Jessi Ulmer: Cancer Survivor

After conquering a brain tumor, a shy, small-town girl finds the inner strength she needs to conquer high school.

Jessi Ulmer
As told to Dana White
In January 1999, I was a freshman at Belchertown High, a school of about 550 kids in the small town of Belchertown, Massachusetts.

I'd made a few new friends, but I was basically a shy, timid person. Part of the reason for my shyness was that I spent elementary school being called "fat" and "four-eyes." Kids would gang up on me in a big circle and call me names, or make fun of me in class until I blew up. Finally I just shut down and stopped talking.
In the sixth grade the teasing got so bad that my mom, Aileen, asked the vice principal at the middle school if I could skip the seventh grade to get away from the kids who were tormenting me. (I also wanted classes that were more challenging.) Eighth grade was less painful, but I was so invisible that a lot of kids thought I’d just moved to Belchertown, even though I’m a third-generation townie. When one girl asked me, “Where did you transfer from?” I answered, “The sixth grade.”

Talking to new people was really hard for me. Face-to-face with kids at school—especially boys—I’d sort of blush and search for something to say. I rarely went to parties or school dances. Even at family gatherings, if a relative came up to talk to me I’d say, “Oh, hi,” and hide behind my mom. Which is hard, because my mom is smaller than I am.

When I started ninth grade, I was only thirteen. This made me the youngest student at Belchertown High. Still, I was adjusting; I’d gotten good grades (as usual) on my first report card and was helping to start the school’s first chorus club. (Other than studying, singing is what I really love to do.) But I was most proud of the fact that finally, for the first time in my life, I’d managed to grow my hair all one length—down to the middle of my back. Life was pretty good.

And then, out of the blue, it wasn’t.

Deadly diagnosis

In January, at the beginning of my second semester, I started getting terrible headaches. I managed to go to school, but by February I couldn’t keep food down. I’d wake up, throw up and not want to get out of bed. Then my vision got messed up. I couldn’t read; the words were shaky and out of focus. This drove me crazy because I was falling behind in my schoolwork. At first my mom wasn’t too worried; she thought I just had a bug or needed new glasses. But by the end of
February, when I was only getting worse, she called my pediatrician. After hearing the symptoms the doctor told her to take me to the hospital immediately for a CAT scan.

On Saturday, February 27, my mom and I drove to the hospital in Palmer, a nearby town, for the test. I'd had a CAT scan before, when my sinuses were acting up, so it wasn't a big deal. My mom wasn't that panicked; we were just getting me checked out. On Monday, the pediatrician called to tell us the test was inconclusive and I needed an MRI, a more complicated test that gives a three-dimensional view of the body. So that afternoon we drove forty minutes to the biggest hospital in the area, Baystate Medical Center, in Springfield. We were both starting to worry that something was definitely wrong.

We got to Baystate at about three in the afternoon. First the radiologist had me lie down on a table in the MRI room. Then he put this helmetlike thing on me and strapped my head to the table to keep it still. Then I was slid up into this big tube. I just had to lie there. It was really claustrophobic and loud in the tube, like a rhythmic thumping that changed in speed and pitch. After thirty-five minutes they took me out and injected a dye into my bloodstream, which would give the radiologist a high-contrast picture of what was going on in my brain. Then I was sent back into the tube for another twenty minutes. The process was boring and freaky at the same time.

Afterward, my mom and I had to wait forever for the results. Finally, at around 6:00, the doctors took my mom into a little dark room. When she came
back to the waiting room, I knew something was wrong because she was crying.

I said, "Mom, what is it, what's wrong with me? I'm going to be okay. Whatever you tell me, I'm going to be okay."

She said, "Well, they think there might be a tumor."

I asked her if I was going to be admitted. She said they were getting a room ready for me, and the surgery would happen in the next couple of days. The tumor was sitting right on top of my spinal column. The doctors wouldn't know if it was cancerous until they did a biopsy after the operation. But they did know that if it wasn't removed right away, I'd have only a few more months to live.

I just kept telling my mom that I was going to make it. It was strange to be comforting her even though I was the one who was sick. For her sake, I was trying to put a good face on my feelings, but inside I was scared.

**under the Knife**

We still had to give my dad, Dale, the bad news. At the time my dad was a window salesman who was on the road all the time (now he owns a restaurant), so we couldn't reach him. My mom left a message at his company's main office. He showed up right as we were checking into my hospital room. He was freaking out and crying, "Oh, my God, what are we going to do?" (I may be his oldest daughter, but I'm still his baby.) My mom, who was trying to be calm, said, "We'll take it day by day. We're waiting for the doctors to come." When the doctors came, my dad started yelling at them. I was the optimistic one. "They're going to get it," I said. "I'm going to be okay."

My surgery took place on March 4, 1999. My neurosurgeon, Dr. Kamal Kalia,

"I'm going to be okay."
cut me open from the base of my neck to the bottom of my cranium. He removed a little trapdoor of bone, carefully cut the tumor out and replaced the bone, fusing it back to the rest of my skull. (Later, when I'd move my head, I could feel the loose bone crunching.) It was a tricky procedure—part of the tumor was growing down into my spinal cord—and it took all day. My mother told me later that while the operation was happening my younger sister, Barbra, who was in sixth grade at the time, congregated in the school counselor’s office with some of my middle school friends and cried.

After the operation, the doctors told us the tumor was cancerous. I don’t remember my reaction or anyone else’s, because I was heavily sedated. I had a malignant tumor called an ependymoma. It was about the size of a walnut and had been growing rapidly. The good news was that the surgeon got the whole thing; they said that with radiation my prognosis was good.

The bad news was that I got pneumonia a few days after the surgery. I was in the Pediatric Intensive Care Unit (PICU) when one of my lungs filled with fluid and collapsed. I had to be wheeled back to the operating room so the doctors could stick a respirator tube down my throat to help me breathe. Back in the recovery room, I woke up, still under sedation, and pulled the tube out. I didn’t know what I was doing; all I knew was that there was something in my throat and I wanted it out. The doctors decided to see if I could breathe without the respirator, but I couldn’t. I don’t like to use the word “die,” but I came closest to not making it on March 7. I faintly remember coughing violently and my dad beating on my back to help me breathe, yelling at the doctors to put the tube back in, which they did. I had tubes draining fluid out of my head, and the nurses tied my arms to the sides of my bed to make sure I couldn’t pull them out, too. The respirator came out after a few days—it was nice to be able to breathe on my own—but I was tied to my bed for a week.
My mom was my rock. She took a leave from her job delivering flowers to stay with me. She and my dad alternated shifts, sleeping every night on a big easy chair in my room. My mom and I have always been close—I can tell her anything—and this experience made us even closer.

There was nothing to do in the PICU. My face was too swollen for glasses, so watching TV was out. I couldn’t talk because of the respirator. And with my hands tied down, that pretty much left my ears for entertainment. My mom brought in a boom box and some CDs so I could have music in my room. My favorite band is No Doubt (I’ve loved them forever), but I couldn’t bear to hear them then because I couldn’t sing along. So mom sang along to the radio and read me the many get-well-soon cards I was collecting—anything to take my mind off the situation. Once in a while she would loosen the restraints so I could scratch my nose or write on a notepad the nurses had given me.

But we usually communicated with our hands. My mother had a brother who was deaf, so a long time ago she had taught my sister and me the letters and alphabet in sign language. One day, while still in the PICU, I signed that I wanted to see myself. A nurse brought in a large mirror and held it in front of my face. My mom says that my eyes got really big. I had tubes sticking out all over the place and a respirator down my throat. I looked like a science project. Worst of all, the hair on the top of my head had been shaved off, along with a two-inch-wide strip down the back. I’d been so proud of my long hair. Then the doctors had had to go and do this.

In early March, I was moved to the adolescent ward. A couple of weeks later, my head started hurting. The doctors did a lumbar puncture—they put a needle in my spine to draw out some spinal fluid—and diagnosed me as having bacterial meningitis. Apparently the incisions had opened up and leaked cerebral spinal fluid, which got infected. Because meningitis is so contagious, I had to be
quarantined in a separate room for twenty-four hours. It was just me and my mom. Anyone who came into the room had to wear a surgical mask, which made me a little angry. It was as if I had the plague or something.

The doctors didn’t want to tell me much because I was only thirteen. I didn’t want them sticking needles into me without knowing what the heck they were doing and why, but I couldn’t talk even after the respirator was taken out. My mom was my voice. She told the doctors flat out, “Just tell her what’s going on. She’s an intelligent girl, and she’ll understand.” After that, they started clueing me in.

**Belchertown Steps Up**

Originally I was supposed to be in the hospital for two weeks, but because of the complications, that two weeks turned into three, then four. It was scary being in the hospital that long. Sometimes I cried because I was in pain, or because I just didn’t want to be in that bed anymore. Other times I was just scared. I had cancer and all this stuff was happening and I didn’t know exactly what was going on. Why did I have to go through this? I’d always been a good person. If someone at school was in trouble or needed help with their homework, I wouldn’t look the other way. It didn’t
seem fair. When I got really down, my mom would sit on the edge of my bed and tell me we’d get through it, I just had to be patient.

Fortunately, I had lots of visitors and gifts. Everyone at my high school, people at the church we used to go to, my mom’s coworkers and random people in Belchertown sent me stuff. Even my fourth-grade teacher came and brought me a stuffed bunny. Looking back, the most amazing thing was how the people of Belchertown rallied around me. I had churches all over western Massachusetts praying for me, and everyone at school signed this big poster. The Belchertown Teen Center did a can drive. The high school held a Jessi Ulmer dance, and my mom’s coworkers sold green and white carnations on Saint Patrick’s Day and gave all the money to me. Our insurance covered my hospital bills, but the money helped pay for other costs. I needed a new wardrobe—because I lost forty pounds in the hospital—and millions of bandannas to cover my funky haircut.

Finally, on April 16, six weeks after I was admitted, I walked out of Baystate on shaky legs with my parents and sister. When we got home I kissed my dog and my three cats. Home. I was home. Then I walked through my bedroom door and stopped in my tracks. My queen-sized bed was piled high with all the presents I’d received. I was amazed—I never knew there were that many people in Belchertown who cared about me.

*Jessi (right) with her little sister after two and a half days at Belchertown’s annual fair—and more than a year after Jessi’s surgery.*
Every weekday for five weeks my mom drove me to Baystate for radiation treatments to kill any stray cancer cells. This big machine would blast radiation into each side of my head for about five minutes. I didn’t really feel any physical effects except all the hair on the back of my head fell out underneath (that was a really great look), and the steroid I was on made me gain all the weight back, though I managed to lose most of it all again.

I spent that summer recuperating, taking naps and making up my schoolwork with a tutor. My muscles were weak and I got tired easily. When I went back to school in the fall of 1999 for my sophomore year, I was a little nervous about staying on my feet for six and a half
hours. But I did it! My teachers were really understanding, but my friends seemed a little scared of me. I’d cough and they’d go, “Are you okay?” Some of my friends didn’t know how to act around me. They thought I was more delicate. I was, like, I’m a big girl, I can take care of myself. I’m not going to break.

More than two years later I’m cancer free. I have to go back for regular checkups, but I don’t think my cancer will come back. I know it won’t.

I’ll never be quite the same. Now I have a plastic tube called a shunt that drains excess brain fluid from my skull to my stomach. And I still have a bald spot on either side of my head where the radiation went in. The rest of my hair has grown back thin and sparse, though at least it’s long enough to pull into a ponytail.

I can’t say that having cancer has changed my life, but it has changed my outlook on life. I live more for today. I can’t live for tomorrow because tomorrow might not be there. And having cancer has made me stronger. Now I don’t worry as much about what other people think. I just walk right up and say hi. I have more friends than I’ve had my entire life, more than all of my old friends combined. I even got up the nerve to ask a guy to the junior prom—and he said yes! My mom made my dress, and it’s so beautiful: a floor-length off-the-shoulder gown with an empire waist. It’s ivory and gold, and modeled after the dress Drew Barrymore wears at the end of the movie Ever After. I’m going for the Cinderella theme this year. Now all I need is my prince.

Most of all, I refuse to be invisible. High school is not the easiest place to be, but neither is a hospital bed for six weeks. Going through what I did makes me realize that stuff like cliques and clothes don’t really matter. Being popular doesn’t make you any more alive.

After six hours of school and six hours of work, Jessi models the new tiara her mother made for her junior prom.