Courage and Voice: The Story of a Young Author and Her Teacher

by

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Each of us has a story to tell, and it’s my challenge as a writing teacher to help my students develop the courage and voice to tell their stories. Two years ago I was asked to work with a young miracle named Jessica Pace, to help her turn her inspirational story of struggle and survival into a published book. Throughout her short life, Jessica had continuously demonstrated that she had more than enough courage for this enormous undertaking, and through our months together, she developed a compelling voice that would be heard nationwide.

I first met fifteen-year-old Jessica about eight months after she’d endured a double lung and heart transplant. She’d also had back surgery to implant rods to correct severe scoliosis that would otherwise have damaged her new organs. I was a bit apprehensive and overwhelmed at the prospect of meeting her. I’m not sure what I expected, but this diminutive, soft-voiced, witty, gutsy teenager captured my heart immediately. Nothing that had happened to her has in any way diminished her spirit.

Jessica was determined to publish a book about her experiences. She and her doctors at St. Louis Children’s Hospital were convinced that such a book would serve two important purposes: it would help others experiencing the same kinds of problems to understand and find hope, and it would also make readers aware of the very personal side of organ donation, and perhaps inspire them to sign donor cards.

This is where I came in. As an experienced teacher of writing, I’ve worked with hundreds of writing students over the years. My sister, who got to know Jessica when she did a series of newspaper features about her illness and need of a transplant, asked me to
meet this determined teenager and see if I could help her get a book out.

Jessica showed me the stacks of diaries she had been keeping almost since she learned to write. She’d been ill all of her life, undergoing her first open-heart surgery when she was only ten days old. Elizabeth, Jessica’s mother, kept a diary about her until she learned to write, and then encouraged her to continue. The disease, the surgery and the medicines necessary to keep Jessica alive took their toll, and she was a frail child, so writing became her activity. She entertained herself when other youngsters were playing by writing down her thoughts and experiences. Writing helped her pass the time, and it kept her outlook positive.

When I read the diaries, I knew immediately I was onto something special. All the spirit, wit, courage, determination, honesty, mischief, and wisdom beyond her years were captured in the pages of the many notebooks she’d filled. Yet they needed work to turn them into a readable, marketable book.

I started working as Jessica’s writing coach. We met whenever our schedules permitted. I used strategies learned through my years with the writing project to help Jessica bring out the best in her writing. During each session we’d focus on a particular writing strategy, try a couple of exercises implementing the strategy, and then apply the strategy to a passage in her diaries.

One of the first concepts we tackled was “show-not-tell” writing. I gave Jessica the following sentence: “The man sitting on the park bench was old.” We agreed that this sentence was pretty bland. I then asked her to write a paragraph about him in which every sentence added to the feeling that he was old, but never used that word again. She wrote:

His gray hair showed beneath the battered felt hat he wore. His wrinkled face showed the passage of time like a road map. He pressed his cane hard against the ground to still his trembling hands. After an hour of gazing into the distance, he struggled up and slowly walked toward his silent, lonely apartment.

Then we looked at her journals and selected a passage we both thought could use more life:

Manaw Ann is another special person in my life. She always cooks something good when I go there, and she’s always trying to get me to eat more. I love her a lot.

After applying the concept of “showing writing,” Jessica came back with:

To describe Manaw Ann is to know her. She’s reliable, and is with me even when I’m coming out of anesthesia and yelling at everybody. She’s clean just like her house. I mean, when she vacuums she does it for at least two hours. (Now I know where my mother gets that from. I just hope it’s not genetic.) She’s predictable. She has worn the same hair style for twenty years. And she always tells me to be good. She says she’s going to leave Papaw Lanny to me in her will because he and I get along so well.

Her writing improved each time we worked together. One day I introduced the “cookie person” writing prompt: describe someone who is so loving, so supportive, that they would give you a cookie right before dinner, even if they knew you didn’t need it. Deciding upon her cookie person, Jessica wrote, “My Papaw Lanny is special because he is always there for me.” She then added showing details, and her writing came alive:

Throughout my life I’ve been sick a lot, and the person I remember standing by me most, other than my mom, is Papaw Lanny. He can always make me laugh no matter how bad I feel. When I’m down and depressed I remember what he’s always told me. ‘First you can always find someone a lot worse of than you, and second, God has everything under control.’

When I was little I couldn’t go out to play because I would get too hot and faint. We would sit by Manaw Ann’s fish tank and read books or play games, and he would make faces like the fish.

We followed these sessions up with others on writing to an audience, using vivid verbs, writing fluently, and other writing skills. Finally I taught her to make a cluster to plan for her entire book. We placed her name in the middle, and then attached every aspect of her life that she wanted to write about, adding details until it looked like a crazy-quilted web. “You know, Jessica,” I told her, “if you wrote about
everything on your cluster the way you wrote about Papaw Lanny, we'd have a book."

Jessica was a quick study, and it's a good thing. My time to work with her was limited, for soon after the clustering session, I missed seeing her for months. Her body started rejecting her new lungs, and she also contracted mucor fungus, which required surgery to remove the affected part of one lung. She was in St. Louis Children's Hospital for months. Sensing that the doctors thought there was little hope, she told them, "If I'm going to die, it's going to be at home among familiar things and people I love. Pack my bags."

As she had done many times before, Jessica proved the doctors and medical science wrong. Against all odds, she got better. Very slowly, but better. When she was able to have me come over again, she showed me stacks of notebooks she'd filled. She had been revising, according to my suggestions, the material for her book during the whole ordeal!

She now had the all the material she needed for her book, so the responsibility shifted to me to turn her notebooks into a cohesive manuscript. I was overwhelmed at first—so much good material, so many choices, so much work. I couldn't allow myself too much ruminating time, though, for I felt a sense of urgency that few projects could ever impose: I was afraid Jessica might not live to see the book.

My first step was a cluster that included all the major topics I'd read in her notebooks. With it I arranged the material in a logical manner, cutting and pasting both literally and on the computer. That done, I went into a typing frenzy. I had to make her words flow and give her sentences continuity without deviating from her intent or losing her voice. After work each night, I would type until one or two in the morning. Jessica's writing was so powerful, I often cried onto the keyboard or threw my head back and laughed aloud at her words. Though I worked hard, it was a wonderful time for me.

When the rough draft was done, I sent her a copy with a sigh of relief; she would at least have seen the first draft of her book. She read it, called me to express her pleasure, and shared it with her strong, supportive family. Then we started a series of many revising and editing sessions. Sometimes we traveled the 120 miles between our homes to meet, exchange copies, talk, and plan. Other times we faxed or mailed copies and waited.

As we neared the end of that process, I began thinking about publishers. Although we had the promise of a national publisher, going through that process would have taken more time than we feared we had. So I talked to my sister, Phyllis Harper, who had first introduced me to Jessica. Phyllis had always dreamed of setting up her own publishing company, and now, recently retired from journalism, she had some time to pursue her ambition. "You could publish Jessica's book to launch Fawn Grove Publications," I told her. I didn't have to twist her arm, for she had worked with us throughout and was as anxious as I for Jessica to see her book.

So Phyllis stepped in and quickly found a printer in a nearby rural town who did quality work and was flexible enough to accommodate our need for a large-scale but quick print job. Phyllis's daughter set the type, designed the cover and got everything camera-ready. The galley sheets, complete with pictures, went to Jessica. Another milestone! Her mother sent the
galleys to a nurse at St. Louis Children’s Hospital who had become a close friend, to have her proofread them for medical terminology. The nurse then showed the galleys to others at the hospital, and when the public relations department saw them, they enthusiastically came on board by sponsoring a national tour to promote the book and encourage organ donation.

The book came out in February, 1998, about a month after Jessica’s sixteenth birthday. All the hard work, time, travel, and frustration were repaid when Jessica held her book with her name on the cover in her hand. She was jubilant. Her health had improved as we progressed with the book and she had just received her best six-month checkup ever.

The night before our first autographing party, I answered my phone to hear a sweet, slightly husky little voice ask, “Miss Jane,” (yes, in the true Southern style, she has given me that respectful title), “what color dress are you wearing to our book signing tomorrow?” I hadn’t had time to think that far ahead—whatever was clean was my first thought! I told her I’d wear something navy. “Okay, I wanted to wear the right color so we wouldn’t clash.” I was again reminded that despite her daily struggle for life, Jessica was still, in many ways, a normal teenage girl.

Soon after the book came out, we were asked to attend an autograph session at the gift shop in Children’s Hospital. What an amazing event! The chairman of the board came by and bought fifty copies for his personal giving. (We almost wore our hands out signing all of those in a hurry.) Nurses, doctors, parents whose children faced transplant surgery—one that very afternoon—all came to buy books. Four television stations interviewed us, as well as several newspapers.

Jessica’s story sold quickly and has already gone into a second printing. We have had book signings in four cities, with others to follow as Jessica and I have time. We have been interviewed on television stations in Tupelo, Jackson, Memphis, and four stations in St. Louis. Newspapers from all those cities have carried full-page articles about Jessica. In August she was featured in a regional infomercial in People Magazine. The producers of Oprah and the Today Show have invited us for interviews, but no dates have been set.

Jessica’s family has shared in all this excitement, traveling with Jessica and me on our book tour. I fully expect to become Mama Jane at any minute, I am so much a part of their circle. They are a special, close-knit family, and people who know them credit their love and support for instilling in Jessica the will to live that has brought her through all her medical emergencies. “We never left her alone in the intensive care nursery, although we could only reach in and touch her with one hand,” Mamaw Ann recalls of the early battles for her life.

Jessica realizes how much they have given her. “Maybe you’ll think I’m a baby,” she says in her ‘Dr. Mom’ chapter,

but when I’m sick I want my mother. She’ll rub my face and arms and sing to me, and even when I’m unconscious I can tell she’s there. Papaw Lanny would move heaven and earth if I asked him to, and Mamaw Ann is reliable. She’ll stay with me even when I’m coming out of anesthesia and yelling at everyone. My sister Reagan kept me from giving up, because I love her and can’t think of her going through life without her big sister. And my younger brother Jordan is the only one who has treated me like I was normal through this whole thing. He got on my nerves and aggravated me; even when I was sick he would fight with me. Still does, but nowadays I can beat him up!

Jessica’s spirit continues to amaze me. Not many teenagers have had a double lung and heart transplant. None have had the combination of subsequent surgeries she underwent. No other person has had mucore fungus and lived. And how many sixteen-year-olds have a book out, already in its second printing, and making an indelible impact on the lives of those who read it? Jessica faced all these challenges with unparalleled courage and determination.

A Will to Live: the Diary of a Transplant Kid has been the subject of at least one book report; to me as an English teacher, somehow that makes it official! We are hearing from sick children and adults who have been inspired by Jessica’s words; some say she expressed things they wanted to say but didn’t know how to. Another goal was realized when a lady told us, “After we read the book, my husband told me that if anything happened to him, he’d want to be an organ donor. Until then, I had no idea he felt that way.” As Jessica’s pediatrician quipped, “Anyone who doesn’t reach for a donor card after reading Jessica’s book doesn’t have a heart anyway!”
All of the professionals who worked on this book donated their time and expertise; even the printer, who admitted he was moved to tears when he read the book, only charged for the actual cost of printing. Profits go to a trust fund for Jessica, with a percentage to a charity she has chosen.

My own compensation came in a note I received from Jessica, the most profound reward that I could hope for. It said, “You have made my dream become a reality. The card catalog says so. Look up the book, and under author it has my name.”

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Lord, Teach This Patient Patience, But Hurry!
An Excerpt from A Will to Live

by Jessica Pace

Patience is a virtue. Whoever said that obviously never had to wait for a transplant. Looking back, one of the hard things is getting your strength back, but the very hardest thing is the wait. You jump every time the phone rings, especially if it rings late at night. The wait is especially hard around the holidays. It’s kinda sad that you’re waiting for someone to die in order for you to live. But the way I think about it we’re all going to die. We don’t know when or how. But when God calls us to heaven we’re going whether we want to or not.

When I first heard about a transplant that could give me a second chance at life, I can’t begin to tell you what went through my mind. Crazy stuff. Will I act or begin to look like my donor? All the medicines. Being separated from my family. The possible risks or setbacks that could happen and the idea of a dead person’s parts being in me and guilt that somebody had to die so I could live. But when I got so sick that going from one room to the other got me out of breath, I started watching the news, hoping and praying that someone would die and leave their organs. I know it’s selfish but I thought of it a lot.

I was afraid to go to sleep at night, afraid I wouldn’t wake up. I felt guilty for putting my family through this. So one day I decided to make out my will. I wanted every member of my family to have something of mine to remember me by. Then when I was getting worse, I started thinking about my funeral. I didn’t tell Mom at the time because I didn’t want to upset her or anyone else.

It’s not a fun way to live, not knowing whether you’re going to make it to see tomorrow. I would be afraid to go to sleep, afraid I wouldn’t wake up and when I would finally go to sleep it would be just as the sun was rising. I didn’t want to die at night. If I was going to die I wanted to die meeting the sun. So I told the Lord if I was going to die I wanted to die in the morning.

I’ve heard that fishermen have a lot of patience. My dad, James, enjoys fishing, and I remember Dad, Mom, Jordan and me going fishing together, always early in the morning. Of course my dad was the only one who had the patience to really fish. Those trips to me learn patience. Plus, the fishing pond, I believe, helped us have fun except when Jordan decided to play with the worms.

Patience is learned early in life, especially for someone like me. I try to think of some of the good ways I’ve learned this characteristic, and not just the bad.

Update: Jessica underwent another lung transplant in August. Her Uncle Bubby and Aunt Lori each donated a lobe of a lung, so she had a good match. She came through the surgery well and is slowly progressing.

Copies of A Will To Live can be ordered by sending a check or money order payable to Fawn Grove Publications for $16.95 plus $3.00 for postage and handling to: Fawn Grove Publications, P.O. Box 3657, Tupelo, MS 38802-3657.

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