

A CONSUMER VIEWPOINT

Windows in Space and Time: A Personal Perspective on Birth and Death

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My daughter was born through a window in my uterus, and she died through the windshield of her car. I don't know what to make of this beginning that became an ending. There are easy parallels: cesarean birth is a rapid transition in which you are suddenly taken from one reality to another. Certainly Peyton's death was like that. But she worked to get born, just as I worked to birth her, for 26 hours before the cesarean was performed. In the end we were both rescued from our mutual travail—I by the epidural and the c-section, she by the doctor's hands pulling her through. Am I then to assume that it was God's hands pulling her through that windshield, tossing and tumbling her body 50 feet down the highway, breaking most of her bones and smashing her internal organs beyond repair?

I don't know how many parallels we can make between birth and death, and I am not going to make any facile ones here. It has been three years since I was invited to write this article, and I have been unable to face it until this moment—1 a.m.—as I rise from my unrestful rest to put fingers to computer keys. Do you want me to tell you there is some sense in this? I can't find any. Do you want me to say that almost three years after her death, I have integrated the experience in the same way I finally accepted and integrated the psychological pain of my cesarean? I

am sorry to disappoint. I am not an enlightened sage who can say that death and life are all one, that it was in the beginning, so it now and ever shall be, that death is the final stage of growth, that ultimately, everything is OK. Somewhere deep in the core of my being I know that this is the ultimate truth—*everything is OK just as it is*—and yet my mother's heart cries out for the presence of my daughter, to touch and hold her in the flesh, to revel in her as I did on that day, two weeks after her birth, when I looked down at her in her bassinet just as she opened her eyes, and was rewarded with her first smile, so brilliant and radiant, illuminating the room with utter delight.

“20 Years and 361 Days Later...”

Twenty years and 361 days later, after diapers and walking, blissful breastfeeding, chauffeuring her to gymnastics and dance lessons, and sharing her joys and sorrows late at night while she poured out her heart to me from behind the shower curtain, I stood by her body in the hospital room, surrounded it with my arms, and poured out my own heart to her corpse. She had been dead for 22 hours, but my mother's heart could not believe that I could not call her back until I tried. I talked, I screamed, I sobbed, I begged her to live and breathe again. I told her I could not live without her. I touched every part of her body and begged the skin to twitch, the head to turn, the legs to move—anything to show me that this wasn't reality, that this inert but gorgeous body lying in front of me was not really lifeless, that those stunning dancer's legs were never going to plié again, that those graceful hands would never again arc, that those lips would not move to kiss mine or to smile, that her voice would never again say, “Mommy.”

Bright red blood oozed from wounds all over her, so even the freshness of death was there. I pulled the

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electrodes off one by one the way I did after the cesarean, when I couldn't wait to get the symbols of medicalization off me. But my medicalization via her cesarean birth was unnecessary and inappropriate, whereas hers was the exact opposite. The system is supposed to respond with all its resources, and it did for Peyton. Truckers on the highway saw the car flip four times, saw her body flying through the air and skidding down the road, saw her friend Kara, who had been driving, unconscious and trapped in the car. Technology was used appropriately—the truckers called 911 immediately, rushed to see if they could render aid, got Kara out, and were trying to resuscitate Peyton when the helicopter arrived a mere 15 minutes later. She stopped breathing; the medics bagged her and rushed her to the hospital, 10 minutes away, and in the emergency room the doctors and nurses poured liters of blood into her veins, tried the shock treatment over and over, and finally cut open her chest. I was told that she died as a doctor held her heart in his hands, massaging it and begging her to live.

For 20 years of researching and writing about American childbirth, I have critiqued the medical system for its lack of humanism and its failure to practice in evidence-based ways. I am so grateful that this time there was nothing to criticize, no failures of care to blame. Peyton's treatment in the emergency room was all I could have asked for, as was the hospital's treatment of me when I arrived there 22 hours later, dazed and trembling but prepared to do battle for the right to spend time with my daughter. I knew that parents whose babies die at birth suffer more if they are not allowed to hold their babies and part with them on their own time. I knew that it was my right to do the same, and I would have fought everyone up to the head administrator for that right. When the nurse who received me took me to her office instead of taking me straight to Peyton, I marshaled my resources and prepared to "fight the system." But her questions were straightforward and genuine: "Why do you want to see your daughter's body? Do you realize what a shock it will be? Do you understand that she went through a windshield and was thrown 50 feet down the road, that she may be unrecognizable to you? Are you prepared for that? Are you sure you wouldn't rather remember her as she was?"

Here was a nurse who was concerned not at all about hospital procedures, but only about understanding and helping me. Her name was Rebecca. The adrenalin drained out of me. I exited fighting mode and went deep into myself to answer, as one must do to give birth. I told her that I was a student of childbirth, that I understood the importance of

facing physical reality, that my daughter was my daughter even if she was in pieces. I told her how devastated I had been years ago when I had suffered a miscarriage, had a D & C, and was not allowed to see the fetus. I told her I would rather deal with reality than my imagination. I told her that I had to, absolutely had to, see my daughter's body before it was moved or embalmed because I had to do my best to understand exactly what had happened, what was. I told her I understood that the hospital might not have a room where I could do this, and that I was prepared to do it in the morgue surrounded by 50 other bodies if that was how it had to be.

Rebecca smiled a little smile, told me that wouldn't be necessary, and escorted me to a private room where she asked me to wait. By then I trusted her. I had co-authored a book about the difference between technocratic, humanistic, and holistic practitioners (*From Doctor to Healer: The Transformative Journey*), and in the moment, that helped. I recognized Rebecca as a humanistic practitioner, one who cared about relationships—and so I simply did as she asked. A few minutes later she appeared at the door of the room wheeling a hospital cart. Together she and I removed the heavy metal frame with its covering, and there was a body underneath covered in blue plastic. Now, finally, was the moment when I could see my daughter. I asked Rebecca to leave, but she was concerned that I might faint when I pulled the covering down. She dealt with her concern, not by dominating, as so often happens in childbirth, but through judicious compromise. She pulled a chair up close to where I was standing, and then she left, and I pulled the cover down, almost frantic to be with my child.

Getting to Know My Dead Child

You know how a mother gets to know a newborn already wrapped in a blanket? She checks her out slowly, face and fingers, then uncovers her little by little, all the way to the toes. That's also the way you get to know your dead child's body when it is all covered up. I pulled the blue down an inch, and there was Peyton's hair, full of glass and matted with blood, but unmistakably Peyton's hair. Then there was her forehead, unmarred, and her gorgeous eyebrows, whose delicacy and perfection of form had been the envy of all her friends. I ran my fingers over them, kissing them again and again. That was bliss.

Then it got hard. Her nose was her nose, but bruised and bloody. Her eyes were sewn shut because we had donated her corneas. (Both transplants were successful, so two people are walking around seeing

the world through Peyton's eyes.) Her cheeks were mutilated. Her lips were swollen, and blood was still coming from her mouth. Is a newborn less beautiful because her face is swollen and she is covered with blood and vernix? Or is she more, because that is the reality of her condition?

I pulled the plastic down further, and there was Peyton's neck, thin and elegant as always, there were her breasts, swelling with beauty as they always had, there was the huge gash cut under her heart as they tried to save her, crudely but most kindly sewn up. Her gorgeous torso. Her pubis, intact and perfect. I brushed my fingers across the dark curly hair, sobbing for the grandchildren that would never be born from her womb. Her arms and hands with their long tapering fingers, still so beautiful but full of cuts, scrapes, bruises. When she unfurled those arms in dance, her presence filled the stage. Her legs, her dancer's legs, each broken in three places, were twisted and unnatural. I almost passed out when I saw her legs. You can't imagine the grace they had in life or the unnaturalness they showed in death.

It sounds so awful, and yet I have to tell you that my experience as I pulled down the sheet, even as it rocked between recognition and horror, was overall one of ineffable beauty. I have never seen anything in my life as beautiful as my daughter's corpse. Spirit and glory hung in the room, light filled her up, her body was a sculpture of perfection. If I am alive today, in spite of all the pain, it is because I spent five hours with her in a rapture of love, in a ritual of caring. Yes I screamed and begged for 45 minutes, pressing my heart to hers, pleading, praying. Yes I sobbed with the anguish of her mutilated face and her shattered legs. Yes I would have given my life and everything I have ever accomplished for her to open her eyes and move her body and say my name.

And it could have been worse. I could have been in a morgue. I could have been given only a few minutes to see and identify her. I could have been yanked away by an uncaring system that gave me no space or time. Many parents have experienced such. Yet I did not have to suffer those additional agonies. Rebecca gave me all the time I needed with Peyton's body, and let me do everything I could possibly have wanted to do. Enough time to explore inch by inch, to scream and touch and love, and finally to understand that I could not call her spirit back, that the only thing I could do was what I was doing—be present to her body.

Parents who have genetic testing and get a "positive diagnosis" experience it as horribly negative, and hope against hope that there was some mistake. And so we had hoped with the diagnosis of our daughter's death. There with her corpse, I called

her dad and her brother Jason, and I told them our hopes had failed, it is really her, there is no mistake. "Do you want to talk to her?" They did. I held the phone to her ear until they had said whatever they needed to. I shared the experience with them as best I could. At first we were all going to come together to the hospital in Roanoke, Virginia, where her body lay, just as a father and a brother often come to a birth. We got the news at 12:30 a.m.; by 3:00 a.m. I was on the phone with the airlines. In the end Peyton's dad stayed home to support our son, and I went to honor our daughter and to escort her body home.

My Doula—"Mothering the Mother"

It was a crazy thing to do, getting on the airplane alone. I thought I could handle it. Just before takeoff, I was still lucid enough to try one more time to reach my partner, Richard, in a last-ditch effort to give him the terrible news in time for him to be able to meet me at the hospital. I had been calling all night, but he is a midwife and was not on call so he had turned his phones off to get some sleep. I left a desperate message. Then, as the plane lifted into the air, I leaned my head back and closed my eyes thinking that perhaps I could rest. That was when the universe imploded into a black hole filled with specks of golden light. I was falling, choking, imploding into that black and gold no-space. I gasped for air—I couldn't breathe.

Almost instantly, the doula showed up. The woman in the seat in front of me moved back and held my hand. Her name was Kim. She asked me to talk about my daughter, the best thing anyone could have done at the time. A beautiful red-haired stewardess brought me water and oxygen and insisted I drink and breathe—again the best thing. During Jason's home birth, I had guzzled water and the midwives had given me oxygen in between pushing contractions—such an appropriate and empowering use of technology. This time it was as important and worked as well to keep me conscious and give me the strength to go on. Air and water—the elements of life.

Just as doula nurture you through the journey of birth, Kim and this red-haired stewardess nurtured me through my journey toward death. They never left me. In the airport in Atlanta, I had to change planes but couldn't see more than two feet around me for the grayness everywhere. They walked on either side of me, holding my arms, to a room where Delta sheltered me. They brought me more water and food, and made me eat it, though I could barely swallow through the lump in my throat. I was given a phone and told I could make all the calls I wanted—so many

people still didn't know. Kim had a plane to catch but didn't want to leave me. I made her go. The red-haired stewardess told her not to worry because she would stay with me, and she did. She changed her plans and flew with me from Atlanta all the way to Roanoke, never letting go of my hand. Did I doubt the existence of angels?

At the airport in Roanoke she handed me off to a friend who had driven four hours from Washington, DC, just to pick me up and escort me to the hospital so that I would not be alone. Sheer love from all of them, 100 percent support. May every doula do as well. You don't need to know a woman to support her in birth or in death. I was not alone.

In the hospital, after the phone call to Peyton's dad and brother, I found myself wiping up blood and trying to smooth her matted hair. I was desperate to get her clean—the only thing I could do to make her form more recognizable, more like she had been. That is when Rebecca came in and asked me, "Would you like to bathe her?" Would a parent like to be the one who first bathes his or her newborn child? "Oh, may I?" I exclaimed. She smiled that little smile, and said, "Yes, indeed." Richard appeared (he had left Philadelphia as soon as he got the message), and he and I walked to the door of Peyton's room. I looked at him questioningly. He held out his hands and said, "I am at your service." And it hit me. "He is a nurse-midwife!" I had always focused on the "midwife," but now the "nurse" appeared to me as a gift. Nurses know death and dead bodies. They have paid their dues in bodily functions, in vomit and blood. He would not shrink from this—indeed, he would know how to handle it and what to do. Nurses went up 100 notches in my esteem.

Bathing My Child's Body

And he did know. Before he arrived, I had been uselessly trying to wipe the blood away with wet paper towels. Now Rebecca brought bowls and wash cloths and soap. I was grateful but bewildered. How do you wash a dead body that can't move? The blood and the thousand pieces of glass that covered her had to go, but how? Nursing sleight of hand. Richard and Rebecca lifted her, turned her, made some moves, and almost by magic the bloody, glass-filled sheet under her vanished, as did most of the glass on her body. Bathing her was suddenly possible. They held and moved her as I moved the cloths, in an act that seemed altogether known and familiar—hadn't I bathed this body, when it was much smaller, hundreds of times? Our movements coordinated. Time stopped.

The dance went on, until she was shining and clean, all traces of blood and glass removed, her hair

washed and combed as well as I could achieve it. I cut some locks to take with me, something of her physical being to hold on to. Her face was still mutilated and her legs mangled, but we dressed her in a clean gown and she looked as if she had just showered. I felt a sense of relief and joy. The ritual was complete.

And then Rebecca said, very kindly, "Well, someone from the ER needs this room—do you think you might be ready to let her be moved in a little while?" And I said, "Please could I have ten more minutes?" And she smiled that little smile, and said, "Yes, of course."

In that ten minutes I blessed every part of Peyton's body, and I kissed her all over a thousand times, even burying my face in her tummy, nuzzling and kissing it as I had done over and over during her childhood. It had always made her laugh, even when she was a teenager, and now it made me laugh, remembering that warm intimacy that only a mother and daughter can enjoy.

Usually, when birth is over, you drive home with a baby in the car seat or your arms. Death needs an escort too, and Peyton's godmother Sharon and I planned to be on the plane that would take Peyton's body home. She had flown in from New York. The next day Sharon, Richard, and I visited the site of the accident to try to figure out how this could possibly have happened. Ruts in the grass and four piles of shattered glass greeted us, showing how the car had swerved and the four times it had flipped. Among the tall weeds, I found the shards of a Japanese vase I had given my daughter at Christmas.

Birth plans are generally made in clarity of thinking and well in advance; death plans have to happen in shock and immediately. Peyton died on September 12 on her way home from New York to Austin, Texas, to celebrate her 21st birthday with her family and friends. So it was utterly clear that we would not be having a funeral but, rather, a birthday party and that it had to happen on the actual day of her birth, September 16. To honor our daughter, her dad and I rose to the challenge, with less than four days to pull it off. Even if we had had years to plan, the obituary that Peyton's father Robert Floyd wrote could not have been more beautiful, nor could the memorial service/birthday party have been a more fitting celebration of Peyton's life. As in birth, so in death—ritual can carry you through.

Living with Loss

I have been happy all my life, living out of a deep wellspring of joy bubbling up within me. When Peyton died, I lost that deep bubbling happiness—it comes back now only in fleeting moments all the

more precious for their scarcity. I have a wonderful son, many friends, and a fulfilling career. But I have lost the very most precious thing in my life, and no platitudes about how I will see her again in heaven, or we will be united past this life, or she is always with me in spirit (which I know to be true) can alleviate for more than a little while the exquisite agony I always feel about her death. I thought I knew the meaning of suffering before she died—I had already experienced a good deal of pain and loss in my life—but I had absolutely no clue what real suffering was.

Shall I try to describe it? How do you describe the pain of labor? Bone-crunching, soul-grinding waves of agony that ripple through your body with the contractions, making you feel you will explode? That's how I experienced the last eight hours or so of my home birth labor—it felt like someone was sticking a knife in my stomach and a dagger in my back, and twisting them. Do I wish I'd had an epidural? Absolutely not. There were breaks from the pain during the contractions, during which I could celebrate the miracle that *I was doing this*, laboring and giving birth. I felt like the most powerful woman in the world. Positive pain—excruciating and empowering all at once.

Peyton's death put a knife in my heart—a big fat butcher knife that tapered down to a fine point. Not to mention the five or so daggers sticking into my back. I was astonished—I had never ever known that grief could have such an intensely real physical component. I honestly don't think it would have hurt more if there had been a solidly physical knife in my heart. I walked around for months pressing my hand to my heart, doubled over in pain. As in labor, there were breaks. When I laughed with friends, when I wrote an article, when I taught class, when I gave talks, the butcher knife would slide out till only the tip was still sticking in. But when the laughter ended, or I stood up from the computer, the knife would slam right back into my heart up to the hilt, and I would gasp and double over again.

The first year, I was in total shock. The intensity of pain and loss was everywhere around me. One day at a time? Impossible to contemplate. I could only live one second at a time: now I am climbing the stairs, now I am sitting down at the computer, now I am turning it on. People say shock wears off in a few months, but that was not my experience. Coming out of shock means accepting that your child is dead. Do you have any idea how many millions of new neural networks, new synaptic connections, your brain needs to create to accommodate that information? The death of a child means that everything you took for granted about life is shaken, in question. The world is upside down. Nothing makes any kind of

sense, especially that you should be alive when your child is not. It takes lots of time and enormous energy simply to accept the fact of the death.

It took me one solid year to begin to accept the possibility that she was really dead, even though I had stayed with her in that hospital room for five hours, had begged her with all my might to live, had realized with my body that no one was there in hers to beg or who could respond. That helped, but it wasn't enough for my mind to get it. I spent much of that first year bargaining with God: "Who wrote this screenplay? Can't we write another one?" "Can't we press rewind on the VCR and watch a different movie?" "I have her hair and her baby teeth—couldn't we clone her?" "Irrevocable" is not something we accept easily in a society where we can change so much through technology—hasn't there got to be a way to change *this*? One year I spent in that process of denial and bargaining, even though my dead daughter's ashes sat on the altar I had made for her in my bedroom. My poor brain just could not encompass this terrible truth.

And what did I gain when I finally, near the first anniversary of her death, got it that she had died, and no amount of bargaining would alter that? Utter despair and the complete loss of hope. Irrational as it was, the hope I gained from bargaining had been sustaining me. When I accepted the finality of her death and let go of my hope that somehow I could have her back, I gained truth but I lost myself. If the pain of death had lasted even only 365 times as long as the pain of birth, I could have stood it without drugs. I did stand it for one year. And then I couldn't stand it any more. Around the first anniversary of her death, just when I thought I was supposed to be feeling better (integrating, accepting, and all that), I cratered into depression. If you haven't been there, you can't imagine what it's like. The simplest act—putting on my socks, going to the kitchen to heat up some soup—is like struggling inch-by-inch through thick black mud.

People told me I had to "do something." So I gritted my teeth and searched. I found a wonderful bereavement counselor, who said to me during our first session, "I bet everyone is telling you that you should be all better now that the first year is past." I collapsed in tears, and she said, "Let me just tell you how it really is: the first year you are in shock, and you still nurture hope. The second year you give up hope, you are left with despair, looking at the reality of the rest of your life without your child, and you have to fight back from that. So the second year is always the hardest." I have never felt so understood. Her words did not magically make me well, but they did reassure me that I was not going crazy. Seven

months of hell before I began to stabilize. Things were looking up—maybe I could survive this after all. Maybe I could even be happy again, for more than a few moments at a time.

Then on my birthday, April 26, one and a half years after my daughter's death in a car wreck, my 18-year old son Jason was almost killed in a car wreck. The circumstances were eerily reminiscent. When I got to Jason, he was basically unharmed but he was covered in tiny pieces of glass, just as Peyton's body had been, and bleeding from lots of places just as she had. The overlapping of images was overwhelming. A second nervous breakdown followed.

If you are anorexic or bulimic or alcoholic or drug-addicted, you will find a plethora of programs ready to take you in, but I could not find one single place to go and find healing for my grief, my two nervous breakdowns, and the posttraumatic stress disorder I was suffering as a result. As with my desire for a natural birth, I finally understood that for healing from death I would not find help in hospitals or "the system." I will live or die on my own. Absolutely no one understands how hard this is except the parents of other children who have died. A doctor with an epidural needle can rescue you from the pain of labor, but no one can rescue you from the pain of losing a child. There is no easy way out (even suicide isn't easy), and if you are to find a path that leads to healing, it must be your path and your choice to take it. Lots of people will try to "fix you" and that, in my experience, often leads to more pain—your friends feel you are letting them down by not taking the path they think that you should.

We work hard not to be the Gestapo of the natural childbirth movement, dictating to women what they must do. Rather, we try to make sure they are fully informed, and then we back off and respect their choices, whether that choice is a scheduled cesarean or a home birth. We must do the same for people we know and love who experience death. There is

nothing that facilitates your own ability to heal more than friends who simply love you when you lose it and trust that you will indeed heal, on your own time and in your own way.

Just as birth is only a physical separation of mother and child, so death is only a physical separation of a unity that can never be broken. The umbilical cord was cut long ago, but the silver thread of energy it represents—the spirit of the umbilical cord, if you will follow me here—can never be cut and always unites Peyton and me. We first met when she was conceived—I knew the instant it happened, and I knew she was a girl. And we have never really parted. Her death so far has almost been my death, but insofar as I have survived, it has become my rebirth. I live for both of us now, knowing that Peyton both dwells in my heart and flies free in the universe, passing by to check on me from time to time. She is always with me and always anywhere she chooses to be. Just as even obstetricians cannot explain the mystery of birth (they still don't know what initiates labor), I can't explain the mystery of this death/near death/rebirthing process that is still taking place in me. As I wrote at the beginning, I can give you no facile explanations or easy answers, only perhaps the sense that in fact, *everything is as it should be*. Certainly it is as it must be. As with labor, we can either surrender to the truth of death, or fight it till the effort kills us.

When I gave birth to my son at home, I learned the power of surrender to the tremendous force of life. Now I am learning the power of surrender to the tremendous reality of death. May these two kinds of surrender balance and sustain me, teach me to let go of my fight to understand, and embrace the paradoxes my life encompasses. Like a mother who has just had the courage to give birth without knowing who her child will become, I am here, not knowing who I will become, but open, cracked wide open, to whatever life may bring.