Little Fingers

Roger Gibson

"Mike and Ellen Harkman are strong people," others have said. But we don't feel strong. Ellen may be strong, but I just plug away. And my story is not a guideline to those facing life-and-death decisions—they know there can be no guidelines. They also know that the "why" may never be answered; but the "fears" must be.

The blinds snapped open, staggering me with a stab of white sunlight, and I covered my face, talking through my hands. "What you're saying . . . ." I paused, taking a breath, wanting to word it carefully. "What you're saying is that I have to choose whether to let my daughter live as an invalid, or to let her die."

The surgeon gazed out the window for a long time. Finally he sighed. "I wouldn't word it quite that way, Mr. Harkman, but that's what it comes to. I must have your permission for surgery."

"The nerves'll *never* grow to their destination?"

"No."

Then there's no way she'll *ever* be whole?"

"Not with present technology."

There was a moment of silence and I began picking at the plastic edge of the table, which wasn't easy with sore, bloody fingernails that I had spent all night chewing. I stared at the back of his damned golf sweater, wondering if I was keeping the good doctor from his game.

I remembered very little of the tons of medical jargon that had been piled on me in the previous hours, since the baby was born; but I could remember them telling me that her nerves were like wires that were too short, and didn't connect the brain to certain parts of the body, so those parts won't work—and, had the problem been higher on the spine, more parts of the body wouldn't have worked.

The doctor must have been reading my mind when he turned to face me. "The opening was fairly low, but I'm afraid your daughter will never walk or have any feeling in her lower legs, nor will she be able to control her bowels or bladder. We hope she won't have any other problems."

During a long silence I kept picking at the plastic, and finally a piece slivered loose that I could really make noise with.

"What did you call this—uh-defect?" I asked, not looking up.

"Spina bifida."

"I've never heard of it."

"I know," he said, turning back to the window. "Unfortunately, most people haven't—not until their baby is born with it—and it's the second most common birth defect. It occurs at the rate of about one in a thousand births. Some places in the world more, and some places less."

The conference room fell silent again, except for the snapping sound of the plastic. My face tightened as I thought about what it would mean to my wife and me, but I was determined not to cry. I was going to approach the problem logically, and make an adult decision.

"I didn't even want to be in the delivery room," I said for no apparent reason. "I get nauseous watching doctor shows on TV. They were teasing me because of it. But then we talked about Vietnam and helicopters—the OB and me. He used to ride 'em and I used to fix 'em. Well, anyway, I went in, and when the baby was born I even raised the camera to take a picture. But then I saw that—that—THING on her back and I didn't take it. Ellen was crying when I looked

down. She couldn't see the baby, but somehow she knew something was wrong."

When I looked up for a moment the surgeon was studying me closely over tented fingers.

Then I saw it all again. I couldn't stop it. Like a dream, it came back again and again. For the hundredth, maybe the thousandth time, I saw the black and green mass on the baby's back as the doctor held her up at the moment of birth. Again, I heard him say, "It's a beautiful little girl." Again, I heard him add, "But—there is a problem." And again, I felt the white-knuckled grip of my wife's hand while she cried.

I glanced up from my trance and he was still studying me, so I went on, not caring whether he wanted to hear it or not. "Ellen was joking that we hadn't practiced Caesarean in the natural child birth classes, and we were all laughing. We only knew the baby was breech. We didn't know anything serious was wrong. I remember someone saying how it was supposed to be such a happy occasion."

I stopped talking for a minute, but kept snapping the plastic. "A couple of hours later they took the baby down here to Children's because it's better equipped, and—well, here we are. Now what?"

He stood to look out the window again. "I need your decision before I can do anything. There will probably be two operations involved." He whirled around as I look up. "You did know that, didn't you?"

"No," I muttered, continuing to snap the plastic, only harder.

"The first one only closes the opening over the spine. But in more than seventy percent of spina bifida cases the brain fluid circulation is interrupted—that's hydrocephalus—and we have to install a small valve and tube on the side of the skull to shunt the fluid to the abdomen. It's all under the skin. Nothing shows."

I said nothing.

"I know it's hard. You've had a lot dumped on you in a short time."

"No, shit!" I sneered to the floor.

"You must have a thousand questions."

"How long do I have to decide?" I kept snapping the plastic.

"Three or four days. I'd like to do the first operation right away. Today, if you want. The sooner you decide, the better for her. Without the operations she may live only a few weeks or a few months. But she will die. Infection is the usual reason."

I was silent again.

"Do you have any other questions?" he asked.

"None that you can answer."

"I can try."

"Why her and not me?" The piece of plastic broke off in my hand and we both stared at it. "I have to go think."

"Don't take the whole burden on yourself," he said quietly. "Talk it over with your wife. Don't hesitate to call with any questions."

I rushed into the hall and around the corner. The elevator wasn't where I thought it was. I rounded another corner and another—no elevator. "How do you get out of this damned place?" I shouted at a stranger.

At home I walked through an empty house and stopped at the door of the baby's room. My wife had furnished it, planning and arranging it with care. She had carefully arranged the colorful toys and stuffed animals, giggling at the havoc our child would bring to their order.

But the brightness had gone from the colors, and the animals seemed lifeless. The joy and dreams they once represented faded with the afternoon light. I took a bear from the chest and sat with it on the floor.

"My wife can't help. They've got her all doped up. How can I make that decision?" I asked the bear. "Right now, life

is too much for me, and all my parts work. If I let them operate and save her, she'll have an impossible life. Kids will tease her, a boy she likes will run from her; and she'll blame me. And I'll hate every minute of it."

"But if you let her die—can you live with that?" asked the bear.

"She'll be happier in Heaven."

"But can you live with that?"

"How can I live with watching her struggle through minor tasks? She won't be able to walk or even control going to the bathroom. She'll never be able to leave home. How can I support her in retirement? Someday I want to live for myself. What if I don't want to be around her? I've never been comfortable around handicapped people. What if I can't love her?"

"But can you live with yourself if you let her die?" That damn bear was persistent.

"Someday she'll be particularly upset about something that she's not able to do, and tell me I should have let her die. That, I couldn't live with."

"Yes you could."

"No. It'd be easier, on everyone, if I let her go now."

"But can you live with that?"

"I DON'T KNOW!" I screamed, throwing the bear into the hall. Then I cried.

It was well after dark by the time I drove to Ellen's hospital. The sedatives made her speech slow and thick-tongued. She didn't say how she was, or ask about, just about the baby. "No," I replied. "I haven't seen the baby, yet. No, they don't know all the problems, yet. Yes, I'm on my way down there now. Yes, I have film for the camera." I just couldn't tell her that she might never see her daughter.

I didn't want to see the baby. I knew that seeing it would hurt, and that I would probably cry again. I was afraid, but somehow I kept driving.

The car was crowded. "They" were watching me: my parents, my friends, the doctors, the nurses, all the ministers I'd ever had, all the congregations I'd ever been a part of, people I'd never met, and, of course, God. I was supposed to want the baby to live no matter what the cost, emotional or dollar, no matter what the hardship. "It will mean a life of catheter tubes, medicines, wheelchairs, frustration, and inconvenience," I whined.

"You are lucky, it could be much worse," they pitied.

"It isn't fair that it happened, at all. What'd she do to deserve this?"

I knew that "they" mustn't matter, but I persistently asked myself what "they" would think. I felt guilty even considering letting her die, but at that moment—with Ellen in one hospital, the baby in another, a life of indifference behind me, and one of demands ahead—I thought that to be the logical solution.

Children's Hospital is quiet at night. Except for cleaning people and an occasional television, the only sounds are snoring parents sleeping on cots, couches, or in a myriad of contortions on chairs. Nurses talk in hushed voices and their shoes squeak down well-waxed corridors.

I asked for directions to the ward where the baby would be. A nurse asked if I was Michael Harkman, and when I said I wasn't sure anymore, she smiled and said the doctor would like to see me before I went up.

The doctor asked if I had any questions, and I asked the same ones I'd asked the surgeon that morning, hoping for better answers—but I didn't get them

"Why?" I said, finally. "What'd we do wrong?"

"During the fourth to sixth week of pregnancy, there is a malfunction in fetal development resulting in an imcomplete closure of the vertebrae around the spinal cord. The spinal cord and its surrounding sheath, the meninges, protrude out through the opening to form a sac on the baby's back. Some of the nerves turn out into the sac and stop growing, therefore never reaching their destination."

I was sure it had been a perfectly understandable explanation, but considering it was late and the kind of day I'd had, I was sorry I'd asked.

"What causes it?" he asked, himself, then shrugged. "It may be caused by the environment, maybe the mother's diet, or it may be drug related. The fact is we just don't know what causes it. It's just a genetic disorder," he said matter-of-factly.

I said nothing, but there was no table to pick at so I plucked at the stuffing through a hole in the arm of the chair. I couldn't accept them not knowing the cause. And I knew that, once I got them to tell me the truth, the solution would be close behind. At least, it had always worked that way fixing helicopters.

"Sometimes two certain people just can't produce a perfect set of genes," he continued. "It's nobody's fault. You can't take the blame on yourselves."

"Who do I blame?" I muttered, glaring at him. "God? Do I accuse God of crippling little girls?" He gave me a very pained smile.

There wasn't much else to say then, so the nurse said she would show me to the baby. "Does the baby have a name yet? We're tired of calling her Baby Girl Harkman," she smiled.

"I don't know. It's been so hectic and all."

"I understand. Well, when you have one, let us know. It just seems to help them somehow. And she's such a sweet little thing." We walked down the hall and into the ward, a brightly lit place, even in the middle of night.

"Baby Girl Harkman is over there," she said, pointing to one of the small plastic incubators.

The steady beep-beep-beep of the monitor confirmed the baby's rapid, staccato breathing, and a second monitor registered her heartbeat with tic-tic-tic. Tubes and wires were attached to her in a tangled maze. Bandages covered her from her chest to her tiny bottom, dwarfing her tiny features with their bulk.

I stared without moving until the nurse called across the room, "You can open it and touch her if you want."

Reaching through the armhole I touched my daughter for the first time. I stroked a soft, pudgy cheek and she shuddered, causing the beeps and tics momentary confusion. I laid my finger in her tiny hand, and five little fingers closed around it—and my heart. She tucked her fist-full-of-Daddy under her chin, and it seemed I could hear her say, "This is mine and I won't let go."

My stomach heaved with sobs and my vision blurred with tears. "No!" a tiny voice screamed from within. "You can't cry now. She needs to feel your strength and your love. She's more alone than you are." Swallowing hard I blinked back the tears. Those little fingers still clutched me.

The nurse brought a stool and I sat and studied my little girl. "Her name is Jennifer," I murmured to the nurse. "She's got my eyelashes and dimples and her mother's nose and mouth."

I just watched her for awhile and occasionally her nose would twitch or her mouth would pucker, or her eyelids would crack open, ever so slightly, and a hint of dark blue eyes would peek out; then seemingly satisfied—or bored—they would close again.

I reached through the other armhole with a free hand and gently pinched her toes. "She'll never walk. She'll have no feeling in her legs," the doctors had said. *Never walk, no feeling,* the words echoed through my mind. I pinched her toes harder, watching her face for a reaction. There was none. I pinched again, still harder, and yet harder, until I feared I might break them. *Cry, damn it! Cry!* I screamed in silent anguish, but only the monotonous cadence of the monitors replied. Those little fingers maintained their grip.

I patted her bottom for a while, then caressed her cheek. "Your mama will be here as soon as the doctors let her our of the hospital. We love you very much." The little fingers held tight.

I told the sleeping Jennifer about her mom and dad, grandmas and grandpas, aunts and uncles, and cousins—as

many as I could remember. I told her about her great-grandpa who, at eighty-five years of age, was in Bermuda chasing women that weekend. At that, she half smiled.

"You're going to be like him," I realized. "He is tenacious and independent, and you're going to make it because you are going to be like him. You'll need his determination and his perseverance—we all will, but we'll find it. You'll be what you want to be."

The hours passed quickly. I talked incessantly, knowing she understood every word. But at last, reluctantly, I freed my finger from her grip and left the hospital.

Driving down a dark, deserted boulevard, not sure of my destination, I acknowledged an ancient promise. "I know you'll be with us. But can't you exchange my legs for hers? They're a convenience to me now, but to a child they're essential."

He did not answer.

"I don't understand. Why her and not me?" and I cried.

"It isn't fair, you know." I wanted to make sure He knew.