

Chapter 1 *Esther Arrives*



All I remember from Esther Tehela's delivery is blacking out, then being woken up, shaking and cold from the emergency Caesarean section. I dozed some more, and when I came to, the obstetrician explained to me that they were trying to transfer her to a hospital with neonatal intensive care facilities. My head was foggy and I couldn't comprehend what he was telling me. By the time I was more alert and being transferred to my room, the baby was getting ready to go to another hospital. I saw her only in passing.

When I finally left the hospital, I went directly to the hospital where Esther Tehela lay with tubes and tape on every section of her body. To secure an intravenous tube, even her beautiful hair had to be shaved in a Mohawk fashion.

How could all of this be? The whole pregnancy had been so easy that I often had to remind myself that I was pregnant. Now this beautiful little doll was fighting for her life. It wasn't fair! By a quirk of nature she had been choked by the umbilical cord thrice wrapped around her neck, changing the course of her entire life.

Expectant parents anticipate beautiful, normal, healthy babies. Their excitement heightens towards the end of the pregnancy and finally, at the climax of the nine months of waiting, labor begins. Most labors are uncomplicated, and most babies are screaming dolls.

But what happens when a labor takes a turn for the worse? All of a sudden, the fetal heart monitor shows a slow beat, or contractions become erratic, even stopping. The doctor could decide to do an immediate Caesarean section, or wait, since a first pregnancy could show "false labor." What happens when the baby is born in great distress, can't breathe, is paralyzed on one side, has a "big" head, or other deformity? In an instant, dreams can be shattered.

BUT. . . life is not over. Not for the mother, father, other family members or the new child.

As this new defenseless, unique person is born, the parents are becoming part of a new world they probably never contemplated. This world is the realm of the parent of a handicapped child. A barrage of sensations and emotions pounds the parents. Denial, anger, fear, sadness, guilt and bitterness all infiltrate a bewildered mind, clashing on a sore spot, leaving one confused and emotionally drained.

Due to the advancements in modern medicine and technology, the survival rate of these fragile children has greatly increased. Many of them can grow to be independent individuals, but that doesn't happen overnight or by osmosis. It takes many, many hours, days, and years of hard work. The sooner the work is begun, the better off the child will be. An early start could be the single most important factor in rehabilitation.

Not all problems are noticeable at birth. Sometimes, a problem does not become apparent in the child until he gets to a particular point of development, such as sitting up, walking, or speaking, and he does not do it.

These children are ostracized from our society. Perhaps people don't want to be reminded of a hidden deficiency of their own, and cannot look at or relate to a mentally or physically disabled person. Whatever the case may be, these children are human beings and have the right to be treated as such, and with dignity. Once, we, the parents can present our children as decent humans, then society will follow suit.

When my daughter was finally discharged from the hospital (after much bargaining with the doctors to convince them that I could take very good care of her at home), I didn't expect all the problems that would arise. How does the parent find out what exactly is wrong with the child, where to go for help, what to do for him, what rights he has, or how to function from day to day?