

The Nursing Role

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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.

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