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Listening in the Silence,
Seeing in the Dark

*Reconstructing Life
after Brain Injury*

UNIVERSITY OF CALIFORNIA PRESS

Berkeley Los Angeles London

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Introduction

This book is about silence
to find one's way
Here I lay side by side
of my young son's life story
to bridge the gap between
to translate my *knowing*
Walking with our son through
back toward a radically revised life
to experiment with
the loss of consciousness
through telling
Breaking apart the self
and integrated,
reveals the inchoate,
On the threshold
and language
Stripped of his ability
and self-representation

and darkness and the struggle
toward the light.
the shattered fragments
and my dependence on metaphors
continuity and discontinuity,
experience into *telling*.
the shadows of nonbeing and
forces this story
fashioning his *not knowing*—
and memory—into *knowing*
and retelling.
that has appeared coherent
traumatic brain injury
hidden from our sight.
between silence
lies the obliterated self.
for self-regard
his condition opens a crack

This is a story of how the already born, when afflicted with traumatic brain injury, must be reborn, taking a far more arduous journey into life. In the second birth, such individuals face greater challenges with diminished abilities. Though this is a book I wish I would never have had

the knowledge to write, it is also a book I wish I would have had as a parent waiting through the long, starless nights of coma or later searching in vain for reliable markings along the path back into life.

In the spring of 1985, our bright, handsome, energetic fifteen-year-old son suffered a traumatic brain injury, thrusting him and us as his family into a chaotic, mysterious space between being and nonbeing. When severe injury assaulted our son's brain and central nervous system, his self no longer functioned in customary ways: motor activity, sensation, and cognition stopped, and all "languages" that support these capacities were temporarily useless. His story appeared to stop. Along with shock and anguish, questions poured out of me. Will he live? Will he ever regain consciousness? And if consciousness, at what level of capability? Can he know himself or be known to others without speaking? Who will speak for Erik? In this void or psychic-liminal space, which is always a nightmarish region for the injured and his or her family, I desperately wondered how our son might become a self a second time or navigate this radical breach in his developing life story. What follows is my description of that silent, empty space with our son and of his struggle to live and to climb back into language and story.

Because traumatic brain injury has reached near epidemic proportions in the United States and the industrialized world, and because the cost of treating brain injury and rehabilitating its victims continues to soar, none of us is untouched. Though this is the story of one young man, I write to bear witness for all who struggle courageously, though often invisibly, to restore their lives following traumatic brain injury. As I write, I have been attended particularly by the felt presence of Neil, Danny, Todd, Caroline, Doug, Don, Tracy, Janet, and David. Each of these people—varying in age from fourteen to the forties, living in different parts of the United States and outside it, and working to live fully despite the effects of brain injuries—has directly shared his or her experience of acquired brain injury with me or, in the silence inflicted by injury, has

left a visible imprint in my mind. Their struggles to recompose their own lives run quietly beneath the surface of the story I know best.

The attempt to portray Erik's process of personal reconstruction, which takes place on many levels at once, requires this book to move on more than one level. First, the process includes the interior territory of Erik's brain and body, of which I can only report from my observations and engagement with the outward manifestations of an inner, invisible story line. Second, my husband, my daughter, and I all had unique reactions to Erik and his injuries and responded to him differently, each making separate, though entwined, stories from the experience. Each parsed the facts individually as we resisted wrong or partial stories and tried to invite a son and brother to second life. Third, every treatment protocol, each doctor, therapist, educator, and friend extended a link in a long chain of being for Erik to grasp.

Just as working with a family member who has suffered a traumatic brain injury demands ceaseless experimentation to help him or her reassemble his or her shattered pieces, so attempting to bear witness to the process of reorganizing a life has required the invention of a form to convey the experience. This is not a book of head injury resources or prescriptions, nor is it simply a medical biography. It is, rather, a meditation, with and through stories, about the dialogical character of our biological, psychological, and social lives made visible in the loss of consciousness and language and through shattered dreams. Using my consciousness to describe the life of our unconscious son, to feel and participate in the pain of his undoing, and to reflect on his reconstruction, I invite multiple audiences—families, medical and rehabilitation professionals, insurance brokers, lawyers, educators, and indeed an entire society in which the preoccupation with being author and lead character of our individual stories always obscures our relational interdependence—to linger and perhaps to learn on the threshold between continuity and discontinuity, death and life.

THRESHOLD ONE

The Impact of Vulnerability

I am a teacher	of stories.
Stories ancient	and mythic.
Stories purportedly	factual and historical.
And stories that are	fictitious, made
in the imagination	and shaped
and reshaped	by tellers.
I am also	a mother.
One who has read	and told stories.
One who has	listened to
and encouraged stories	from my children.

In 1985 my husband Robert and I were rearing twelve-year-old Sonia and fifteen-year-old Erik in Princeton Junction, a New Jersey suburban community, with the attendant pressures and opportunities typical of professional suburban commuter families. Robert commuted to New York City three days a week to his office at a research institute; on Tuesdays and Thursdays I traveled south to teach American literature at Stockton State College.

One October evening in 1984 my son approached me. “I need to write

a poem. Well, actually two poems for English class tomorrow. One must tell a story, and the other can create an image.” Sensing Erik’s impatience with an assignment falling outside his interest in math and computers, I asked, “Any other guidelines?” I was stalling for time, thinking how to surmount his frustration and to entice him into this wonderful linguistic territory. “No models?” I asked. Growing more visibly restless, he said “Nope” in a tone that only slightly concealed a “how many times must I tell you?” attitude. “I get it,” I said; “this is an assignment that simply throws you out into the deep water, where you’ll sink or swim.” “Yeah, I guess,” was all he said.

Scenes similar to this typically occur in homes where teens reside. Often they end here, with parent and child parting company, each feeling a bit at sea. This particular evening, however, we pursued our conversation despite the anxiety these unknown waters produced. Soon we were talking about the song lyrics of his favorite musicians—Phil Collins, Yes, Genesis. We considered the stories their songs tell. Then I asked if he had ideas about a story he wanted to tell. His ideas were broad and abstract: about love, about sadness. I thought of Shakespeare’s sonnets. We read a few and talked about their stories. About the emotions and the images used to convey emotions. About compression of language. About metaphors and rhythm in language.

Then John Donne’s “A Valediction Forbidding Mourning” popped into my mind. Perhaps the regular rhythmic pattern in which it relates its story would provide a structural framework for Erik’s attempts at poetic storytelling. We read the first stanza.

A VALEDICTION FORBIDDING MOURNING

As virtuous men pass mildly away,
And whisper to their souls to go,
Whilst some of their sad friends do say,
“Now his breath goes,” and some say “No”;

We read on, he speaking one stanza, then I the next, on throughout the poem, letting the rhythm seep into his ears and mind. We continued on

through the last four stanzas, attending to the sounds and images. Many years later memory brought that night of reading and the prophetic power of the closing stanzas to my full consciousness.

Our two souls therefore, which are one,
 Though I must go, endure not yet
 A breach, but an expansion,
 Like gold to airy thinness beat.
 If they be two, they are two so
 As stiff twin compasses are two,
 Thy soul, the fixed foot, makes no show
 To move, but doth, if th' other do.
 And though it in the centre sit,
 Yet when the other far doth roam,
 It leans and hearkens after it,
 And grows erect as that comes home.
 Such wilt thou be to me, who must
 Like th' other foot, obliquely run,
 Thy firmness makes my circle just,
 And makes me end where I begun.

The regular meter seemed to offer Erik a life preserver for the choppy waters of poem-making, and, fortunately, the subject captured his attention. He began to link his abstractions of love and sadness to the concrete physical form and his perception of his maternal grandmother. He compared Grandma K's worsening osteoporosis and stoic silence in an environment of criticism and denial to Donne's advice to make no noise, to shed no tears nor sigh. Together, back and forth, we tossed out images and possible lines until, ready to launch out on his own, Erik began to piece together his poem born of imitation and conversation.

When he brought the finished product to me we both were pleased. My son's satisfaction derived largely from completing an assignment before midnight and gaining a superficial appreciation of poetic form. Mine

came from recognizing in this exchange the ways that language permits us to narrate stories and, indeed, becomes the bricks with which we construct our own life habitations. It was impossible on that autumn evening to anticipate the events that lay ahead and the ways our poem-making from Donne's metaphor in "Valediction" would become incarnated for Erik and our family. As Donne's poem had become the "fixed foot" for Erik's poem-making, so our bodies and souls would be required to "in the centre sit" as Erik's roamed afar.

By the end of his sophomore year, which had begun with the poem-making, Erik was completing courses in architecture, calculus, Bible, ancient history, French, and physics in addition to English. He had traded in piano and cello lessons for playing baseball and was advancing through the beginning belts of karate with enthusiasm and adeptness. He had taken the PSAT and received scores that put him on the mailing lists of the country's finest colleges. Because of his interest in computers and programming, he resourcefully had written a résumé, circulated it, and, much to our surprise, landed a summer job at a local computer store.

Almost every Sunday morning our family attended worship at the Society of Friends Meeting. Erik and Sonia had participated in the religious education classes, and my husband and I had contributed to the religious education program, for about six years. The Young Friends, a group of high school youth, had planned a one-day canoe trip for the last Sunday in May 1985, only a few weeks before the end of school for our children. Erik waffled all Saturday evening about participating; he wanted to take a school friend with him, but he couldn't reach the youth adviser to check whether there would be sufficient canoe space for a visitor. Finally on Sunday morning, with his father's encouragement, he decided to join the group without his friend. He made his bag lunch and jauntily said good-bye in the kitchen. I reminded him to call us if he discovered he wouldn't be home in time to join us for an evening picnic with a group of family friends. Robert drove him to the meeting house

and bade the zestful two-car group farewell, after ensuring that Erik would ride in the adult adviser's car.

Later on that gloriously clear May morning Sonia, Robert, and I returned to Meeting. During the last five minutes of the worship a member rose and delivered this short message: "None of us knows how long he will live." Shattering the silence, these few words disturbed me, turning my peaceful meditation into brief but uneasy reflection. Then the rise of Meeting lulled me back into the customary complacencies of enjoying the weather and our friends.

After worship Robert and Sonia went home, but I remained at the meeting house for a committee meeting. My own academic year had just ended, and I was looking forward to cleaning the large bucket of strawberries that Sonia and I had picked the day before. Shortly after the meeting began it was interrupted by a telephone call from Kessler Hospital in Hammonton, New Jersey, two hours south of Princeton. The caller was trying to locate some family member of an injured party. I was the only one on the committee who knew anything about the Young Friends' canoe trip, so I took the call, knowing only that there had been an accident apparently involving our young people.

Even as I write, fourteen years later, I feel my pulse quicken and adrenaline pump through my body. Within seconds I was informed that *our* son was injured, that hospital personnel were seeking permission to care for him, and that I should come as quickly as possible. I had the presence of mind to ask if Erik was conscious; the caller said only that she had not seen him but thought that he had been banged around pretty badly.

Incredulous and terrified, I desperately tried to hang on to any thread of hope that he would be all right. She hadn't said he was unconscious, I argued with myself, so why should I imagine something worse than might be? I tried to concentrate on the directions to the hospital the caller was giving me, staggering mentally between collapse and refusal to believe. I almost missed her closing words. "I think you should bring someone with you." When I hung up the phone it was 12:30 P.M., but it might

as easily have been 5:00 A.M., or 9:00 P.M. tomorrow, or in another lifetime. I felt no breeze and heard no birds. Totally unaware that two hours away the words “survival in question” were being written in a hospital admissions report, I walked past the meeting house cemetery to the car and began to fight unconsciously for my son’s life.

A rocklike silence rose in me as friends drove me home to break the news to Robert and Sonia. Into that silence rushed questions, questions like “Where was the youth adviser in whose car Erik had been riding when they left the meeting house?” and “Why didn’t he call us?” I tried to subdue catastrophic mental images of death and severely mangled bodies of the entire canoe party. When that failed, I took a thread of my fear, stretched it as far as I could away from what was happening, and emotionally climbed onto it to avoid being devoured by terror. Within a few frantic minutes of my saying, “Erik is hurt,” the three of us were on the road, with our close friend Mike driving us the two hours to Hammonton.

As we rode on the highways I used twice each week to commute between my home and Stockton College, the bulwark of silence within me grew. Riding beside Mike in the front seat, my husband expressed his fear, anguish, and grief visibly and audibly: “Oh, God, I shouldn’t have told him to go. . . . This is awful. . . . It’s all my fault.” Sonia and I sat close together in the back seat; eventually she laid her head in my lap, moving between dreadful waiting and the oblivion of sleep. Out of the silence and without conscious bidding, words from a hymn I had played and sung in church as a child began to circle repetitively in my head: “My hope is built on nothing less than Jesus Christ my righteousness . . . on Christ the solid rock I stand, all other ground is sinking sand. . . .” Over and over, mantralike, “on Christ the solid rock I stand” bore me to our injured son.

At the hospital we were met by Richard Weeder, the Young Friends’ adviser, who was a surgeon himself, and the emergency room physician. Both tried to be reassuring, describing for us everything that had already been done for Erik. Yes, he was unconscious, for he had received significant blows to the head, but the paramedics had arrived within min-

utes of the accident. They had started oxygen even as the Jaws of Life worked to extricate him from the car. They had pumped particles of food, inhaled during the impact, from his lungs. They had checked for signs of internal bleeding and injury. They had already taken a CT scan, which looked ambiguous—they couldn't tell how much the brain stem might have been affected. He had no major external lacerations or broken bones except for the left clavicle. I listened stoically to this important recital of services rendered, but all I wanted was to see our son.

Finally we were allowed in. I proceeded on rubbery legs and with a pounding heart through two sets of double doors. I was not prepared to see Erik, bone of my bone and flesh of my flesh, looking physically much as he had when we had said good-bye six hours earlier. Some small cuts on his face had been cleaned up. My whole being inwardly leapt to gather his motionless and silent form into my arms. As he lay in a half-reclining position with a tube in his nose and other lines attaching him to monitors and a respirator, we talked to him, telling him that we were there and would stay with him; we touched him, trying physically and verbally to convey our love. We called to him, asking him gently if he could hear us, trying to reassure him and ourselves. I kept hoping that familiar voices would rouse him, as they always do in the movies. He made no response even to strong pinches of his skin and the pulling of hairs on his legs. While we stood by him the attending physician lifted Erik's eyelids to check his pupils. What I saw registered in those brown eyes was utter terror, not unlike the expression I'd once seen on the face of an injured deer that had been hit by an automobile. How could I reach the being behind those eyes?

Though he had first told us that Kessler Hospital had everything Erik would need, the physician now recommended that we move Erik to a hospital better equipped and staffed to handle traumatic injuries. Since this was a holiday weekend, the Kessler units were short staffed. Cooper Hospital in Camden was the closest with a specialized trauma unit. Later that evening, I wondered why Erik had not been taken there originally. Was it because his survival was in question? Or was it that initially no

one knew the severity of his injuries and could only begin to speculate about them as the hours passed? Confronted with a world of medical crisis wholly new to us and committed to securing the best care we could for our son, we relied heavily on the advice of the hospital doctor, our doctor-friend Richard, and our own instincts. We decided to move Erik to Camden and asked if one of us might accompany Erik in the ambulance. My husband and I were refused permission, but Dr. Weeder was allowed to join the transport. That was our small effort not to leave Erik comfortless in this threatening terrain.

As we drove over unfamiliar roads, trailing several miles behind the ambulance, the physical gulf widened between us and our son. Not only was he unconscious and incapable of communicating; now also he had become the ward of medical guardians. When he arrived at Cooper Hospital he was whisked into examination. The trauma physicians on duty detected internal bleeding, which had not been discovered previously, and informed us that surgery was necessary. A severe impact, one in which the human body becomes a projectile, often damages the spleen, liver, kidneys, and even the lungs and heart. The doctor explained that a seriously damaged spleen can be removed if necessary without unduly endangering the patient's life. Seven hours into this nightmarish ordeal we again were required to make a decision for which the outcome could not be assured. We signed the appropriate papers and moved to the trauma unit waiting area. Weary and tense, Robert and I sat numbly in a stream of grief rising steadily. After three hours the doctors reported that Erik's spleen had been lacerated but was repairable. To our great relief and gratitude his other organs seemed not to be in jeopardy, though the condition of his brain remained uncertain.

Night fell as nurses completed postoperative routines and settled Erik, armed with multiple mechanical monitors, into a curtained cubicle in the trauma unit. Night brought other darknesses. It was obvious that we would not take Erik home with us; indeed, we ourselves would not go home that night or for many subsequent nights. But our friends could not stay. And what about Sonia? What was best for her? Slowly we were

forced to consider the “ordinary” world of school and jobs, of a missed picnic, of our extended families half a continent away, and of Erik’s friends. We made the fewest heartbreaking calls we could, soliciting hope for Erik in this dark hour in which his life dangled uncertainly before our eyes. We decided to wrap Sonia in our friends’ love and send her home with them for the night. They would return the next day, Memorial Day.

By the time Erik’s surgery was finished all the people who had been in the waiting area earlier had disappeared. We did not realize that visits in the trauma unit were limited to two hours per day, one hour in the late morning and one hour in the early evening. The hospital staff did not discourage us from staying in the waiting room the first night and told us that we could see him once each hour. Having had previous exposure to pediatric intensive care units, where brief visits once an hour were the norm, I did not think to question whether this was a standard practice or a courtesy accommodation extended to families in the initial throes of shock. Did the hospital staff perhaps offer this opportunity because they were not too busy? Or was it because Erik’s life hung delicately in the balance that first night?

That night Robert and I, together or singly, sat by Erik’s inert form, listening to the blips and beeps of his machine-generated breathing, watching his body functions represented through electronic signs. It was as if we had suddenly been transported into a foreign country, the language, signs, and symbols of which we had little understanding. Our son was absolutely helpless in this new world. We could and did ask questions about the procedures performed on him, about the normal ranges for heartbeat, respiration, and blood pressure, about this totally new phenomenon of intracranial pressure following a traumatic blow to the head. We were curious, intelligent, and generally informed, and we knew instinctively that we would assist our vulnerable son.

What did we expect that first night? I cannot now remember expecting anything, for all our physical energy and mental attention were poured into navigating in this nightmarish set of circumstances that we

had never imagined for ourselves or our children. Through bizarre, chance events on a rare day in May we joined the vast company of earth's people who are forced to struggle merely to survive. I am sure that every minute I hoped Erik would open his eyes, rejoin us in consciousness, and allow us to leave the fear that bound us.

Some time after midnight we began to take turns trying to sleep, wrapped in hospital blankets on vinyl chairs pushed together to hold our legs and feet. At some level, the lack of response from Erik's body to painful stimuli and the pessimistic tone of doctors' voices when they reported that no one could predict the outcome of Erik's injuries hinted that our sojourn in this foreign world of medical crisis might end abruptly, a hint I missed as we began a defiant watch. As one of us slept fitfully in hour-long shifts, waiting for some flicker of hope, the other sat by Erik, stroking him, speaking gently to him, humming or singing to him, watching for any sign of life, and trying to stave off reversals.

Although we felt Death lurking in the shadows of that first night, my mind held the door tightly against Death's press. I have no notes in my journal about that night, even though many years later the sense impressions seem as vivid as yesterday's activities. Shock stalled my speculative capacities. I did not, for example, wonder about the accident. I did not lament that Erik had left home that morning, though I tried repeatedly to picture him as he had been when he walked out the door. I had no concern for the car. Even telephone inquiries from other passengers' families barely registered in my consciousness. I was restlessly searching for some transcendent ground on which to stand my watch.

By early morning the institutional routines that govern hospital activity replaced the small, though significant, gestures of compassion we had experienced during our night-long vigil. The whooshing sounds of rising and falling elevators, the rattle of glass test tubes in metal baskets being whisked efficiently down the halls by rubber-soled medical technicians, and the clatter of breakfast carts greeted us as day broke. At dawn the hospital workers' treatment of us changed dramatically. No longer were we two loving parents in understandable shock; instead we were

cast into the line of anxious visitors who waited, like supplicants, for the twice daily access to the sanctum that held the traumatically mangled bodies and brains of our loved ones. A nurse told us that we would now be restricted to the rigorously enforced rule of only two one-hour visits each day. In short, within eighteen hours after the accident that changed Erik's and our family's lives forever, we were forced to navigate in, and find some balance among, three dimensions: the inner space of anguish, the medical space of experts and fixed rules, and the external space of everyday life.

Our initiation into the liminal space of anguish on the one hand, and the technological-medical environment on the other, was not mediated by mentors like social workers or chaplains and certainly not by doctors. No one in a position of authority would talk to us. No one would help. Instead, we desperately picked up random pieces of information about hospital procedures, personality idiosyncrasies of doctors, various kinds and degrees of injuries, and the progression of treatments and interventions from a few communicative nurses and other families on similar vigils at the trauma unit gates.

As we entered the second day a trauma unit nurse, concerned for our well-being and medical efficiency, told us to go home and get some rest since we couldn't see Erik again until 11:00 A.M. When we reminded her that we lived over an hour away from the hospital, she suggested that we might be eligible, as out-of-town family of a critically injured patient, to stay in the Ronald McDonald House across the street behind the hospital. Since getting rest was far less important to us, whose vigorous, bright son now lay in stony silence, than it was to medical personnel, for whom this was simply another routine intake in the trauma unit, we put off investigating accommodations until later. We wanted to talk to a doctor.

But seeing a doctor was not easy. The physician who had performed Erik's surgery did not reappear during the night, though a trauma unit resident did stop by frequently to check on Erik, while one of us sat by

his bed. He willingly answered informational questions but assiduously avoided any discussion about prognosis. By morning we had discovered that the trauma unit medical team of four doctors rotated shifts every twenty-four hours, each trying to stay abreast of every patient's condition. Interns, residents, and nurses also rotated on similar schedules. Though this organization may work well for the medical staff, it requires family members not only to comprehend a new medical language but also to interpret a wide range of communication styles and to fill in gaps that inevitably result when medical responsibility for patients is shared.

Finally, right before the eleven o'clock visiting hour, we found a doctor who reported that nothing had changed in Erik's condition since his arrival. We learned later from one of our relatives, a pediatrician who tried to get information from the hospital, that Erik's condition was described as critical for the entire first three weeks. The trauma unit physician reported that they had taken another CT scan during the morning and would have results later in the afternoon. In the meantime the staff would cool Erik's body to inhibit excessive swelling in the brain and watchfully monitor intracranial pressure. This was only the beginning of an endless chain of scans and X-rays and blood tests that hospital personnel would run on Erik. Clearly our son's physical care lay beyond our control. Even though outer appearances seemed to suggest that he was not registering our presence in any discernible way, Robert and I resolved not to abandon him. Questions poured from us. What was intracranial pressure? I made a layperson's guess that this referred to pressure on and around the brain caused by a severe assault to the head. Was there an acceptable pressure range? What were the consequences of pressure that exceeds that range? What factors would influence the rise of pressure?

During the first regular visiting hour we found ourselves in the strange company of the similarly distressed, a company that would expand and contract over the next three weeks and that we would come to experience as a wounded community. A mother and father called loudly and impatiently to their young adult daughter in a bed next to

Erik, imploring her to wake up. Within a few hours of Erik's arrival a girl just his age was admitted, having been thrown from a horse. For several nights one of the patients in the unit had police protection.

Looking for any clues that might help me negotiate through the unfamiliar world of trauma and among such a diverse group of waiting penitents, I instinctively became an unabashed eavesdropper. I listened to new words, asked for definitions, or wrote the terms in my journal to search for later; I overheard comments about kinds and locations of injuries; I learned about the Glasgow Coma Scale for measuring depth of coma and levels of responsiveness in three areas: motor response, eye-opening, and vocal response. Erik registered at the least responsive level. He showed no motor response, no eye-opening, and no vocal response, giving him a score of 3.¹ We began to talk to other parents and spouses as we waited together prior to visiting hours. We rapidly learned that most traumatic brain injuries occur to the young—most frequently to people between the ages of fifteen and twenty-five. Many injuries occur on motorcycles or in automobiles and involve guns or alcohol; secondary complications from delayed bleeding inside the brain, other injuries, seizures, repeated surgeries, or infections are common, and there is no predictability in the course of recovery from traumatic brain injury. As if these discoveries were not sufficient to depress us, most of the medical personnel were routinely pessimistic about favorable long-term outcomes, especially given the early ambiguity about the extent of damage to Erik's brain stem. While we desperately desired reassurance for our fear and grief, we instead moved more deeply into a terrain where violence, danger, and terror lurk and from which we had been largely insulated most of our lives.

After lunch on Monday, as I maintained our vigil outside the trauma unit, Robert made arrangements for us to stay in the Ronald McDonald House for what we naively hoped would be only a night or two. The urban setting mirrored the psychic state we were experiencing. Headquarters for the Campbell Soup industry, Camden was in visible decline. Some streets near the hospital looked like a war zone; poverty and crime

held many city residents hostage. Guards and electronic monitoring systems protected hospital entrances, and we were advised not to walk across the street to the Ronald McDonald House after dark without a guard.

During this first twenty-four-hour, Memorial Day watch, Mike and his wife, Pat, returned with our daughter, a few overnight supplies, and a list of people they had called and others who had heard of Erik's injury and had called them. Even though we could not register the details of the calls reported to us, I felt increasingly, if precariously, upheld by a web of human connection quite distant from the hospital. At noon Richard came to see Erik and to offer freely his knowledge about head injury. In contrast to the trauma unit doctors, and perhaps to sustain his own hope, he was encouraged that Erik's condition had not worsened. "Severe injuries can result in responselessness," he counseled, "but the intricacies and mysteries of the brain make it impossible to predict anything for the next day, let alone weeks or months distant." He confirmed what we had already picked up in overheard conversations and doctors' responses: damaged parts of the human brain do not regenerate, but sometimes new connections can be made. Erik's was indeed a very serious injury but, our friend observed, his youth and physical fitness were in his favor. Although he said nothing as he lifted Erik's eyelids to look for any eye reactivity and as he pressed and pinched various places on his body, I interpreted his silence as his own uncertainty. His most reassuring words were that he would come again later that evening.

We had learned a few extremely sketchy details about the accident when we had arrived the previous day at Kessler Hospital. First among our concerns was how Erik had gotten from the adviser's car into the car of a young, inexperienced driver. This dismayed and angered us—we had given him specific instructions to ride with the adviser, and he had left the meeting house in the adviser's car. Apparently, as the group neared their destination, they had loaded another canoe onto the adviser's car. When the car dragged too close to the ground, one of the passengers was asked to move to the other vehicle for the two-mile trip

to the river. Perhaps because of Erik's kindness or willingness to be cooperative, he was the one to move to the other car. As a result of that fateful decision, and despite the short distance, Erik's life now hung in the balance.

By our second evening in Camden we had received numerous calls in the trauma unit waiting area from family and friends wanting to know about Erik and expressing their concern. What could they do? Our parents, who were devastated by the news of what had happened to their first grandchild, wondered if they should come. We asked them not to but to keep hope alive for his survival and healing. We urged them to hold mental pictures of Erik strong and healthy in their minds and to gather around them some of their friends who could wait with them even at a distance of 700 miles. I knew at the time, and they confirmed it subsequently, that it was hard for them to remain helplessly at home. But we knew that we could not care for both their needs and Erik's in these critical circumstances.

At the close of the Monday evening visiting hour we finally looked at several scans of his brain with one of the trauma team doctors. With these visual images to examine, we were learning to decipher yet another language. How could I assimilate this smudgy two-dimensional image? Did that dark representation of a spherical mass of cells, presumably laced together with invisible neurons and synapses, belong to my son? I didn't know what the interior of an uninjured brain looked like, so how could I interpret the splotches that appeared under the lights as we viewed the scans? I felt overwhelmed by this new visual information, yet I tried to grasp, or infer, as much as I could. Despite the doctor's intention to inform us at least minimally about the brain's organization and function, these documents belonged to the initiated. Through them the doctor conveyed his authority and expertise as my own sense of powerlessness to aid my son increased hour by hour.

The scans showed diffuse, as opposed to localized or focal, bleeding in all parts of the brain, with special concentration in the frontal and temporal lobes. Indications about the extent and consequences of brain stem

involvement were ambiguous. It was too early to predict the long-range implications of the injury. I desperately tried to grasp and hang on to the words the doctor was saying, but only later did I fully understand the physiological operations of the brain and its response to traumatic injury. Upon impact, Erik's brain had been jostled sharply from side to side inside the bony skull. Such wrenching movement produced bleeding from blood vessels throughout the brain. Blood had leaked into the surrounding tissue and was causing edema, which put additional pressure on the injury site and contributed to further swelling. Brain cells deprived of their blood supply die and do not regenerate, I heard the doctor explain. In addition, the dying tissue creates toxins that further exacerbate the swelling. Much depended on how the bleeding might be reabsorbed by the brain and whether swelling could be held at a minimum, thereby reducing further damage from intracranial pressure.

From asking several different nurses and residents during the first twenty-four hours I was beginning to understand that intracranial pressure occurs when the injured brain swells inside a fixed space—the skull—thereby causing a kind of compression chamber for the brain. The initial questions about direct damage to the brain stem at the time of the accident were now compounded by the problem of swelling, for edema can push the brain stem, which governs all the vital bodily functions, down into the spinal canal, producing a kind of herniation. To protect against such swelling Erik was kept on a cooling blanket, through which cooled water constantly circulated. It was clear that Erik was still very much in crisis. The doctor said developments during the coming week would provide better, important indicators of the true nature of his condition. None of the doctors was optimistic, although this particular one was, at least, kind.

We reported this discouraging news to Sonia and our friends, who were waiting both for some report from the doctors and for discussion about how to balance Sonia's need to complete the school year and ours to be close to Erik. If there were other options (and I imagine now that there were), we did not think of them, for Sonia thought she could, and

wanted to, get back to school. Since 1981 and the founding of a small house church in Princeton, Pat and Mike Cox had become like surrogate parents or an aunt and uncle for our children. Their presence with us from the receipt of the fateful phone call onward provided us with essential strength and the courage simply to carry on. They had already said that they would provide a home for Sonia and transport her back and forth to school each day. Making these arrangements for the week ahead heightened our awareness that we would be staying in Camden for a while.

As we parted that evening Sonia sadly and gently asked, “What about my birthday party? Can I still have that?” With sharp poignancy her questions reminded me that she and Robert had been fixing up the basement for her party on Sunday when I arrived with the news of Erik’s accident. Everything other than Erik’s status had simply dropped from our minds, but the life force of our twelve-year-old pressed onward within her. Yes, we agreed that she should have the party, but we did not know how we would manage preparations that had barely begun. Exceedingly resourceful in every way—from hooking an old television to a videotape cassette player, to buying and preparing party food, to decorating a basement that was only partially cleaned, to helping our daughter feel as secure as possible in conditions that were inexplicably threatening—Pat and Mike quietly took over the at-home management of Sonia’s overnight party, which was scheduled for the following Friday.

Reluctantly, with anxious hearts, we said good-bye again to Sonia, Pat, and Mike, and we left the hospital—the first time since we had entered it thirty hours earlier—and headed toward the Ronald McDonald House. The house itself was a lovely haven graciously hosted by a kind resident director and filled with caring guests. We asked the nurses to call us at the slightest change in Erik’s condition at any hour, which they agreed to do. On the way out a rear exit we passed a vending machine snack shop and selected some soup and juice, a practice that would become habitual in the days and weeks to come.

Our sleep brought spaces of oblivion but little rest, for we were awakened repeatedly by the sirens of the ambulances bringing the injured and sick to the emergency room throughout the night. Each arrival startled us out of sleep to face the reality of a bad dream from which we could not escape. We were relieved when dawn broke and we could “reasonably” call for a report on Erik’s condition. “No change,” came the response. No worse. No better. Still critical. More waiting. By 8:30 we resumed our watch outside the trauma unit.

Although we didn’t realize it at the time, our actions on the second morning in Camden would, over the coming weeks, take on the character of ritual. Upon rising we telephoned the unit, then showered, dressed, and ate breakfast in the hospital cafeteria. Well before 11:00 we were in the waiting area, usually sitting by ourselves unless a new patient had just been admitted. For both of us, being close by was important. We sat in silence, writing perhaps, praying or meditating. Frequently we received phone calls, and we would repeat the story another time or report “no change.” Often during the first week I retreated to the small bathroom off the waiting area when the weight of my anxiety and grief became publicly unbearable; there I could hurl my anguish soundlessly at the walls.

On Tuesday morning Robert returned a call we had received from the police department. The officer was kind as he inquired about Erik, asked about insurance matters (New Jersey was a no-fault state), and then proceeded to explain that the driver of Erik’s car had made a left-hand turn across two lanes of moving traffic. Apparently his view had been obstructed by a van that was waiting to make a left-hand turn from the opposite direction, or perhaps he thought he could get across the lane in which an oncoming vehicle was traveling. The car was hit broadside at the back door, right where Erik was sitting, and was propelled into a telephone pole on the opposite side. The car was so compressed that the Jaws of Life were required to extricate Erik. Questions about the speed at which the oncoming vehicle was traveling were ambiguously answered. Before the call ended, however, the police officer advised us to

get a lawyer, a need that seemed inconceivable at the moment, given our focus on the immediate survival of our son.

This additional information about the circumstances of the accident troubled us deeply. The previous day the eighteen-year-old driver of the car in which Erik had been riding had come to the hospital with his father, and I had felt immediately torn. I was incredulous that Erik was the only one who had been severely injured in the accident. I also struggled with anger that somehow Erik chose or had been chosen to move to this young man's car. Then I felt compassion for what I imagined I would be feeling if I were in the driver's shoes. The father and son expressed their regret, and Robert and I hurried to tell them not to blame themselves. Now, after Robert's conversation with the police officer, we realized that Erik's driver, although inexperienced rather than reckless, bore significant responsibility for the crash. Anger sank more deeply into our hearts, sat beside our grief, and confounded the charity.

Later on Tuesday a trauma physician asked our permission to perform a tracheostomy on Erik—a procedure to open his trachea for air passage. We hesitated, for we knew the risks involved—possible direct damage to the vocal cords or later compromise from scar tissue. We deduced from his request that the medical team thought Erik was not on the verge of waking up. The doctor explained the comparable hazards of leaving the nasal tube in place, and so we gave our permission to perform the surgical procedure. Facing choices with equally undesirable outcomes would become commonplace over the next weeks and months.

Waiting to see Erik each day created profound anticipation, even excitement, for we kept believing that this time he would surely awaken. Although the excitement was mingled with dread, the feelings were similar to those that I had experienced immediately after giving birth, when I wanted to see and hold this unknown being who had come forth from my flesh. To quiet myself and to find inner resources for facing the unknown, I tried to meditate. Often it was impossible to still my active, pleading mind. Why? Why? What is the meaning of this? What had

Erik done to deserve this fate? I had come unwittingly to rely on reasonableness in life, and this event simultaneously exposed and subverted that illusion. During these attempts to meditate I wanted to visualize Erik as I had remembered him just two days before. I could not. I could recall topics of conversation or an article of clothing; I was able to remember his activities the day or two before the accident; but I could hold no unitary picture of our son in my mind's eye. It was as if my own memory cells had been damaged by his injuries.

Quickly the rituals of meditating and waiting to see Erik anchored our lives, which edged close to disintegration. When we were with Erik my anxiety abated because I had his physical presence with which to communicate. I was grateful when the medical staff would leave us alone with him so that we could speak freely with him. Yet these one-hour visits were also the only times we could easily seek information or ask for interpretation. We learned to read and interpret the monitors just as expectant parents listen for the heartbeat of their in utero child or view its image by means of ultrasound. We observed closely when doctors or nurses looked at his pupils to see if they responded to light and, by asking questions, learned crudely to detect their reactivity. But from Erik, no response.

During much of the time we spent with Erik we found ourselves relating to him as we did when he was first born. Now, however, he was somewhere far beyond our reach, and he gave us no clues about his needs. Nonetheless, we spoke to him gently, telling him each time we came who we were and that we loved him, reassuring him when we had to leave that we would be either just outside in the waiting area or across the street and only a phone call away. We routinely caressed his head and limbs. Amid the tubes and machines, I practiced the ancient technique of energy movement a few inches above his body. We told him about the good wishes of those who had called and suggested that he imagine these people all standing around his bed. From the depths of our spiritual reservoirs came unsolicited passages from the Psalms, childhood lullabies, lines from poems we had read when he was a child or that he had

learned recently in school. Whenever we mentioned relatives or friends we would remind him of the person's relationship to him and describe a recent interaction or recall a special occasion with the individual. We sometimes included the monitors in our communication, reporting what we saw. Particularly when a sudden change registered, we asked him if he was frightened, in pain, or upset.

On one level, unconsciousness and the absence of speech may make such comments and questions seem ludicrous. Yet at another level we sensed we were engaged in a new form of communication that was directed largely by our instincts, our bodies, and the impression that we had to reach behind the veil of language and consciousness to seek our son. As our visiting time drew to a close we would usually hum quietly to him, pray a very simple prayer, and reassure him of our continuing nearness to him even when we were physically absent. Each day these meetings briefly grounded our lives.

Often in class discussions and in teaching writing I have counseled students to risk vulnerability by disclosing their thoughts and feelings, which could help them discover their own values and ideas and communicate them clearly. As our son hovered in these early days between life and death, I learned how wide the chasm is that separates vulnerability that is chosen from vulnerability that crashes upon us. The impact of what was happening to us dawned on us by degrees. Our first reactions of terror and disbelief registered physically in persistently knotted stomachs, grief lumps in the throat, and restless sleep. Our identification with our son produced vicarious pain and a continuous feeling of powerlessness to mitigate what we imagined he might be going through, even while unconscious. In an instant all the care and caution with which we had protected our children were rendered irrelevant, and we could do nothing to change that reality. This vulnerability promised no clarity, but threatened to reveal meaninglessness.

The accident disturbed the family nest for each of us as father, mother, or sister, or even grandparent, aunt, uncle, or cousin. When we spoke to our relatives and our friends on the telephone we heard, in their

voice tones if not in their words, their troubled efforts to make some kind of sense of an event that seemed so incomprehensible and so unjust. I frequently wondered how Sonia was experiencing and processing this assault on the family system.

As we grasped for our psychic centers and the spiritual resources to carry us through this enforced vulnerability, we had to learn to read the signs, language, and ways of organizing medical knowledge. We had to construe meaning for medical information encoded in specialized jargon and cryptically hidden in case notes usually not available—or, if available, virtually undecipherable—to patients or their families. We had simultaneously to tolerate the depersonalization of our son and resist the routine that turned him into an object analyzed by medical professionals.

Those who cared for our son and kept records on him were in effect telling a story about him. Their protocols, the tone of their voices, their investigation and interpretation of the data about his condition acquired from the machines—indeed, the pervasive impersonality and instrumentality of most relationships in the trauma unit—dismayed us and reduced Erik to a body struggling for survival. In these circumstances I felt like a wandering soul cast into Limbo, the first circle of Dante's hell.

Each day Erik's and our vulnerability deepened and manifested itself in new ways. In retrospect I understand that as the gap widened between the hospital and the strawberries left in the kitchen and the work abandoned on our desks, we became engaged in a cosmic struggle not simply between good and evil, as we understood them, but more wrenchingly between love and perfection. This struggle appeared in various guises. Sometimes Robert and I experienced it together as a contest between our need to relinquish everything and our mutual desire to control outcomes. Often we found it expressed in our differing responses to the crisis. There was no doubt that we both loved deeply, but through our separate styles of coping with fear and grief, we sometimes grew impatient with each other. Robert's take-charge rationality and desire to fix whatever breaks down or falls apart clashed with my need to turn

inward to process my feelings and to persist in calmly attempting to communicate with the spirit of our injured son. In the confusing throes of anger, fear, and heartbreak, each of us clung tenaciously to the hope that, through our love and will, perfection would kiss our son's brokenness and return him as we knew him.

During these first four days, the persistence of our hope for restoration to perfection illustrated both our naivete about traumatic brain injury and our denial of the severity of Erik's particular injury. We struggled mightily with the temptation to measure love's efficacy by images of perfection. Never before had we confronted anything our love could not protect, control, or improve. On this threatening threshold we waited.