



**Emily's Story** *Finding a way at Harvard*

Audio slideshow Part 2: **Not your typical brain surgeon**

His operating room echoes with rock 'n' roll. His office is filled with silly toys. He impersonates Elvis. Alan R. Cohen, the doctor who worked to save Emily's life, is not your typical brain surgeon.

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## A life-or-death battle begins

The Boston Globe

**On a family trip, a tumor's early symptoms have a worrying effect on all**

By Thomas Farragher, Boston Globe | June 20, 2005

*Second in a three-part series chronicling how a young woman disabled by brain tumors came to terms with her first year at Harvard, and how Harvard came to terms with her.*

She was a shy little girl, a curly-haired kid content to lose herself in books and sing softly alone in the warm embrace of her bedroom.

But Emily Crockett could be headstrong, too.

If her older brother, Jackson, received a sugary treat, she demanded her fair share. If she believed a teacher treated a classmate unjustly, she quietly fumed in her seat.

And if the family was going to climb a mountain, she wasn't stopping until she reached the summit.

"When you get to the top, you can see 5 (miles)," she wrote after conquering New Hampshire's Mount Monadnock two days before her fifth birthday.

She was the picture of a happy, healthy girl.

So there was something peculiar about Emily's behavior in the summer of 1991 as her father's family gathered in two adjoining cabins on the edge of Rocky Mountain National Park.

Walter Crockett saw it in the angle of his daughter's arm.

"Her arm was kind of hanging," he said. "She just looked pale. She looked really beat."

Valerie Crockett saw it in the fall of her daughter's foot.

"She was walking funny," she said. "She was putting the front of her left foot down instead of her heel."

Six-year-old Emily, too, noticed something odd. Suddenly foods she loved — even her favorite vanilla ice cream — served disappointment instead of delight.

"Nothing was tasting right," she said.

But the distress signals were fleeting. And soon enough the Crocketts were again enjoying their family reunion, singing songs and swapping stories under the majesty of the Colorado sky.

Within weeks, Emily walked into her first-grade classroom at the Chandler Magnet School in Worcester. Her teacher, Mary McKiernan, instantly recognized the talents of this bright-eyed new student with her sly sense of humor and dazzling talent for math.

But if Emily's grammar school life was off to a promising start, her parents knew something wasn't quite right.

She was using her left arm less and less. When Walter gave his little girl a bath, he noticed the arm was oddly cold, and slightly purple. She complained of nausea and intermittently blurred vision.

At Emily's regular checkup with her doctor the following week, Valerie mentioned the changes the family had first detected in Colorado.

"And he checked her out and said, 'Well, you know I think sometimes one side develops a little faster than the other. But you should probably check in with a neurologist.'"

The first available appointment was two months away. As a favor, a friend with connections at the UMass Medical Center made a quick phone call. And then, unexpectedly on a Sunday afternoon, the neurologist was on the phone to the Crocketts.

"She said, 'I just heard about your daughter's symptoms and I think she should be seen tomorrow,'" Valerie recalled.

The doctor's tone, if not quite urgent, was insistent.

Valerie could feel her heart pounding in her chest.

“That’s when I started getting scared,” she said.

### **'I would expect it to show something'**

As soon as Dr. Beth Rosen saw Emily on Oct. 9, 1991, she knew something was terribly wrong.

Emily was clearly weak on her left side. Over the previous two nights, she had had headaches so severe that they woke her. And when the pediatric neurologist tested Emily’s reflexes, there was another sign of trouble. Brain tumors can cause unusually sharp reflexes. Emily’s were so brisk on her left side that Rosen did not need a rubber hammer.

Though new to her practice, Rosen, 32, by now was familiar with delivering bad news. She tried to convey the seriousness of the situation without triggering panic. But her sober demeanor sent Valerie Crockett into something close to shock.

“She said, ‘We need to have an MRI and I would expect it to show something,’” Valerie recalled.

Walter Crockett accompanied his wife and daughter to the MRI examination the next day. The results, recorded on slide after slide of black-and-white images, hit with staggering force.

Emily had a malignant tumor bigger than a golf ball deep in the right side of her brain. The growth, called an astrocytoma, takes its name from its star-shaped cells and is one of the most common brain tumors in children.

One neurosurgeon offered little hope, predicting their little girl might survive for six months. “His recommendation would be to do nothing because there is no cure,” Valerie said.

Walter collapsed in tears. Valerie struggled for breath. Emily, who was not in the room as her parents consulted with her doctor, remembers only that that word “cancer” packed powerful force even with a first-grader.

“I remember lying there thinking about it a lot,” she said. “I knew what cancer was.”

The Internet was still in its relative infancy in the autumn of 1991, but Walter summoned his skills as a newspaper reporter to scour for information that could save his daughter. Valerie was fully engaged, too, contacting support groups and devouring information about tumors and their effect on the brain. In their living room, they began their family’s equivalent of an emergency command center that would never really shut down.

Chemotherapy and radiation were considered, but their effectiveness was deemed questionable. Surgery was the most effective way to remove the growth, but the tumor lay just millimeters from Emily’s brain stem. A surgical misstep could kill Emily or badly impair her intelligence, motor functions, speech, or senses.

At first, her doctors were reluctant to take that risk. The Crocketts searched frantically for other opinions.

In Reader’s Digest, they read about Dr. Fred Epstein, an acclaimed pediatric neurosurgeon from New York with a reputation for aggressive treatment. They sent him copies of Emily’s MRI, and asked for his opinion.

Epstein was encouraging. If this was his case, he said, he would operate and believed he could remove most of Emily’s tumor.

“There really was nothing to lose,” Epstein explained in an interview. “You have to take risks. It’s a very logical thing when you’re treating children.”

The Crocketts told Epstein that they had already contacted a neurosurgeon at the New England Medical Center in Boston. And when Epstein heard his name, his voice noticeably brightened.

Alan R. Cohen had been his protege when they worked together in New York in the 1980s.

Emily, Epstein told them, was in capable hands.

### **The sounds of silence**

In the early years of their marriage, Walter and Valerie formed a band named for themselves. “Crockett” toured New England in a used Volkswagen bus, building a modest fan base drawn to Walter’s clever lyrics and Valerie’s smooth, sweet voice. Jackson, their first child, was born in 1983 and Emily followed two years later. The sound of children blended beautifully with the rhythms of their lives.

But now, in October 1991, the melody had tailed away.

A day after the MRI revealed the growth in Emily’s brain, the Crocketts were in Boston to see the doctor they hoped could save her life. Valerie had drafted math problems for Emily to puzzle over while they waited for the surgeon to see them. Abruptly, the office door swung open.

“Hi,” Cohen said, “You must be Emily. I’m Big Al.”

The unexpectedly informal introduction made her giggle — the first of many grins the unorthodox doctor would evoke from his patient.

One wall of his office is adorned with the standard fare of an elite professional — wood-framed diplomas, honorary degrees, and awards he has collected from medical societies around the country. Another is a study in Crayola — brightly colored pictures drawn by little boys and girls, thanking him for saving their lives. Al Cohen impersonates Elvis. He plays rock ‘n’ roll in the operating room. In medical lectures, he leavens dense material by flashing goofy slides of the Three Stooges.

“Certainly not your typical neurosurgeon,” said Emily.

Cohen, at first, balked at the idea of surgery to remove Emily’s tumor, which a biopsy showed to be slow-growing. Ask five surgeons, he said, and you’d get five different plans of attack. But in the end, Cohen agreed to operate.

“In children, we try to be as aggressive surgically as possible,” he said. “They’ve got the rest of their lives in front of them. They bounce back really quickly. The pediatric brain is resilient.”

Before surgery, Emily wrote out 10 questions for Cohen on lined composition paper she decorated with a colorful flower, a heart, and two stars. “How big a spot will they cut off on the side of my head?” she wondered. “Do you think I will need a wig?”

Emily Crockett was wheeled into Cohen's fifth-floor operating room on the morning of Nov. 13. He made an incision on the right side of her head just in front of her ear. Using a small drill, he bored a silver-dollar-sized hole in the bone, removing a "trap door" piece of skull. It was placed in a bowl of antibiotic solution and replaced later with titanium plates and screws.

Working with magnifying lenses and, at times, a surgical microscope, Cohen worked his way into his 6-year-old patient's head. He opened the linings to Emily's brain and calculated the trajectory to her tumor.

In some places, Cohen recalled, the tumor looked very much like normal brain tissue. In others, its texture and color were distinct. Cohen had to calculate how far to go and when to stop. On the other side of the tumor lay critical neural pathways.

"You can do a lot of damage in a few minutes in surgery ... that can take years to be undone," he said in an interview.

Once inside the mass, Cohen used a variety of equipment to emulsify the tumor from the inside out, eventually suctioning it out.

"We want to take out the bad stuff and leave the good stuff alone," said Cohen, now surgeon-in-chief at Rainbow Babies and Children's Hospital in Cleveland.

And after a five-hour operation, he believed he had done just that. He walked out to the family waiting area; the Crocketts, wound tight with worry, snapped to attention.

"Cohen very happy," Valerie recorded in a handwritten log of the surgery. "Cored out tumor, removing more than expected. She has some movement on left side. Eyes look good. Very groggy, sore throat, headache."

Emily patted her mother and father on the head. She asked her mother to stay with her.

In the weeks since her diagnosis, the Crocketts had had no appetite for music. They could not summon the strength for their weekly sessions with friends who played with them in their kitchen. Emily noticed the quiet and did not like it.

You guys never practice, she told her parents. Aren't you musicians anymore?

"We were pretty mopey and devastated and we weren't playing any music," Valerie said. "That annoyed her to no end and it made us feel really guilty."

Emily and her brother, Jackson, were accustomed to drifting off to sleep to the thump of music downstairs. They didn't want to live in a house cloaked in gloom.

And so on Monday nights, the Crocketts began to crank out music in their kitchen again.

### **An intellect unharmed**

There never had been much doubt about Emily's intellectual wattage. She devoured books. She polished off fractions in kindergarten. She used the stuffed animals in her bedroom as objects in complicated mathematical calculations.

Still, the results of her psychological exam just before surgery were stunning.

She repeated 12-word sentences from memory. In a quiet voice, she explained the virtues of recycling paper and why cities should have more than one newspaper. At times, her examiner noted, she was “unstoppable.”

Her IQ was scored at 161 — in the “very superior” range.

A post-surgery test showed the tumor had not dimmed her intellect. Within weeks, she was back in school and back in Brownies with her best friend, Elena Cordova. The girls exchanged elaborately decorated birthday cards, played with dolls, and drew countless pictures of Emily's dog, Brufus, at a small kids' table in the Crocketts' front room.

There were stretches of normalcy. She went to swimming lessons and played piano for a while with two hands. She won citywide science competitions, writing impressively about rocketry pioneer Robert Goddard, a native of Worcester. Her basketball coach made sure she scored her first points before the buzzer sounded in her last youth league game.

“Emmy, you have the gift of intelligence,” her third-grade teacher wrote on a report card crowded with A's. “Use it well and wisely. I have a feeling that you are going to be famous someday! ‘Dr. Emily Crockett Makes Great Discovery,’ the headlines will read.”

Still, never far from the surface was the threat that her tumor would grow back. In the fall of her fourth-grade year, it did.

Emily's left-sided weakness grew progressively worse. Her face drooped slightly. She battled frequent nausea. Her fine motor skills deteriorated. Simple things, like tying her shoes, became a vexing chore.

By now, Big Al had moved to Cleveland. Her new doctors recommended a regimen of radiation to prevent damage they feared could be irreversible and possibly fatal. Valerie had planned to buy Emily a new bicycle for her birthday. She asked whether she should proceed with the purchase.

“When I pressed [the doctor] hard, he said, ‘My best guess is that her 10th birthday will be her last. ... I really think we should think about quality of life and not quantity of life,’” Valerie said.

Emily's hair had begun to fall out. She tried to hide her hurt feelings when a young classmate laughed at her wig — an act of cruelty so piercing and rare that she would never forget it.

She outlived the doctors' dark forecast, but the tumor continued to grow.

In mid-November 1998, on a day she was well enough to go to school, Emily sat in a math classroom, listening as her teacher explained the shapes that result when a three-dimensional figure is dissected.

“Just to include me in class, she said, ‘Emily, what would the cross section of this be?’ And she held it up,” Emily recalled. “I blinked my eyes and all of a sudden it was like I was looking through a piece of waxed paper.”

She thought the vision loss was transitory. But Emily, who was in the middle of reading “The Diary of Anne Frank,” would never finish the book. Within months, she was certified as legally blind.

## **'Better left to chance'**

Her health had reached its nadir. Emily was in a wheelchair with headaches so severe she needed to keep to darkened rooms. The Marty Lyons Foundation, which fulfills the wishes of children with life-threatening illnesses, arranged for her to meet Garth Brooks, the country music superstar in whose music Emily found inspiration. His lyrics of optimism and perseverance spoke to her almost religiously.

“And now I’m glad I didn’t know the way it all would end — the way it all would go,” Brooks sings in “The Dance,” Emily’s favorite. “Our lives are better left to chance. I could have missed the pain, but I’d have had to miss the dance.”

## **[Click here to watch Emily performing 'The Dance' at her senior recital.](#)**

She was hoping for five minutes with him, but Brooks met with her and her mother across three days as he made a series of television appearances in New York to promote his new live album in early December 1998. Brooks put Emily and Valerie up in a first-class hotel, bought them a video camera, paid for a shopping trip, and treated them like longtime friends.

All the time, Emily’s head pounded. Brooks helped dim the lights in the backstage rooms. He sat on the floor, his hand on Emily’s knee, chatting easily for 45 minutes. “Just focused on me,” Emily said.

He arranged for them to see the Christmas tree lighting ceremony in Rockefeller Center at which he performed. And before he said goodbye, he took out a black, felt-tipped pen, autographed his touring guitar and handed it to her.

“Thanks for the coolest week!” he wrote across the body of the handsome six-string instrument. “Love you. God bless. Garth Brooks.”

As Valerie wiped away tears, Brooks stepped toward Emily and hugged her.

“I love you very much,” he told her as the new video camera rolled. “Take care of yourself. And believe. If you don’t believe then truthfully you haven’t heard a single Garth Brooks song.”

Five days later, doctors at New England Medical Center removed a tumor and an accompanying cyst from Emily’s brain that was about as big as the first one.

Deep sections of the right hemisphere of her brain had now been damaged by the tumor. In the years to come, doctors would be amazed at her recovery. They wondered whether the left side of her brain had learned to perform some functions typically done by the right.

Because of the tumor’s location, not all of the malignant cells could be removed. Her prognosis remains unknowable. But Dr. Carl B. Heilman, the neurosurgeon who performed the second brain surgery, said because the tumor has been dormant now for more than six years, he is hopeful that it will not recur.

“She already beat the odds, I think,” Heilman said. “She’s in uncharted territory.”

## **A whim and a prayer**

In the gathering dusk of her third-floor room in Thayer Hall, Harvard freshman Emily Crockett sits at the cluttered desk in the corner of her dormitory living room and marvels at how she landed here. How she beat the long medical odds. How she refused, despite the hurdles, to lower her expectations.

“You have people telling you all the time, ‘Well, you can’t do that,’” she said.

But she never listened.

Every student at Harvard has a tale to tell about the day the welcoming letter arrived on their doorstep, inviting them to spend their undergraduate years among academia’s elite.

Emily begins hers in Worcester, where she graduated in the top 10 of the Burncoat High School class of 2004, an overachiever in a public school system that seemed, at first, unprepared for a bright disabled student.

By her junior year, after years of being taught largely by an instructor at home, she was attending school regularly again. She loved jousting with fellow students for top honors in the math club. She navigated her course work with the help of a teacher who transcribed math into Braille and sat near her in class to describe the work she could not see.

Her tumor was stable and her academic credentials sterling. With SAT scores of 770 in math and 710 in English, the little girl who once was given six months to live began to envision life as a college undergraduate.

She aggressively courted Brandeis, where she was energized by that school’s tradition of social justice. Wheaton, Tufts, and Bridgewater State were also on her list. When her father pointed out that her credentials just might be good enough for Harvard, she applied there, too.

The thin letter from Cambridge arrived in early 2004. Walter was in the living room where Emily sat on the couch and he yelled for Valerie, out back with the family’s dogs, to come quickly inside.

“Val, there’s a letter from Harvard!” he shouted.

Walter opened the letter and began to read, but quickly choked up. He handed the letter to his wife.

“Is he crying?” Valerie asked.

Valerie got only a word or two further before she, too, was in tears.

“Will someone please just read me the letter!” Emily said.

*Tomorrow: A semester on the brink.*

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