

The Role of the Primary Care Physician

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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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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.