tell me again

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Poetry and Prose from The Healing Art of Writing, 2012

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First published in 2014 University of California Medical Humanities Press in partnership with California Digital Library San Francisco - Berkeley

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Designed by Lesley Benedict

Library of Congress Control Number: 2013957683

ISBN 978-0-9889865-3-4

Printed in USA

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Something Always Knows

The snakes slither. Black crosses cover their bodies. In the presence of evil, the snakes contract. When they sense good, they weave and dance across the sand, leaving trails of gold, and fractals of light.

I have to gather the light.

This desert is the place of no life. The snakes must find their way out. If they stay here, the body will die.

All is silent except for the sound of a machine, and, under that, maybe a faint beartbeat.

My hands are tied down because I keep trying to pull out the tubes. Fever blazes despite the cooling blanket. A ventilator pushes air into my lungs, breathing for me, as blood and gunk pour out. A tube to bring nutrition is threaded through my nose; it had earlier caused a massive nosebleed, which, combined with a low red blood cell count, necessitated transfusions. A catheter takes away urine, which is bloody. Compression stockings pump on my swollen legs, to prevent blood clots. An arterial line is sutured into my wrist, so they can get blood from an artery to check the oxygen levels. Tubes pierce my arms, bringing in drugs: to kill bacteria, to stop wheezing, to cut the pain, to stop blood from clotting, and to make me forget. Especially to forget—Versed, Valium, Vecuronium, Haldol, and later morphine course through IVs so that I lose consciousness, am paralyzed, and to keep the horror of what is happening to the body from getting to the mind. But something knows. Something always knows.

It's hard to say my body; the impulse is still, after so many years, to say, "the body," to dissociate. I wasn't there, I was having visions.

I was in a desert. I was with snakes, their trails glittering with light, or shepherded by angels with wings of silk, their caresses on my cheeks so tender that even today the memory brings tears to my eyes. No, I wasn't that body, tied down, dead but for the machines. That wasn't me.

I had just had a baby, a beautiful, healthy, 9 lb. 10 oz. baby boy named Colety Joseph. Labor had been a bitch—it was everything you pray won't happen when you give birth to your child. I had back labor, stalled labor, morphine so I could rest and recoup my strength, and my water had to be broken. Two epidurals and Pitocin were administered. After fortyfour hours of ineffective labor, four hours of pushing, and still no baby, vacuum forceps were used, and failed. When fetal monitors indicated distress to the baby, I had a Caesarian section.

I remember thinking, as I was freezing cold, shaking, under the too bright lights on the operating table, a very simple, very protective, and probably very destructive thought, "This isn't happening to me."

I was far, far away. I saw a baby arching his back over the curtain and the blue curly slickness of the umbilical cord. The doctors were joking, saying he'd be a football player, "Even if his head had come out, his shoulders would've gotten stuck." They called it cephalopelvic disproportion, meaning his head was too big for my pelvis.

The surgeons handed the baby to other doctors, who passed him to my husband, Roy, who brought him over to me. Colety had clear, clear eyes. I had been trying for twelve years to get pregnant; he was our miracle. It was April 22nd. He was born at 2:37 a.m.

I held him in the recovery room, nursed him, shielding him from the harsh lights by making a tent for us with a hydrangea-colored paper gown. The light filtered blue as I gazed in wonder at those pure eyes. He had a conehead from the failed vacuum forceps, and his nose was pugged from the back labor. His hair was black and coarse and he had a little, red wrinkled face. The poor guy was a mess and my heart cracked open wide enough to hold the whole world just looking at him.

I had a fever. At first, it was unnoticed by staff, then they sent me down for an x-ray and I couldn't get off the x-ray table by myself. The technician didn't help; he'd already left the room. I lay there, in pain from my C-section incision, finally crawling down, and somehow I hauled myself into the wheelchair. I sat in the ugly hallway, sobbing, until Roy found me.

The baby had a fever too. They came to take him away and I couldn't stop them. I was too weak to cry out, and Roy was asleep, so I threw a book at him to wake him up. He was mad at me for doing that. They took the baby anyway and returned him with his little arm splinted and strapped down to an IV. I cried, seeing my son, only a few hours old, knowing that he had felt pain. He also had the shakes, so they kept pricking him to check his blood sugar. We both had FUOs—Fevers of Unknown Origin.

I wept more, and they diagnosed me with hormones. No one understood I was crying because they had put my baby in the intensive care nursery. My fever continued to climb, and blood cultures were ordered. They sent a portable x-ray to the room when it was clear I could not walk anywhere. They put me on oxygen and Albuterol to help with breathing.

I remember only the heat of the fever, the pain of the wound and wanting my son. I would doze, deliriously come to, say, "Where is my baby?" and sink back into my febrile dreams.

Colety and I are on a journey together, on a ship. It's an old wooden ship, with many sails, like a pirate ship. I don't know where we are going. Deep blue waters surround us as we glide over the sea.

Day 2: April 23

My fever continued to rise, and I was too weak to walk. Again, they wheeled the x-ray machine to my bed. The x-rays showed a deteriorating situation. What had begun as a left lower lobe density—probably pneumonia—

had spread to the right lung, and there was evidence of congestive heart failure, and possibly the partial collapse of a lung.

Day 3: April 24

Another chest x-ray showed continued worsening in my lungs. Roy left mid-afternoon to coach a Little League game and to have dinner with his kids, Kira and Evan. He must not have known how sick I was becoming, or he wouldn't have gone. They transferred me to the Critical Care Unit after diagnosing a "significant pulmonary problem."

Machines roared, whirred, and hummed. It felt too noisy for Colety and me; me somehow, in my delirium, believing they would bring a baby into the critical care unit. They stuck a hard plastic tube of oxygen up my nose and yelled at me when I took it out, because it hurt. I kept asking for my son, kept repeating, "Where's my baby?" They wouldn't bring him to me, wouldn't tell me how he was.

Another X-ray was taken, and this one showed "bilateral air-space consolidation ... most consistent with pulmonary edema." This meant my lungs were getting worse: where oxygen was supposed to be, there was fluid or solid material. Pulmonary edema leads to shortness of breath, and is usually caused by heart failure.

Of course, I didn't know any of the x-ray results. All I knew was that I had been transferred to this loud place, away from my son, and my husband was gone. Speaking was hard, due to the shortness of breath. I could only get out two to three words at a time, gasping, "My baby?" I was afraid he was very sick, and that they were lying to me.

A nurse came in and I begged for ice for my Caesarian section wound, which hurt. A lot. My abdomen had been cut open, my uterus pulled out of my body, sliced apart and shoved back in, after removing a giant baby, and I was being given no pain medication. That was cruel. I asked for ice for the intense pain, but secretly I was planning to suck on the ice, because they were "keeping me dry" for possible intubation, although I didn't know that at the time. I just knew they wouldn't give me any water or ice and I was burning up with fever and had never been so thirsty in my life. They didn't bring me the ice.

I called my older brother, Tom, in L.A. He and his wife had just arrived in Desert Hot Springs with their infant son Jake, escaping the smoke of the Rodney King Riots. He told me later that I said, "The doctor is trying to control me. I'm going to pull out my IV and my oxygen and go and get the baby and wait for Roy in the parking lot." It was primal; I knew only that I needed to get out of there, with Colety, or something bad would happen.

My brother, who is a doctor, called my doctor, who said I needed to be intubated. Then Tom called my father, who is also a doctor, and my dad somehow tracked down Roy. He scared Roy enough that Roy raced back from the Little League game, saying later he'd never driven so fast in his life. My brother called my sister Chris in Berkeley, across the Bay, and said, "Go, now! She is refusing to be intubated, and she may die." Chris popped her four-month-old daughter in the car seat and took off, speeding. She and Molly made that drive, over one hundred miles, round trip, many times during my hospitalization.

The doctor came in to see me, spitting mad. She yelled at me for calling my brother. She said, "You have hypoxia ... not enough oxygen to the brain. We may have to intubate you."

I said, "Over my dead body."

She said, "It may come to that. If we don't, you might die."

I found out later, from my brother, that he suspected that the doctor's plan was that if I continued to refuse to be intubated, and Roy could not be located, that she would wait until I either passed out from lack of oxygen or had a cardiac arrest, and then she would intubate me. If you are unconscious, then you have given implied consent to a life-saving medical procedure. She would be able to do this because I hadn't signed a DNR—Do Not Resuscitate—order, nor did I have an Advanced Directive on file.

X-rays showed a complete whiteout of my lungs. I had ARDS—Adult Respiratory Distress Syndrome, a life-threatening lung condition that prevents enough oxygen from getting to the lungs and into the blood. People die from ARDS.

They didn't know the origin of my ARDS, so they weren't sure how to treat it. Was the source an embolus of amniotic fluid that had injured the lungs? After a Caesarian section, fluid from the birth can get into the veins and enter the lungs, causing extreme damage by a chemical reaction—a rare but catastrophic event with a high mortality rate. Was it caused by pneumonia? Or endometritis, which is an infection in the lining of the uterus, perhaps from childbirth? All of this was complicated by hypoxemia—an abnormally low concentration of oxygen in the blood, the fever, extreme swelling in my limbs, the Caesarian section, a racing heartbeat, and possible congestive heart failure.

I still refused to be intubated; I had so little oxygen going to my brain, all my thoughts were fixated on getting to my son. It made perfect sense to me at the time; if I was intubated, I couldn't be with him, in the intensive care nursery, so of course I said no to the procedure.

The doctor's notes say:

Patient's pulmonary status has clearly deteriorated with respiratory rate 40-50 [Normal range is 12-18 breaths per minute.] Patient is acutely ill, agitated, anxious. Does not believe MDs (me) are being honest with her. I have had extensive discussions with the patient, her father, her brother, her sister. Intubation is necessary secondary to ARDS. I have asked anesthesia to intubate—I believe patient will allow another MD to do this more easily than she would allow me.

It was night when Roy came tearing in. They explained to him that I had Adult Respiratory Distress Syndrome. The doctor told Roy that treatment for ARDS needed to be started to reduce the risk of death and to prevent further damage to my lungs and other organs. The goal was to keep me alive and breathing while finding out and treating whatever had caused the ARDS.

The doctor told him that I needed to be placed on a ventilator to stay

alive. With ARDS, the oxygen in the blood drops quickly to dangerously low levels, causing damage to vital organs and even severe brain damage. Intubation could save my life.

I saw Roy, and that was the last thing I remembered, consciously, for the next ten days. He gave them permission to intubate me, and at 9:00 p.m. on April 24th, I was sedated and an endotracheal tube was pushed down my throat into my trachea. I was sedated and paralyzed and put into a type of medically induced coma. I was gone.

There is a moment between the end of the day and the beginning of the night, a space between, a place between. There is a world where worlds meet, a moment between the awakening and the dream, a place between night and morning. There is a world where worlds meet, a moment between the dream and the awakening, between dawn and dusk, in the place between sleep and waking. The veils between worlds are thin here. It is the threshold. Cross it.

Later that night, they told Roy that I had a less than fifty percent chance of surviving. He went and held our baby, and then spent time with me. He ended up at the chapel, trying to sleep, and talking to God. He prayed that I wouldn't die and that our son would have a mother.

Colety was in the neonatal intensive care unit, struggling with his fever.

Day 4: April 25

My body was intubated, with a catheter for urine output, and an IV bringing in medications including three different antibiotics, and Versed and Vecuronium, two paralytics. Fevers continued. Coarse crackles sounded in both lungs. My abdomen was distended and soft. White blood cell counts increased, meaning infection was present. A sample was taken from my lungs to rule out viral, fungal, and Legionella bacteria as the cause for the ARDS.

I feel the wings of the angels of childbirth caress my cheeks like the softest silk. I cry; it is so tender. They reassure me that they will be there for Colety if I die.

But where is my baby?

Is he dead?

My brother Tom arrived, much to Roy's relief. My brother consulted with the doctor, who told him, "She's going to hate me. Patients always hate the doctor who intubates them."

Tom told me later that he was quite heartened by two things:

1. My lungs were not stiff. He thought, "That's totally great. I was used to people whose lungs got stiff when they were intubated, which meant they were never coming off the vent, or they were going to be on it for a long, long time."

2. "You got great care. Everyone talks about how people in comas hear everything, but they really respected it. They never did anything without talking to you. They'd say, 'Katie, we're going to suction you now.' They gave great human care—probably the best I've ever seen."

Late that afternoon, my parents arrived from Connecticut, and the first person they saw was my brother, standing by the elevator. They met with the doctor, and together my parents, my brother, and Roy, arranged for my breasts to be pumped (because everyone knew how much I had wanted to nurse my baby) and for Colety to visit me, even though the doctors didn't want this to happen, my family insisted.

My family also recognized that I was in pain from the C-section, and they convinced the doctor, because she started prescribing morphine.

The doctor's notes reflect:

1. ARDS

2. C/Section – Rule out possibility of septic pelvic thrombophlebitis [in which a blood clot from the pelvis has caused sepsis, a systemic infection]

3. Attempting to pump breasts—not very successful, given acute illness

4. Anemia—urine brown—? hemolysis [breakdown of red blood cells]

5. Will allow baby in if OK with ob/peds

I am convinced this last intervention saved my life—that the love from Roy and my family, and most of all the contact with my son—the strong spirit in that tiny body—pulled me back.

Day 5: April 26

Still the fevers persisted, despite the siege of the antibiotics. A cooling blanket was added to the regimen of treatments. My temperature had climbed to 104 degrees, and the white blood cell count, indicating infection, continued to rise. A feeding tube was placed through my nose, into my stomach. Compression stockings were being used on my legs, swollen due to the congestive heart failure, and I was at risk for deep vein thrombosis, or blood clots. A blood thinner, Heparin, was prescribed.

I was deeply sedated. When the Valium, Vecuronium and Versed wore off, I became highly agitated. Yet there was minor improvement in my lungs, and they had been able to lower the volume of oxygen going through the ventilator. And whenever they brought Colety into see me, and laid him on my belly, skin touching skin, my pulse, respiration, and blood pressure went down dramatically. I was soothed.

My sister Chris arrived with her daughter Molly again, and friends came, too, joining Roy, Tom, and my parents. Colety's half-brother and sister, Evan, age twelve, and Kira, fifteen, visited and, gowned, held Colety, his fever gone, for hours. And Roy later told me that he was there for every procedure they did on Colety, even when they weighed him, so that he would not feel abandoned.

The tribe was gathering round Colety and me, sitting vigil by our bedsides.

Day 6: April 27

The doctor's note reads, "Extremely agitated when allowed to wake up. Requiring large amounts of sedation."

The snakes writhe and contract, making whorls in the sand. They have stopped their journey out of the desert. The black crosses on their backs shrink to dots and the light in their trails disappear. The light is gone and they are angry.

Left lower lobe pneumonia was still present, and the cause of the ARDS had yet to be determined. I was fevered, in spite of the cooling blanket. My chest wheezed and crackled when the doctor listened to it. All cultures and stains for specific bacteria were negative. It would remain a mystery what had happened to make me so sick.

Crisis with Colety: Ironically, because he was so well, the hospital decided to discharge him. His fever was gone and he was thriving. The problem was that there was nowhere for him to go, as Roy and my parents were staying at the hospital all day, and at a hotel at night; there was no place to leave a five-day-old baby. The social worker met with my parents, Roy, and my doctor, and they convinced the nursing manager that it was important for "the patient's recovery" (meaning me) that my baby be nearby to visit. They arranged for him to be transferred out of the pediatric intensive care unit (where truly he must have seemed like a giant) to the pediatric ward.

Four angels appear, one for each direction. They gently float down, the air silken. They are the colors of sunset—purples, mauves, pinks, blues. They softly, sweetly float. They are the angels of childbirth, of the babies whose mothers have died when they were born, so the babies are not alone. They watch over children without mothers. The angels touch me as gently as butterflies, brushing their wings against my cheeks. They are real.

Day 7: April 28

The medications were unchanged, my abdomen quite distended, and still there was swelling in my limbs. My lungs were putting out copious secretions—blood and gunk—and they popped and rasped. The fever remained, the x-rays were bad, but the ventilator settings were going down, a good sign. The doctor was concerned that weaning me from the mechanical breathing would be difficult though, due to my agitation. They had tried rousing me, and I had reacted with an unusual pattern—I had started a fast panting: 60 - 80 breaths/minute.

An obstetrician was consulted, and he ordered an ultrasound to rule out abscesses or any post-surgical complications. He also requested a consultation with an Infectious Disease Specialist.

Day 8: April 29

Clinically, everything was the same—the Fever of Unknown Origin cooked along, my lungs rattled and whistled, and I was still sedated with morphine, although Haldol, an anti-psychotic, had replaced the paralyzing agent Versed and the tranquilizing Valium. This change allowed my eyes to open, "sluggishly."

The doctor started me on a steroid, Solumedrol, "with caution," her notes say. Steroids are good when there is inflammation and asthma, but dangerous if there is infection, so it must have been a hard call to make.

The good news was that my abdomen was slightly less distended, my limbs less puffy, and the slow weaning from the ventilator continued. I received a blood transfusion for the hemolytic anemia. And they were bringing my beautiful baby boy to me, allowing skin-to-skin contact, as they placed him on my chest.

He's alive, he's here.

The Infectious Disease Specialist reviewed all the records and examined me. He stated that he:

Ruled out zoonotic exposure, travel, TB exposure, HIV risk factors, etc. Negative bacterial cultures do not rule out an infectious process such as bacteremia [the presence of bacteria in the blood.] Many pneumonias are culture negative, unfortunately, and endometritis is often a clinical diagnosis without a positive culture ... Most likely, patient's course is explained by post C-section pneumonia, and/or endometritis, leading to sepsis, leading to ARDS.

The pelvic sonogram the obstetrician had ordered came back clear—no signs of infection or abscesses.

My friend Lauren came to visit. Later she told me that when she saw me, I looked asleep, peaceful. She mentioned it to the nurse, who sharply corrected her, saying, "She is a very seriously ill young woman. She may not make it." Lauren was stunned.

She said she told me she wanted to massage my feet, but when she did, she could see, from the bank of monitors above us, that I was getting agitated—my heartbeat, blood pressure and respirations were all rising. She stopped, and instead just talked to me, sitting close to my head, saying, "We are all waiting for you to come back. Your parents are here, and they love you. Roy is here and he loves you, and Colety is here, and he loves you, and he is being taken care of, but we are all waiting for you to come back. You can sleep for as long as you need to, but please come back." As she spoke, my vital signs slowed down; her voice and words calmed me.

Then she went to see Colety. She held him and told him, "Your mommy's here, your mommy loves you, your mommy's going to come back."

Day 9: April 30

A failed extubation, accompanied with severe wheezing, and I got very agitated. My blood pressure soared to 210/130. (Normal for me was 110/70.) I developed increased bronchospasms, sudden constrictions of the muscles in the walls of the bronchioles, deep in the lungs.

I got a dangerous nosebleed when they were placing the tube in my nose for feeding me. It bled so much that they couldn't control it, due to the Heparin (blood thinner) that I was on to prevent blood clots. They packed my nose with gauze and planned to remove it over the next four to five days. Because of the bleeding, they feared the airway had been compromised, so they used the bronchoscope to clear it. They tied my hands to the side of the bed so I wouldn't pull out my tubes or lines.

Due to the low hemocrit (the number of red blood cells in the blood) level, the diagnosis of postpartum hemolytic anemia, and the blood loss from the nosebleed, I received more blood transfusions.

Day 10: May 1

Still I had ARDS, pneumonia, asthma, hemolytic anemia, and post-Csection healing, but was down to only two antibiotics, along with the Solumedrol, Valium, morphine, and Haldol. The catheter and the ventilator remained.

The doctor's note says, "sedated, tries to communicate."

I remember trying to write the word "ice" on a pad, because I couldn't drink and was terribly thirsty, due to the tube down my throat and the fevers. No wonder my visions had me in the desert, with its merciless sun and heat.

My lungs were better, with decreased wheezing, and I had no more edema, or swelling, in my limbs. My white blood cell count was down, and the x-ray showed, for the first time, that the ARDS was resolving. The doctor's plan was to restart the Heparin (she'd discontinued it after the nosebleed) and decrease the steroid. She continued to wean me off the ventilator.

Big news—a lab reported a positive Legionella titer from one of my samples. The information was greeted with caution; the doctor wanted another test, from a more reliable lab, before calling the diagnosis. The medical records don't reflect whether such confirmation ever came, so I could have had Legionnaires' Disease. Breathing in mist or vapor that has been contaminated with the bacteria causes Legionnaires' Disease. According to the CDC, "Hospital buildings have complex water systems, and many people in hospitals already have illnesses that increase their risk for Legionella infection."

Day 11: May 2

The medical chart reported that I was sedated, calm, and able to open my eyes. They did not remove me from the ventilator. No extubation was attempted.

I remained on two antibiotics, Heparin, morphine, Haldol, Valium, and the steroid. Diagnostically, I still had ARDS, asthma, pneumonia, postpartum hemolytic anemia, an increased white blood cell count, and was healing from the Caesarian section. My lungs still wheezed and crackled.

Day 12: May 3

I am awake and I do not understand what is happening. I can see and hear, but I can't talk. I am very hot and thirsty. A nurse comes up and tells me not to try to talk, and then more people surround the bed and I am confused and overwhelmed. I hurt. They tell me to cough, and I cough and gag and they pull and pull and this horrible snaky long thing comes out of my throat. I don't know what has befallen me and I want to know where my baby is. They are taking gauze out of my nose and telling me not to blow my nose, as if that mattered. I am extubated, they tell me.

All I wanted was my baby. My voice was horrid and raspy when I asked for him, due to damage to my larynx from the intubation, a condition that persisted for months.

I was disoriented. Roy was there, and I asked him where the baby was. When he brought our son to me, I felt peace descend and the caress of the angels. Holding Colety in my arms, I gazed into his wise eyes, at last awake for him. I loved him and put him to my breast to nurse. It had been a long journey back to him, but I had made it, grateful for the love and support of my family and friends, and the care of the hospital staff, often given in spite of my opposition. All the light that I had gathered in the desert was for this one precious life, my son's. I had found my baby, and he had found me.

I didn't know what had happened, or what day it was. I didn't know what to believe when Roy explained about the ARDS, the intubation, and how many days I had lost. I was stunned to see my parents there, in the hospital.

I remembered only the C-section, holding my son, and the fever, but not much after that. I recalled wanting to go out to the parking lot and wait for Roy, to get us out of the hospital. But I didn't remember calling my brother, or the intubation, or any of the last ten days, except for the visions I'd had.

Days 13-20:

I spent seven more days in the hospital, recovering from my ordeal, including, according to the doctor's note, "withdrawal from the tremendous amounts of narcotics and benzodiazepines," I had been on. I barely could allow my son out of my arms. I cried a lot, patting my heart.

Chris came, with Molly, and she showed me how to breastfeed. Many of the staff visited me, often late at night when I couldn't sleep, to hear about my visions in the coma. They, too, were in tears, when I spoke about the angels of childbirth, knowing that no motherless child is left unprotected.

The last morning, I spiked another fever, but I did not tell staff. I just needed to get my baby and myself home, blessed home, alive.

My mom stayed with us for about a month to help out, as I was still quite depleted. It took me six more months to recover my strength, as my new doctor explained, "the body cannibalizes itself when it is intubated."

The mystery of why I got ARDS was never definitively solved; the three most likely possibilities are:

1. An amniotic fluid embolism.

2. The stress of the labor and C-section exacerbated an undiagnosed pneumonia, and/or endometritis, into sepsis, which became ARDS

3. Legionnaires' Disease.

Psychological recovery from the trauma and the dissociation has taken years, and I am only now beginning to understand, and only partially, the visions I had while I was in my coma.

Today, my body dances and my lungs breathe deeply. My son thrives: a brilliant, beautiful artist, full of life and light. And I know now, with certainty, that no one dies alone. The angels were with me when I was dying, and then they would have gone to comfort my motherless child. Now, they are with us always, their wings gently caressing our cheeks.