"A NEEDED RESOURCE FOR PARENTS OF CHILDREN WHO HAVE EXPERIENCED TRAUMA."

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Does My Child Have PTSD?

What to Do When Your Child Is Hurting from the Inside Out

JOLENE PHILO

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Chapter One

A Mother's Story

I picked up the telephone. "Camp Crook School, Mrs. Philo speaking."

"Jolene?" asked the woman on the other end of the line. "Dr. Brown wanted me to call with the results of your pregnancy test." She paused. I held my breath and turned away from the ten children busily completing seat work at their desks.

"You're pregnant," she announced.

I stifled a shout of joy, and we chatted for a moment or two. I promised to call back the next day to schedule an appointment once my husband, Hiram, and I could get an afternoon off. I didn't know how we would manage the feat without raising suspicion in our town of ninety-two people—soon to be ninety-three—but somehow, we did it.

A week later, Hiram and I made the ninety-mile trip to Spearfish, South Dakota, together. After the examination, the doctor informed us that our baby was due at the end of May.

My husband smiled and squeezed my hand. I breathed a sigh of relief. "School gets out on May 21. Perfect timing."

We spent the remainder of 1981 and the first five months of 1982 preparing for the birth of our first child. We painted the spare bedroom, bought a crib,

and installed a washer and dryer. We scoured baby name books, took Lamaze classes, and marveled at the increase in my appetites for both food and sleep. We dreamed about who our baby would look like and how our lives would change when our little one arrived.

The school year ended without a hitch. Around ten o'clock the next evening, Hiram eased me onto the living room floor to practice Lamaze breathing. He coached me through the early, deep breathing before we moved on to short, panting breaths that accompanied the bearing-down period. That's when my water broke.

Hiram called the hospital, I changed clothes, and we got in the car. "How far apart are the contractions?" he asked a few miles later.

"No contractions," I reported. "Just cramps." I thought for a few seconds. "They're maybe a couple minutes apart."

He floored the accelerator, and a little more than an hour later, he steered the car up to the emergency room entrance. By then, the cramps—still no contractions—were continual, and I almost hugged the nurse who opened the car door and led me inside. An hour later, at 12:35 on the morning of May 23, Allen Craig Philo entered the world.

Hiram placed our beautiful baby boy on my stomach, and I looked into his wide, dark eyes, traced his button nose with my finger, and wept to see his long upper lip—a tiny reproduction of my father's.

"A bit on the small side," the doctor said, "but he was a week early."

"He's perfect," I whispered to Hiram, who helped me put Allen to my breast. But after a few feeble attempts, Allen turned his head away.

"That's perfectly normal this early," the nurse said. "Can I take him for a moment? He's got a lot of mucus." She held a baby syringe in her hand. "Let me suction it away."

When Allen left my arms, a dull pain in my lower abdomen commanded my attention. "Your placenta tore a little," the doctor explained as he palpated my uterus. "I know this hurts," he went on, "but I have to make sure the entire placenta has been delivered."

The next few minutes were a blur of nauseating pain and light-headedness before the doctor got things under control. By then, Allen was in the nursery. "You lost some blood," the doctor told me while the nurse rolled my gurney to a regular hospital room. "You shouldn't get out of bed without help. When you want to see your baby, ask the nurse to bring him to you."

A few hours later, Hiram and I asked to see Allen. The nurse brought him in, and I once again tried to breast-feed him. Again, he showed no interest. "He certainly has a lot of mucus," the nurse commented. "I'll take him back to the nursery and suction him."

She didn't sound concerned, but a sense of unease stirred inside me. The unease grew each time Hiram visited the nursery and returned with a new update.

"All the nurses are gathered around his bassinet."

"He's breathing hard."

"They've elevated the top of his bassinet."

The unease twisted the pit of my stomach until morning, when the doctor came and sat on a chair near the foot of my bed. First-time mom though I was, I knew it wasn't a good sign to have the doctor sit down in my hospital room.

He gazed at me, then at Hiram, and drew a deep breath. "Your son's having trouble breathing. We'd like to transfer him to Rapid City to find out why."

My unease exploded in a volley of anxious thoughts. *This can't be happening. Not to my baby. Not to our family.*

"An ambulance is on the way."

I nodded mutely and blinked back tears, knowing that if I tried to speak, I would cry. And if I cried, I didn't know if the tears would ever stop. They were taking my baby away. The baby my husband and I had loved from the moment we heard he was on the way. The baby we wanted to hold and feed and love. The baby who, at least for now, we were powerless to protect from whatever lay ahead.

Shortly before noon, a nurse wheeled me from my room to the nurses' station. "A pediatrician in Rapid City is on the phone. He wants to talk to you and your husband."

Hiram was at a friend's house taking a shower, so the nurse handed the phone to me, and I had to face my son's diagnosis alone.

"Hello," I said, determined not to cry in front of the nurses eavesdropping on our conversation.

A doctor I'd never heard of introduced himself and said, "The top and bottom of your baby's esophagus aren't connected. The anomaly can be corrected with surgery—the sooner, the better. The closest hospitals equipped to perform the surgery are in Omaha and Denver. Where do you want him sent?"

Never in my life had I felt so alone. So weak. So young—only twenty-five—and being asked to make a life-and-death decision for my baby. I wanted the support of my family. My parents lived in Iowa, not far from the Nebraska border.

"Omaha," I whispered as tears fell from my eyes onto my thin cotton hospital gown. "Omaha."

Allen was immediately life-flighted to the University of Nebraska hospital in Omaha. The surgeon called shortly before midnight to say the operation had been a success. Our baby was in recovery.

Once again, tears flowed. I called Hiram, who was staying with friends, and he could barely understand my words through the sobs. Once I calmed down, he prayed for our baby before we said our good-byes and hung up. Only then, almost twenty-four hours after our baby's birth, did I take a sleeping pill and close my eyes. But even so, sleep refused to come.

Questions whirled through my mind: *Why is God allowing our child to suffer? Will our baby live? Who's taking care of him? Is he frightened? Is he in pain? Does he think we've abandoned him? Will he remember the surgery? How will this affect him?*

Two days later, after fifteen hours on the road interrupted by an overnight stay with my parents, Hiram and I saw our baby again. Nothing could have prepared us for this first glimpse of our son after surgery. Allen lay in a neonatal intensive care unit (NICU) incubator. Patches and monitor wires dotted his chest. Drainage and feeding tubes pierced his soft baby skin. A splint

made from a tongue depressor and tape immobilized his arm and held an IV needle in place. A two-inch vertical incision slashed his abdomen. A much longer cut ran across his back, from armpit to spine.

The medical paraphernalia and incisions shocked us, but our shock paled in comparison to the expression on Allen's tiny face. Wrinkles furrowed his forehead. His wide mouth was a thin, grim line.

Almost in unison, my husband and I said, "He's in pain. Can you give him something?"

"Babies don't feel pain," the kind nurse assured us. "In a month or two, he won't remember a thing." She patted my shoulder. "He just needs to be held by his parents." She maneuvered her way through the tubes and wires, lifted Allen out of his incubator, and placed him in my arms. At that moment, he winced, opened his eyes, and stared intently at my face.

Returning his gaze, I wanted to believe our baby didn't feel pain. I wanted to believe my embrace protected him from pain. I wanted to believe that my touch was more powerful than his hurt, big enough to suck the pain away from him. But deep down, I suspected he was hurting. His wrinkled forehead, his thinly stretched mouth, and his dark, strained eyes fed my suspicion.

Our baby initially gained NICU rock-star status for the speed of his recovery—he was released after only three and a half weeks in the hospital—but that status didn't last. At two months of age, I was nursing him one night when he stopped breathing.

"Hiram!" I screamed, and my husband came running. He administered some sort of baby CPR, and I rushed to the phone to call our local emergency medical technician. Two days later, Allen and I were in Omaha again. He came out of surgery sporting a feeding tube along with a string threaded through his stomach and esophagus and out his nose.

The surgeon explained what had happened. "The scar where the two ends of the esophagus were connected had swelled shut. So milk pooled above the stricture and aspirated in to Allen's lungs. Once he heals from this surgery, a doctor in Rapid City will tie tapered rubber tubes to the end of the string and

pull them down his throat to stretch out that scar. He'll need to have dilations done several times a week for quite a while."

"Will he be sedated for the procedures?" I asked.

"Oh, no," the surgeon shook his head. "It's much safer to have him awake. Besides, he's a baby. He won't remember any of this when he grows up."

"He won't remember," I told myself a few months later when we took Allen to his first dilation. Hiram lay Allen, now four months old, on a cold metal gurney covered with a thin white sheet. Our baby lay there shivering in his diaper and hungry; he'd had nothing to eat for eight hours per the doctor's orders. Allen locked his eyes on mine and wailed. His tiny arms reached for me, but all I could do was watch as the doctor threaded the tube down his esophagus. Allen gagged and screamed and cried.

My arms ached to hold him until the doctor finally placed our hysterical, exhausted baby in my arms. Hiram and I comforted him until he settled down.

He won't remember.

I whispered the words over and over during the next three months of dilations and other hospital procedures.

He won't remember.

Little did I know that I would repeat that sentence many times over the next four years as Allen endured five more surgeries, countless invasive medical procedures, tests, and feeding issues as well as frequent bacterial and viral infections that landed him in the hospital or at the pediatrician's office far too often.

By the time our bright-eyed boy was six months old, he screamed bloody murder when anyone in a white coat entered the room. He dug his razor-sharp fingernails into my shoulder at the sight of a stethoscope and clamped his mouth shut when approached by anyone holding tongue depressors, pen lights, or swabs. Still, when we mentioned our son's behavior to doctors, nurses, and other medical professionals, the answer was the same.

"Don't worry," they promised, one after another. "He won't remember."

As Allen gradually overcame his health challenges, the memories of his early

trauma seemed to fade away, as his NICU nurse and others had promised. He grew into a precocious, imaginative child who loved Sunday school, preschool, and day care. At age six, he was still small for his age but raring to get on with life. At the supper table the day before he began kindergarten, he confidently announced, "They're all gonna love me." He was right. Friends and teachers alike all loved him.

Every now and then, though, his reactions to everyday events were way over the top. One day, he felt cornered at the babysitter's and bit a child hard enough to break the skin. After a minor bike accident complete with scraped arms, knees, and a little blood, he shook and screamed and wailed for over an hour. His second-grade teacher called one day to say he bit a girl on the playground. Later, he explained they'd been playing "prisoner." Two girls stood on each side of him and held his hands. Feeling trapped, he asked them to let go. When they refused, he panicked. "I had to get away," he explained tearfully. "So I had to bite her."

Still, these incidents were months and years apart. For the most part, Allen was a delightful kid: funny, compassionate, and creative. We assumed his responses were just normal kid stuff. That is, until he hit adolescence and his behavior changed in more significant ways.

When Allen entered middle school and as he progressed through high school, his decision making became more and more impulsive. At first, we chalked up the changes to adolescence. It was not hard to do, because Allen was highly successful in many ways. He was on the academic team, became the jazz band drummer, had the lead in several school plays, and remained active in the church youth group. But in other ways, he became increasingly impulsive and self-destructive. Whenever we worried aloud to his teachers, counselors, or youth pastor, they said the same thing. "He's being a normal teenage boy. Give him time. He'll grow out of it."

But he didn't grow out of it. After the end of his junior year of high school, Allen ran away for the first time. From then on, people didn't know what to say. Neither did we. Even Allen couldn't explain his reasons when he returned

home. When we asked him why he ran, he shrugged and said, "I'm eighteen. I can go where I want." That incident marked the beginning of a pattern of running away that continued sporadically during the next eight years.

Allen wants to keep the details of those years private. Suffice it to say that as time went on, my husband and I noted similarities in our son's behavior to the behavior of teens who had experienced physical or sexual abuse. We were quite certain he hadn't been the victim of either, and Allen reassured us that he had never been abused.

"But," I wondered aloud to my husband, "to a baby, all those needle sticks and surgeries and dilations would have felt like abuse." And gradually, our conviction grew that our young adult son's erratic behavior was related to the medical treatment he received as an infant and as a very young child.

By then, Allen had entered a monastic community. It was part of a Christian denomination, quite different from the church in which he'd been raised. At first, the highly structured environment seemed to be exactly what he needed. His behavior stabilized. He became more compassionate and caring and more appreciative of his family, more like the Allen we'd known when he was at his best.

For a few years, we believed God had heard our diligent prayers and restored our son's mental and emotional health. But then his urge to run resurfaced, and the pattern of running resumed. Allen unsuccessfully fought the urge for a year. Then, on the Monday after Thanksgiving in 2008, he called. "I can't do anything until this is fixed," he said. "Will you help me?"

His request unleashed a whirlwind of activity. Within a day, we located a cutting-edge outpatient clinic in Morgantown, West Virginia, only three hours from where Allen lived. In the next few days, a therapist completed an assessment and diagnosed Allen with PTSD. Because of the unusual logistics surrounding our situation, the clinic rearranged their schedule, and Allen began a weeklong treatment almost immediately.

Every morning, I drove our son to the clinic, took him out to lunch, and picked him up in the afternoon. When I picked him up on Thursday, after his fourth day of treatment, he turned to me.

"Mom, for the first time in my life, I'm not looking over my shoulder waiting for them to take me to surgery again."

The next afternoon, I joined him and the therapists for a final treatment session. At the end of the session, Allen smiled and said, "I don't need the monastery anymore. Let's go home."

From that day on, Allen never looked back. He was still emotionally fragile for the first few months after treatment, but he followed the self-therapy prescribed by his clinicians and learned to manage the vestiges of his PTSD. Today, he holds a good job and is a valued employee. He's continuing his education. He's married. He and his wife are parents.

Twenty hours after his birth, surgery gave Allen the opportunity to lead a physically healthy life. Twenty-six years later, treatment for PTSD restored his mental health, too.

Allen still has PTSD.

He always will.

But when symptoms surface, he knows how to cope and when to get help. Today, our son is whole in a way he never was before treatment. For that undeserved and life-restoring gift, our family is truly grateful.