

Infant Death

"... I watched her breathe every precious breath on the respirator. I saw her covered with wires and tubes. I kept watch. She was special to me and I would tell her over and over, 'Daddy is here. Daddy loves you.' The three days she lived were hell—not knowing if she would make it, uncertain about what plans we should make. Somehow I thought she would live; I was hopeful. When she died, at least I was there with her. The grief was unbearable. But there was also a sense of relief. The uncertainty, the waiting were finally over."

The baby who is alive at birth but critically ill, whether he or she lives a few hours, days, weeks, or even months, creates for parents a painful time of waiting. They are tormented by the uncertainty, the hopes and the fears of the outcome.

One of the most difficult feelings for parents to deal with in a situation like this is the uncertainty of not knowing if the baby will live and be healthy. Yet they have other worries too. At a time when the mother is physically weakened by the birth (particularly if she has had a Caesarean), she is anxious about wanting to spend time with the infant and also wanting to care for her other children at home. If the baby is transferred to a distant medical center, there are additional complications of traveling there and staying in a strange city and having to rely on unfamiliar doctors. The often exorbitant costs of travel and of care for the baby also trouble the parents.

For many, there is the added dilemma of not knowing how to

relate to this new baby. How attached should they become to a baby who may be dying? Should they have a baptism or naming ceremony as they had planned? Should they send out the announcement cards? What should they do with the clothes and toys they have already received as gifts?

Some cases are complicated by the birth of a baby with such severe physical or mental abnormalities that a decision about whether to treat the baby becomes an issue. This situation thrusts the parents into an area of considerable medical, legal, and ethical controversy, but also, more important, one of severe personal anguish.

Until recently, parents were excluded from the hospital nursery and suffered all the more from being unable to do anything for their babies. But new developments in research have both dispelled worries about infection when proper precautions are taken and demonstrated the value of parental contact with their babies. Now, many hospitals encourage parents to visit, to feed, and to care for their baby.

A variety of conditions are responsible for early infant death. The most common are premature birth, brain damage occurring before or during the birth due to a lack of oxygen, and congenital abnormalities. A rapidly growing cause of newborn death is the passage of the AIDS virus from an infected mother. In other cases a baby appears to be healthy at the time of birth, but then a life-threatening condition (such as a defective heart or liver) becomes evident after several days or weeks.

Prematurity and low birth weight (below 2500 grams) are still the leading causes of neonatal death. There is no known reason why some babies arrive early, and there are as yet few ways to prevent this from happening. Many of these babies, with the aid of intensive medical care, live healthy normal lives, yet other babies die or will be chronically ill. Parents whose baby has a premature birth are caught off guard, and the ideal natural birth becomes a frantic and frightening experience. They are not prepared to be parents so soon.

Sally and Ken's response to the birth of their second child ten weeks early typifies some of the feelings that many parents have. Sally, a nursery school teacher, had planned to have the baby

after the school term was over. She was totally surprised and unprepared when she went into premature labor one morning just as she was getting ready to go to work.

We were all sitting at the breakfast table—my husband, our son, and myself—and suddenly I felt like I was sitting in a puddle. My water had broken. I was astonished to realize that I was in active labor. I went upstairs quickly so that my son wouldn't see me in such a state. Ken called for an ambulance, and because there wasn't enough time to get to my obstetrician in the city, I was taken to the emergency room of a local hospital where a resident delivered the baby. Everything was so chaotic. I just couldn't believe I was really having a baby already. Then I heard her crying faintly. I had only a quick glance of a tiny baby before she was rushed away.

She was transferred immediately to another hospital that had the equipment and special care for her needs. My husband went with her. I asked if I could be transferred to the same hospital that she was in, but was told that they did not have enough bed space. So I just lay in my bed feeling more alone and empty than I'd ever felt in my life, wondering if it were all a dream.

I thought I was being punished, that I had caused her to be born early because I had a cold and was constantly coughing. I felt totally useless and unneeded and convinced that I was a terrible mother.

I couldn't do anything to help my baby. I didn't even know what was happening to her. I was so isolated. And I worried about my son, who must have been scared and confused. I was a total failure and felt very sorry for myself.

It helped a lot when Ken came that night and brought a Polaroid picture of the baby. What a surprise. I was glad at least to have that picture, because my fear was that I would never see her again. We had decided if it were a girl we would call her Rebecca. Even though we weren't sure whether she would make it, we felt at least she should have a name. So the little baby in the picture was now Rebecca.

She died the day I left the hospital. I never even had a chance to hold my baby. I'll never stop regretting that.

In most cases a premature birth is an emergency situation. Many women do not recognize the first signs of labor, thinking the contractions to be gas pains. By the time the pains are

recognized as labor, delivery may be imminent. It is a frightening time for the couple.

If the baby must be transferred to another hospital, the father has a special role, very different from the one that he had expected. Suddenly his responsibilities are enormous, and he is the one who at first has the most contact with the baby. Ken was amazed at his own reaction:

I went to the medical center when Rebecca was transferred there, and all I could think about was how scared I was. I was scared for Sally and hated leaving her behind, and I was scared for the baby, that she might die. When I went into the intensive care unit, a nurse asked if I wanted to touch Rebecca. That really petrified me. She was so tiny, I was sure I would hurt her and then never be able to forgive myself. But the staff was very helpful, and over those next few horrible days I developed a special relationship with that baby. I felt that I was responsible for her, and I struggled with her as she fought to live. I was devastated when she died.

The survival rate among premature infants has been greatly improved by new medical techniques and by the organization of regional intensive care units for newborns. But all too often the physical problems presented by these tiny infants, particularly their inability to retain heat and the poor development of their lungs, cannot be solved. Frequently appropriate medical care is not available. Some forms of prematurity continue to be a mystery to obstetricians. If the numbers of infant deaths can be dramatically reduced in the future, thousands of families will be spared the grief that Ken and Sally experienced.

One of the risky conditions that may lead to premature delivery is a multiple birth. When two or more infants are born together, the chances of death are increased. Parents then grieve for several children at once. When one twin is dying and the other survives, parents must face the almost impossible task of caring for and grieving for one child while rejoicing over the other's survival. There is resentment toward the sick baby for requiring so much energy and attention and toward the healthy baby for being so well and expecting all the loving care any new

baby needs. Added to anger is the feeling of guilt for not being able to give enough attention to either of them.

Whether a baby is in trouble because of prematurity or because of some other cause, parents wonder what was wrong with their own bodies that caused the tragedy. If there is a possibility of genetically caused deformities, the crisis of self-doubt can affect grandparents and other family members as well.

When an infant's death is due to brain damage resulting from a break in the oxygen supply around the time of birth, a common feeling is one of anger toward the doctor. The baby was healthy; the doctor should have been aware of distress, should have prevented it somehow. In some cases this anger is justified, but often it is simply a natural response to the frustration of not being able to control every aspect of birth and guarantee a normal outcome.

Physicians also experience this frustration, and in response some may avoid the parents whose infant represents a failure to them, even if nothing they could have done would have made any difference. This is especially unfortunate at a time when parents are seeking to understand as much as possible about their child's condition.

For example, when Janet and Ed's son, Joshua, was born with a condition called spina bifida, they were very concerned to know just what this meant. They were fortunate to be in a hospital where a medical team was accustomed to working with infants who have this condition and with their parents. Having six weeks with Joshua gave Ed and Janet a chance to know him, to feel at ease with the nursery and staff, and to begin to prepare themselves for their new son's death.

When Janet went into labor and arrived at the hospital it was decided that, because the baby was in a breech position, a Caesarean would be performed. Janet was awake during the birth, and so she was aware that something was wrong:

At the moment the baby was born, I heard him cry. Everybody was working hard around my feet, and no one said anything. I asked, "What is wrong?" The doctor didn't say anything. As they

moved the baby to an isolette I could see a sac on his back. I asked, "What is that on his back?" and the doctor quietly said, "Let's talk about it later." My heart was pounding and I said, "No, what is that?" I had to know. He said the baby had a little problem and that we would not know more until he talked to the neonatologist. I had no choice but to wait. The nightmare had just started.

I was in the recovery room for four hours, still not knowing what was wrong and how serious the baby's condition was. I was very uncomfortable and in a lot of pain. I was angry at that baby for causing me so much pain and then for not being perfect.

Later, when I was in my room, the doctor came in with a specialist. They told Ed and me that it was spina bifida—I had never heard of that condition. They explained that it was a serious birth defect resulting from the abnormal formation of the spine, and that in Joshua's case, there were other problems as well. They presented a very bleak outlook. They thought that he would not live through the night. I was too weak to go up to the nursery that night, but the next day, when they told me he was alive, I was determined to go and see him.

I knew that the baby had abnormalities, but I had no idea what to expect. It was a very strange feeling, waiting to see my baby, wondering how I'd react to him. I felt self-conscious and embarrassed, sure that everyone knew that I was the one who had the deformed baby.

The nurse helped me to scrub and then wheeled me into a quiet spare room in the nursery area. She prepared me a little by saying what Joshua would look like and what kinds of equipment were used in the newborn unit. When he was brought to me, I thought, "Is this my baby?" I felt uncomfortable as the nurse watched, but she left and then I was able to look more closely at him. I was surprised that he looked just like a baby, not a monster.

I was exhausted after the Caesarean and couldn't stay long. The nurses let me know that I could call or come any time, day or night. They would answer any question I had about his treatment. They always talked about little Josh, and they asked how my husband and I were doing. Their attitude was fantastic. It was the best thing that happened to me since I entered the hospital.

The staff members in many neonatal intensive care units throughout the United States are not only skilled at providing for the baby's care, but they are also increasingly sensitive to the emotional needs of the parents. Working in teams, they are

specially trained to recognize the importance of involving parents in every possible way. The nursery, with all its machinery, wires, tubes, and fragile babies, may seem ominous to the outsider, but for the parents who have a baby in the unit it becomes a special place—their baby's home.

The staff in these nurseries work hard to create this homelike environment for the baby. They decorate the walls, encourage parents to bring in toys, music, and mobiles, and attempt to stimulate the infants' senses in as many ways as possible. In some places tapes of the parents' voices are often played.

When several families have infants in a special care nursery at the same time, they can sometimes provide one another with encouragement and consolation. Even though they are strangers, they recognize the common bond that helps them understand each other's feelings better than anyone else can. In some medical centers, formal groups have been organized so that parents have the opportunity to meet and talk with each other and with a staff person, who can answer the many questions that always arise.

One way that mothers can become more involved in the care of their babies is by nursing. On her second visit to the nursery, Janet was asked if she wanted to try to nurse her baby. She recalled:

I jumped at the chance. I had no idea they would let me. I had felt so inadequate compared to the nurses—it seemed that they were more his mother than I was. Now that I had a special, important function, it made me feel useful. The baby did not suck very well and I was tired after the Caesarean, but I used a pump most of the time and the nurses were very encouraging. I finally began to feel like I was really his mother.

For many parents who know that the baby is sure to die, the decision to nurse can be difficult. But many mothers are not even aware that it is possible to nurse their baby. If the baby is on a respirator, they can use a breast pump and the baby will be fed the milk through a tube. When a hospital does not have a pump, a member of La Leche League can be helpful to a mother who wishes to nurse.

Janet was fortunate to be in the same hospital as the baby so that she could visit him often. It was also easier for Ed. He did not have to run back and forth between two hospitals, visiting his wife in one and the baby in another. They had easier access to the information they needed and could share in decisions concerning the baby's care.

Sally and Ken did not have such an advantage. Sally had a very difficult stay in the hospital because her baby was transferred to another hospital. Had she been able to move too, she would have had a chance to see her baby and her feelings of isolation would have been avoided. Although there are often valid reasons why a mother cannot be moved with her child, such as lack of bed space, the woman's condition, or the doctor's reluctance either to refer a patient or travel to see her, both hospitals should make every effort to allow a couple the possibility of being with their baby.

When the hospital with the intensive care nursery is very distant from the woman's family or when the transfer would create a great financial burden, some families prefer not to move the mother. If she does not go with the baby—for whatever reason—the possibility of calling the second hospital at any time to talk about the baby's condition is crucial. It has also become the practice in many hospitals to bring a baby to the mother to hold or at least touch before he or she is transferred. If this had been done for Sally, she would not have to regret so strongly the lack of any contact with her baby.

Cost is a factor for most parents in this situation. They worry about the bills for the specialists and the operations, and the expense of the intensive care nursery, which in many places is well over \$1000 per day. They rarely talk about finance at the time because their main concern is the life and health of the baby, yet they wonder how they are going to be able to pay for everything.

After the baby has died and the bills begin to arrive, some parents feel very bitter. As one parent said, "Don't you think watching the suffering and death of our baby was punishment enough? Then to get a \$50,000 bill to pay on top of that. It's so

unfair." Some doctors reduce their charges when a baby dies, but the total cost is usually still enormous.

When Ed began to recover from the initial shock of his son Joshua's diagnosis and realized that the baby would live for many more days or even weeks, he started to worry about finances. Since he was embarrassed to ask anyone about cost, fearing he would be thought heartless, he was very relieved when the social worker working in the newborn unit raised the issue. She helped him review his insurance coverage and fill out the necessary forms for financial assistance. With this taken care of, he could concentrate more completely on his son's health.

Ed and Janet worried a great deal about how to behave toward the baby. Aside from fearing that they might harm him by any wrong move, they were afraid of becoming too attached to him. As Ed recalled:

I wanted to love that baby, to cuddle him and kiss him just like every other parent with a normal child. But I needed to protect myself too. I worried that every day I spent with him would make it harder to lose him. We grew to love him in spite of ourselves—he looked so cute and helpless. We wanted him to live and come home with us, but we also knew that if he survived, our lives would be totally overwhelmed by the care of a very sick child. We felt that he could never live a happy life. I was torn apart by all these different emotions.

As the days went on, I was getting used to the fact that he would die, and I found myself letting go and wanting to go see him less and less. I felt guilty about that, and I felt self-conscious about how people expected me to be acting. The social worker helped by just reassuring us that whatever we felt comfortable doing or whatever we were feeling was okay. Now I look back at the time I spent with him as being very special.

One of the worst dilemmas for parents arises when there is a question about whether their baby should be allowed to die. Because of advances in medical technology during the past decades, doctors are able to keep many gravely ill infants alive. However, the medical profession and the public have become concerned with the "quality of life"; the question of whether every infant should be treated with heroic measures, no matter what its condition, has been hotly debated.

Newborn euthanasia is never voluntary. A decision is made for the baby, and the baby cannot state his or her feelings. Part of the problem is determining who should make the decision. Who will be the baby's advocate? How does one define the "quality of life"? Is it legal to let a baby die?

Several well-publicized "Baby Doe" cases focused public attention on these questions in the early 1980s. An Indiana infant born in 1982 with Down's syndrome died from a condition which could have been surgically corrected after his parents refused surgery and obtained court approval of their decision. This case prompted a response from the Reagan administration, requiring that all handicapped infants be treated. Hospitals risked losing federal funding if they did not comply, and notices were posted in hospitals giving a toll-free hotline for people to call with anonymous reports of violations. "Baby Doe squads" were assigned to enforce these rules.

Objections from professional groups such as the American Academy of Pediatrics and several court rulings led to some modification of the rules, allowing very limited circumstances for withholding care—essentially, when the treatment would not prevent the death of the infant. The posted notices, the hot line and the "Baby Doe squads" were eliminated. The revised regulations also recommended the establishment of Infant Care Review Committees for discussion of complicated situations. These strict criteria for withholding treatment were overturned in court, but further regulations have led to continued restrictions in some states.

The controversy and publicity which surrounded the Baby Doe rules have reduced the possibility, which once existed for parents and physicians, to choose not to keep a severely deformed baby alive. Such choices were made with great pain, but with an awareness of the likelihood of very negative effects of further treatment on both the infant and the family.

Parents usually need and want the opportunity to be included in the decision, to have all the information shared with them. This requires considerable effort and patience on the part of the physicians, since it is difficult for parents who are upset and still in shock to comprehend all the facts and opinions.

Dr. Raymond S. Duff and Dr. A.G.M. Campbell, who have written about the ethics of the intensive care nursery, explain the way cases are treated at Yale-New Haven Hospital:

As a given problem may require, some or all of several persons (including families, nurses, social workers, physicians, chaplains, and others) may convene to exchange information and reach decisions. Thus, staff and parents function more or less as a small community in which a concerted attempt is made to ensure that each member may participate and know the family will not have to bear that heavy burden alone.

This sounds ideal. However, because many physicians have a difficult time dealing with these situations or want to spare parents from the heavy burden of making a decision or because of hospital practices, this "community participation" does not always occur. Many hospitals have created ethics committees to review individual cases where there are special problems to be discussed. But most often the physician makes a decision, and it is carried out without further discussion or consultation.

Generally, parents accept the physician's advice. If there is a disagreement, however, this adds to their frustration. For instance, parents may feel that life with a retarded or deformed child will be intolerable and ask that treatment be discontinued. In some hospitals they are treated as if they are criminals committing murder. Some doctors insist on taking every possible measure to save a baby's life. As one doctor said, "I was trained to cure, to heal, not to let die." Many physicians believe that they must be the baby's advocate, defending every effort to save life. The physicians may take the parents to court to obtain a decision. In extreme cases, if the court decides against them, the parents may give up custody of their infant.

In a reverse case, parents may urge the physician to take every possible measure to keep their baby alive when the prognosis is hopeless or when the physician believes that the parents do not comprehend the consequences of doing so. The physician in these cases will continue treatment but may also continue to advise the parents about the situation, allowing them time to reconsider.

To make any decision under such circumstances is horrendous for everyone, but to avoid the issue altogether is worse. As Duff and Campbell wrote, "... pretending there is no decision to be made is an arbitrary and potentially devastating decision of default. Since families and patients must live with the problem one way or another in any case, the physician's failure to face the issues may constitute a victimizing abandonment of patients and their families in times of greatest needs."

Whichever option is taken, the parents suffer the consequences of wondering if they made the right decision and what their lives would be like if they had made a different choice. If the decision is made to let the baby die, the torment for the parents continues. Watching their son or daughter die is devastating, and living with the choice takes courage.

Peg and Rick's experience illustrates some of the feelings and confusions that surround parents when they must decide whether or not to preserve the life of their child. They had been married eight years and had been trying to have a family since they were married. They desperately wanted children and were ecstatic when Peg was pregnant. Then their daughter was born with a severe abnormality that was diagnosed soon after birth. Peg recounts their ordeal:

I can't tell you how happy we were when Kim was born. Although the doctor had noticed at the delivery that two of her fingers were webbed, he left on an optimistic note, and we were very proud and confident of our new little daughter. Later that day, another doctor noticed that one ear was set lower than the other, and we were told that there was a good possibility that there were other abnormalities. We panicked. We could tell by the way they told us that it was very serious.

The next day they noticed other problems with her heart, and the neonatologist who was called in expressed his concern that it was adding up to a syndrome. We thought he meant Down's syndrome, since that is really all we knew about. He explained that they thought it was something called trisomy 18. The picture he drew of our little girl was grim—severe mental retardation, major heart problems, and many other abnormalities. He called for a second opinion and they were ninety percent sure it was this syndrome, but they could not be absolutely certain without chromosome studies.

Then they asked us if they should continue rigorous treatment. I was astounded—first that they should ask that question and second of all I thought that there was a ten percent chance that everything was not as bad as they thought. In the back of my mind was the fact that I was a miracle baby. I was an Rh baby and it was thought with certainty that I would not be alive. Knowing this, I would grab onto any golden thread about her condition. I couldn't make this decision without knowing for certain.

Other doctors were called in—a geneticist, another neonatologist—names of specialists I had never even heard of. It all happened quickly and I was confused and numbed by the experience. I thought that period of time was the most difficult in my life. My whole body was affected—I couldn't eat or sleep. It was hard to digest all the information from all the different doctors.

After the tests confirmed that what they had said was certain, my husband and I agreed with the medical staff that all heroics should be stopped. As much as we desperately wanted a child, we felt that it was not fair to bring a child into this world who would live only with such pain.

We never shared the decision we had to make with most of our friends and relatives. I guess we were afraid how we might look to them and that they would not understand. During the time the baby lived, people would try to be encouraging about her survival. This may sound terrible, but I would go to the hospital every day and pray that she die. People didn't understand that; they were praying that she live and I was praying that she die. I don't understand it all myself.

The nurses showed me how to feed Kim and change her. I would dress her in cute clothes. She was a good baby. As time went on, it became harder to visit her. I knew she was going to die and felt guilty if I did not go. I wanted to be with her, especially when she died, but it was also so hard to be there.

Kim lived three and a half weeks. She died at 2 o'clock in the morning. We went back that day and they let us see her. I dressed her and held her and then said good-bye.

After she died, I felt temporary relief, and then the grief started all over again. But soon after I kept thinking to myself over and over, what have I done? What if we had continued treatment? Did I make the right decision? Even though I knew that I was not alone in making the decision and the doctors had encouraged it, I felt responsible. I was her mother. I had a veto. It took many months of hashing it out and talking it over with the few people whom I did tell. Eventually I felt resolved with the facts and believed that the decision was for the best.

Rick was also very upset by the events:

I saw Kim every day, but after a week I could no longer visit her—I felt I was torturing myself watching her die. I came one last time and said good-bye. I am sorry it all happened and that we had such an ordeal to go through. However, I would still make the same decision and I am still convinced that it was the best thing for the baby.

The majority of infant deaths occur despite every effort to preserve life, and the question of discontinuing treatment does not arise regularly. But it does happen often enough to be an issue for many parents.

All these parents, except Sally, had an opportunity to be with their infants. This gave them vivid memories to cherish, even though they were of a brief and trying time. All of them remember the painful day when they buried the baby. They selected simple markers with the baby's name and dates of birth and death. One family chose a plot next to the grave of the beloved grandmother for whom the baby had been named. Another couple decided to cremate their child and bury him in a beautiful countryside setting under a cherry tree. They wrote their own simple memorial service to say their farewell.

All the parents mentioned their depression, their constant preoccupation with the events surrounding the baby's birth and death. As one mother said: "It takes a long time before these feelings are no longer a part of every day or even every hour. I always picture in my mind that tiny baby, crying in the nursery, fighting to live. But I can think of her now without so much pain and feel glad that she was part of our family at least for a little while."