

Prologue

We met as young children, we grew up together, and together we almost became mothers. We were both thirty when we became pregnant, and we shared with each other the joyful anticipation of motherhood. But nothing in our experience had prepared either of us for what actually was to happen. Childbirth is supposed to be a natural, a blessed event. But not all stories have happy endings. Neither of ours did.

Judy's experience:

My pregnancy was an easy one. Although I had the usual fears and worries of any expectant mother, I felt healthy and confident. I had read a number of critiques of present-day childbirth practices in America, and I looked for a physician who believed, as I did, that delivery should not be assisted with potentially harmful drugs and machines, unless necessary. Since I lived in a small town, my choices were limited. But I found the physician I wanted, and in long and friendly discussions during prenatal visits we planned for the baby's arrival.

My husband, Barry, participated with me in both Lamaze and hospital classes, and I took a prenatal exercise course at the Y. Besides reading and rehearsing and planning for the big day, we also took great delight in shopping for baby clothes, bedding, furniture, and all the supplies. We bought a secondhand crib and refinished it lovingly. We decorated the nursery with colorful mobiles and pictures. We even addressed the birth-announcement cards and drew up an invitation list for the party we were planning.

On a sunny June day I went into labor. At the beginning, since the contractions were still at least ten minutes apart and I was not really uncomfortable, we spent the day walking and working in the garden. We even commented on how considerate and gentle this baby must be to begin its arrival so easily and on such a pretty day. That evening we went to the hospital, calm but excited, and began our familiar and very helpful Lamaze routine.

At 10:00 P.M. the doctor told us the baby was in a breech position. He brought in the obstetrician who was on call that night to assist with the delivery. Our hopes for a labor room birth vanished, and for the next several hours the possibility of a Caesarean was considered.

I was wheeled to X ray, then hooked up to an intravenous, and had a blood sample taken. I began to feel poked and prodded from every direction. The doctors decided, on the basis of the X ray and the progress of labor, not to perform a Caesarean.

Hours later, I was wheeled into the delivery room. When I saw myself in the overhead mirror, I experienced a sudden feeling of panic. I felt as if I were watching some strange theatrical production, with elaborate costumes and scenery and myself at center stage. It seemed like the baby inside me was being ignored while three doctors performed their rituals: the masks, the sterile field, the anesthesia, the forceps, the episiotomy.

Then a nurse checked the fetal heartbeat and said it was low. (Later my doctor told me that she might have been hearing the beating of my own heart.) When the time came, I felt no desire to push; but I pushed when finally told to. The baby emerged easily, without the use of forceps.

To everyone's surprise, both the baby and the cord were still. While the resident worked at sewing up the episiotomy, causing me pain, Barry and I watched the obstetrician who was trying to breathe life into our baby girl. Each of us kept an eye on the clock, desperately wanting the baby to live but fearful that she would be revived too late to be healthy. We held tightly to each other, numb with shock, telling each other that everything would be okay, and knowing it would not.

Abruptly the drama was over. The obstetrician stopped. There was no more hope for our baby. A hug from my own doctor; then suddenly the room was empty. The one nurse who remained encouraged Barry and me to hold our baby. She was beautiful, surprisingly clean of the slimy vernix we had expected, looking very much like me, we thought. We held her gingerly, never having been so close to death before. And we wondered at such a beautiful, gentle child, who all of a sudden was dead.

Susan's experience:

A few days after Judy told me her tragic news, I discovered I was pregnant. My husband, Andy, and I had been trying to conceive for over a year and had begun to fear that there might be some fertility problem. So when the results of the pregnancy test came back positive, we were ecstatic.

For the first three months, everything seemed normal. At the end of the fourth month, my obstetrician said that by my next appointment I should be feeling the baby kick. But two months and two more visits to the doctor passed and still I didn't feel any movement at all. My doctor didn't seem concerned, but I began to worry. Finally, I asked her if anything could be wrong. She said that the baby seemed small for my due date, which was only three months away. She recommended that I have an ultrasound test to determine the age of the fetus. The results indicated that the baby was four weeks younger than I had thought, and this probably accounted for my small size and the lack of movement as well. (Later the test results were proved wrong—the original date had been correct.)

I was somewhat relieved for a while, thinking that everything was fine, but then a new problem developed, this time with my back. I was so uncomfortable that I had trouble walking and sleeping. Finally it became so painful that I had to quit my job.

As my pregnancy progressed, Andy and I were attending classes in childbirth at the hospital. We were looking forward to a natural childbirth experience, now to be in March, the new due date for our baby. But in mid-December my amniotic fluid began to leak. I met my obstetrician at the hospital. She recommended that I remain at home and stay in bed, to delay the labor as long as possible.

As each day passed, I became more fearful, yet I could not really believe that anything could be wrong with my baby. After two anxious weeks of lying in bed, I went to a specialist in New York City to get a second opinion. He felt that I should be hospitalized. He said there was a seventy percent chance that I would go into labor soon and that my condition was serious. The two opinions were so contradictory that I didn't know which to believe. I weighed the many factors and finally decided to remain at home—but I was increasingly anxious about the situation.

Two days later, on Christmas Eve, I went into labor. Everything happened very quickly once we got to the hospital. My contractions were three minutes apart. Since the baby was in a breech position, a Caesarean section was decided upon. A resident

made three unsuccessful intravenous attempts. I was in pain and emotionally in a state of shock. They wheeled me into the delivery room and administered a local anesthetic. Then I began to watch the clock.

Finally, I heard my baby crying weakly. Nobody said anything, so I asked, "Is it a boy or a girl?" My doctor responded that there were problems and she couldn't tell. I was confused; I must have heard wrong. I asked her again. She repeated the same answer with no other explanation. No one showed me my baby.

In the recovery room Andy said that our baby was dying. My body began to shake so violently that I wondered whether I would recover.

The neonatologist present in the delivery room did not know immediately what was wrong with the baby, but he told us that there were a number of severe deformities. He found the syndrome in a textbook and recommended that we not operate, that we let our baby die. We were shocked; we were scared—but we accepted the doctor's advice. We thought we had no other choice. Tests showed that the baby was a boy. We named him Daniel.

The next day relatives came. They mentioned seeing the baby and told me how beautiful he looked. I could only imagine a deformed monster, and I didn't believe them.

By the following day I was determined to see my baby. The nurses were encouraging and wheeled me to the special care nursery. I was frightened and didn't know what to expect. I scrubbed and put on a sterile mask. Then they brought him to me. Daniel. He was a beautiful baby!

While Daniel still lived, Andy and I spent as much time with him as we could emotionally bear, holding him and crying with him. We watched him lose weight and grow weaker. A week after his birth, I went home reluctantly, without him, but I continued to visit him every day in the special care nursery. On January 9, at 4:30 A.M., Daniel died.

Although our individual experiences differed in detail, we began to discover in our long discussions together just how similar our feelings were. We were both shocked, grief-stricken, and depressed. We had been ready for a normal birth, but totally unprepared to handle what did happen. We both felt angry about our powerlessness, our lack of choices in the medical setting. We wondered what we would have done differently. But in one very important way, we two were fortunate: we had each other to share our grief afterward.

We began to exchange the many stories we had heard about others who had suffered similar misfortunes: the grief of miscarriage, the shock of stillbirth, the trauma of deciding to abort a deformed fetus, the pain of watching a sick baby die. Families like us had shared the excitement, anticipation, and sometimes ambivalence of beginning a pregnancy. Yet none of us had that new baby to take home, to love, to plan the future with. For all of us, pregnancy had ended in failure.

Any pregnancy is a time of major emotional and physical changes. Psychologists consider pregnancy—especially the first—an important life crisis, a turning point in the individual's development as significant as puberty. Ordinarily this crisis is resolved by the birth of a healthy child. When this does not happen, the crisis deepens. Parents may feel they have suffered a major setback in their lives. They wonder if they will have to live their lives without children or without as many as they wanted.

These parents suffer a loss of self-esteem. The plans and dreams they shared during the pregnancy have been destroyed. They experience the pain of failure, the failure to fulfill one of the most fundamental of human acts: to give birth to a healthy child.

They experience these feelings alone, isolated from others. Most of their family and friends do not understand what sort of emotional support is needed. "At least you never knew this child," they will say, hoping to ease the pain. Or "It could have been worse." Or "You'll have another one." In their own way they might be trying to offer hope for the future, but to the bereaved parents it often seems that these people do not comprehend the enormity of what has happened.

What others do not understand is that the parents are grieving for the loss of a very real person. As pediatricians Marshall Klaus and John Kennell have shown, "bonding" between parent and child begins early in pregnancy. Long before the actual birth, parents are readying themselves for the arrival of their son or daughter. An image develops of how the infant will look and act. Parents may talk to the baby and even call him or her by name. The mourning after an unsuccessful pregnancy may be

different from the mourning for the loss of an older child, but it is still grief for someone who already exists in the parents' minds.

Many professionals who come in contact with the mourning couple—medical people, clergy, funeral directors—often fail to provide appropriate support and counseling. This is true in many situations of death and dying—these are still difficult subjects to talk about. But when a miscarriage, an ectopic pregnancy, a stillbirth, an abortion of a deformed fetus, or an early infant death occurs, it is especially important for professionals to assist parents in beginning to grieve. They can do this by helping to create concrete memories for the parents to hold on to. Yet in too many hospitals, still, all reminders of the baby are removed quickly, and parents are not encouraged to consider a funeral or other formal mourning practices.

These parents are further isolated because they seldom know anyone else who has experienced a birth tragedy. They have no assurance that their own feelings and reactions are normal. Hardly a word is written about unsuccessful deliveries in any of the numerous books about childbirth for consumers.

And yet birth tragedies are not as rare as we like to think. In one year, in the United States alone, according to the National Center for Health Statistics, close to one million families are affected. Of the 3.67 million infants born alive, over 25,000 (one in 144) die during the first twenty-eight days of life and are counted as neonatal deaths. An additional 30,000 babies (about one in every 123 deliveries) are stillborn, having died between the twentieth week of pregnancy and the time of birth. These rates have been declining steadily, yet they are still higher in the United States than in many other countries. And no matter how rare a tragedy, when it happens to you, it is 100 percent.

In contrast to the drop in stillbirths and neonatal deaths, the number of ectopic pregnancies has been rising sharply, almost quadrupling since 1970. This is probably due to the increase in pelvic infections and in some cases to IUDs. Seventy thousand women each year experience this life-threatening condition, in which the embryo grows in the fallopian tube instead of in the uterus.

The most common pregnancy failure of all is miscarriage, which is estimated to occur in fifteen to twenty percent of all recognized pregnancies. Miscarriages are not uniformly recorded, but there is no evidence that this rate has changed. However, as the total number of pregnancies has risen, so has the number of miscarriages. Up to 900,000 families each year may be affected.

When these figures are combined with the many thousands of infants who die in their first year (e.g., from congenital abnormalities, crib death, or accidents), the tens of thousands who survive but with severe deformities, the millions of couples who experience infertility, and an unknown number of women who abort a wanted baby because of deformities (selective abortion), the number of people grieving for the lack of a healthy child is even more astounding.

Statistics do show that the problem is widespread, but they tell nothing about the tears, the regrets, the feelings of guilt, the long process of rebuilding hope. They hide the loneliness of those who feel they are the only ones in the world who have failed to become parents. We have written this book in an attempt to help grieving parents break through the barriers of their isolation; to offer them reassurance, information, encouragement, and advice. Our book is also for those professionals who want to understand and help them and for the families and friends who wish to console them.

In preparing to write this book, we interviewed many bereaved parents. We talked to some mothers and fathers whose tragedies had occurred a few weeks earlier, some after several years, and others after more than thirty years had gone by. Almost all parents were eager to share their experiences with us. For some, it was the first time they had ever talked about what happened.

Although the people interviewed were not chosen by any scientific sampling method, they represent a wide variety of social and economic backgrounds and of experiences with their pregnancies. There were many feelings these parents shared in common, but each of them found his or her own unique way of coping. No one approach worked for everyone. No one set of feelings was more appropriate than any other.

We also interviewed other family members and the professionals most often involved—doctors, nurses, social workers, midwives, clergy, lawyers, funeral directors, and childbirth educators. At the same time we read the literature on the subject, both the scientific research and the personal accounts. And from our own experiences, our interviews, and our readings, the ideas in this book emerged.

Since writing the first edition, we have spoken to many groups of professionals and bereaved parents. We have participated in creating hospital programs to help bereaved parents and have started and been part of support groups. All of these experiences have contributed to our thinking about loss and about the needs of bereaved parents.

The death of an infant is a great tragedy, but often the pain that the parents feel is greater than it needs to be. A better understanding of their feelings and the problems they face can help spare them that needless suffering. We hope our book will help accomplish this.

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THE PARENTS' EXPERIENCES