PARENTS...

The Other Victims Of Infant Killer

By SHARON DARNIEDER

He was only 9 1/2 weeks old when it happened, and it didn't make any difference what color he was, what income bracket his parents were in or if he was their first or sixth child.

Within a few seconds one crisp Fall evening four years ago, Jeffrey Potter Jr. (not his real name) became one of the thousands of otherwise healthy infants across the country to die annually of Sudden Infant Death Syndrome (SIDS).

SIDS, or crib death as it's sometimes called, strikes without warning, quickly and quietly, and often minutes after a mother has just assured herself that her child is sleeping peacefully.

It happened just that fast for Jeffrey's mother, Ellen (not her real name.)

"After I fed the baby supper, I put him in his crib. I was gone perhaps five or ten minutes and when I returned he was as white as a sheet and wasn't breathing," she said.

Ellen says she didn't panic, "but the only thing I could think of was to get him to the hospital as fast as possible."

Transportation was a problem because her husband works the night shift, so she called a friend who tried mouth to-mouth resuscitation as they raced to the hospital.

"When we got there, I called Jeff at work but by the time he came it was too late. The baby was already dead," she said quietly.

An attractive, middle class couple in their midtwenties, the Potters were stunned at the suddenness of their son's death. Like thousands of other couples who lose children to SIDS, they had never heard of the disease before it claimed their baby, and they couldn't understand why.

But they got no answer to their questions because there wasn't any to give. Neither the cause nor a cure is known.

"Even though there are no specific answers to SIDS now," said Ellen, "I feel the hospital could have given us a clearer explanation. After all, we knew nothing about SIDS then."

How about her doctor? Didn't he help?

"My pediatrician was useless. He didn't ask us to come in and talk about it and he never called to see how we were," she said angrily. "I changed doctors for our second child, and I now have one that is sympathetic to SIDS parents."

Ellen has described over and over the events of the day her child died — in her own mind, for the hospital, the police, her husband.

She got up that morning as usual, fed him and left him with her sitter, a neighbor who was experienced in child care, and drove to work.

"I started working again when the baby was six weeks old because we needed the money," she explains. "When I came home that night, the sitter told me he had been constipated, so I gave him some medicine before supper."

And it was shortly afterward that her normal evening routine turned into a nightmare.

While the Potters were at the hospital, they were questioned by police — standard procedure when a child dies in a sudden, unexplained manner.

Some are immediately suspicious of SIDS parents, but Ellen had nothing but praise for the Rochester policeman who questioned them.

"He was very nice and he didn't imply any child abuse. I thought he handled it very well," she said.

Even though the baby died four years ago, Ellen's eyes still fill with tears when she talks about him.

"Each year she cries on the anniversary of his death and his birthday," her husband says softly.

Brought up a devout Catholic, Ellen admits she felt bewildered after the baby's death.

"I went to church and I kept asking God why. Why did he have to take an innocent baby?"

A relative, who is a priest, helped them a great deal and Ellen says she didn't feel bitter. She continued to go to church "because for some reason that was where I felt closest to the baby."

Her husband, although baptized a Catholic, never attended Mass regularly.

"After the baby died, I lost interest in Cod completely and I denied his very existence until just recently," he says reflectively. "Ellen and I had a very special intention that was answered after we prayed together, and I guess that made me realize there really is a Cod."

Some couples never readjust after losing a child to SIDS, each blaming the other for the death. Often, divorce is the result.

The Potters began to follow this pattern, but realized what it was doing to their marriage.

"Just when neither of us could stand it any longer," Ellen recalls, "we were put in touch with the Genesee Valley Chapter of the National Foundation for SIDS Inc., and our whole life changed."

Although they were getting support and understanding from their friends there was something missing. "Most of them didn't know anything about SIDS. We even lost a few because they thought it was our fault," she said.

They attended their first chapter meeting two months after the baby's death and there they found others who already knew what they were going through.

"The people in the chapter were wonderful. There were many nights and days that we called someone in the chapter and they helped us through the bad times," said Ellen.

Both agreed that talking with others who shared their grief helped immensely.

"I think not talking about it is had," said Ellen. "There must be a lot of questions that go unanswered in some parents' minds just because they'd rather shut out the baby's death completely."

She also pointed out that having another child helped.

"We took Jeff's death hard because he was our first child. It's never easy but somehow it's harder when you don't have any other little ones, she said.

Both were overjoyed when they learned she was pregnant with their daughter, now 2 1/2, although they worried the whole nine months before she was born.

Ellen recalls that they worried afterwards too "because we would constantly check her when she was sleeping. If I couldn't hear her breathe I'd shake her until she moved."

The most common time for SIDS deaths is during sleep and it happens most frequently from two to six months. It's rare at one year, but it can happen up until the child is two. And Ellen is quick to mention that it hardly ever strikes two children in the same family.

"It's also important for people to know that SIDS is not hereditary or contagious," she adds.

Both Ellen and Jeff have become active in the SIDS chapter here and share their concern with other parents about finding the cause of SIDS so it can be prevented.

Of all the theories doctors have explored with regard to this mysterious malady, one called laryngospasm "sounds the most plausible" to the Potters.

"The child has a spasm in his vocal cords, caused by the nervous system, which shuts off the air passage," said Filen

No matter what the answer is, parents like the Potters will continue to band together in chapters throughout the country to lend their support to other SIDS parents and to inform the community that SIDS is not child abuse and that research must be continued to find the cause.

Chapter's Aim:

To Tell Others of Plight

The Genesee Valley Chapter of the National Foundation for Sudden Infant Death Inc., (SID) has been in existence for about three years.

However, even before the organization received its charter interested parents were holding meetings.

The nonprofit organization does not have a inembership because there are no dues. However, there is a substantial mailing list of donors and those who attend meeting, which are usually held every other month or so. More information can be obtained on meeting times and dates by calling 223-1980 or 288-6638.

The chapter is financed entirely through donations and projects undertaken to raise funds, and its goal is two-fold, according to Mrs. Jean Healy, vice president.

"We exist primarily for the help and support of Sudden Infant Death Syndrome (SIDS) parents," she said, "and a very close second is to educate the community about SIDS."

She said independent, regional SIDS studies have borne out the fact that it's the "number two child killer in the country" after the first week of life up to one year. Within the first 14 years, she said such studies have shown SIDS second only to accidents.

However, Mrs. Healy also pointed out that it was hard to get national figures on the number of SIDS deaths "because not all are reported and not all babies who die from SIDS have autopsies."

SIDS is frequently confused with child abuse because of its suddenness in claiming lives. Doctors have not yet found the cause. However, autopsies quickly point out the difference between child abuse and SIDS. They are not the same.

According to figures supplied by the chapter, the Monroe County Medical Examiner's office shows that in 1971 there were four cases of child abuse resulting in death and 15 SIDS deaths.

Office figures show that in 1972 there were again four cases of child abuse deaths and 20 SIDS deaths. Figures for 1973, through mid-October, show two incidents of child abuse deaths and 10 SIDS deaths.

When asked if race makes any difference in SIDS deaths, Mrs. Healy said that percentage wise

nationally "there seems to be a higher incidence of black babies that die from it than white. There also seems to be a nationally higher percentage of SIDS deaths in the core areas of the city."

She added that it is not known if this is because the babies are black or because they happen to live, in the core.

"The thrust of the Genesee Valley Chapter this year is to reach black SIDS parents and to show them we want to help," she said.

She also mentioned that the chapter is trying to get into the rural areas and health departments to provide SIDS information.

Chapter figures from the Monroe County Medical Examiner's office show that of the 20 county babies that died of SIDS in 1972, 14 were white and 6 were black; 14 were male and 6 female. — **Damieder.**

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