Project which studied 53,518 pregnancies. Of the infants subsequently born, 125 died of the Sudden Infant Death Syndrome (SIDS). Through the mass of information gleaned from looking at the pregnancies, labor, delivery, examination of the placenta and subsequent events in the infants' lives, Dr. Naeye was able to determine nine historical factors that increase an infant's risk of dying of SIDS. According to his statistical analyses, these are additive factors so that the presence of a number of them increase the risk in any one infant. The risk factors are 1) poor prenatal care, that is, few prenatal visits; 2) maternal smoking; 3) maternal anemia; 4) abnormal insertion of the umbilical cord, 5) lymphocytic infiltration of the decidua at the placental margin; 6) blood group B; 7) premature delivery; 8) abnormal neurological evaluation of the infant at the time of discharge from the hospital; 9) crowding in the home, that is, more than 2.0 people per room. In addition, there are two clinical factors that increase an infant's risk of dying of SIDS. These include a history of apnea and a family history of two siblings who have had apnea or died of SIDS.

The clinical problem of apnea is particularly important and can be put into two categories—*asleep* and *awake*. Within the *asleep* category are three types of infants at risk: 1)

those who are *asleep* and have an apneic episode that requires mouth-to-mouth resuscitation, vigorous stimulation or gentle stimulation to resolve the episode; 2) those who have color changes, either pallor or cyanosis; and 3) those who are noted to have bradycardia during sleep.

The *awake* category of infants having apneic episodes is also divided into three types: 1) those infants who first cry out and then become apneic, pallid or cyanotic, unresponsive and need resuscitation; 2) those who choke, cough or vomit, become apneic and need resuscitation; and 3) those who have apparent seizure-like episodes resulting in apnea and are resuscitated. All of these infants having apneic episodes, both *awake* and *asleep*, are at increased risk.

We know that in premature infants there are many causes of apnea and we are now learning that there are certain specific causes of apneic events in older children and that these, too, can be treated. The etiologies now known include sepsis, meningitis, seizure disorders, intracranial hemorrhage (more common in premature than full-term newborns), metabolic abnormalities, cardiac anomalies and arrhythmias, gastroesophageal reflux, pneumonia and congestive heart failure. The infant should be evaluated to determine if any of these abnormalities are present. After treatment, the infant should be tested for signs of impaired control of ventilation as should the infant in whom no abnormality was found.

We test by ascertaining if the infant is having hypoventilation or if he or she has an abnormal breathing pattern. Hypoventilation is tested by measuring minute ventilation on room air and response to breathing carbon dioxide during

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This is an edited transcript of the remarks by Dr. Kelly at the Sudden Infant Death Syndrome Symposium held June 1, 1979, at the Richmond Hyatt House, Richmond, Virginia.

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quiet sleep. We compared a group of “near miss” and control infants, and found that the “near miss” infants’ response to CO<sub>2</sub> was significantly less than control infants’ and that while breathing room air, the partial pressure of carbon dioxide in expired air was significantly increased. We concluded that the “near miss” infants had relative hypoventilation in quiet sleep and a depressed response to breathing 5% CO<sub>2</sub>. We also found that while some “near miss” infants have poor control of ventilation, some do not, indicating that there are at least two different mechanisms that cause an infant to require resuscitation.

We evaluate an infant’s breathing pattern by recording respirations and heart rate during sleep. We record the infants for 12 hours at night.

The “near miss” infant will frequently have abnormal breathing patterns, including prolonged sleep apnea, excessive short apnea, disorganized breathing and periodic breathing. Any of these can be accompanied by bradycardia. In a recent study, we have found that periodic breathing is a qualitative marker for respiratory instability.

We have also found these abnormal patterns in siblings of SIDS victims whom we have tested prior to any clinical apneic episode and therefore believe that these abnormalities are not the consequence of a resuscitative event but in fact may result in an episode of prolonged apnea that may require resuscitation to terminate.

The markers are intriguing and may help to explain some of the pathologic findings that have recently been described in the autopsies of SIDS victims. Some of the changes in the infants who died of SIDS resemble changes found in infants who were known to be hypoxic prior to death. These changes include hypertrophy of

the smooth muscle of the pulmonary vasculature, an increase in extramedullary hematopoiesis, an increase in the periadrenal brown fat, right ventricular hypertrophy (as yet unsubstantiated), and a depletion of the adrenal medulla. All of these indicate that the victim has had chronic hypoxia prior to death, although these are victims who have had no history of any cyanotic or apneic episodes. Therefore, the desaturation must occur while the infant is not being observed.

Recently, in separate studies, both Dr. Naeye and Dr. Takashima at Toronto Sick Children’s Hospital have found a proliferation of glial cells in the medulla of SIDS victims. The proliferation, which is a response to hypoxia, was very prominent in the respiratory control centers in the medulla and in the nucleus ambiguus. These areas correspond to the watershed zones of the microvasculature. Dr. Takashima concluded that the change was the result of hypoxia. Since this occurs in the respiratory control centers, whatever initiates the first hypoxic event can subsequently result in poor control of ventilation which itself can lead to more hypoxia and thus set the SIDS victim in a vicious circle. Takashima also described periventricular and subcortical leukomalacia, a change known to be caused by hypoxia. Some victims therefore, without any history of a cyanotic episode, have pathologic evidence in brain, lung, liver, heart and adrenals of having experienced significant hypoxia while they were alive. Certainly, it is possible that the abnormalities in respiratory pattern that we have noted in siblings of SIDS victims and in “near miss” victims, could result in these abnormalities.

In summary, infants who have experienced an apneic episode which was terminated by resuscitation have signs of impaired control of ventilation.



# The Role of the Primary Care Physician

DAVID A. DRAPER, M.D.

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All of us at one time or another have been involved either professionally or perhaps personally with Sudden Infant Death. My first experience dates back to one of my brother's children who was a victim of Sudden Infant Death in the 1950s. My brother and his wife had had two daughters prior to that, and this child was the male infant, the heir to the throne. The Draper clan is a very close one, and this was going to be the third generation of Thomas Frazier Draper III. The child died at three months of age, and I think that the parents did not receive the kind of support they needed and that all of us should be able to give people who have lost a child in this way.

How do we go about giving support, especially as we may not have resolved our own reactions to the news that a child has been the victim of Sudden Infant Death? Initially, the physician has feelings of fear. Why did the child die? Did I miss something? Is someone going to sue me? The physician often experiences inward guilt and a reluctance to face the family. As professionals we need to resolve these feelings and recognize that we could possibly have missed something. We must also realize that we have probably done the best we can and that we are now needed to support the family.

After hearing the news that a child has experienced Sudden Infant Death, the physician must get in touch with the family as soon as possible, sit down and talk with the parents and

be able to listen to them. Just touching the hand of the mother or father can be a very consoling and reassuring thing. This lets the parents know that you care.

What are the parents' emotions as they discover that their child has been the victim of Sudden Infant Death? Initially, they also feel fear about what has happened and why. They probably also feel anger that this has happened to them, and want to blame someone. They may blame the physician, who perhaps saw the infant two or three days before and gave him his routine DPT shot. Or the parents may feel guilty themselves. Did they do something? If they had gone into the room a few minutes earlier, perhaps this wouldn't have happened—if they hadn't placed the child on his stomach, if they hadn't put that blanket in the crib, if he didn't have the pacifier. There are so many questions parents ask themselves. One parent invariably may blame the other and yet be unable to express this feeling, thereby creating more problems. Here is where the primary care physician and the pediatrician can take an important role. They ought to encourage the parents to express their feelings, listening as well as interjecting an occasional thought about how some parents would blame each other when they are faced with a situation like this.

As physicians we should attempt to tell the parents as best we can what Sudden Infant Death is, let them know that there are children who die of sudden and unexplained causes, and assist them in obtaining more information about their child's death. The parents should be encouraged to get in touch with the Central Virginia Guild for Infant Survival to find out more about Sudden Infant Death.

A significant aspect of the physician's as-

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This is an edited transcript of the remarks by Dr. Draper at the Sudden Infant Death Syndrome Symposium held June 1, 1979, at the Richmond Hyatt House, Richmond, Virginia.

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sistance to the family is helping them to obtain an autopsy. The autopsy is important because it can better define whether or not the death was truly from a sudden, unexplained cause. Whatever the findings, the parents should know what happened, especially if they decide later on to have other children. Whether this was or was not Sudden Infant Death, the parents should seek genetic counseling before planning to have more children.

Another important task for the physician is to explain to the pathologist what is being sought in the autopsy and to make the pathologist aware of some of the characteristics of Sudden Infant Death so that various crucial specimens will be examined properly. Although the length of time varies from one institution to another, a few weeks is ample time to get the autopsy report back. It is critically important that the information be relayed to the family as quickly as possible with the physician explaining the findings to the family in terms they will understand.

At this time it is appropriate for the physician to attempt to find out how the parents are coping with their child's death. Here is another opportunity for the physician to put out some feelers for possible reactions of guilt or blame. The parents may want to run away from the situation. Some parents have a lot of blame placed upon them by their own parents, or they may have been bombarded by questions from friends and neighbors. If you as a physician cannot get the parents to open up, you should get in touch with someone from the Guild for Infant Survival or a social worker who can establish a continuing relationship with these parents until they can resolve some of their feelings. This relationship may last for two months, four months, six months or even longer, depending upon the family's need.

So far I have talked about mothers and fathers and about resolving our own feelings about a child's death. I have also discussed the autopsy and the importance of making the pathologist aware of what needs to be examined. One of the frequently neglected aspects of Sudden Infant Death is the reaction of the sibling. What are the feelings of the sibling in relation to the sudden loss of a young brother or sister? This is particularly pertinent where children of the age of less than seven are concerned. Many

times children of this age and at this stage of emotional development may have wished that their brother or sister wasn't there. Then, suddenly for some unexplained reason, the wish has been granted. The sibling may feel guilty for having in some way caused the child to die. These children may have a lot of nightmares and other behavioral problems that conceivably can be traced to their feelings about the sudden death of their brother or sister. It is important for the physician to explain this to the parents. The parents need to be aware of the fact that their remaining children will be affected by the infant's death and of the importance of encouraging these children to express their feelings, whether they are of fear or anger.

The next area in which the physician can assist the family is in the process of deciding whether to have more children, and aspects of genetic counseling. There is an increased risk for a future child to experience Sudden Infant Death among families where it has already occurred. I have dealt with mothers who have had a child with arrested Sudden Infant Death and who have gone through a subsequent pregnancy with a great deal of anxiety about that experience, particularly as they got farther and farther into their term. The mother and I would spend a long time talking about her feelings in an attempt to look at them more objectively. We would talk about what kind of methods we would use to study the baby once the child was born, and how we could assist the mother at home with her new baby. I have attempted to make these mothers feel secure in the knowledge that we would do whatever could be done medically to prevent a possible Sudden Infant Death from occurring in that family.

Lastly, we must consider the arrival of the new baby. How is that child perceived? Is he or she a replacement? Preferably, the baby is not the same sex as the baby who died, because if the infant is the same sex and looks like the one who died, it is going to be difficult, if not impossible, for the parents to think of this as a different child. In this instance the role of the pediatrician or family physician is to understand the parents' difficulty in perceiving the new baby as anything but a replacement for the lost infant while emphasizing the need to see the new child as an individual with his or her own needs and problems.

# The Nursing Role

ANN BARR, *Northeast Regional Director, National Sudden Infant Death Syndrome Foundation, 9 Follett Street, Marblehead, Massachusetts*

I will talk about setting up a program for nursing visits to SIDS parents and its importance. The first thing the parents need to know is what their baby died of; they need to know facts about SIDS, how to relieve their guilt reactions, and a set of guidelines for grief reactions. A four-point management system has been set up by the National SIDS Foundation and includes (1) an autopsy, (2) notification of cause of death within 24 to 48 hours, (3) use of SIDS as the cause of death on the death certificate when appropriate, and (4) availability of information and counseling to the parents.

In Virginia the first three points are well covered. The fourth point is probably covered but in a haphazard manner; there is no formal program where nurses systematically visit SIDS parents.

There are two basic ingredients to a four-point program—the medical examiner and the nurse. The nurse who goes out and visits the SIDS family after a death can provide information about the cause of death, back up what the family has been told by the medical examiner, reassure the parents that the death was not their fault, help the family to express its grief reactions, help the parents decide what to tell the

other children, and refer them to a social worker or psychiatrist if necessary. If a family can receive this basic help and information, it rarely needs referral for psychological help.

Nurses are the most likely persons to set up such a program because they (1) are the most receptive, (2) are available to the families for long periods of time, (3) are medical professionals who are accepted by the families, and (4) can go into the home. When parents lose a child to SIDS, they are devastated and cannot reach out on their own unless they happen to be very aggressive. Yet they are more than willing to open the door and let someone come in, but that person has to go to them.

The ideal program consists of a nurse and a SIDS parent working as a team to reach out to the SIDS family. There are SIDS families who do not want to talk with other SIDS parents but who will talk with a visiting nurse, and vice versa. Preferably, if possible, reach out to them as a team. A parent will accept medical facts from a nurse more readily than from another parent, but what they will accept from the SIDS parent is "This is the way I felt," and "I understand what you are feeling."

I think Virginia has the potential for setting up this type of program and I can't stress enough how important it is. It is a quicker and healthier adjustment for the SIDS families when they are involved in such a four-point program.

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\* The following are the edited transcripts of remarks by a special seven-member panel of guest speakers at the Sudden Infant Death Syndrome Symposium.

# Legal Aspects of SIDS

T. S. ELLIS, III, J. D. HARVARD, D. L. OXFORD, *Partner, Hunton & Williams, Richmond, Virginia*

My remarks today focus on four legal aspects of SIDS; the first three are problems of long standing and the fourth is less well recognized, an immediate problem to some but more of a cloud on the horizon to others.

At the outset, I want to emphasize that I bring you no certain solutions. Rather, my more modest objective is to provide a focus and framework for further discussions.

The first legal aspect of SIDS I want to discuss is the capacity of the legal system to distinguish between SIDS and criminally actionable infant death caused by neglect, abuse or worse. Great progress has been made on this problem since 1933 when in England, for example, SIDS was thought to result from inadvertent suffocation of the infant while sleeping with its mother. Acting on this myth, Parliament passed a law stating that sleeping with infants was a criminal offense under certain circumstances. Of course, that is no longer the law there or here and this, I suppose, helps to illustrate that substantial progress has been made in distinguishing between SIDS and criminally actionable homicide. Still, some relatively recent examples illustrate that the problems our legal system has in making this distinction may not be entirely behind us.

The first situation is particularly unfortunate. In 1973, a young couple in the Bronx lost an infant to SIDS. The infant was a second child and delivered by Caesarian section. At the time of death, the mother was undergoing psychiatric care for postpartum depression and the father was caring for both children at home. The infant had a cold during the last week of life. On discovering that the infant had died, the parents were understandably distraught and for this and a number of other reasons, delayed three hours before calling the authorities. An autopsy was performed and the diagnosis was listed as "congestion of the viscera." The cause of death was noted as "pending further study."

The parents were taken to a precinct station and questioned by a detective. Inexplicably, the detective misunderstood the father to say that the child had not been fed for three days. The autopsy, however, made no mention of dehydration, malnutrition, bruises on the body or abnormal findings in the liver or thymus. After the interrogation, though, the medical examiner noted on the autopsy report that the cause of death was "abandonment and neglect."

On the basis of the detective's conclusion and the medical examiner's report, the couple was indicted and then jailed because they were unable to post a \$1,000 bond. Lamentably, the father remained in jail for eight months and the mother for six months before bail was posted. During this period, the older child was placed with grandparents. Ultimately, the parents were exonerated.

By any standard, this is an aggravated case and I must say that I know of no similar documented incidents since 1973. Still, the potential for recurrence of a similar incident remains in those states where the death investigation laws are inadequately sensitive to SIDS as an identifiable disease entity. The potential also remains because large segments of the public, particularly the authorities in some states and cities, remain relatively ignorant about SIDS.

The second case I shall describe illustrates the opposite facet of failing to distinguish adequately between SIDS and criminally actionable infant death. This case comes to us through a published decision of the Court of Appeals for the Fourth Circuit in Richmond.\* The decision reveals essentially the following facts: A foster parent was charged with first-degree murder and a number of other charges of assault with intent to murder, attempt to murder,

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\* See *United States v. Woods*, 484 F.2d 127 (1973).

and mistreatment and neglect of an eight-month-old, pre-adoptive foster son. The evidence showed, among other things, that the infant spent the first five months of his life in a foster home and that his physical well-being and health during this period were uneventful and unremarkable. At the end of the five-month period, the infant was placed in the defendant's home. Thereafter, a bizarre series of events occurred. On at least six occasions, the infant suffered episodes of gasping for breath and turning blue from lack of oxygen. On all but one of these occasions, the infant responded well to mouth-to-mouth resuscitation. On the final occasion, the infant lapsed into a coma and died. During the hospitalization, no cause for cyanosis could be discovered and at the trial on the criminal charges, the state forensic pathologist expressed the view that he was 75% sure that the infant's death was homicide. He explained, however, that he was 25% uncertain because the infant could have died from a poorly-understood disease referred to as "natural crib death."

On that evidence alone, the defendant might well have escaped conviction. Recognizing this, the government lawyers went on to attempt to introduce other incriminating evidence. This evidence showed that beginning in 1945, the defendant had had custody or access to nine children who, collectively, had experienced a minimum of twenty episodes of cyanosis. Seven of these children died, while five had multiple incidents or episodes of cyanosis. Three of the children were her own natural-born children, two were children she had adopted, one was a niece, one was a nephew, and two were children of friends. On one previous occasion, the defendant had been charged with assault and attempted murder, but had been acquitted.

On the basis of this and the other evidence in the case, the defendant was convicted. On appeal, an important issue was whether the evidence of the other incidents should have been admitted at the trial. This issue, long debated by legal scholars, is not important to our discussion today. What is important is the near failure of the legal system in this instance to distinguish SIDS from homicide. For those of you who are curious, though, let me say that the evidence was held admissible and the conviction affirmed. Significantly, though,

one judge dissented, relying in part on the medical examiner's equivocal testimony to the effect that the diagnosis of suffocation was no more consistent with the facts than a diagnosis of crib death.\*

What do these cases reflect? The first reflects that the tragedy of SIDS is cruelly compounded when the legal system confuses SIDS parents with criminals. By the same token, of course, the second case reflects that those guilty of abuse, neglect or worse should not be permitted to masquerade as SIDS parents.

The capacity of the legal system to distinguish properly between SIDS and homicide depends, at least, upon the following basic requirements:

1. Full legal recognition of SIDS as a disease entity that results in natural death and not culpable death;
2. Provision for prompt, *expert* and thorough postmortem examination; and
3. Well defined and generally accepted postmortem findings for SIDS that distinguish this disease entity clearly from various deaths by homicide.

Whether a legal system satisfies these three requirements depends upon the details of the autopsy or death investigation laws. As many of you know, the manner in which a death is handled by a medical examiner or coroner is largely a matter of state law and varies widely. Only a few states, not including Virginia, have death investigation laws that are explicitly "SIDS sensitive." That is, only a few states have statutes specifically recognizing or dealing with SIDS.\* Many states do not have death investigation laws that satisfy the three criteria I just mentioned. Notwithstanding the absence of SIDS-sensitive legislation, Virginia has achieved substantial success in dealing with the problem. This success, it seems to me, is attributable to the special sensitivity and competence medical examiners in Virginia have with respect to SIDS.

The second legal aspect of SIDS is closely

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\*For another court decision involving this issue, see *People v. Nyberg*, 24 Ill. App. 3d 41, 320 A.2d 546 (1974), *reversed*, 356 A.2d 80 (1976).

\*For an informative study of the state death investigation laws, see *Death Investigation: An Analysis of Laws and Policies of the United States, Each State and Jurisdiction [as of January 31, 1977]*, DHEW Pub. No. 78-5252 (1978).

related to the first; it is, simply, the obligation of, or necessity for, the legal system to aid or at least not hinder the families of SIDS victims in recovering from the psychological trauma of the experience. The example I discussed of SIDS parents in the Bronx jailed for six months underscores how insensitive some legal systems can be to this problem.

The insensitivity of death investigation laws to the trauma suffered by SIDS parents has been studied—in 1975 by Allan Cleveland, a New Hampshire lawyer,\*\* and in separate findings conducted under the direction of Dr. Bergman in 1972.\*\*\* In essence, both investigators concluded that the death investigation laws were largely inadequate in this respect.

Both studies show that the problem is most likely to arise where the death investigation system of a particular state fails to make adequate provision for an autopsy conducted by an expert pathologist familiar with SIDS. A necessary first step in helping a family to recover is an immediate autopsy. In many instances only an autopsy can furnish the evidence necessary to identify a SIDS death. Armed with this knowledge, the family's physician and other counselors can reassure the parents, and the authorities can make unmistakably clear that the child's death is one wholly attributable to natural causes.

Notwithstanding this obvious need, Dr. Bergman's studies reveal that not only were autopsies rarely done routinely but they were performed in only 25% of all cases of sudden unexplained death of an infant. In an additional 20% of the cases, only deaths involving suspicion of a crime were investigated by autopsy. In the remaining 55%, autopsies were occasionally performed depending upon the inclination of the coroner or medical examiner, availability of funds and other factors.

Dr. Bergman's study also indicates that autopsies were frequently performed by persons unfamiliar with SIDS and that death certificates were signed by pathologists in only 27% of the cases, by physicians not trained in pathology in 30% of the cases, and by non-physicians in 43% of the cases.

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\*\*Cleveland, *Sudden Infant Death Syndrome (SIDS): A Burgeoning Medicolegal Problem*, 1 Am J Law & Med. 55 (1975).

\*\*\*A. Bergman, *A Study in the Management of Syndrome Death in the United States* (1972).

Other exacerbating factors revealed in the Bergman study include the failure to make autopsy results available to parents and the use of a bewildering variety of scientific terminology to describe the cause of death. For example, Dr. Bergman found that pneumonia and suffocation were sometimes listed as incorrect diagnoses of SIDS. He also found that SIDS was the diagnosis in only 52% of the cases of sudden, unexpected, clinically unexplained infant death. On the other hand, SIDS was the diagnosis in 85% of the sudden infant deaths where autopsies were performed by expert pathologists. That is a telling contrast.

Finally, both Bergman and Cleveland noted and decried the lack of any legislative provision for counseling aggrieved parents. While the value of counseling is generally conceded,\* public funding for this service presents a difficult political question. Why, for example, should public money be spent for counseling SIDS parents and not for those parents whose children died from cancer, accidents or other causes?

In summary, the two legal aspects of SIDS I have discussed so far underscore that the capacity of the legal system to deal effectively with SIDS depends on full recognition, preferably in statutory form, of SIDS as a disease entity that results in natural death. Additionally, there is compelling evidence that there should be a provision for prompt, expert and thorough post-mortem examination with well-defined and generally accepted postmortem findings for SIDS that distinguish the disease from homicide. Legislation should also provide for the cost of the autopsy to be borne by the state and for prompt disclosure of the results to parents and to counseling personnel.

In Virginia, we are fortunate to have an enlightened death investigation system.\* Problems seem to arise in states that elect local coroners and permit them to operate with broad discretion and little supervision. We have a state-wide medical examiner system and while there is no explicit statutory recognition of SIDS, we are fortunate to have physicians and coun-

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\*Hoekelman, *The Physician's Responsibility in the Management of Sudden Infant Death Syndrome*, 128 Am. J. Dis. Child 16 (1974); Nakushian, *Restoring Parents' Equilibrium After Sudden Infant Death*, Am J Nursing (October 1976).

\*See Virginia Code §§ 32-31.9, et seq.

selors who are sensitive to the problem and who use their discretion under the statute to the fullest and most beneficial extent in the SIDS context.

But even states with specific SIDS legislation sometimes fall far short of the mark. Massachusetts, Maine and California, for example, leave unclear the parents' right to receive autopsy results. Oregon has an administrative program that seems to be the most SIDS-sensitive of all.

The passage of SIDS-sensitive legislation in Virginia and other states may also be important to the third SIDS problem I want to discuss today, a medicolegal problem that involves the effect of the legal system on the ability of the medical community to conduct epidemiological studies. Extensive, reliable and uniform data are essential to an epidemiological approach to studying the nature, causes and cure for SIDS. At present, 33 private groups collect SIDS data that are neither uniform nor mutually coherent. Surprisingly, there is, to date, no central or uniform data collection organization or entity. This long-standing need will not be met until at least 1980 when, pursuant to a 1978 amendment to the 1974 SIDS Act,\* the US Department of Health, Education and Welfare plans to establish a national uniform collection system. Under this system, HEW will also establish a national clearinghouse to disseminate educational materials if Congress provides the funding.

The HEW data collection plan is a welcome addition to the fight against SIDS, but the national system will be an effective epidemiological tool only to the extent that the state death investigation systems are adequately SIDS-sensitive or otherwise equal to the challenge of collecting reliable data.

We come now to the final legal aspect of SIDS I want to discuss with you today. This is the one I described as being of immediate concern to some and as a cloud on the horizon to others. The problem I am referring to is civil malpractice liability risks for physicians, hospitals and nurses in the SIDS context. Before I review the analytical framework needed to consider the problem, let me give you a hypothetical situation to put things into perspective.

You are a physician, an internist or gen-

eral practitioner, or perhaps a pediatrician in a relatively small community in Virginia. A couple comes to you who has just moved to the community. They have an infant child two months old. They tell you that this is their second child and that their first child was found dead in his crib at three months for reasons they have never understood. They may show you a death certificate in which the cause of death is noted as "crib death" or SIDS. They further tell you that their first child was premature as was their second. Next, they tell you they are consulting you because on four occasions they have noticed that their child has had difficulty breathing and on two of these occasions the child apparently stopped breathing altogether. On these occasions, the child seemed to turn ashen or gray before starting to breathe again after frantic efforts by the parents to blow in the baby's face and shake the baby. They are concerned that this child is in the same danger as their first child and they seek your advice. You examine the child and find him normal in all respects. What do you do and what do you advise the parents?

To answer these questions, you should refer to two sources. The first is the standards of excellence in medical care that you set for yourself personally because of your commitment to medicine as a physician. These standards are personal and not relevant to our discussion. The second source is the standard of care expected of you under the law, a violation of which could subject you to substantial legal liability.

What is the standard of care the law expects and requires of physicians? The definition of this standard of care, like the death investigation laws I spoke of earlier, is generally defined by state law. Three or four decades ago, the definition was fairly uniform around the country. It was defined simply as the action or failure to act by a physician in contravention of the standard of care observed by a reasonably prudent physician in the same locality. In order to prevail, an injured party had to produce an expert physician witness who could testify as to the appropriate standard of care for the locality and as to the defendant physician's failure to meet that standard. Further, the expert had to be prepared to testify that the defendant physician's failure to meet the local standard of care proximately caused the injury.

In response to a number of pressures, this

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\*42 U.S.C. § 300c-11.

standard was generally modified to include the notion that a physician had to meet the standard of care in the same *or similar* locality. This modification meant that an expert witness could be brought in to testify who, though not familiar with the standard of care in the specific locality, was nonetheless qualified to testify by virtue of familiarity with the standard of care in a similar locality. Whether localities were similar for this purpose frequently depended upon the number of hospitals, hospital beds, similarity in hospital equipment available and the number of practitioners and specialists.

Until July 1, 1979, the foregoing standard generally described the law in Virginia. The last session of the General Assembly, however, amended the statute to provide for a new definition.\* In essence, as of July 1, 1979, the standard of care applicable to physicians, nurses, hospitals or other health care providers in Virginia is that degree of skill and diligence practiced by a reasonably prudent practitioner in the particular field of practice or specialty in this Commonwealth. Thus, in the first instance, the standard is a state-wide standard. Note, though, that a local standard of care may still govern if any party proves by a preponderance of the evidence that the health care services or health care facilities available in the locality give rise to the standard of care which is more appropriate than the state-wide standard. The decision maker is the jury or the judge trying the case without a jury.

Unlike Virginia, some states like California have nation-wide standards of care so that a pediatrician from New York or Virginia might well qualify to testify in a California case.

Now, what sources do we refer to in order to determine the standard of care? In general, these include at least the following:

1. The practice and procedures actually being followed in Virginia at the time;

2. The content and teachings contained in current widely distributed literature such as *Pediatrics*, *Journal of Pediatrics* and the *New England Journal of Medicine*. Particularly pertinent here would be the statement of the American Academy of Pediatrics, 61 *Pediatrics* 651-52 (April 1978);

3. The training of the physician involved may be important. Thus, a board-certified neo-

natologist may well be held to a higher standard than a non-board-certified general practitioner;

4. The extent to which the subject matter, in this case SIDS, is treated in continuing medical education programs and other seminars throughout the state; and

5. The general state of the art in monitoring equipment.

Now, with this analytical framework as background, let us return to the hypothetical situation I described at the outset. Obviously, it is intended to raise the question of a physician's duty with respect to identifying high-risk SIDS infants and prescribing monitoring or other treatment for them. What, then, should the physician do in order to comply with the standard of care in Virginia? No definitive answer is available to this question, in part because no Virginia court has specifically addressed the question and in part because the state of the medical art is evolving in this area. Despite this, a few tentative observations seem warranted.

To me, it appears that the state of the art has reached the point where many believe it is feasible to identify high-risk SIDS infants, particularly in cases involving siblings of SIDS victims and survivors of near-miss episodes. This, of course, was the point of my hypothetical situation. The work of Drs. Kelly and Steinschneider certainly supports the notion that a reasonable standard of care requires identification of high-risk SIDS infants. Whether such a standard should apply to practitioners in rural or remote areas is less clear, though I think these practitioners would be imprudent to conclude otherwise.

Identifying the high-risk SIDS infant is only part of the problem. Once high-risk SIDS candidates are identified, what steps should a physician take or recommend? Again, while no definitive legal answer is available, the literature suggests that monitoring and surveillance are indicated. Thus, the statement of the American Academy of Pediatrics is instructive in noting that apart from specific treatment of any underlying disorder, "twenty-four-hour surveillance is critical to the management of prolonged apnea." As the Academy's statement notes, this may require electronic or other monitors, and the setting for the observation may include properly staffed acute care hospitals or the infant's home. Of course, it is not enough to place the infant on a monitor at home if the per-

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\* See Virginia Code § 8.01.



sons charged with surveillance are not skilled and trained in infant cardiopulmonary resuscitation and other pertinent matters. Nurses and nurse practitioners and other health care providers in the SIDS context risk incurring civil liability unless they are adequately trained to take the proper action in the event of an episode. Physicians in rural areas should consider sending the infant to an appropriate hospital if facilities are not available locally. But home monitoring may be appropriate\* where the persons involved in the surveillance are adequately trained.

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\*The question whether to prescribe an electronic monitor in appropriate situations is sometimes complicated unfortunately by the question whether such a monitor is covered by the pertinent insurance carrier. This is frequently a matter of insurance contract law and beyond the scope of my remarks here. Some suggest coverage turns on whether a specific expense is treatment of a condition or prophylactic care. I find this distinction unhelpful in the SIDS context.

The physician's duty in this context seems to me to have been summed up succinctly by Dr. Kelly, et al., in a recent article.

We conclude that infants who have experienced near-miss SIDS are at great risk of recurrent apnea, hypoxia, and sudden death. Most deaths can be prevented by supervised home monitoring of respirations and appropriate intervention by parents trained in resuscitation.\*

In closing, I must say I do not know whether the civil liability problem in the SIDS context is an immediate one or merely a cloud on the horizon. It could be neither and the problem can be avoided permanently by continuing medical education programs such as this to ensure that physicians and other health care providers in Virginia remain abreast of the latest developments in medicine.

Thank you.

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\*61 *Pediatrics* at 514 (April 1978).

## The Grief Reaction

ELOISE HAUN, M.D., *Clinical Assistant Professor of Psychiatry, Medical College of Virginia, Health Sciences Division of Virginia Commonwealth University, Richmond, Virginia*

For most parents the death of their infant is the first serious crisis in their lives. This event is regarded by all young parents as more stressful than previous deaths in the family, divorce, separation, alcoholism, or suicide. The infant death may be the first death in the family. The grief reaction is not stereotyped; it is as varied as the individuals experiencing it and the families of which they are a part. Several patterns of grief will be treated here.

One of the features of the grief reaction is reminiscing. Old people who die have a history. There are photographs, objects that are meaningful, shoes, dresses, suits and ties are left be-

hind. There are memories. A 3-month-old infant doesn't have a lot of memories associated with it. It may have a little toy or blanket. The process of internal bargaining is lost in the SIDS death. There are limited experiences and a lack of time associated with the death. Rationalization of the death is difficult because there was no recognizable cause. There is no opportunity to speculate or predict what might have been.

This leads us to the subject of guilt which has been mentioned before many times; the guilt of the parents and let us not neglect the physician. I would like to introduce the thought

that the physician might also feel grief and this should not be left out of this process. The guilt extends to family and friends. The neighbors tend to remove themselves from the parents. They don't know what to say and if they say something, it comes out wrong. The families may take offense, and in their sorrow, they may be difficult to work with and the neighbors may turn away. There is confusion among the neighbors as to what to do. There is always the lurking suspicion of child abuse and neglect. It never really goes away, regardless of what the facts are. The family is usually the resource to which the parents of the deceased child turn. It is the safest and most familiar resource, perhaps the most comfortable. However, what is happening to the American family? Is it home down on the farm or in the same old house? No, it is dispersed. We have a fragmentation of the American family and therefore a dissipation of that much needed resource. There is also the possibility of exacerbating previous psychiatric difficulties at the time of grief. Marital problems that existed prior to the infant's death are certainly amplified at the time of death. The entire extended family reacts with predictable patterns established years before the crisis. The family may be a great source of secrecy, denial, blame, ostracism, and other reactions. Among family members where there had been competition, this past hostility is revived and reinforced by the guilt.

Family also includes siblings. The siblings may be denied access to their parents because the mother and father are busy talking to the pathologist, their attorney, pediatrician, and funeral director. The little ones are left at home with a great void. The children do react. The parents are in shock or severely depressed and unable to communicate. Perhaps they are irritable. Three fourths of all siblings of a dead baby are symptomatic. Nightmares, insomnia, enuresis, syncope, and school failure and discipline problems are recorded. Children under 5 years old regard death as temporary. It is a reversible concept. There is always the fantasy that the baby is asleep or will come back. It is not a final phenomenon. Between the ages of 5 and 10 years, children have some magical thinking about death. They contrive a cause; someone or something is responsible in their mind. It is important to know that children older than 10 regard death as inevitable, irreversible

and final. These children can and should be included with the adults in sharing reactions and information.

Little children are fearful that the same thing will happen to them. There are two components to this fear. One is that if the baby died, they too could die, especially if they are under 10. They must understand that infants are the only ones who die like this; that this will not happen to them. A little child often has rich fantasies which help him or her cope with stress. These fantasies are useful and needed and it is better to let the child have them and for the family to intervene in a supportive way than to belittle them. As long as the small child can avoid the terror of expecting to die, he or she can indulge in fantasy. In the interim, brief disturbances are very common. There is a little prayer, "If I should die before I wake, I pray the Lord my soul to take," that has persisted for generations. Even without trauma children have believed that they could die in their sleep.

A second component of the fear of dying is that a young child often implicates himself or herself as contributing to or being the cause of the infant's death. Rivalry may have existed, in fact, it always does. The young child 5 to 10 years old may have wished that the infant would die. I hear this frequently in my practice. Children can say this to me because I promise I won't tell anyone else. Such a wish, if it comes true, is indicative of magical powers too frightening to tolerate. In a magical reference the person having successfully willed the infant's death must also die as punishment for the evil wish. Fear of going to sleep occurs because the child feels he or she will die as the infant died. Some children may have touched the baby or taken the bottle or blanket on the fatal day. Guilt will often occur, manifest by behavior, because the guilt itself is unspeakable. Behavioral problems are the first sign that the child needs to have more time to talk about this.

Subsequent children of SIDS death parents are targets of overprotection, anxiety, and indulgence. Sterility and spontaneous abortion are also higher in these parents. Having a replacement child is another mistake. No child can be replaced. One of the psychiatric complications of a replacement child is identity confusion. He or she asks, "Who am I? What is my significance in this family? Am I Jane, John, Tom or Jim? What is expected of me?" Survival

guilt ensues. "I lived and she died. I shouldn't be alive." Chronic depression with suicidal inclinations and resentment with its behavioral equivalents can occur.

Fathers tend to withdraw to work or pursuits outside the home. Separation and divorce are not uncommon. The young mother is abandoned emotionally by her husband and left with the responsibility for caring for the siblings. Postpartum hormonal equilibrium is often not yet established. A physiologic vulnerability exists which further accentuates the emotional reaction. The mother will "hear the baby cry" or make formula. Concentration and memory are impaired, leading to accidents in the home and possibly younger children getting injured because the mother wasn't thinking. More guilt arises. Lactation persists and the let-down reflex with flow of milk occurs at the thought or suggestion of the deceased infant. Lactation is a big problem for nursing mothers whose baby has died. Sleep disturbance occurs, too, and without sleep one doesn't cope very well anyway, so it's a vicious circle. Insomnia and nightmares can be helped with a mild sedative for a few days.

But drugs do not cure grief; they complicate and prolong it. One of the biggest problems I have is the pressure applied to prescribe medication for grief. This should be resisted, but the physician may be required to devote more time to emotional support.

Families often go away for a few weeks after the funeral of a deceased infant, but returning home is difficult. Sixty percent of families move away six months to two years after the funeral. With every subsequent loss or bereavement the memory of the infant is revived or referred to. Anniversary syndromes develop; Mother's Day, or the birthday of the infant, becomes unhappy.

I would like to share a poem written by a mother 14 years after the event. This appeared in *Pediatrics*, April 1979, and is called:

The Tenth of July\*

It was so many years ago  
When you left us.  
Why you died  
No longer matters.  
But the when remains  
And serves, one more time, as a memorial  
To remembering.  
Today is very like that day long past  
Clear and cool and out of season

For the midst of Summer.  
It stirs the memory so carefully submerged  
Until today.  
And it matters.  
Because you were.  
My mind does not mourn yesterday.  
It mourns today.  
The images that pass before my eyes  
Do not recall the infant son  
But see you running through my house  
A teenage child in search of food and gym shoes and  
maybe me.  
I do not mourn you for what you were,  
But for what can't be  
The unfinished life we didn't share.  
The very briefness of that life  
Has reached this day and makes me pause and know  
I miss you.

I remember my first SIDS death. I was a resident in Pediatrics and pregnant at the time. The clinic was about to close and the nurse was sending people away who came late. One lady protested. I was very tired, but I examined her baby. It was a well baby. The next day the ER staff said "Hey, there were three guys in here with black suits, white shirts and black ties looking for a pregnant lady doctor who examined a baby late in the Well Baby Clinic and it died suddenly." I never knew why the baby died.

Currently, I am a child psychiatrist and inevitably, in the course of history taking, I look for a dead baby. It comes up very often and the grief and mourning process goes on. It has been resolved incompletely. Often I see an alive child years later who is affected by it—a surviving twin, or a near-miss, or a child adopted to replace the dead baby. That history is very relevant and many times the whole box of tissue is gone in the course of history taking. It is worth looking for that dead baby because if it is there, its memory persists.

In conclusion, I present more questions. What happens emotionally to the infant at risk? I wonder what effect the monitor has in the home and what effect it has on a baby. I wonder what effect a monitor has on a sibling. I don't know. I wonder what can be said about physicians' anxiety about litigation, regardless of their feelings for caring for people. The emotional ramifications of SIDS are far-reaching. The grief reaction and its attendant components affect the quality of life. We have only begun to study and respond to the serious and emotional sequelae of SIDS.

\* Reprinted with permission from *Pediatrics* (63:615, 1979).

# The Parents' Reaction

SUZANNE ROWDON, *President, Northern Virginia Guild for Infant Survival*

As I sit here it appears to me that most of you are aware of SIDS through your profession and education. My awareness came like a lightning bolt one sunny afternoon when I was getting ready for Thanksgiving dinner. It left a wound that is very slow to heal and my reaction from that continues to this day.

It was 18 months ago that I had a bouncing 7-month-old daughter whom I had put to bed for her afternoon nap. I went in one hour later, which was halfway through the nap, or should have been, and found her lying on her stomach looking very relaxed. She had the blanket over her head, which was not uncommon. I reached down to pull it back into place and my heart fell—she didn't feel right—I screamed for my husband. He came running and administered CPR while I called the rescue squad. They were around the corner and were there in about one minute and rushed the baby and me to the ER. My husband brought the car as we assumed that the three of us would need a ride home. While I was waiting for him, they made me fill out forms. I waited in the "family room." No one had mentioned the word "dead," no one had stopped doing anything in the ambulance, they were working on her constantly. I assumed everything would be all right. It didn't occur to me that my child could be dead—that thought had not entered my mind—I was wondering what had happened, how long she would be in the hospital, what they were doing. I stood up and walked to the door of the family room and as I looked out the fireman who had brought us in was leaving. He saw me walk out and he turned around. He had tears in his eyes. I'll never forget those tears and I'll never forget the look of the doctor and the nurse when they were walking towards me. I don't really remember what happened after that. I remember the words "did all we could." I remember a piece of paper with a name of an organization and the words Sudden Infant Death Syndrome. The doctor took the time to tell us that there was no cause that he knew,

nothing we did had caused it. I didn't really hear. I didn't see how it could be nothing we had done; it was my baby, a baby in my care. I was responsible for feeding her, putting her to bed, getting her up, making sure she was clean, making sure she was healthy; I was responsible for her and if she died, I didn't see how it couldn't be my fault. The reaction of a parent at this point, as did my reaction, depends a lot on what happens and on the people who deal with the parent. I must say that I was a very fortunate parent; I was treated with respect by very informed people. Our rescue squad knew SIDS, knew that what they said would have an affect on me, not only that day, but the long, lonely nights ahead. The ER personnel didn't just tell me that I was not going to have a baby to take home, they took the time to explain what SIDS is and isn't, hoping that a little of what they said was going to sink in. They gave me the name of a group to contact. Unfortunately, the information was outdated, but I was lucky in a way some people aren't. A friend of mine took her baby to the ER and the resident looked at it, saw some froth around the mouth and said, "Looks like a baby who spit up and choked on it." My friend will never forget that. An autopsy proved his diagnosis wasn't right, but she'll never forget it. It is routine that a policeman must investigate unwitnessed death. Here again I was fortunate; I don't remember talking to him. He was aware of SIDS and he knew it could occur; he did not assume that it was a homicide. My pediatrician had been aware of SIDS and its management and contacted us immediately, giving us some time to pull ourselves together and let the realization set in. After being at the hospital I don't remember how I got home. I remember making funeral arrangements, but all of a sudden I was in a room looking at a bunch of baby clothes that I had to put away, that I didn't need. As I walked to the kitchen there were baby bottles, bottle brushes that I didn't need either. Luckily for my husband and me our pediatrician called and explained what was go-

ing to happen, that there would be an autopsy, that we would have to wait and that we would be discussing the autopsy. Two days later the reality had sunk in and my pediatrician said, "Let's go over this autopsy." I had been wondering why the baby was gone.

The most important thing to me at this point in terms of a reaction was dealing with other people, people who didn't know that my daughter had died. It's hard to tell a neighbor that the baby I had over at her house yesterday was dead. It's hard to say dead. You look at their faces. What do they think? Some weren't familiar with SIDS. When you say, "My baby is dead; she died of SIDS," they look at you like, "What's that?" or "I've heard of that. That means your baby suffocated. Were you taking a nap with her?" You have to explain what SIDS is because they look at you with disbelief. I was lucky in that I was able to get in touch with other parents who had lost a baby to SIDS and it gave me the opportunity to talk with people who could say, "I was there." One of the hardest things for me was to tell people that my baby was dead and for them to say "I know how you must feel." Like hell you do. You don't know what it's like to lose a baby, to sit there at night and want to rock the baby to sleep, or to wonder if the basement door is closed and to realize that it doesn't matter anymore. I was able to talk with parents in the Guild for Infant Survival. They said it was hard, but they had made it and they knew I would too. They were there in the night and in the morning.

As time went on I was able to deal with reality. Everyone began asking when I was going to have another baby. Everyone was waiting to see what I was going to do. When you do decide to have another child, your grief does not end; you are still a SIDS parent, your future chil-

dren and pregnancies are affected by that fact. You go to your obstetrician and if you're lucky, he or she will realize that this is going to be different. A SIDS parent will react differently to another pregnancy, with all the worries that every prospective parent has. Will my baby be all right? Will it be deformed? No one can say to you that only 1% of the babies born have problems and it probably won't happen to you—it already has. You have memories tucked away. Once you have gotten yourself together it is easy to push memories to the back, things that are difficult to think about. All of a sudden the emotions that you have buried are there; you want to be excited about your new baby, but you can't bury again the old emotions. You get excited at the point of birth; a whole new baby. You have this child in your arms and maybe it looks like the child you lost and maybe it doesn't. In my case they were identical—different sex but almost the same face. You begin to wonder how long this one is going to last. Is it something you can look forward to? Are you afraid? I was and I think most parents are. I think now the more you know, the more you realize that there are certain risks. No one knows the answers, but at least someone knows the correct things to ask. I think many parents are now asking the questions; they want to talk about apnea, about near-miss. SIDS parents are asking questions and the questions have to be dealt with.

I know there will be a time when I can walk into my son's room and not wonder what I'm going to do if I find him dead. My son is 7 months old, one day older than my daughter was when she died. The reaction to SIDS certainly doesn't end when the baby is two months dead. It doesn't end when you have another baby. When it ends, it is different for everyone.

## The Guild for Infant Survival

JOANNE HESBACH, *Past President, The Guild for Infant Survival of Central Virginia*

The Central Virginia Guild was started in 1976 by three families who did not know each

other. We had one family who had lost a child to SIDS and two families who had babies on mon-

itors. We all shared the same goal—we wanted to see an end to SIDS some day. We joined together and started a guild here with tremendous cooperation from the medical community. We worked mostly with Dr. David Draper and Dr. Edwin Myer.

The Guild's functions in Central Virginia are a little bit different from the other guilds throughout the country. Our SIDS families do a wonderful job talking to the new SIDS victim parents. We are notified through an Emergency Room, a physician, a nurse or a friend to call someone. If I get the number, I pass it on to our SIDS family, because these parents need someone who can say, "I've been there." Our SIDS parents are available 24 hours daily, so if a parent needs help all he or she has to do is call. We make follow-up phone calls and we visit the families.

A second function of the Guild here is that we are called when a baby needs a monitor. We get our calls strictly from the physician in charge, usually Dr. Draper or Dr. Myer. It is only through a physician's suggestion that the Guild gets involved. Our chief function is to help the parents secure a monitor whether it be through the monitor program that was established at the Medical College of Virginia in August 1977, to whom we have donated six monitors, or through insurance companies. We show the families how to operate the machine, where to put the electrodes on the baby, how to rearrange the furniture in their house so that when the alarm sounds they don't run into a chair or trip on a rug—we just give them little hints and lots of support.

Another function of the Guild is that we provide speakers for civic, church or any community organization. We try to make the community more aware of SIDS, what it is and what it is not. We tell people how to react to a SIDS death when it is a family member or a friend, what to say and how to support them.

Sue\* mentioned the rescue squads and police departments. These are usually the first people on hand after a SIDS call. What they say can make or break the parents. If they are suspicious at all because of the baby's appear-

ance, or make any remarks, such as, "what did you do to the baby?" or continue to question the family, they can heighten the guilt complex, and instead of helping the situation, really drive it into the family. The parents are going to be so much more guilt-ridden that it will take much longer to help them. When my son, Michael, was found, he was cyanotic and completely limp; I thought he was dead. I did not know he was just on the way out. I called my father-in-law in New York and told him Mike was dead and that I had killed him. That is as far as I can identify with a SIDS mother, because I had no way of knowing he was still alive until my husband yelled from the other room that he was breathing. My husband told me three years later that when the detective was questioning us he had asked if I had really beaten the baby up or had I tried to suffocate him. It is a good thing he didn't ask me that because I'd probably be in the State Mental Hospital by now. Our Guild is helping the Police Departments avoid situations like ours by showing films on how to handle such a call and what to say and what not to say. We've also donated video tapes to the police departments entitled, "SIDS—The Role of the Police Officer," and these films also show them how to be a little more compassionate. We have also had a lot of cooperation with Dr. Marcella Fierro's office.\* She has sent our brochures to new SIDS victim parents so they will know we are here, but we do not push ourselves on the parents.

When we are called by a SIDS family, we invite them to attend our meetings. Our meetings are open to anyone who wants to see an end to SIDS. We try to show the parents that they will make it after their baby dies—it will be hard, but they will make it. Our meetings are not mourning sessions. We try to look on the positive side—we want to keep the research going. We feel our meetings are good for families and we encourage people to attend them. A lot of people wonder what goes on at a SIDS meeting, but we are just like any other organization; we plan our meetings and we plan our year's activities. We are here and we want to help in any way we can.

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\*Suzanne Rowdon, a SIDS parent and President of the Northern Virginia Guild for Infant Survival.

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\* Office of the Chief Medical Examiner.

# Emergency Room Procedure

DAVID DRAPER, M.D., *Professor of Pediatrics, Medical College of Virginia, Health Sciences Division of Virginia Commonwealth University, Richmond, Virginia*

After having sat here and listened to the panel and particularly to Sue Rowdon describe her experience with her child's death, I think it has been amply explained what emergency room procedure ought to be. Obviously, there has to be someone to take responsibility for evaluating the infant, and generally that person is going to be a physician. At the same time there has to be someone who can be attentive and compassionate to the family. The physician needs to recognize and explain some of the thoughts that must be going through the parents' minds, such as, What's wrong? What's happened to our baby? What are you doing? Will he be okay? The physician is not going to have all the answers, and in these instances, it is best to say, "I don't know." At least he or she shouldn't turn away and escape behind the desk.

The physician must attempt to be as supportive as possible and explain to the family that as soon as there is more information they will be told exactly what is going on, what the doctors are trying to do as far as evaluating the baby, and if they can do anything. Finally, the physician must be able to sit down with the parents and tell them in simple terms that their baby is gone, understanding that they may not accept or totally comprehend everything. The physician should point out that the death is not anyone's fault and explain what Sudden Infant Death is to the parents. They should be encouraged to get in touch with the Central Virginia Guild for Infant Survival to find out more about Sudden Infant Death. Again, the parents are really not going to

totally comprehend everything said to them; they may only hear one out of every ten words or something of that nature. It is going to be difficult for them, but at least the process has been initiated properly.

It is important to notify the family physician as soon as possible so that he or she can be supportive of the family and quickly available to them. It shouldn't be assumed that the family physician doesn't want to hear the news. I certainly hope that I was always notified, and I hope that if it should happen again, I will be notified as soon as possible.

The people in the emergency room ought to be aware of Sudden Infant Death. In certain hospitals the infant might be taken to an emergency room that is not a pediatric emergency room. The infant may be examined by a physician who is not a pediatrician. Perhaps the only one who is available to examine the infant is a surgeon who may have no real awareness of Sudden Infant Death. Therefore, it is incumbent upon all of us who are aware of Sudden Infant Death to make everybody who might be coming in contact with it aware of the problem and how it should be handled.

Finally, I think that it is most important to be cautious of what you say to the family. You must choose your words carefully because, although the parents may only be hearing one or two words of what you say, you want to be sure they are not going to remember something that is going to have a perpetually depressing effect upon them.

# Community Involvement

MARGARET DALBY, *SIDS Consultant*

As a health care professional I want to remind you that we have come a long way in making the community aware of the Sudden Infant Death Syndrome, and we should be very proud of the State of Virginia. Part of our success is due to the cooperation we have had from the medical examiner system and to Dr. Marcella Fierro\*, who has really supported our programs. We are also lucky to have such people as Dr. Dorothy Kelly, who is working so hard toward the prevention and cure of SIDS, and the dedication of Dr. Ed Myer in getting the Medical College of Virginia to put on a program to make people aware and knowledgeable of what their response should be.

When a baby dies, the parents are the victims. You, the respondent, by attending a program like this and becoming more knowledgeable, are going to make Sue Rowdon's story the rule rather than the exception, because Sue's case was handled sensitively. It gives me hope that this will be the case for every SIDS parent,

but it takes so much education, caring and feeling; just the touch of a hand. You have no idea what one tiny human touch means at that point.

The resources in the community are there for the SIDS parent to reach out to. I can't stress enough how important education in the emergency room is, because that is where it all happens. I think that every six months there should be training sessions for the emergency room staff because there is such a frequent turnover. There should be a protocol in each emergency room where if a dead baby is brought in, a social worker is called to set in motion the procedures for dealing with SIDS parents.

Where the medical examiner is called in, through Dr. Fierro's persuasion, we now have cooperation throughout the state to notify the parents and the pediatrician; SIDS is noted as the cause of death on the death certificate and the parents receive follow-up help. Again, we have all the resources necessary here in the community; we want to educate, to assist, and to keep the awareness of SIDS moving in the positive direction it is moving in now.

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\* Office of the Chief Medical Examiner.



# The Counseling Visit

*Prepared by members of the board of the National Sudden Infant Death Syndrome Foundation, Chicago, Illinois*

The counseling opportunity for the health professional is generally referred to as the "home visit." While the most valuable setting for assistance to the family is probably within the home setting, it should be recognized that other areas or settings can be utilized. Periodically, the telephone may be the only means of reaching the family. The decision as to where the counseling visit should take place rests with the family and the counselor.

The counseling visit is an option for the family and may be refused by them. It is suggested that families in a period of grief do not always make appropriate decisions. Initial contact with the family in terms of determining a time and location should carry a positive and affirmative note from the counselor.

Whenever possible, the counseling session should include both parents or the persons primarily involved in caring for the infant. This is sometimes neither possible nor practical. The tone of the visit is determined by the nurse or counselor, but most families will take the lead without too much difficulty. The initial visit should be carefully managed so that the family can discuss the infant and the events surrounding his life and death without feeling interrogated or regarded with suspicion. The most frequent observation by personnel participating in such visits is that the family is grateful for someone who will listen and who is also capable of dispelling any potential guilt feelings.

While there are many similar patterns in SIDS families in terms of reactions and questions, each family must be considered unique in their appreciation of the event that has oc-

curred. Different lifestyles and patterns provide any number of coping mechanisms and support systems. The counselor should be prepared to accept some unique attitudes that may not be within the counselor's personal attitudes or concepts.

Since SIDS occurs primarily to young parents and families, the visit is also an opportunity for the public health professional to identify other living problems that may be intrinsically involved in the death of the child but not necessarily related to the cause of death. Marital problems, inadequate housing, financial problems, single parents, and other health and emotional problems will most likely be brought to the counselor's attention. The management and assistance of other problems should be handled in such a manner as to not potentially reinforce or provoke guilt feelings related to the child's death.

In addition to its original intent, the SIDS counseling visit can be a unique opportunity to assist families living in situations that might have otherwise been overlooked or ignored by the professional and the family.

## **Preparing for Visits to SIDS Families**

### *Choice of a nurse for visiting SIDS families*

1. Choose as few nurses as possible to make the visits so that each nurse will benefit from seeing a number of families, making her more effective.
2. The nurse should be empathetic, having a warm effect, and be a good listener.
3. The nurse should have an interest in the program.
4. The nurse should be emotionally mature and stable.
5. The nurse should be planning to remain in her position for at least a year.

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Correspondence and reprint requests to National SIDS Foundation, 310 South Michigan Avenue, Chicago, IL 60604.

### *The preparation of a nurse*

1. Orientation is essential: She must be confident about the facts of SIDS.
2. She must understand the normal grief reactions and the normal grieving process. She must read, discuss, and come to grips with her own feelings about death.
3. She must be alert to abnormal or appropriate reactions; i.e., emotional rigidity (no emotion), overintellectualization (obsessed with scientific details), and refer these people to the mental health professions.
4. She must understand the special problems of SIDS families and how to bring them out.
5. She must be familiar with sources of referral—religious advisors, family counselors, psychiatric help, social workers, and SIDS parent groups.

### *Contacting SIDS families*

1. The nurse may be the one to convey the diagnosis to the family when it is not possible for the physician to contact them. Funeral homes can be very helpful in locating families or in getting in touch with them within those first few days. It is essential to contact them immediately.
2. For making an appointment to visit the family, it is best to contact them just after the funeral services are over (within about 3 days after the death). Suggest a date and time, rather than risk the rejection of an appointment by those who are immobilized by grief and unable to plan when the decision is left up to them. In talking to a person in deep grief, the voice is a monotone, without inflection, referred to as “a wooden voice”; the answers are short and without embellishment.

### *Visiting the SIDS family*

1. Visit within two weeks of the death—usually at about one week from the date of death.
2. Consider making these visits in street clothes, rather than in uniform, if this is allowed. It has made the visit more relaxed and friendly.

3. Allow 45 minutes to an hour for each visit.
4. Questions to ask: the following outline of questions has been prepared for the nurse to use as a guide in visiting SIDS families. It is to be used as a guide only and in no way should it take on the tone of an interrogation. It will not be possible, nor should it be attempted, to cover all points in any one interview, but in visiting and talking to hundreds of parents, these are the points most often discussed.
5. A return visit may be indicated or perhaps several, depending upon the family. The nurse may leave her name and phone number, in any case, so that the family may get in touch with her if they feel the need.

### **Questions for the Nurse to Ask:**

1. How did the baby seem to you the week or so before his death?

This may bring forth a history of respiratory or other minor illness. Reassurance can be given that there is nothing that could have been detected or done to prevent the death. There may be guilt feelings if they did not take the infant to the doctor. If they did take the child to the doctor, they may be blaming him for not finding anything or for routine treatment.

2. Can you tell me what happened? (time of last feeding, when put down, when found?)

This may bring forth feelings of guilt about propping the bottle, not having checked him often enough, finding him with covers over his head, etc. They can be reassured that babies do not normally “choke to death” on milk, no matter what their position in bed. Checking a baby frequently will not prevent a death of this type. Babies do not smother in their bedclothes even when they are completely covered.

3. Had you heard of “crib death” before?

This will give you an idea of how much information is necessary.

4. Does your husband (or wife) understand the disease? (when interviewing only one parent)

This may bring out differences in adjustment or problems of one parent blaming another. Men and women seem to grieve differently. Women generally seem to have a need to talk about the death for some time; generally they are at home with constant reminders of the infant; the death has changed their whole pattern of life for the moment. The man is usually involved in work, and this offers him a diversion from the thoughts about the death. Generally he is less inclined to talk about the death.

5. Do your relatives and friends understand the disease?

This will give you the picture of how much help they have from those who are close to them. Often disturbing comments are made, out of ignorance, by those who care the most about the family. If those can be ferreted out, dealt with and information passed on to the offenders, much family turmoil will be avoided. An understanding, informed family can be the greatest asset.

### Questions the Family May Ask:

1. Do these deaths always occur at night?

No. They have occurred at all hours of the day and night, though more often at night because that is when most sleeping is done.

2. Do these deaths always occur during sleep?

Yes. Some investigators have observed an occasional infant who was awake, but in a five-year study at the University of Washington, all infants dying when awake, were found to have another disease.

3. Are all infants found on their stomachs?

No. Infants have been found sleeping in all positions—back, side, stomach.

4. What caused the blotches on the infant's face when found face down?

The blood pools by gravity after death, causing the discolored blotches. Sometimes when the baby is then put on his back, the blood drains out of the face; but this does not mean the baby was alive.

5. What caused the baby's face to be turned down into the mattress?

This occurs frequently when the baby is sleeping on his stomach and may be caused by a spasm at the time of death. Often blankets are pulled up over the head or the baby may get into peculiar positions during this terminal spasm.

6. Would it have made any difference if I had gotten him up sooner?

No. As far as we know, SIDS cannot be prevented in any way. Instead of finding your baby dead, you would have to watch him die, which is no better. We know of no evidence that resuscitation can save a SIDS baby.

7. Could he have cried and I not heard him?

No. In interviewing hundreds of families, many slept in the same room with their infants, often with the bassinet right next to the parent's bed; and no one reported any sound at all at the time of death.

8. Does this occur more often in low-income families?

Yes. The rate is higher in low-income families, living in crowded conditions. However, this does not eliminate SIDS from middle and high income groups.

9. What caused the blood around the baby's nose and mouth?

This is found frequently and results

from a drainage of fluid from the lungs. Tiny pinpoint hemorrhages occur in the lungs in SIDS, and these can discolor the lung fluid that drains out after death.

10. How do you know it wasn't suffocation?

Studies have been done which prove that babies do not suffocate in ordinary bedclothes. Deaths have occurred from suffocation due to plastic bags over heads or a thin plastic sheet adhering to an infant's face, but these are rare. The changes at autopsy in babies whose faces were uncovered in the crib are identical to those in babies whose faces were covered by bedding. The very fact that SIDS spares the newborn infant proves it is not due to weakness or inability to keep the face free of bedclothes.

11. What about having another baby? Won't I be afraid? How long should we wait?

The chances of losing another baby to SIDS are the same as for your next door neighbor who has never lost a child to SIDS. The risk is low—3 out of 1,000. You will be anxious for the first six months, but don't overprotect your new baby. You should have another baby when you feel you are ready, if your doctor feels that there are no contraindications.

### Points for Discussion:

1. You will have emotional "ups and downs" for a while.

It is common to have mood swings for quite a while. One day you feel that you are finally getting back to normal, and the next day you are "down in the dumps" again. Often the anniversary of the day, of the week of the death, the date of the month, finding an item belonging to the baby, seeing another infant, walking through the baby department, etc. will be enough to bring on depression.

2. Learn to turn off the "if only's".

Every parent goes through a series of "if only" I had gotten him up sooner, had put him to sleep in his own bed, had gotten up to check him, had covered him at midnight, etc. These thoughts have to be turned off or they continue to upset the parent. Parents have to tell themselves over and over again until they believe it, that *there is no prediction or prevention*.

3. Insomnia and bad dreams are common.

Sleep is difficult but essential for the well-being of the parent and the family. Sometimes a mild sedative will be prescribed by the family physician. Bad dreams involving death and the deceased are frequent and may be upsetting but seem to be a normal part of adjustment.

4. Somatic complaints are frequent. (stomach ache, "heart ache," etc.)

These complaints are common. A mother may comment that her stomach feels like "it is tied in knots." Usually just knowing that others have those same feelings is a comfort.

5. It takes time to accept reality.

Mothers have continued to get up at night to check the baby, have heard him crying, have continued to prepare the bath and fix the baby's food for some time after the death. This is fairly common and again this fact may be reassuring.

6. It is common not to want to be left alone.

This is a very common feeling for mothers. They find it especially disturbing to be left alone in the same house or apartment where the baby died. Many have a friend or relative come and stay with them when the husband is at work. The classic example is of the young mother who sat out in the middle of the back yard

on a tree stump whenever she was left alone at home.

7. It may be difficult to concentrate for any length of time.

Mothers especially complain of feeling that they were "going crazy" because they could not concentrate or do routine tasks that they had done all of their lives. Reading is difficult because the mind seems to wander.

8. Anorexia is common.

There is no appetite. Parents merely eat because they know they must. As mentioned above, the stomach may feel like it is "tied in knots." Try eating small amounts of easily digested food frequently, rather than three large meals.

9. Parents may be irritated by children and yet overly concerned for their welfare at the same time. Well-meaning friends and relatives may irritate.

Parents, rather than outwardly clinging to the remaining children, may be irritated by their behavior. Their "tolerance level" of naughty behavior may be very low. At the same time, they may feel overly concerned for

their safety and may want to escape the weight of responsibility for them. Being irritated by friends and relatives, often leaves the parent feeling guilty again for resenting those who are trying to help.

10. Children may need help in adjusting to the infant's death.

Children are very aware of the emotional tone of the family and will be affected in some way by such a death. The very small child (toddler) is too young for an explanation and merely needs lots of love and affection for his own security. He may have some frightening thoughts that he cannot express: "The baby died in his sleep, maybe I will too. I wished they would take the new baby back, and now he's gone." He may cling to his parents and do naughty things to get their attention. The older child may have his own guilt feelings and should be encouraged to talk about the death and the infant whenever he wants to. Parents should be alert for any problem which might relate to the death: difficulty at school, reverting to bed-wetting, nightmares, and other manifestations.

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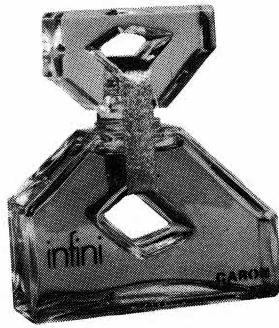
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*Presented by the Guild for Infant Survival, the National Sudden Infant Death Syndrome Foundation, and the Department of Continuing Medical Education, Medical College of Virginia*

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