

## While I Was Sleeping

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### While I Was Sleeping

*Why my husband finally refused to end my life during my two-month coma.*

by **Lindsey O'Connor** | posted 01/30/2004

My blood ran cold as I watched the video of Terri Schiavo. I shivered at the news that this brain-injured woman was comatose or in a persistent vegetative state while the video seemed to show otherwise. The chill was more than just my journalistic intrigue. People everywhere were debating the right to "die with dignity" and wondering what it would be like to be in Schiavo's place, but I didn't exactly have to imagine.

One year before the day Schiavo's feeding tube was pulled, I awoke briefly from a 47-day coma, only to go back under for several more weeks. Severe childbirth complications resulted in two emergency surgeries and the transfusion of 20 units of blood and blood products—about twice the blood volume of my body. I remained comatose and on life support in the ICU for two months.

My family expected my death repeatedly during my coma. I developed acute respiratory distress syndrome, which is often fatal, and it critically impaired my lungs. I had pneumonia, a toxic blood infection, blood clots, kidney failure, and life threateningly low blood pressure and oxygenation. My family was told I had anoxia—brain damage from oxygen deprivation. I lay hooked up to a ventilator and a feeding tube, receiving maximum doses of drugs to keep me alive. Heroic measures and life-and-death decisions were daily realities for my family.

My husband slept and ate little. Tim juggled his job with being constantly available to me, to doctors' consultations, and to our family. He described our surreal journey in e-mail updates that were forwarded by many people around the world. He also undertook "Caroline therapy": laying our mother-deprived newborn on my chest while I slept, so she would sleep too.

Tim learned to be an effective advocate for a critically ill patient by researching my

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diagnosis thoroughly and making the doctors make him understand. And on days when his faith was in shock and he was too numb to pray, the prayers of others and a Holy Spirit-inspired mind propelled him beyond his capacity. Yet the possibility of a brain-damaged wife, or the thought that he was about to be a single father of five, including our newborn baby, always hovered.

Our children took on responsibilities uncommon for their ages. Three birthdays and our 15-year-old Claire's high-school homecoming came and went while I slept. The children discovered that profound sadness can coexist with moments of normalcy and surprising pockets of happiness. But in the dark, a brave front gave way to deep fears as 10-year-old Allison finally admitted to her father, "I'm so afraid of not having a mommy."

We experienced the body of Christ in action as our local church and others completely ran our home and came in the middle of the night when I'd take a dive. My fellow members of the Advanced Writers and Speakers Association held a day of prayer and fasting, unaware that their prayers ascended on my worst day.

Three of my close friends took weeklong turns in our home caring for the baby and children. Our eldest daughter, Jacquelyn, decided to leave her freshman year in college to become the baby's primary caregiver.

She also experienced a faith crisis. One night, in her car in the hospital parking lot, she pictured her life two ways—with God and without. Was her faith in God just her parents' teaching to invoke good moral choices, or was it real, hers, and worth anything at all? She pondered that age-old question: How could God let something so terrible happen? She decided that as difficult as this was to get through with God, going it alone terrified her. Her faith became her own that night.

Our story is like a movie shown on two screens: my loved ones' experience on one, my experience on another. Their story happened to me but I missed it, missed two months of my life and the greatest tragedy my family's been through. My story shows me giving a happy birth, then having trouble, then going to sleep before the surgeries. I awaken from a drug-induced coma, thinking it was the next morning, and hear my husband say, "You've been here for 47 days." Later that day, I slip back into the coma for several more weeks, then awake to the invasion of the body snatchers, unable to breathe or move on my own, my heart severed from my newborn.

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When Schiavo's story broke, I waded through the murky ground of what many felt but few voiced. Many prolife Christians agreed that what was being done to Schiavo was terribly wrong, but still deep questions swirled: Who would want to be in her position? Is there a morally acceptable line for relinquishing life support? Could sanctity and dignity of life walk hand in hand?

### **The In-Between**

When Dr. James Dobson was a guest on Sean Hannity's national talk-radio show discussing Schiavo, he recounted my story. Add me to the list of poster adults for not pulling the plug. Yet from my new perspective, the sanctity of life versus the dignity of life still seems complex.

Gradually I've begun to remember bits of my comatose state: The swimming-through-mud feeling of trying to surface to awareness. The frightening dreams. The intense and very real spiritual warfare, a battle as unto death. The fog of being strapped in a chair with daytime television on to "stimulate" me, vaguely registering that people were in my room, but unable to comprehend that, let alone communicate. It was like watching someone through opaque glass underwater, visible but obscure and unreachable. And the weeks of living in the shadowland between my coma and full awareness, with times of frustration beyond belief.

I remember Tim holding one of my hands, a neurologist the other, and telling me to squeeze their hands. Unable to do so or to speak, I felt my brain screaming, "Why can't I do this? Maybe I'm dying." Later, my inability to use the call button left me banging a spoon on the bedside table for an hour and a half. No one came. They thought it was the repetitive motor response of a brain-damaged woman.

These memories seeded a need for clarity in answers and—just as important—a passion to ask the right questions in life-and-death issues. William Temple, who was Archbishop of Canterbury in the 1940s, wrote that the "church must announce Christian principles and point out where the existing social order is in conflict with them."

What then are the Christian principles at the heart of this argument? Two come to mind: "Thou shalt not murder" is a protective boundary whose removal would incite societal moral free-fall. And life is sacred and reflects God's image, with innate value regardless of its quality or productivity.

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But if God values us, whole or brain-damaged, and there's value in being a loving caregiver to an incapacitated person, what about the seeming purposelessness of that patient's existence? A second biblically derived principle sheds light here: if our chief end is to glorify God, then we can find purpose and meaning in a life that society deems a mere existence. God can be glorified even through our suffering.

But how do we apply this truth in the modern hospital, especially when science can seem to be extending suffering while extending life? When is it morally right for a Christian to remove or refuse medical treatment? How do we determine when or if we can remove life support from our loved ones? When is it okay to issue a Do Not Resuscitate (DNR) order? Can we request that we not be kept alive artificially without violating the Sixth Commandment?

My family lived these agonizing questions. Two weeks after the initial dance on the edge came a death vigil. As I lay dying, the respirator whirred, pumping air into my lifeless-looking body and then sucking it out. My chest rose and fell to the machine's rhythm, yet my lungs failed to properly oxygenate my blood. Paralytic drugs immobilized me. Vasopressor drugs fought to keep my blood pressure up. My limbs were blue and as cold as refrigerated meat. It did not look like I had any upper-level brain function. I was expected to die before morning.

I later learned that 40 or more friends and relatives stood vigil in the waiting room. My friend Sue brought our son in to join his siblings for the grim task of saying goodbye. She said to my pastor, Brent, "So, this is it?" He nodded.

Sharon marveled at our Christian paradox through grief: "She may see the face of Jesus today."

Susan, one of my best friends, looked at my gray, barely recognizable body and said, "Death is ugly, isn't it?"

Kathy, my other best friend, said goodbye and left distraught with my baby.

My dad touched my feet and said, "I taught these feet how to walk." He agreed with Tim as he made end-of-life decisions.

Tim said, "Even though we have hope, there is still pain. The difference with a Christian worldview is that the outcome is established. Even if we leave things

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unsaid, we'll have an opportunity to talk again."

Through the long night, Tim hammered out the heart-rending ethics and options. He cited the radical drugs I was receiving, which essentially cut off blood flow to my extremities so the body could concentrate circulation and pressure to the vital organs.

"Does this constitute heroic measures?" he asked.

"Yes," answered the doctor.

"So would it be ethically acceptable and appropriate to limit this medicine?"

"It would be acceptable," she said.

Tim anguished about the ghoulish side effects and the possible dire outcome. Torn by his pain in my suffering, he issued a DNR order under certain circumstances. Then he rescinded it. Then he issued it again. Then, again, he rescinded it. Removing the respirator and feeding tube was never an option. What he questioned continuing was the heroic measure of a drug so strong that doctors privately call it "leave 'em dead."

"She's suffering and she's not there," Tim said.

"But we don't know that," Susan said.

"Tim, there's a high likelihood she's going to die tonight, so keep your fingerprints off of it," counseled Brent.

### **Mama Goes North**

Thankfully, God's leading through the counsel of community left every lifesaving measure in place, including the "leave 'em dead" drug. Tim's was a model decision-making process: He researched my situation; he consulted with doctors; he considered the futility or burden over benefit of treatment; he remembered my wishes; he questioned his own motives. Most important, he prayed constantly and sought godly counsel.

I don't remember waking up the second time. Weeks after I woke up I was still on a vent, unable to speak. I went into the hospital on August 30, 2002, and came home just before Christmas, still unable to walk or breathe on my own. But in February

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2003, while still incapable of driving and doing most things, I did rewrites on a book I had turned in the week before the birth (ironically titled [If Mama Goes South, We're All Going with Her](#)). Discovering I could still think and write was another miracle, since in the hospital I couldn't read (coma can affect vision) or concentrate. I didn't know if I'd ever be able to resume my work.

I sometimes hear comments that Lazarus could have heard. One of my Christian doctors said, "There's no medical reason you are alive. You are a miracle at the hand of God." Tim often reminds me, "Life is fragile, so leave nothing unsaid." In spite of daily physical effects of the trauma, I've learned that radical obedience (in my case, having a baby at 40) is worth any cost, that prayer is inconceivably important, that miracles still happen, and that I have a faith worth dying for.

Would I want to live without cognitive awareness? Well, no. Wanting to avoid suffering is human. Even Christ asked if his suffering could be avoided. I believe there are times when it is acceptable and ethical to remove medical treatment from our loved ones. But in all cases, we should weigh our desire to be released from suffering against a greater desire to glorify God. If I had predetermined no life support (or only short-duration support), as some have in advance directives, I'd be dead. I'd also perhaps have missed the greatest opportunity of my life to bring God glory, because he can use us for his purposes in any bodily state—even while we're sleeping.

Lindsey O'Connor is an author, speaker, and former news anchor. Her most recent book is *If Mama Goes South, We're All Going with Her* (Revell, 2003).

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