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## Children at Home

Understanding Their Needs

"He stood outside my hospital room window and stretched up to see me. I knew he was disappointed, but all he said was, 'It's okay, Mom. Come home soon and we'll play together.' When I got home, he gave me his favorite toy along with a big hug and did a lot to help me around the house. I loved him more than ever then."

It is terribly difficult to explain the loss of a child to one's other children, especially when they are very young. But talking with those who are so close, whose love and concern for their parents is so complete, and helping them understand and accept what has happened can be beneficial for the parents, and the presence of these children can be wonderfully comforting. They seem all the more precious when another child has died, and their efforts to reassure grieving parents are often moving.

Every member of the family, including the children, is affected by a birth tragedy. Psychiatrist Cain noted this in writing about miscarriage: "Miscarriages do not occur in a uterus, but in a woman; and miscarriages do not occur solely in a woman, but in a family." One seven-year-old boy's response shows this impact. When his teacher said she was sorry to hear that his mom's baby had died, his reaction was, "It's OUR baby who died!"

Birth and death together. It's confusing and frightening enough for adults, but how are young children to understand it? For them the baby never really existed, or lived only briefly. What does this mean for them? Why are the parents so distraught? Too often, children's feelings about these issues are ignored or misunderstood. When parents are struggling to deal with their own feelings, they find it even harder to respond to the emotional needs of their other children.

For some parents, the dual task of trying to make sense of what has happened to them and also helping their other children may be so overwhelming that they decide to tackle only one aspect. They ignore the children or send them to stay with others until they themselves feel better, or they attend to the children's needs so completely that their own feelings are repressed. Either of these strategies may shortchange both adults and children in their need to face and respond to reality. This is why involving children and explaining to them what is happening is crucial for the parents as well as for the children. Understanding some of the possible reactions of children to infant loss can allow parents to anticipate their children's concerns and to reassure them.

Under the best of circumstances, when everything about a pregnancy and birth goes well, other children in the family have difficulty dealing with the separation from Mother when she enters the hospital, the confusion about birth and hospitals, the shift of everyone else's attention to a new child. These are "normal" problems. But if the new baby is seriously ill or has died, there are many additional problems that children may experience: confusion about what happened, the guilt of believing they might have caused the baby's death, isolation from their grieving parents, and fears for their own lives and security. They too, like their parents, are bereaved; they may be saddened, disappointed, and angry about not having the baby they expected.

During the pregnancy, the children's parents had been talking to them about birth and life, preparing them for a new sibling. It is unlikely that the possibility of a death will have been considered or mentioned. It is no wonder that children are shocked and confused when the parents tell them that the new baby will not be coming home, that he or she has died, or that the pregnancy ended in miscarriage.

Children's emotions are sometimes revealed by the explanations they give for the baby's death. When Zoë Smialek, a nurse, asked siblings why their baby brother or sister had died, they responded, "God wanted him," "I hit him," "He was bad and wouldn't stop crying," "Mommy dropped him on his head." Like their parents, children also seek explanations and try to make sense out of what has happened.

They may, as their parents do, look to their own thoughts and behavior to find a cause, feeling guilty even though there is no way they could have been responsible. Many children view the world in a very self-centered way, so they naturally see everything as somehow related to themselves. They feel alternately extremely powerful and totally helpless, and it is the feeling of powerfulness that allows and encourages the child to feel responsible.

Young children are convinced that a wish can cause something to happen, and when a death occurs they might remember wishing—perhaps unconsciously—that the baby would not arrive. Every young child watches Mother's growing abdomen with ambivalence. A new baby will be a playmate, a potential ally against parents or other siblings, a friend. On the other hand, the infant will also be the center of attention, a rival for the parents' affection and time. It is not surprising then that a child would have negative thoughts during Mother's pregnancy and, because of these thoughts, blame himself or herself for the baby's death.

A child can focus not only on his or her wishes but also on specific actions—bumping into Mother's belly, demanding to be picked up, or making too much noise and upsetting Mother. Although parents also feel guilty about their own thoughts and activities, they at least have the intellectual ability to tell themselves that the guilt is irrational. Children cannot always make such distinctions.

In some cases, children may blame their parents for what has happened to the infant and become disappointed and angry. Mother and Father had promised a cute little brother or sister and failed to produce one. One mother remembered vividly her five-year-old daughter's furious outbursts after a second miscarriage: "You're always promising me a baby and then it doesn't come! Other people have babies. Why don't we have one?"

The death of a baby is very frightening to a young child. After all, he or she was carried and delivered by the same mother whose pregnancy, this time, ended in tragedy. What is to prevent a similar fate from attacking him or her as well?

If a child has seen Mother bleeding and in severe pain, there may be fear for her safety. The images of Mother suffering physically and of both parents anxious and depressed can be frightening to the young child who thinks of adults as all-powerful.

Fear of abandonment by the mother appears to be a predominant feeling in children less than five years old when confronted by death. They are likely to be particularly frightened when the mother is in the hospital and cannot be seen. As one mother whose infant died during childbirth recalled:

My son, who was three at the time, was sure that I had died. Even though everyone told him I was okay, he saw that I was gone and that the relatives were upset. There was no phone at home, so I couldn't call. Until I actually left the hospital and saw him, he was convinced that I was dead.

The introduction of sibling visitation in many hospital maternity services for families who have had a healthy baby has helped to lessen children's fears of abandonment. When a baby is ill or has died, these fears are intensified by the awareness that something is wrong, and it becomes especially important for a child to have the chance to visit the mother in the hospital.

Scared, remorseful, and confused by the unexpected tragedy, a child can easily wonder if he or she is still loved. If the parents are so upset, they must not be satisfied with the children they already have. Parental support and reassurance are essential at this time.

Sometimes children do not express their feelings of guilt, fear, or insecurity but keep them hidden. Professionals who have studied children's reactions advise parents to raise the issues even if a child has not said anything. They suggest that it is important to remind children how normal it is for them to wonder if they are responsible for what happened, but that in no way are they to blame. The parents must emphasize that they

will be there to love their children and that the baby's death does not mean that Mother and Father will die too.

Just when they need special attention and care, children are often isolated from their parents. Mother is in the hospital or hiding in her bedroom. Father is distraught and overwhelmed, trying to help Mother, take care of house and kids, make funeral or other arrangements, and also keep up with his work.

The need to be with, talk to, and constantly reassure other children is often too much for a parent to handle. As Helen Arnstein writes,

When a child has died, it may be an almost unsurmountable burden for grief-stricken parents, struggling with their own shock and depression, anger and guilt, to give comfort and reassurance to their other child or children. It is almost cruel to ask a parent not to withdraw his attention and love from the surviving child or children who may be needing emotional support more than ever due to their own distraught feelings about the tragedy.

She assures parents that it is common for them to withdraw or for the child to be unreceptive at first and that they should not let such reactions make them feel worse than they already do. This is a time when close friends and relatives with whom a child feels comfortable can be helpful; they can spend time with him or her until parent and child are ready to reconnect.

The children may feel particularly cut off when the baby is still alive and struggling for survival in a hospital. Parents spend much of their free time going to a medical center, possibly far away and perhaps excluding children. The focus of parents' energy and concerns is necessarily on the baby, and the assistance of relatives and neighbors is crucial for the care of other children.

Siblings do not have to be excluded from this vigil, however, and may be enormously reassured when they are made a part of the family's efforts. Some sisters and brothers make pictures or select toys for the baby. When there is a long ride to a medical center, parents who bring their children have the extra hours of the trip for the family to be together. A family friend can keep children company in the waiting room. In a few hospitals, the children are allowed to see the baby through the nursery win-

dow, an important step in making the infant who is the center of so much concern a real person to them.

When there was never a visible baby—in the case of most miscarriages or ectopic pregnancies—it may be difficult for parents to know what to tell their children. The task is especially troubling for parents who choose to abort a deformed fetus. For all parents, it is hard to know how to tell a young child that the expected baby will never be there. As one parent said, "You can't even explain it to yourself; I don't know how you can explain it to the children."

Because it is so difficult to find the right thing to say, there is a temptation, especially with miscarriage, not to say anything at all. As one mother who had a two-and-a-half-year-old son at the time of her miscarriage said, "I didn't say anything to Tommy because I didn't even think he was fully aware that I was pregnant, even though I had told him we were going to have a baby." Even children under five react to the actions and feelings of their parents. Although a child may not have known for certain that his or her mother was pregnant, he or she most likely senses that something happened to upset the parents and thus becomes upset by that.

Sometimes parents, in their own confusion and shock, tell the children something that is not true and have to change their story later. This was the case for one woman who gave birth to a severely deformed infant who was expected to die almost immediately:

When you have two others at home, you don't know what to say to them. They were all very little and waiting at home for their new baby. At first I told them the baby died. I just didn't know what to tell them. I couldn't believe this was happening to me. My youngest child was four years old—how do you go about trying to explain? Then the baby didn't die right away. The kids could tell I was upset. People were coming over and whispering. The phones were ringing. The hospital kept calling. A social worker came to talk about whether we would institutionalize him. Finally, I had to sit down and tell them that the baby was still alive but would never come home.

Just as in the case of Tommy, the two-and-a-half-year-old whose mother miscarried, these two children were certainly aware

of their parents' moods and of the changes in their environment. Children cannot be deceived easily nor can they be protected from tragedy. A child who is misled or told nothing may later on wonder whether other important matters are being discussed honestly.

Death has been a taboo subject in American society, and children especially have been protected from it. They rarely see people dying because this usually occurs in hospitals. Funerals have been deemphasized and grieving is often suppressed. Even so, children are aware of death and need to understand it when it happens.

Rabbi Earl Grollman, the editor of Explaining Death to Children, acknowledges that it is easier to advise parents on what not to say about death. No one formula exists that is always appropriate. Grollman suggests introducing the idea and the reality of death to children at an early age, using examples of animals and flowers, so that a family crisis is not their first exposure to death. The best that grieving parents can be expected to do is present the facts simply and clearly, taking into account the child's age and experience.

The thought of dying occurs at a very young age. Most school-age children have thought about death a great deal, and although they may not mention it, it is a part of their fantasies and play. At all ages, children have misconceptions about death. For example, one three-year-old was about to visit her aunt's new baby a few months after her own mother's stillbirth. The three-year-old said, "Mommy, let's go visit the baby now before he dies." She thought that all babies die.

Children's reactions vary considerably according to age. Very young children may be most concerned about the disturbance in their routine and fear they will not be taken care of. A very common reaction in somewhat older children is a change in behavior, such as increased aggressiveness, playing dead, or breaking toys. It is more difficult for an older child to express grief directly if he or she has been told that crying is a sign of childishness.

The efforts of adults to protect children from the reality of death often add to their confusion. For instance, saying that a dead person has gone on a trip or is asleep may lead a child to be afraid that he or she will die while traveling or sleeping. Even explaining simply that the baby was sick and therefore died, without distinguishing a life-threatening disorder from ordinary diseases, may result in tremendous anxiety in a child when minor illness occurs.

A very common source of confusion for a young child is not understanding what happens to a person after death. Told that the baby is in heaven, a child may be confused by a grave in the ground or may look for the infant whenever he or she is in a high place. One child was afraid of going in an elevator because he connected it in his mind to the baby going up to heaven. Even saying that God wanted the baby to be with Him may lead the child to be angry at God and afraid that he or she will be chosen next. The lesson that God loves good children may frighten a child into thinking it is better to be bad and survive. The familiar phrase "We lost our baby" may also be confusing to a young child, since many children interpret what they hear literally. This can be seen in the account cited by Dr. Roberta Times in Living with an Empty Chair:

At age three or four while shopping with my mother I overheard a conversation with a neighbor—"It's a shame she lost her mother—she was so young." I envisioned a girl my age walking out of a store, noticing her mother wasn't following, and not being able to find her.... For years I couldn't understand why the girl had stopped looking for her mother, and how it was possible for them to never find each other.

It is essential that both younger and older children express their feelings, fears, and questions. Yet discussions are unlikely to occur all at once, as children usually resent being forced to talk about their feelings. In many cases, however, when there is no release for emotions, symptoms of disturbance may appear at a later time. Dr. Cain and his associates found some cases of long-term psychological problems, such as fears of marriage and childbearing, rooted in a mother's miscarriage. These might be prevented if the child is encouraged to ask what happened and

feels reassured by parents. Sometimes professional counseling for the parents and/or child may be required.

One child's temporarily disturbed reaction is cited by Eda LeShan, in *Learning to Say Good-by*. She tells the story of a seven-year-old whose parents had a premature baby who died shortly after birth. The baby was cremated and there was no funeral. The boy wanted to know where the baby was but didn't ask. Instead, he imagined the baby was in the house. As a result, he would not open closets or drawers because he was afraid of coming upon a dead baby. When his parents finally understood the reason for their son's behavior, they were able to assist him in overcoming his fears, with the help of counseling.

Having a funeral is a healthy way for the family to start to share the mourning process together and to avoid the kinds of problems this seven-year-old experienced. Some parents choose to protect their children by keeping them away from the funeral and from the other aspects of mourning. Most professionals believe that a child around seven or older should be encouraged—but not forced—to attend the funeral in order to recognize the reality of death and feel included in an important family event. An explanation in advance about what will happen can lessen the anxiety and confusion a child may have. If the child is with someone he or she feels close to and is given a chance to ask questions, the funeral can be beneficial and provide a basis for talking about the baby with parents later.

Often children seem to understand, change the subject quickly, and act as if it is forgotten. But questions frequently arise later as they continue to seek an understanding of what happened. It is not unusual for children's concerns to emerge in forms that may not be obviously related to the loss—in their games, in their drawings, in their dreams—providing parents the opportunity to discuss the events and their feelings with the children again.

Talking with their children about the dead infant, even years afterward, can be helpful to parents and children. One woman told of her son's reaction to her six miscarriages:

My son complains sometimes that he is an only child. I tell him that there might have been six others and look at all the fights

you'd be having now. We sit down and talk about what their names might have been. He would say, "Oh, you wouldn't call them this or that name." It is a good relationship, and talking with him about something that is so important to both of us brings us closer. We're very open with each other, and I always try to answer his questions.

Parents are sometimes shocked when children bring up the tragedy some years later and use it as a convenient vehicle to express their anger or insecurity. One mother of an eight-year-old whose twin had died in infancy had such an experience when she scolded her daughter. The child responded, "I'll bet you wish my sister were here instead of me, that it was me who died instead." The mother was able to remain firm in her scolding while still reassuring the daughter of her love.

The SHARE organization (see Appendix) has published a book for children called *Thumpy's Story* about a bunny rabbit whose sibling dies. In a simple and straightforward way it conveys to a child the emotions he or she may feel in this situation. The child can use a Thumpy workbook to write down his or her own feelings. Books like these can give parents a way of opening the discussion with their children.

Having experienced one tragedy, parents may be tempted to spoil their children, those they already have and the ones who come later. They are also certain to be extra fearful for their well-being. These normal fears may lead to overprotectiveness and anxiety in relations with the children.

Carolyn Szybist writes about what happened to her soon after the tragic death of her son:

I became the perfect, overprotective, smothering, all-consuming parent to my young daughter. I was afraid to let her from my sight but also afraid to accept the responsibility for her care. It was a time of decisionless decisions. I was her constant companion and playmate. I needed others to help with her care but resented their helpfulness.

The difficult task of explaining arises again when the parents have children later on. Some parents prefer to hide the tragedy until the children are grown, but a child who becomes aware of a 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.

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## 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-