

Chapter 3

Wednesday's Child

I went to other doctors, visited big hospital centers, therapists, clinicians, psychiatrists. One recommended tranquilizers, but this had a devastating effect on Jesse. The smallest dose sent him into deep depression, followed by a drug-like sleep, and I soon discontinued using them. The only good thing that came from all the visits was the confirmation that Jesse's problems were neurological, not psychological; central nervous system dysfunction, not mother's disgraceful malfunction. But no help for that battering ram of an arm.

The self-torture was growing worse. Jesse would start the moment he woke up in the morning and continuously hit himself, harder and faster, until he screamed with pain. I was spending all of my waking minutes with him, carrying him, holding his arm down, playing with him to distract him.

My beautiful little boy was beautiful no longer, with bluish welts around his nose and eyes, and new ones starting in other places when he could no longer take the pain there. What would he do to himself? I was fearful that he would inflict permanent damage.

When no one else could find a remedy, I was to find it at home, through Hal. In what turned out to be a brilliant maneuver, Hal devised a splint out of shirt cardboard rolled up into a cylinder and taped over Jesse's elbow.

I watched the little face so full of misery as Hal approached him and took his right arm.

“Now, my son, let’s see if this helps you. Daddy’s going to make you feel better, okay?”

The crying stopped as Hal started to adjust the splint. He let go for a moment as more adjustment was needed. Jesse got in one more jab at himself, an angry cry escaping his lips at the same time. Both Hal and I grabbed for him at once. This time I held him until it was finally ready.

As the splint went on, Jesse quieted down, almost as though he understood from the start what it would do for him. A placid, peaceful look came over his face, and Hal and I stood back, hardly breathing, watching warily to see what would happen. But Jesse didn’t even try to reach his face.

He could now raise his hand but not bend it toward his face. Relief was immediately evident, and placidity returned to our lives until the worn-out cardboard had to be replaced. The fighting and crying would begin the moment we approached that silly-looking but effective device. Bathing time was a watery battle scene, and I was even spoon-feeding him so we wouldn’t have to remove the splint.

How many times a day, now that I could afford the luxury, I stood and looked over at that helpless, sad little boy in his playpen, the bruises looking worse than ever in the healing process, the once-handsome features still swollen out of proportion. How many times did I find myself beating my chest in the intensity of my emotions, as though physical pain would relieve mental anguish. This is laughing fate’s answer to a foolish mother’s vanity.

My way out was found by running away. I spent more and more time away from home, leaving the children in the hands of the housekeeper, a good, kindly lady, but certainly not a replacement for their mother. I was bringing home lots of clever new toys and games for the children, as if the purchase of these things would take the place of my time. The chemistry set for Andrew, and the plane models...

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only he needed someone to do these things with him. The new books and expensive dolls for Lynn...but who would read them to her or chat with her as she played with the dolls?

I welcomed the stimulation of a variety of activities—political, social, cultural—which kept my mind wholly occupied in other channels (except for the moments of guilt). I was filling my time with community activities, which I could rationalize was productive, except that even when I was home, I was too busy for the children.

With nerves straining, I was frequently sharp when they intruded on my work.

“Mommy, when can we do the airplane model?”

“I don’t know, Andrew, not now. We’ll do it another time.”

“But I want to do it now.”

“Stop bothering me and try it yourself. I told you I’m busy now. You can figure out some of the parts yourself.”

The airplane model never did get built, and the chemistry set remained unused until the parts got lost, as did lots of the doll clothes.

Poor Lynn and Andrew. They weren’t responsible for Jesse. Guilt was building up in me like a dam. The response to this feeling wasn’t more justice for the children, but less, for one tends to rationalize the need to find escape, bringing more layers of guilt and rationalization, until the vicious cycle entrapped me.

I sought out still more specialists, looking for more answers, but really searching for someone to say, “It’s all right, Mother, your boy will outgrow it.” It is a common phenomenon, this hysterical searching for the right answer. Why do we do it? Perhaps because we are so puzzled by the seeming contradictions in our children’s behavior, making us despondent one moment and joyful with renewed hope at the next sign of progress. Perhaps it is because we don’t want to bear the burden alone, for this means a final reckoning with ourselves. We can rationalize that we are involving ourselves in our children’s problems when we are really still running. Whatever the reason, it would appear to be a necessary ritual that we must work our way through before wisdom and insight are ours,

a physical and mental exercise to the point of exhaustion, before we can rest.

They were using more labels—more dreadful words, things like mental retardation, autistic symptoms, possible institutionalization, and each time it would strike terror in my heart. Each time I refused to accept them. What do these cold, clinical purveyors of doom, with their little bags of tricks, know about my child? They spend a half hour testing him and are ready to close the book on his life's course, on my life's hopes.

“Well, isn't that what you wanted,” a little voice says, “someone to tell you what will happen to him?”

But I only wanted to hear good things, for I knew him better than they ever could. I had seen little chinks of light in the darkness. Like the day he picked out a new object in his room too high for him to reach, and he found a way to reach it with a stool, even though no one had shown him how. Finding answers for himself, isn't that supposed to be a sign of native intelligence? And this so soon after he started walking, finally. The joy I felt when he took those first steps. And then the trip to the store to buy his first pair of walking shoes. Almost like a normal mother and baby, that purchase. He was still only two years old, and I'd heard of other children who didn't walk until almost two. He'd also increased his vocabulary, saying a lot more words. They were not meaningful to him yet, but it would come, I felt sure. I even had something to boast about. Jesse had always put his slippers on correctly, right slipper on the right foot and vice versa, which seemed almost precocious at his age, a small but important symbol.

There was nothing to go on but a mother's intuition, and I had to laugh as I recalled how once I would have scoffed at other mothers' bragging about such incidentals. Doctors are not God. They don't have all the answers, I reassured myself.

Dark Moments

The last doctor had been seen. Hal had finally put his foot down and said ENOUGH! The moment of reckoning had come, when we had to face up to it, talk it out together and bring into the open everything that had been crammed away in the dark, inner recesses of our minds. We looked at each other numbly at first, with bits and pieces of things learned over three years' time a jumble in our heads.

“What more do you expect to learn?” Hal was saying. “Every time you see a new doctor, you find out you know more than they do about Jesse. Or else you won't accept their diagnosis. Maybe they can't tell you what he'll grow up to be like. All they can tell you is what you already know, that he is brain damaged and has severe mental and behavioral problems as a result.”

“But there must be some way to teach him,” I replied. “Some way to reach him and communicate with him.” I felt as though my hands were tied. All the little joyous discoveries children make every day had been denied him, and the pleasure parents take in watching their children unfold like blossoms nurtured with a mother's love was cut off. Somehow I expected the doctors to tell me what part of the brain was hampering my efforts, what I could do to compensate so that I could get through to Jesse, as though this would make him normal again.

“It may be that Jesse will always have these problems,” Hal was saying, and I felt rebellion rising in me at his words. “You're being simplistic, looking for easy explanations to a very complex problem. And anyway, why do you expect anyone to tell you what will happen as Jesse grows up when no one can tell you this about Lynn and Andrew? Who knows what war may someday take Andrew's life, or what troubles may overtake Lynn and cut short her bright promise? All we can do is give them the best we have, and hope they will live full, happy lives.”

My tears were coming with his words, bitter, hot floods of self-pity that had been locked up all this time. For the hard truth was

that all our searching had been a kind of shadow-boxing. I had been fighting for myself more than for Jesse. What did he know about normality or abnormality?

Only I couldn't accept the dashing of my hopes, my illusions. This smug, private world I had built had isolated me from life. It wasn't a reality, it was a fairy tale, with all of us living gloriously ever after, beautiful people creating a beautiful world of our own.

The blow to the ego is worst of all. The knowledge that we have borne an imperfect child has a special effect on parents, and perhaps even more on women. Though our husbands may share this feeling, it is we who carry and nurture the growing fetus in our bodies, and so it seems somehow like a reflection of our incompleteness—blood of our blood, flesh of our flesh, the fruit of our womb that tells the world what we are, or are not. Our children are part of us, and we of them. No matter what our sophisticated intellects say about their individuality as separate people living their own lives, our dreams and emotions are tied up with them in an inseparable bond. We live on through them and in them, even after death. Under all the layers of rational thought and education lies this inescapable, indigenous claim with its first priority on nature.

We may denigrate parents whose lofty ambitions for their children lie brazenly naked for all to see. We may camouflage or mute its truth in the comfort of watching our children's potential unfold. But let this potential be cut short—then in negation it lies exposed, through pain, the raw wound of unrequited nature. Immortality denied.

All the more unbearable, then, if you're a mother who's always been so certain of your capability, a believer that your children are bound to grow up straight and strong because of your smart ideas on good psychology, good nutrition, and good heredity. All the more unbearable in a world that prizes its bright, beautiful children, where all around you are parents proud about their children's accomplishments and encouraged by an approving society. It is no good to tell us, "Accept your child, love him as he is." We know it, and

desperately need to. But we are torn between this and a competing need to make him more like those peers society approves of, to make him more acceptable to the rest of the world. It is easy to ask that we be accepting, but will others? Wednesday's child has been christened by society.

In the weeks and months that followed, Hal and I were to question many things we had previously taken for granted or never analyzed. A constant, basic theme in our searching had been the need to find a cause for Jesse's problems. No one had ever satisfactorily answered that. Why had it been so important to us? We recognized that even if we could determine the exact etiological explanation for all his behavior manifestations, it would change nothing for Jesse. Unlike physical medicine, knowing the cause does not usually provide a basis for finding the cure. There are no cures.

Yet, knowing this, we had never given up looking for answers. Why? Was it that we were looking for something apart from ourselves, outside of ourselves, to blame; something that would relieve us of our burden of guilt? Was there a secret fear of genetics as the cause—a faulty seed? Was it something I had done, through neglect, during my pregnancy?

Thinking back to my pregnancy, I remembered I had gotten sick in my sixth month, and the doctor prescribed some rather strong medicine for fear I might abort. I caused that illness, I thought, with my smug attitude about child-bearing and child-raising. I had kept up all my usual activities, even adding new ones. Like that big, lively party I hosted for so many people, doing all the work myself. It was a week after that when a urinary tract infection hit me hard and I was in bed with a fever that rose as high as 105 degrees. Maybe I should have pampered myself like other women do, I thought, or maybe I should have continued my neglect and let nature take its course. (And then I would reprimand myself —“Oh, God, what am I thinking?”)

“Okay,” Hal said, “let's have the rest of it. Let it all hang out.” And so I told him the terrible thoughts that had lain buried deep in

my subconscious for so long. The wish that something might happen to Jesse, not of my doing, of course; just an accident, unavoidable. The images that flashed into my mind, unannounced, that I never wanted to admit—a fall down the stairs, a call from the hospital: “Mrs. Lustig, we regret to inform you...” And then the shock. Unnatural mother! Horrible woman!

Finally the remorse as I looked at this innocent, helpless baby. I loved him. He was still my beautiful child, and he needed me so much.

There were still so many little pleasures he gave me, like every time he learned a new word or made some new discovery. No different than any mother watching her child take his first steps.

Then why do these sinister thoughts invade the mind? Ha! The tables are turned on you, Freud, old man. Children are supposed to harbor a secret death wish toward their parents when their desires have been thwarted, but here’s a parent with a death wish toward her own child! How does a mother live with such guilt!

“But you’re not alone,” Hal was saying. “I have had similar thoughts. We have two other lovely children, with whom we faced only the usual problems until now. Jesse has been a traumatic experience. It is natural,” he was saying, “to wish it away as though it had never happened, or will soon end.”

The fantasies of our subconscious will not be quieted by moral conscience. Best to recognize it, bring it out into the open, for then I could relegate it to its proper place, a perverse but superficial trick of the mind which cannot dominate two reasonably balanced people. We had been doing everything we could to save the life of our child.

And so the confessions tumbled out. “Remember the night you heard Jesse fall in the crib?” Hal asked. “I told you he fell out of my arms, but the truth is, I threw him down in anger.” Hal had been living with the memory of that sound when Jesse’s head came into contact with the crib bars, a sound grown larger and more ugly with memory. Always he had wondered if he’d caused any brain damage.

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Now it was my turn to relieve him. “Put it out of your mind,” I told him. “Jesse bore no bruises from that incident, nor any symptoms not present before. Whatever damage there was had already been incurred.” Yet, though he knew, rationally, that this was so, the scars remained, and the incident could not be remembered without pain.

So, too, my running away from the children blights my memory of their growing years. How many times all three had been left with housekeepers. (Did they ever drop Jesse?) How much I had missed of the moments when I could have been playing with them, reading to them, watching them experiment with their environment and enjoying them; moments that can never be recovered. What they had missed for not having enough of me can only be guessed at. (I was to talk about this with them when they were older).

Ah, no wonder that mothers bubble over with endless talk about their toddler’s newest discovery. No wonder, too, that parents are somewhat fearful about having other people, especially little children, hold their baby. Memory carries me back to that moment when little Lynn, left alone in Jesse’s room, appeared to have picked him up out of that high-sided crib and brought him over to the rocking chair. But all was well then, reason tells me. Jesse was sleeping peacefully in Lynn’s arms. Could I have placed him there absent-mindedly? I was sure I hadn’t. Reason would indicate otherwise. I was to go over that moment many times, every detail of leaving the room (I didn’t remember Lynn being in the room at the time), the ten or fifteen minutes of being downstairs waiting for the bottle to warm up.

Every incident, not only that one; every possibility of moments when Jesse was left alone, or with someone else, was examined, magnified, in a vain effort to relive my experiences, see something, some clue I may have missed. When was the first time he exhibited behavior traceable to brain damage? I wondered. Was it when he lay in the crib as an infant in that half-flexed position—is that really different enough to be considered a symptom? Or was it later,

when the developmental and behavioral symptoms were much more discernible?

With so much energy being invested in the search for answers that could pinpoint the moment of trauma, I seemed to be on a repetitious cycle. All my vague fears and guilt had to be concentrated into one area. If it were genetic, I had my role cut out as someone with inferior genes; lucky with the first two, but bound to produce a blemished child as inherent female frailties were tested too far. Hal could not acquire equal share of the blame in this—I reserved the torture, and the pity, all for myself.

And what of the other children? Would Lynn and Andrew be affected by my taint? Would their children, and their children's children, carry the vulnerable gene?

Suppose it was something I had caused through physical neglect during pregnancy, or afterward, when Jesse was in the care of nurses and housekeepers? Then I could despise my reckless, neglectful nature and do penance for the rest of my life by giving up everything I wanted for myself in the service of my children.

It all came down to the same thing, though: a need to wreak vengeance on myself for this conspicuous demonstration of unworthiness. And so it went, the self-indulgence and self-flagellation, an outcome of being alone for too long with a problem which became more and more overwhelming.

In later years, with the advent of maturity and professional training, I was able to see how the patterns of my own family upbringing played a hidden role in creating excessive guilt, a need to punish myself. For it is when one parents a child who presents unusual problems or stresses that all the unresolved conflicts from one's own childhood come home to roost. I was later to learn, as I started to work professionally with families having a member with mental disabilities, that feelings of guilt are a frequent companion to the caregiver, and not only when the vulnerable member is a child—I have seen it also when a spouse or elder parent is involved. For many such families, sacrifice and martyrdom become a way of life.

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At the time, though, talking about it with Hal was cleansing for both of us. It was like an ingrown infection, blown out of proportion to the original wound, being finally exposed for treatment. We could now reason that no one was to blame. Cerebral palsy is a symptom of brain damage, usually suffered by the fetus either prenatally, when illness or mishap to the mother's support system may affect the baby's vulnerable neurological development, or paranatally, when the trauma of birth, particularly with prolonged labor, may cause a diminished supply of oxygen.

Jesse had been born through natural childbirth, dismissing any possible dangers from anesthesia, but it was a difficult birth, nevertheless. With two toddlers to take care of, I had been very active right up to the moment of labor. I can remember feeling weak during the last stage of labor, and almost unable to produce that last spurt of energy called for. The combination of illness and a difficult birth seemed the most logical explanation. There might even be some genetic tendency toward weakened organic functioning during the stress of pregnancy. When Lynn was born, I had contracted a similar infection, which fortunately for her, had occurred after her birth.

I was also able to learn much later that the particular medication, a sulfa pill, prescribed for me during my illness was no longer given to pregnant mothers, possibly because of potential danger to the fetus. One could lay the blame at the doctor's door, but he was using the knowledge available to him at the time, and was alarmed at the hazard to my and the baby's health posed by the infection and high fever.

In any event, no useful purpose could be served for either Jesse or us in this kind of thinking. If I wished, I could find ample reason to see Jesse's condition as genetic or environmental, as my fault or others'. He was here, a living, breathing child, with many beautiful ways, deserving of love just for what he was. We are what we are, and can be nobody else.

It was not in my nature to pamper myself during pregnancy, and that has its own merits. Many women do the things I did right up to the moment of birth, with no ill effects. I decided I must not let myself become fearful of life, especially now when my vitality was needed, and I also didn't want Lynn and Andrew to have such fear communicated to them. Life is full of risks we must all take in order to go on growing and learning.

How lucky I was to have had Hal's strong support to lean on. I don't know if I could have felt this much courage without it. Our bonds had grown deeper with the years, and facing our problems together had drawn us closer.

I have learned over the course of years of working with parents that frequently, the experience of having a child with disabilities who cannot live up to their expectations may cause an irreparable rift between the couple. Often it is the mother who takes on all the burdens of raising this child, while the father distances himself from them. I have heard of many instances of marriages foundering from this kind of strain. In my case, while much of the day-to-day care fell on my shoulders, Hal was always supportive and frequently involved with me.

Mothers (and fathers) often face a difficult decision—whether to give up much of their personal lives in support of their more vulnerable children, or to give up the child for their personal lives. Whatever their decision, it is one they have to live with for the rest of their lives.

The question arises, in such a society as ours, where the family unit, even the nuclear family unit, is the cultural, social and economic foundation of our way of life, should people be so alone with choices such as these? The decision to choose one sacrifice over another might not have to be made if there were adequate support services for family needs. (Today there are certainly more of them than there were when I raised Jesse, but nowhere near enough).

We recognize the need for counseling in everyday situations, whether they be marital relationships or child-related problems. When

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serious illness visits the family, there are any number of agencies we are invited to call on for help, but when faced with children such as ours, family services in those days were few and frequently too late. There appear to be very few, if any, centers even today that marshal all the support services needed—medical, psychological, therapeutic and educational—that would enable us to pull our lives together and plan for our children. And so we run around like chickens without heads, and along the way, we lose our sense of balance.

There is much compassion due people who must face such burdens as single parents. They have to be even stronger than people like Hal and me. How very lucky we were to have each other.