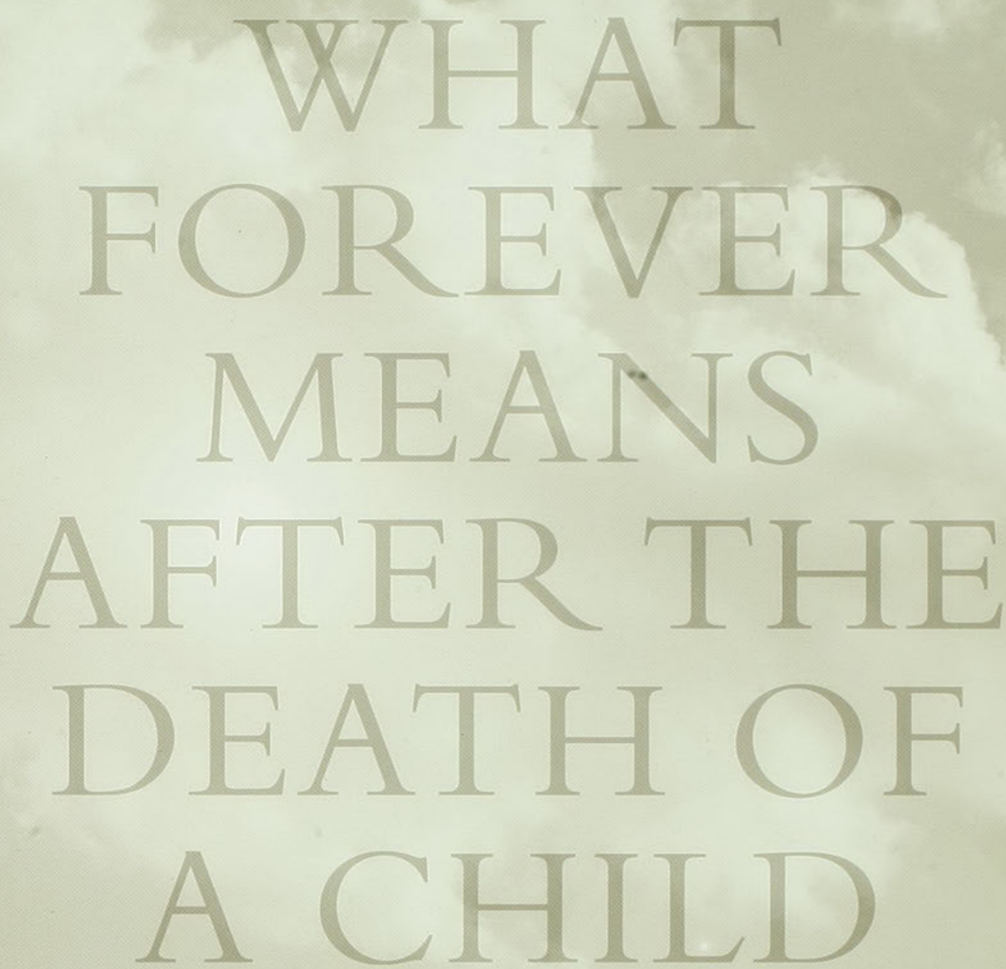

What Forever Means After the Death of a Child

Transcending the Trauma, Living with the Loss

KAY TALBOT

WHAT FOREVER MEANS AFTER THE DEATH OF A CHILD

The Series in Trauma and Loss

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BECAUSE OF

Leah Talbot
[August 16, 1973–July 9, 1982]
who came to bring love and joy to our world

AND

IN HONOR OF

all the children gone too soon, who teach us that love never dies,

THIS BOOK IS DEDICATED TO

all bereaved parents and those who support them.

Blessings for your continuing journey—I hold you in my heart.

—Kay Talbot, Vallejo, California

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Series Editor's Foreword

"When do you recover from the death of a child?" It was a question, asked of me by a survivor of the New York City terrorist attack on the World Trade Center. He was a survivor. Call him Manuel. He worked for the Local 32B–J of the Service Employees International Union. There were 1,500 fellow union members in the WTC when it was hit. I was there as a volunteer with the Green Cross Projects (www.greencross.org).

Manuel, like many traumatized and bereaved survivors often looked past his own sadness and stress to others worse off. But he knew the answer to his own question. "I haven't," he said gently, as tears in his eyes welled up. "Sissy passed 12 years ago next month." His struggles to cope with the loss of so many people he had known for so long brought forward numbing feelings of losing his youngest daughter.

Yet it does not take an extraordinary, deadly event like the September 11 tragedy to awaken the pain connected with the loss of a child, no matter the years since that loss. Not understanding this hampers the effectiveness of mental health professionals working with the parents of children who have died. This is why Kay Talbot's book should become a timeless classic, to be cited by experts, students, and professors as a source of guidance in working with survivor parents like Manuel.

What Forever Means after the Death of a Child: Transcending the Trauma, Living with the Loss will become a classic because Dr. Talbot combines all of the vital elements of a vital resource for helping. She has assembled the lessons of science. The few good studies of parental survivorship are explained and applied in ways that provide concrete direction to helpers and to the parents themselves. She has also assembled the lessons of fellow specialists in this area. Her final chapter, "The Legacy of Loss," is an example of these lessons, starting with the "Mothers Now Childless" study and ending with a discussion of the clinician's role in helping.

Losing a child is one of the greatest fears of life and its biggest agony. Yet,

over time the survivor parents accommodate but never fully recover. As Dr. Talbot notes, "healing evolves—it is not a destination."

This is the latest in the Brunner-Routledge Series in Trauma and Loss. As series co-editor with Dr. Therese A. Rando, a pioneer in thanotology and herself a parental survivor, we are proud to welcome this new addition. The series intends to publish innovations in understanding the interface between trauma and loss. For far too long those who attend to the grieving have not appreciated the extra burden of the traumatic circumstances of the death. They were not aware of how the trauma slowed the grief process. At the same time, for far too long those who attend to the traumatized have not appreciated the time required to accommodate to loss. This book and those in the series published before it are closing the gap of awareness and providing the tools and theories for helping and studying the traumatology of grieving.

My experiences as a member of the Green Cross Projects working with Local 32B–J blocks from "Ground Zero" reinforce my faith in God and working with the traumatized and the grieving. As the world braces for a new era of uncertainty and fear this book and the others in the series will, perhaps, reduce the pain, strengthen the resolve, and renew our love in life.

Charles R. Figley, Ph.D., Series Editor
Director, Florida State University Traumatology Institute, Tallahassee, Florida

Preface

It has been said that life is what happens to us while we're busy making other plans. This was true for me in 1982 when tragedy struck. I wasn't planning for trauma or loss of any kind, and especially not for the death of my beloved nine-year-old daughter Leah, my only child. Given any other set of circumstances, I never would have planned to write this book, to conduct this research, to become a therapist helping people understand and cope with their own life-changing experiences. Back then, at age 34, I hadn't done much thinking about either death or destiny. Since then, I have come to appreciate that while we feel helpless in the midst of tragedy, in its aftermath there are some choices we can make. I have chosen to share with you what I have learned both personally and professionally about surviving the death of a child. In reading this book, you are choosing to accompany me and the people I have learned from in exploring what possibilities lie beyond traumatic loss. My hope is that having read this book, you will then choose to pass along whatever you gain from it to others. In doing so you not only honor the lives of bereaved parents and their children, you participate in humanity's reach toward immortality in a very personal way. Those who are committed to helping others know only too well that "we can only comprehend the consciousness and behavior of others to the degree that we accept our own humanity" (LeShan, 1990, p. 156).

PURPOSE AND SCOPE OF THE BOOK

The goal of this book is to offer a deeper understanding of the lifelong, evolving bereavement process after a child dies. A child's death under any circumstances is traumatizing (Figley, Bride, & Mazza, 1997; Rando, 1994). In this book you will read about parents who demonstrate it is possible to transcend the trauma of a child's death and embrace life in new, meaningful ways while living with the ongoing loss. You will read about what helps and what hinders bereaved parents as they strive to understand their loss, adjust to and accommodate the pain, and move toward reinvesting in life, often in new ways.

The epistemological stance I take in my research is that human beings are

able to transcend themselves (Schutz, 1966). We are able to assert ourselves in the world in which we find ourselves and forge considerable changes, sometimes abandoning our personal world and creating a new one (Wagner, 1983, pp. 16–17). Looking at the phenomenon of survival as experienced by bereaved parents requires looking at both their inside and their outside experiences. By *inside experiences* I mean those thoughts and feelings that arise in consciousness to a level of awareness and reflection. By *outside experiences* I mean the conscious behavior and decisions of parents as they relate to the significant others in their lives. The totality of these two kinds of experience, inside and outside, comprises an individual's life-world, the world of everyday life. "Whether I cooperate, fight, or manipulate, I live actively in the world of my daily life, and can and do influence and modify some things, some events, and some people. I am part of the dynamic of the world" (Wagner, 1983, pp. 108–109).

The search for meaning, the symbolic, spiritual, and existential modes of dealing with death, the lived experience of losing the role of parent—all of these are elements for exploration within the life-world of bereaved parents. The major distinction I describe in this book is between mourning process and outcomes (which may or may not be correlated to specific attributes or actions that are part of the grieving process) and the lived, consciously perceived experience of surviving the death of a child. It is the difference between "how" or "how well" and "what," between how and how well or how poorly a parent believes he or she has dealt with the condition of bereavement, and what that someone's view of their irrevocably changed world looks and feels like. My aim has not been to assess or diagnose these parents but to understand and describe how they experience their life-worlds. Their stories convey the *qualitative difference* between what it means for a parent to survive and reinvest in life after a child's death and what it means for a parent to remain physically alive but in a state of chronic mourning (Rando, 1986, 1993).

The main focus of this book is on issues that impact personal identity and reinvestment in life following the death of a child. My research questions prior suggestions that it is necessary to give up attachment to the deceased child in order to heal parental grief (Bowlby, 1980). Catherine Sanders's (1999) integrated model of movement through bereavement describes a "healing phase" that includes searching for meaning, relinquishing roles, and restructuring identity. My research suggests that the role of parent becomes an integral part of the self, and in order to survive the death of a child, it is necessary *not* to relinquish this construct. Rather, it is important to find meaningful ways to continue "nurturing" as a part of a new, more integrated identity, which acknowledges the child's death but also preserves the child's memory and honors the parent's past life.

This is crucial information and especially important for anyone who may be encouraging bereaved parents to detach from their child and "accept" the death in ways that are counterproductive to the healing process. Clinicians are encouraged, instead, to help bereaved parents (a) reframe their role as that of the child's biographer (Walter, 1996); (b) build a new relationship with their deceased child

(Rando, 1993); (c) integrate their child into their life in a different way than when the child was alive (Klass, 1996); and (d) find personally meaningful ways to reinvest in life that honor what has been learned from parenting their child and from surviving that child's death.

UNIQUENESS OF THE BOOK

This book grew from the first and, to date, only existing study of the death of an only child and thus the ioss of the role of parent (Talbot, 1996, 1996–1997, 1997–1998, 1998–1999). The research participants were 80 mothers whose only child had died 5 or more years previously due to accident or illness. The book goes further to point out differences and similarities in the experiences of mothers and fathers and of parents with and without surviving children.

Both empirical and phenomenological research methods were used to answer key questions such as:

What does life as a bereaved parent look and feel like now?
What level of grief is still being experienced?
Does the parent attend a support group and/or discuss the grief with others?
How helpful are family and friends?
Has the parent experienced a spiritual crisis resulting from the child's death?
Has the child's death changed the parent's beliefs about how the world works?
Have there been other significant losses since the child died?
Has the parent made a conscious decision to survive the loss?
How has the parent's personal identity been changed by the child's death?
Has the parent found ways to build and maintain a new relationship with the deceased child?
Has the parent found personally meaningful ways to reinvest in life?
Does the parent reach out to help others?

These critical questions help us understand the "what," and to some extent the "how," of daily life years after the death of a child. The purpose of phenomenological research is to see the phenomenon being studied ("survival") in its own right, with its own meanings and structure, and not as an example of this or that theory. The editors of *Continuing Bonds: New Understandings of Grief* (Klass, Silverman, & Nickman, 1996) pointed out that "we need to bring into our professional dialogue the reality of how people experience and live their lives, rather than finding ways of verifying preconceived theories of how people should live" (p. xix). That is what this book does—it illuminates the life-worlds of bereaved parents, what their irrevocably changed lives can look and feel like. I do not intend to offer a new model, or to imply there is one best way of grieving this loss. Reading this book will, however, help you understand how the bereaved parents included here view their adaptation to life without their child and what has been helpful or hurtful to them.

OVERVIEW OF MAJOR TOPICS

Becoming a parent is a milestone event for those who have or adopt children. Learning how to parent is not a singular event, however; it is a process—one that parents expect will continue throughout their lives. Similarly, the death of a child is a milestone event; it marks a before and after in parents' lives. Parents who were learning how to parent their child must now learn what they never wanted to know how to do—how to be that child's bereaved parents. Chapter 1 describes how I began my study of surviving the death of a child and introduces what I have learned from my research and continued clinical work with bereaved parents. Chapter 2 is different in format from the other chapters. It describes the design and findings from the "mothers now childless" study. Readers not interested in this level of research detail will still benefit by understanding the design of the study as described at the beginning of chapter 2 before going on to chapter 3.

Bereaved parents *do not expect to ever "get over" or "recover"* from their child's death. Rather, as discussed in chapter 3, they expect to continue processing what the death of their child means to them for as long as they live. Those who are eventually able to reinvest in life see their bereavement as an evolutionary process, and many see themselves as becoming better people as they actively confront key issues and experiences. I am *not* saying here that there are "appropriate" ways to grieve that lead to survival and once they know these ways, parents have only to put their new knowledge into action in order to achieve a better outcome. What I am saying, building on my study of "Mothers Now Childless" (Talbot, 1996, 1996–1997, 1997–1998, 1998–1999), is that *there is a qualitative difference in the life-worlds of parents who come to feel they have survived this loss versus those who don't.* Such differences are discussed throughout the book.

Bereaved parents *struggle to make sense of their suffering and re-evaluate their worldview* in light of what has happened to them. Chapter 4 discusses the use of "logotherapy"—therapy through meaning (Frankl, 1955, 1963, 1969, 1975, 1978, 1997; Yalom, 1980) and meaning reconstruction techniques (Neimeyer, 1995, 1998).

A child's death sets in motion a multilayered continuum of experiences that evolve over a lifetime. As their bereavement evolves, parents search for *understanding* from others (discussed in chap. 5), for answers to their *spiritual questions* (discussed in chap. 6), and for *new meaning and purpose in life* (discussed in chap. 7).

The trauma that accompanies the death of a child often brings stress symptoms that require intervention before parents can proceed to process loss-related aspects (Rando, 1993). Parents can be incapacitated by unrelieved stress; they can find themselves fixated on certain aspects of their loss and unable to move beyond this point; some may grieve acutely until they die (Sanders, 1999). As discussed in chapter 8, most make a conscious *decision to survive,* to move forward in their bereavement, sometimes backward and then forward again, but gradually learning and adapting to a life without the physical presence of their child. It is a life

that is meaningful in new and different ways because of their loss, even as it remains a life "made poorer" by the child's death (Klass, 1988).

Surviving and adapting to their new role of bereaved parent does not mean detaching from or forgetting their child. Rather, chapter 9 gives examples of the many ways parents find *to remember and honor* their child and their life as that child's parent. Many bereaved parents who re-invest in life do so by *reaching out to help others,* as discussed in chapter 10, either by volunteering or by making career changes to "helping" professions.

The death of a child directly impacts parents' identity, both how they see themselves and how others see them. Some parents experience *identity disintegration*, while others experience a less severe *identity crisis. Identity reconstruction* after the death of a child, as discussed in chapter 11, continues the bond with the child in new ways and for most requires validation from the parent's social group, relatives, and/or friends (Doka, 1993b; Klass, 1988, 1999).

Thus, the death of a child presents not only a severe challenge to survival but also the *potential for personal transformation*. Five or more years after the death of their only child, some women in the "mothers now childless" study felt they had changed in *negative* ways. Some felt they had changed in both *positive and negative* ways. Those who felt they had survived their loss and changed in *positive* ways had four transformative factors in common. These mothers had:

1 Resolved a spiritual crisis brought about by their child's death (discussed in chap. 6).
2 Made a conscious decision to survive (discussed in chap. 8).
3 Reached out to help others by volunteering or working in a helping profession (discussed in chap. 10).
4 Integrated what was learned from surviving the child's death into a new, more compassionate identity (discussed in chap. 11).

It is the content and context of bereaved parents' lives that get us closer to understanding what forever can mean after the death of their child. The experiences described here begin to answer a compelling question posed by Phyllis Silverman and Steven Nickman in *Continuing Bonds* (1996, p. 29): "In what way is the past incorporated into a new identity after a death?" The kinds of reinvestments made by many of the parents described in this book help answer that question. The material presented also supports prior research that has identified "altruism" and "commitment to social and political activism" as essential to the healing of psychological distress (cf. Higgins, 1994).

THE AUTHOR'S PERSPECTIVES

All researchers know that it is important to recognize, clarify, and as much as humanly possible set apart one's own biases. Those of us who do phenomenological research know this as "bracketing the researcher's experience." My challenge

has been to integrate my "insider's perspective" as a bereaved mother, my clinical experience as a therapist, and a researcher's scholarship in order to comprehend the life-worlds of bereaved parents. Although I see my three roles as separate but interrelated, I am frequently viewed by others first and foremost as an "insider," one who has shared the experience, rather than as an "outsider," someone who has relevant expertise but no similar personal experience. Often I've been told: "I would never tell you this if you hadn't lost a child too." I would never have chosen this kind of "insider" status, yet I know it has helped me connect and share with other bereaved parents at very deep levels. I feel honored and entrusted to pass along their collective wisdom as accurately and honestly as I am capable of doing.

The research findings and conclusions presented here cannot be generalized to the entire population of bereaved parents. It is equally true, however, that what has been learned is potentially transferable to others in similar situations. As I interviewed bereaved mothers, living in different states around the country, I began to wish I could gather them together in the same room so that they could share and learn from each others' perspectives and experiences. I envisioned those who felt they were further along in surviving, sharing what had been helpful to them and demonstrating hope to the others who at that time were still struggling with acute trauma and grief. In a sense, what you will read here is a gathering together of collective wisdom. These parents show us that there is no one best way to survive this devastating loss. Rather, the lives described here demonstrate the multiple realities of parents who are changed forever by the death of their child, and how others help or hinder them in their evolving process of learning to live with this loss.

I try throughout this book to clearly delineate my voice and my reality. Thus I begin by introducing you in the Prologue to some of the details of my own loss. Throughout the remaining chapters I describe some of my experiences where it seems appropriate to explain how my perspectives may be similar to and/or different from other bereaved parents. Similarly, each reader brings a set of experiences and perspectives to the reading of this book. "We all see the world through the windows of our own eyes and interpret our perceptions in the light and darkness of our own experience" (Mindess, 1988, p. 173). The snapshots in time that any research and evaluation produces continue as an evolving work in progress. If this book adds a new level of understanding to your own experiences and clinical challenges, however different or similar they may be to the life-worlds of the bereaved parents presented here, then it will have been more than worthy of my efforts in writing it.

I welcome your comments, which can be mailed to me at this address:

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Prologue

I became a bereaved parent on July 9, 1982, when my daughter Leah died unexpectedly after an unexplained brain seizure. During the night of July 7, while at a one-week summer camp for the blind and visually handicapped, Leah suffered a low-blood-sugar attack. She was found unconscious beside her bed in the early morning hours of July 8 and was rushed to the hospital. The emergency-room physician called me at my office and while I drove to the hospital he worked to stabilize her blood sugar level. When I arrived, she was crying frantically and fighting the nurses, and as I told her, "it's OK, mama's here," she collapsed exhausted into my arms. As Leah's blood sugar level returned to normal, the doctors did not understand why she remained semiconscious. Twice she moaned, "I want to go; I want to go," but did not respond when we asked her where she wanted to go. A spinal tap ruled out meningitis. That afternoon Leah was transferred by ambulance to the hospital where her pediatric endocrinologist practiced. There a brain scan showed no change from previous scans. Leah's father and I stayed with her throughout the night as she tossed and turned restlessly, occasionally moaning softly. Leah awoke the morning of July 9 lucid enough to answer her doctor's questions. Did she know where she was? "Yes, in the hospital." How old was she? "Eight and three-quarters." She complained of a headache. Her father and I argued briefly about the level of her bed, and Leah irritably told us, "Oh, just forget it." She was given some Tylenol and ate part of a Popsicle. By late morning on that fateful day, she was resting somewhat peacefully. Her doctor assured us he expected her to continue to improve, as she had after previous hypoglycemic episodes. I told her I loved her, was going home for a shower and change of clothes, and would be back soon.

A few hours later as I drove back to the hospital, I felt tired but relieved. I realized I hadn't eaten since the day before, so I stopped at a store long enough to pick up an ice cream bar. I expected Leah to be sitting up in bed to greet me when I arrived. Thus I was totally unprepared for what I saw when I entered her room. What I saw first were her feet, sticking out from under the covers, and they were blue! With disbelief, I called her name as I looked up and saw she had slumped

down in the bed and was unconscious. I stumbled out of her room toward the nursing station just outside, too overwhelmed to speak. The look on my face alerted the young resident on duty, who dropped the phone he was speaking into and ran into her room. Before I could begin to speak, "code blue" rang out over the PA system. Within minutes a tracheotomy had been done and Leah was breathing with the help of a respirator. The resident came out long enough to tell me this and that he had called a surgeon to install a pacemaker in Leah's heart. I paced up and down the hallway just outside Leah's room as the doctors operated on her. I began to feel the physical effects of shock—dry mouth and chills. Someone brought me a cup of water. My mind fought the numbness as I took stock of all I had seen. The resident came out again, this time to telephone Leah's endocrinologist and brief her on Leah's condition. When he finished, he motioned me to come take the phone and talk with her. I remember telling her, "They're doing everything they can think of but I don't think it's going to be enough." She tried to reassure me that there was still hope, but already my mind was admitting the possibility that Leah was beyond medical help. My heart desperately hoped I was wrong. A nurse suggested I call someone to come be with me. I phoned my cousin at work, leaving a message that I needed her to come right away. Then I returned to my pacing outside of Leah's room.

It wasn't long before the surgeon and assistant emerged and walked off down the hall. I was encouraged when I overheard the assistant say, "You did a good job on her." The resident then came out and asked me to follow him to another room. I hoped those words "good job" would translate into good news. Instead, he quickly told me Leah was still alive but that she had suffered too much brain damage to ever recover. He added, "We can keep her on the respirator if you want, but Leah will never be Leah again—it's just a matter of time." I used every ounce of self-control I had left to tell him, "No, I won't do that to Leah. I want you to disconnect the machine." As he left to do so, I collapsed into a chair and allowed the tears to come. It was my first experience with the horror and indescribable pain of emotional anguish. My body responded with the kind of shrieking and wailing I had seen on television but never experienced personally until that moment.

Nothing in my 36 years of living prepared me for the trauma of a loss such as this. And I had had quite a few losses and challenges. My mother had given me up for adoption at birth, and although I was blessed with loving adoptive parents, I will always live with unanswered questions about my biological heritage. My childhood was further complicated by my adoptive mother's congenital heart condition—the reason she could not have her own children. Shortly after she and my father married, she became pregnant and had to have an abortion because neither she nor the baby would have survived. This was a "forever loss" my parents mourned deeply.

When I was four, my mother underwent open-heart surgery at the Mayo Clinic, while I remained in the care of my aunt. As I watched my parents drive off, no one had to tell me my mother might not be coming back. And the mother I had known did not come back. The mother who returned several months later was so

thin, so ill, I barely recognized her. The structural repair of her heart was successful with the help of an experimental drug, but 3 days later she had to have lung surgery. She spent months recovering physically but lived the rest of her 78 years with deep emotional scars. She yearned for more children, and I yearned for siblings. When I was 10 my parents adopted a baby boy. Helping to care for my new brother became early training for later motherhood.

I married at age 18 and 7 years later, we decided to start a family. After a year of trying to conceive, we learned my husband was infertile and began the long, emotional wait to adopt a baby. The pain of not being able to bear my own children was a bittersweet irony. Adoption was, after all, the form of motherhood I knew the most about. I will never forget the overwhelming joy I felt as 2-week old Leah was laid in my arms by the county adoption agency's social worker. The joy, however, was accompanied in a few weeks by worry about her health.

Leah's birth had been a difficult delivery that required forceps rotation of her head. She had a low-blood-sugar attack a few hours after birth, and the adoption agency told us she had inherited hypoglycemia from her father. Within a month, we began to notice problems with Leah's vision. She often opened only one eye at a time and she didn't seem able to focus. At 3½ months she developed a cold and had what appeared to be another low-blood-sugar episode. Thus began a long series of doctor visits, tests, and infant stimulation therapy sessions. During Leah's first blood test when she was a month old, I was amazed at the intensity of my own pain as the needle pierced her skin. It felt like that needle was piercing my heart. I couldn't know then that there was much greater pain to come. I am grateful that I didn't know. I wonder if knowing would have robbed me of the joys that came from helping Leah develop her potential despite the limitations of precarious health. I hadn't expected to love being a mother this much, to find caring for this beautiful, unique child so fulfilling! I knew Leah's vision problems were serious and as yet unexplained. I just chose to set aside my fears and focus on what I could do to stimulate her growth. Each day brought new excitement as she continued to grow. She would wake in the mornings cooing and "talking" to herself and her toys.

At 6 months of age, Leah had another frightening low-blood-sugar attack. She was referred to a pediatric neurologist for a week-long neurological workup at a hospital in Los Angeles. We were shocked when X-rays revealed she had suffered a skull fracture at or just after birth, which had since healed. An electroencephalogram (EEG) showed a slight discrepancy on her left side, but no cause could be determined for her low vision. Leah was referred to an ophthalmologist to evaluate her vision. I held her on my lap in his darkened exam room, as he shone a bright light in Leah's eyes. They didn't move or respond at all. He concluded she was virtually blind and would never be able to see. He followed this prognosis with the question, "Have you considered not keeping her?" I was stunned and horrified. How could he think that our daughter was exchangeable? I grasped Leah even more tightly to me. It felt like he had punched me in the stomach. When I was able to get my breath, I responded, "No, we will just work with

whatever eyesight she ends up with," and quickly left his office. He obviously had not believed me when I told him I knew Leah was not blind, that she had begun to reach out to grasp her toys.

With physical therapy, lots of play stimulation, and a high-protein diet, Leah's growth and development continued, but at a slower pace than for healthy children. Her father completed college and accepted a new job that required us to move to northern California. In 1975 I wrote to Leah's neurologist to request that her records be transferred, telling him that she had had another hypoglycemic episode and her vision was limited but "despite these minor problems, Leah is very much a normal, active two-year-old now and her charm and intelligence never cease to amaze us."

I was sure by this time that Leah's neurological damage would not result in her being mentally handicapped, and I was so grateful for this. Yet whenever we were around other children her age, I felt the painful reality of her visual handicap and compromised motor skills. Loud noises such as the lawn mower frightened her; she couldn't see what was making the noise. Playground equipment that was so enticing to other children challenged Leah's courage. I tried to envision in my mind what it must feel like to be at the top of a slide and not be able to see the bottom. There was little time to grieve for what Leah would miss out on in life. Our energy as parents was instead devoted to helping her use what vision she did have as efficiently as possible.

I was concerned about whether Leah would be able to attend regular school by the time she was old enough. I requested an evaluation from the Blind Babies Foundation in San Francisco and a vision counselor was assigned to visit us monthly. She helped get Leah referred for additional testing by a world-renowned pediatric ophthalmologist at the University of California-San Francisco. At age 3½ Leah underwent a 2-hour Visual Evoked Response test. This required her to lie very still with electrodes pasted on her scalp and her eyes held open by a metallic apparatus, leaving her unable to blink. Patterned images were flashed in front of her eyes for periods of 2 minutes at a time. The electrodes measured the electrical impulses from her retinas through the optic nerves to the areas of her brain that received visual information as the images were flashed in front of her. It was a test that had not been done on someone so young before. The technician met us with a straightjacket and was skeptical when I said no, Leah would be able to do the test without that. After explaining what was going to happen, I handed her a Kleenex for one hand, held her other hand, and sang to her for the next 2 hours. I sang every nursery rhyme I knew, several times. Everyone was amazed at how Leah was able to remain relaxed and cooperative for so long. When it was over, she was up bubbling with excitement about going home; I was exhausted! That test was followed by a computerized tomographic scan of her brain. It confirmed the neurological damage shown by previous EEGs ("mild to moderate enlargment of lateral ventricles; mild to moderate hydrocephalus"), which was thought to be the result of either lack of oxygen during delivery or convulsions due to low blood sugar shortly after birth. These tests allowed the ophthalmolo-

gist to finally diagnose the cause of Leah's impaired vision as congenital maldevelopment of the optic nerves. Her vision would not get worse, he believed, and her astigmatism could be corrected with glasses. He predicted she might eventually be able to read small print but doubted she'd ever be able to drive a car.

By the time Leah was 4½, her vision had improved to 20/100 with corrective lenses. She could watch television up close and recognize faces across a room, but she had poor peripheral vision and was considered legally blind.

As Leah grew and embraced life, I returned to college part-time, taking evening classes. Slowly I completed a degree in behavioral sciences at the University of California–Davis. During my final semester there Leah attended the university's preschool while I attended classes. She loved school and frequently amazed her teachers. One told me of how another child began crying one day because her mother had left. Leah went over and patted her and said, "I know, I feel sad sometimes when I miss my mama too, but she'll be back." Her teacher added that Leah loved to sing songs and would entertain groups of other children by singing to them.

At age 5 Leah had another low-blood-sugar attack, was hospitalized, and doctors had to do a "cut down" to insert an intravenous (IV) line in order to stabilize her blood-sugar level. Shortly afterward, another neurologist reviewed her brain scan results and concluded that additional seizures due to "mild to moderate hydrocephalus" were "possible but not anticipated." Additional testing by a pediatric endocrinologist confirmed that a lack of normal adrenal and pituitary function was responsible for Leah's slower than normal growth in height. She was accepted into an experimental growth hormone treatment program, which involved my giving her injections three times a week. Over the next few years, this treatment helped her grow and gave her more energy.

Although Leah was usually carefree and optimistic about life, she wasn't immune to angst. On one occasion when she was 4½ I recorded one of our discussions in her baby book:

> This morning Leah told me, "Mama, I'm unhappy about me." I asked her, "What are you unhappy about?" And she replied, "about my inside voice." "What about your inside voice?" "Well, it's ridiculous!" "How is it ridiculous, I asked?" "Well, because it's 'contraire,' and I don't like being 'contraire!'" [Since she was 2 this had been our word to describe disagreeable behavior.] We then had a short discussion about how to become happy and cheerful after you've been feeling "contraire."

Leah's doctors were always surprised when they compared the child before them to the files of test results. Despite her physical limitations, she just flourished. She loved school and her teachers described her as "very self-directed, with inner strength, and a precocious ability to empathize. She is extremely verbal and does not attempt to limit her motor activities." Leah's physical growth had improved over the past few years but still lagged behind other children her age. She was assigned an adaptive physical education teacher, who wrote us a lengthy letter after her death. In it she described how Leah dealt with her physical challenges:

> Sometimes Leah was frustrated—walking the balance beam and stepping off in the middle, tossing the ball but missing the catch—but she'd eventually accomplish the skill. She never used her vision as an excuse for not being able to do something—she just worked longer and harder to accomplish the tasks. She was such an extraordinary girl. She always had such a good time, especially on the bowling alley field trip and the Special Olympics meets. (When we were at the Special Olympics this year your note in her lunch box brought such a bright smile to her face as she read it!). Leah had such a free spirit. I can picture her during free dance time as she twirled round and round. I turned rope as she chanted the lyrics. Just walking to and from the classroom, she'd hold my hand and relate the latest adventures of Huck Finn, how she'd made a tent in her dad's living room, roller-skating, and the trip to Disneyland. She had such a wonderful, positive outlook on life. She was always so eager to learn, looking forward to everything. I hope I've been able to convey to you what a unique, special child you have shared with others. I know she loved you and her father very much and had a beautiful life with you.

Besides music and dancing, Leah relished humor. When she was 5, we were driving to the zoo one day when her grandfather jokingly asked Leah if they had any "eggephants" there. Leah laughed and said, "No—elephants!" Then he asked if they had rhinosofrus. She laughed again, then thought for a minute and replied, "No, but they have catalopes! Ha-hah!"

Parenting a child with special needs can be wonderfully rewarding, and certainly this was true for me. It was also emotionally and physically exhausting. While Leah grew and made remarkable use of what vision and energy she did have, her father and I grew further apart. Ending our 15-year marriage was a difficult decision we struggled to make for some time. Ultimately, our divorce in 1980 was amicable, yet it meant heartbreak and many changes for each of us. Leah's father took a new job in a town 50 miles away. Leah and he missed each other terribly. She spent weekends and the summer months with him, relishing their special times together, and they talked on the phone and wrote each other. Leah loved her "Papa" dearly, and I don't think she could have had a better father. She was not hesitant to let us know she hated the divorce, but she seemed to adapt as well as any child ever can to divorce—it is another "forever loss." There were ups and downs in adapting to life as single parents. But I am grateful that we parted as and remain friends. I'm so grateful Leah did not live the last years of her short life in the crossfire of a war zone, as happens in many divorces. I believed and still do that the divorce was the best decision, given all the complexities of our disintegrated relationship.

While staying with her father during the summer of 1981, Leah had another low-blood-sugar attack and had to be hospitalized. She recovered quickly, however, and later flew by herself to visit her grandparents in southern California. She loved these visits. After one return flight home the stewardess who brought her off the plane told me, "This is just a delightful child. I wish I could take her home with me. And I mean that!"

By the end of third grade, Leah was reading above her grade level. She loved

to make up stories and wanted to become a writer. After Leah's death as I was cleaning her room I found the table of contents she had compiled for a book she planned to write. She has helped me write this book instead. Leah also left behind a letter to her grandparents, written during her last week at summer camp, that was both heartbreaking and comforting:

> Grandma are you still taking that awful tasting medicine? Are you still drinking cranberry juice and water? If you are, are you used to it by now? Well, I hope your kidney stone gets better. I hope you and Grandpa are both feeling fine. I have a cough and I can't go swimming but that doesn't spoil my fun one bit. I read and drink water out of cups. And I talk to people who need company. . . . Happy birthday Grandpa. I hope you have a nice time for your birthday. I hope this gets in the mail in time for your birthday. Love, Leah [Leah died on July 9, her grandfather's birthday.]

Her father and I summed up Leah's short "eight and three-quarter" years with these simple words engraved on the stone covering her grave: "She brought love and joy to our world."

During those first years after Leah's death, I experienced the intense and varied emotions that accompany acute grief, as well as physical symptoms—chest pains and insomnia. I went for counseling, took antidepressants and sleeping pills, and despite the warnings of my psychiatrist used alcohol to numb the pain. I continued working, finding work was the only place I could get any respite from grieving. It took every ounce of energy I had to focus my mind while at work. I often cried as I drove to and from my office each day. My nights were filled with images of Leah's death and funeral. An autopsy had revealed no specific cause for her death. The doctors could not explain why she had suffered a brain seizure when she did, just 10 minutes after a nurse had checked her, finding her vital signs normal. And so I struggled, as so many bereaved parents do, with the why question. My psychiatrist encouraged me to find a way to say goodbye, and I wrote the following poem:

To Leah
I remember so well the day they called to tell us
Someone cared enough to give you life
And give you away.
I remember like it was yesterday.

You cried when I first held you.
Until I rubbed your back
And told you your name.
Then you seemed to remember there was a reason why you came.

The doctors weren't quite sure why you couldn't see
And it really didn't matter much.
In your mind's eye you saw enough to teach us all
About "to be or not to be."

Nearly always you had a dimpled smile,
A confident, happy spirit.
And there was never any doubt the world was a better place
Because you were in it.

It's been five months now
Since you've gone.
No one knows exactly why,
And I don't know how to say goodbye.

Because despite the hard times we both endured
One thing I know for sure.
The nine years we shared together
Were worth far more than any other forever.

As the shock of Leah's sudden death began to wear off, the reality of her absence hit hard. This was not a bad dream that would soon be over. As my mind tried to grasp the enormity of my loss, my body rebelled at the constant stress. My muscles tensed and when I moved I could hear popping sounds; shooting pains down my arms and legs were diagnosed as tendinitis. I strained my back and developed a bladder infection. Physical pain intensified my extreme emotional pain and brought me to the brink of suicide. More than once I held a bottle of pills in my hand and asked God why I should bother to go on living. I was in existential and spiritual crisis. Eventually I got an answer. It came in the form of questions. "How could you ever face Leah again if you kill yourself? She lived with such courage and joy. How can you do any less? Do you really want to risk taking these pills that might not be strong enough to kill you, leaving you in a vegetative state suspended between this world and the next?"

For a long time I believed that I had failed in my duty as Leah's mother. I should have taken her home with me on July 4, the day her father and I visited her at camp and learned she had caught a cold. I was guilty of not being diligent enough. At the same time, there was the guilt I felt because of the freedom I now had from the exhausting challenges of being a divorced parent raising a child with special needs while working full-time in a demanding job. It was only through a long process of counseling and spiritual exploration that I eventually concluded my guilt was misconstrued. I did not have the power to keep anyone else alive, not even my beloved daughter. Sometimes it is easier to live with guilt than to feel powerless (Talbot, 1999).

It was many years before I began to feel I had truly survived Leah's death, before I was strong enough to wonder how my experiences might compare with other parents who had experienced such a loss. Two and a half years after Leah's death I remarried. The happiness this union brought was very healing. With my new husband's encouragement and support, I completed graduate school and was promoted to a challenging managerial position. I enjoyed the rewards that accompanied my career success and for several years found the work intellectually stimulating. Gradually, however, I began to recognize the symptoms of burnout. My

academic and professional accomplishments distracted me from the existential questions I had not resolved. It felt like my soul was dying, but I didn't know why. Eventually alcohol no longer worked to deaden my pain. I returned to counseling, joined a church and a 12-step support group, and in 1990 left the corporate world to return to graduate school.

I spent the first year of my doctoral work studying human development and applying what I learned to my own life experiences. By 1992, 10 years after Leah's death, I was in transition toward an unknown future. I had moved beyond the why of Leah's death to the question, who am I now? It was during this time that I had an epiphany experience. Late one evening I was reading Helen Rose Ebaugh's research (1988) on the process of role exit. She had studied a wide variety of people who had left major roles: ex-cops, ex-prostitutes, ex-nuns, retirees, divorcées, and so on. She wanted to understand what it means to leave behind a major role and whether that role gets incorporated into a new identity. Included in her study were interviews with divorced mothers without custody of their children. They were struggling with the loss of a daily parenting role. Reading this was one of those great "ahah!" moments. When no one calls you mother anymore, what do you do with the part of you that has learned how to be and loved being a mother? Instantly I knew this was the missing piece, the reason my soul felt like it was dying.

Ebaugh's material on the process of role loss helped me understand the need to confront the loss of my parenting role as a separate loss. She pointed out that role loss creates multiple psychic realities and the need to confront role residual, the "hangover identity" from a previous status. I felt I had made peace with Leah's death in many ways and that that process would be ongoing for the rest of my life. I had come to believe she was where she was suppose to be, doing what she was suppose to be doing. I knew I would always miss her terribly, and that we would always be connected by love, which never dies. But I was still struggling with the loss of my parenting self. I did not know other bereaved parents and wondered how others felt about surviving this loss. I reviewed the thanatology literature and was surprised to learn there were no existing studies about the death of an only child. There were several studies of bereaved parents, but I could find no specific investigation of the loss of the role of parent after a child's death. If I wanted to know how other parents dealt with this loss, I would have to do the research myself. It was a life-changing call to action. I continued reading the bereavement literature, developing a lengthy list of questions.

Did other mothers who had been bereaved for many years see themselves as survivors, and if so, what did that mean for them? How had bereavement changed them, especially those who had been bereaved for many years? How were their experiences similar and how did they differ? Were there identifiable patterns to the experience of surviving such devastating trauma and loss? Did other bereaved parents choose to survive, and if so, did some pivotal incident or sudden realization influence their decisions?

I began looking for answers by deciding how I would select whom to ask. I