

dead sibling at an early age will not be shocked by hearing the information secondhand or as an adult. It is important that parents who have borne a defective child speak with other children as they get older about the possible implications for their own offspring. They might seek genetic counseling together to obtain clearer answers.

Since the parents are deeply affected by their tragedy, it is impossible for the children to be shielded from it. Yet parents who find ways of coping well with their own grief are providing the best possible atmosphere in which their children can also come to accept and grow from the experience. More important perhaps than the specific words they say to a child are the love and security they provide and the impressions they give of being able to express and deal with their own feelings—this in itself is reassuring.

There are as yet few studies of the impact of birth tragedies on other children in a family. Surely their lives are touched by these events, some in subtle ways, others more profoundly. Because so little is known about the effects of infant death on children, parents are left to their own resources and to the help of those around them in assisting their children. Yet children are unusually resilient, often more so than adults. And it is the other children who are also remarkable resources for their parents—the source of caring, distraction, and comfort.

# 10

## Grandparents

### A Special Grief

*"It has been my dream to have a grandchild—to watch my daughter's child grow. When my daughter became pregnant, I was so happy and proud. What should I be called—Grandma—Nana? Then when my son-in-law called and told us that the baby had died at birth, I was totally devastated. How could this terrible thing have happened to my little girl? And my grandchild—the one I loved so much already. At the hospital I found it unbearable to see my daughter and her husband crying, knowing that there was nothing I could do."*

For grandparents, the death of a child is a double blow: the disappointment of their expectations for a grandchild and the pain of seeing their own children suffering.

They had shared with their children the anticipation of a child, the excitement of the growing belly, the planning of the birth. Most likely they had told all their friends about the expected grandchild, imagined how the child would look, and planned visits and gifts. Even if they never saw the baby, they still feel grief for a person who was very special to them.

Grandparents bear the added burden of knowing their own children are grieving. They wish they could protect them from the hurt as they had tried to protect them as young children many years earlier. But the young children are grown up now, and their parents can only help. They cannot take away the pain, and they are saddened by their own helplessness.

If there are no other grandchildren in the family, grandpar-

ents must go through a wrenching process of readjustment. They had gradually become accustomed to the idea of a new life stage, to their new identity as grandparents, with all the joy and ambivalence about aging which that change entails. Now they must accept a new reality. One woman described herself as a "grandmother not-to-be," and this phrase captures well the difficult shifts in identity.

Psychiatrist Robert Jay Lifton writes about the feelings of "survivor guilt" experienced by people who have lived through a holocaust that killed many others around them. They cannot understand why the others are gone and they are still there, and they feel terribly guilty for having escaped the fate of their friends and relatives. The parent, and especially the grandparent, of an infant who dies often has a similar sensation—it makes no sense that they have survived an infant. The world is in disorder, turned upside down. One grandfather said:

I'll never forget having to bury my grandchild. I felt it should have been me in that grave, not him. The children and grandchildren are supposed to bury the old people, not the other way around.

Some grandparents—grandmothers in particular—expect to have a major share in raising the baby. Their daughters may be young and unmarried, still living at home, or they may be married but planning to return to work quickly, and Grandma had planned to take care of the baby. For some grandmothers, this new role may have been unwelcome, and their sadness is mixed with relief, but for those who looked forward to the presence of a new baby in their homes there is an extra sense of personal loss.

Whatever feelings of grief the grandparents may have, most bereaved parents acknowledge that they were the most helpful and supportive people in the difficult first few days and weeks. They offered consolation, physical care, distraction, and, most important, their love. One woman remembered:

My parents were just terrific. They came immediately and took care of everything—the cooking, the cleaning, screening phone

calls, entertaining visitors. It was just what I needed those first few days—to be totally pampered and not have to worry about a thing. And there were some special moments—my mother gave me a bath, just as if I was a little girl again. And my father helped me start walking around again. Every day he took me for a beautiful walk in the park, walking slowly with me as I regained my strength.

For grandparents who live far away from their children, there are special frustrations. They want to help their children but may not have the money or time to travel. They can help by talking on the phone or writing, but they wish they could do more. Those who do visit may feel they do not want to invade their children's privacy by staying with them for an extended period of time, so their visit is brief.

Some grandparents, on the other hand, may try to control the situation more than their children want. They seek to protect the bereaved parents, making decisions for them about the funeral or about care of the grandchildren at home. This may be appreciated as helpful, but sometimes it is seen as interfering. The bereaved parent may not understand that such actions are often an effort to cope with the loss.

The grandparents' grief may be expressed in a variety of ways. Often they are extremely angry—at the doctor, at the son-in-law or daughter-in-law, and even at the baby. As they watch their children's pain, they sometimes cannot help feeling angry at its source. If the baby survives for a while, in some hospitals grandparents may visit and participate, even if briefly, in the infant's care. In this way they share more fully in the parents' love for the tiny patient.

Many grandparents also feel guilt, just as the parents do. If the baby had a genetic problem that led to the miscarriage, abortion, stillbirth, or infant death, the grandparents may feel responsible. "What if it was my genes that were passed to the child and caused this? I wonder if they blame me for what happened?" one grandmother feared. Yet the genetic process is complicated, and often abnormalities appear that are not hereditary.

If the grandparents are quite sure, based on tests or family

history, that they have transmitted a genetic problem, they must make an effort to accept that this is in no way their "fault." In talking with their children they may learn that their children do not blame them in the least. A skillful genetic counselor may also help to dispel many of the anxieties surrounding hereditary illness.

Sometimes there is a history of reproductive problems or infant loss in the grandparents' generation. The grandmother especially may wonder if she has passed along to her daughter a propensity for tragic pregnancies. This predicament has become especially acute with discoveries of the effects of the drug DES (diethylstilbestrol) on the daughters of women who took it to prevent miscarriage. These daughters are now known to experience higher-than-average fetal death. Since the drug was prescribed by physicians to assist in the creation of life, how could any of these mothers have known its potential dangers?

The tragedies of pregnancy and birth are still mysterious, and everyone involved looks for reasons to help make sense of what is so frustratingly incomprehensible. This search for explanation most often creates unnecessary suffering when it results in excessive self-blame.

One grandfather found relief from his guilt after talking it over with his daughter. He had worried that she hadn't really wanted to get pregnant and did so only in response to subtle pressure from him. When she miscarried, he felt responsible for her grief:

I was getting old and I really wanted a grandchild before I died. My daughter sensed this, and I was afraid she probably wouldn't have become pregnant as soon as she did. After talking to her one day about this feeling, she told me that she and her husband also desperately wanted children. It was a great relief.

Denial is another type of response. One man, for instance, tried to block out the existence of his dying grandchild. Finally his wife talked him into realizing that there was a baby alive and that he had to acknowledge this. He had visited his daughter at the hospital, but now he asked her to accompany him to the nursery to see the baby.

Some grandparents express their grief very openly. For example, Smialek found in her study of reactions to infant death that "in many families it has been the grandmother rather than the mother who shows the more pronounced grief reaction. In some instances it becomes apparent that the grandmother is . . . deeply grieving over the loss of a significant loved one in her past." She describes one grandmother who had herself lost an infant and felt the painful revival of her own bereavement with the death of her grandchild.

A similar example appears in another grandmother's comment:

I think I felt worse when my daughter's baby died than I did when my own died. I know how painful such an experience is and was terribly upset that my own daughter should have to face such suffering.

Grandparents should share their feelings with the parents as an important part of the recovery process for the whole family. Many grandparents feel, however, that they must conceal their pain in order to provide much-needed physical and emotional support to the bereaved couple, as well as to avoid upsetting them further. In many cases when grandparents act this way, the couple misinterprets their response. That was one mother's experience after her baby died:

My in-laws came to stay with us for two days afterward. They were helpful in preparing meals and taking care of other physical needs, but I don't remember their crying or saying anything about the baby. Afterward I wondered if they had felt any grief.

Grandparents may cover their feelings so as to reassure the grieving couple that someone in the family is in control and will take care of the household without needing to be taken care of themselves. Showing their grief, however, will probably give the bereaved the feeling of understanding and sharing.

As one grandfather of a stillborn child wrote in a letter to the *British Medical Journal*:

It may be worth mentioning that grandparents, too, can feel bereaved. My wife and I were, I think, surprised at the depth of

our own sense of loss. The main point here, of course, is that if this is ignored or repressed it can lead to family resentments . . . but if it is faced and shared, it can provide strength to both parents and grandparents and can . . . deepen relationships within the family.

# 11

## Friends and Relatives

### Helping the Bereaved

In a Baoulé village in West Africa a death has occurred. Relatives and friends gather quickly from surrounding villages, and as they arrive they all greet the bereaved family with the word Nyako. The word is repeated many times by the visitors, and the family responds, "Nyako." The men gather in a circle, and individuals rise to recite words of comfort, beginning and ending with Nyako. The mourners again respond, "Nyako."

In contrast to the Baoulé and many other cultures, Americans have no prescribed words to express their sympathy after a death occurs. Even when there are set rituals—a funeral, a wake—most Americans are uncomfortable with people who have experienced a death. We have no phrases to convey the feelings of solidarity and compassion in the face of loss. And yet it is the support of others, family and friends, that eases the isolation and anguish of bereavement.

Dr. Glenn Vernon, author of *Sociology of Death*, asked 1,500 college students what they would do if they met someone who had recently lost a loved one. Only twenty-five percent said they would mention the death. Forty percent said they would rather the other person brought up the subject. And another twenty-five percent preferred that the death not be mentioned at all. The remainder had no idea what they would do.

This study showed the feeling in a clearly defined bereavement situation. But when a pregnancy ends in tragedy, friends