



In the image above is a guitar that was signed by Garth Brooks and presented to Emily Crockett after she spent three unforgettable days with him in New York City in 1998. It says, "Emily, thanks for the coolest week!" and lists the things they did together.

Pushed to the brink by pain

The Boston Globe

Terrible headaches immobilize Emily, jeopardizing her freshman year

By Thomas Farragher, Boston Globe | June 21, 2005

Last 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.

The sturdy door to her red-brick dormitory swings open and Emily Crockett steps into Harvard Yard, her hair caught in the sudden bluster of a piercing winter afternoon.

Her coat is unbuttoned. Her long, thin cane sweeps across small arcs of sidewalk. Despite her blindness, she appears to be looking pleasantly straight ahead. Despite the limp in her left leg, there is a confidence to her stride.

And as her first semester as a Harvard freshman speeds toward its conclusion, she has found good cause for that confidence.

After nearly two months adrift, alone in a swirling sea of theoretical math formulas that she can hear but not see, Emily has finally grabbed a lifeline.

It is anchored by a smiling young man from Florida.

Sergio Martinez, a freshman from Miami, was one of the first classmates to volunteer to be Emily's reader and study guide — her eyes — and the only one to commit to a schedule she could rely on. After an e-mail glitch delayed their connection for two months, they clicked almost instantly.

Like Emily, he was a high-school math wizard who found himself a little overawed by Harvard.

"This math has made me very humble," said Martinez, 19, the son of a doctor and a social worker. "I realize that people who come here are very, very, very, very, very, very smart."

They meet two or three times a week on the second floor of the Cabot Science Library in the university's Science Center, just a short walk from Thayer Hall where Emily lives. Martinez reads the problems aloud, and reviews the notes he has taken in lectures. They examine together the underlying theories.

Back and forth. A real collaboration.

"She told me lots of people just gave her the answer to the problem and I was allowing her to think it through," Martinez said just before the college's holiday break. "I am a witness to how amazing her math skills are."

And he is learning about Emily's brain tumor, the intricate surgeries to remove it, and the improbable path she traveled from Worcester to Cambridge.

"I see in Emily this person who's always smiling through life's difficulties," Martinez explains. "And I thought to myself, 'You know, I complain a lot about stuff. What's the reason for complaining?'"

Emily, her parents, and her advisers knew she would need help to thrive at Harvard. A patient note-taker, a careful reader, was essential. A friend would be nice, too.

And finally it seemed that Emily had unlocked the gate blocking first-semester success.

It almost worked.

A freshly painted room

An early-morning snowfall has dusted Harvard Yard with a fine, icy powder on Jan. 5 as Emily Crockett, 10 minutes late for class, hurries across the quadrangle toward Jefferson Laboratory.

When she arrives at the small seminar — Quantitative Methods in Public Policy Decisions — she is confronted with something stronger than a dense, three-hour analysis of how policy and science intersect.

The room has been freshly painted. And the fumes immediately stir trouble somewhere deep in her head. Because of her

tardiness, she is at first reluctant to leave. But when another student, Tim Schmidt, excuses himself, so does she.

A headache, she fears, is not far behind.

Emily and Schmidt, a Seattle freshman whose third-floor room in Weld Hall was once the college domain of John F. Kennedy, stand outside on the blustery afternoon, amiably swapping riddles. When the class reconvenes in a nearby common room, they go back inside.

For Schmidt, it is a passing nuisance. For Emily, whose brain tumor has triggered an extreme sensitivity to light, taste, and smell, it is the beginning of immobilizing headaches that threaten to derail her freshman year.

She finds herself unable to concentrate for more than an hour at a time, and barely able to complete the seminar final — an analysis, with two other students, of the nation's color-coded system for terrorism alerts. And now she faces final exams in math and in a course about the Earl Warren-led US Supreme Court. She is prepared for neither.

As the math final creeps closer, Sergio tries repeatedly to reach her. He wants to schedule time together for a thorough review.

“He must think I'm an idiot,” Emily says. “He keeps calling and asking me if I want to study for the final, and I have to keep saying, ‘I can't. I don't feel good enough. I need to sleep.’”

The headaches only abate, somewhat, when she lies down. When she is upright at her computer, it feels like someone is stomping on her head — always on the right side, where the tumor lingers.

At home, her parents are on full alert. On a drizzly Monday night, they drive to Cambridge with some strong pain relievers. The medicine does nothing for her head pain, and, instead, leaves Emily's body flush with hives.

Emily's health hasn't been this bad for six years. Valerie fears the worst.

“I'm scared to death,” she says, walking at nightfall through the neighborhood where she has lived for 26 years. “Please, please, please may this turn around and not become a nightmare.”

Over the years, Valerie has become her family's emotional seismograph, detecting and deciphering subtle clues she finds in Emily's mood or voice and relaying warning signals to physicians, therapists, and the constellation of adults who work to keep her well.

Emily has adopted a more detached approach, often describing her pain as if it were tormenting someone else.

“One thing I've learned is that I have to separate my physical health from my emotional health,” she said. “I have to live my life or I'm not going to be able to.”

On Jan. 17, two days before Emily is scheduled to take her final in math, Valerie contacts Dr. Carl B. Heilman, the Boston neurosurgeon who performed the second brain surgery on Emily in 1998. Emily is under a great deal of stress, Valerie tells the doctor, but these do not seem to be stress headaches.

"I didn't think an MRI was likely to show anything, but I'm changing my mind," Valerie writes in an e-mail to Heilman. "If the paint fumes triggered a migraine, is it possible that the dilation of the blood vessels may have caused another hemorrhage?"

The MRI shows that the tumor is stable. Still, the headaches remain.

And on Jan. 19, the day Emily is scheduled to take her oral final exam from math instructor John Boller, she is back home in Worcester, where tensions have boiled over.

The night before, just after Walter Crockett picked his daughter up in Cambridge, Emily snapped at him after an argument both will later call silly. Later, on one of the coldest nights of the year, she stormed out of the house wearing only a sweatshirt and walked around the neighborhood block where she once rode bicycles as a little girl.

"I can't live here anymore!" she exclaimed, angry at the suggestion that, woozy with medication, she needed to get to bed especially early.

Now, a day later, the dust-up is forgotten, but the larger issue remains: Will Emily have to leave Harvard?

"Things are not working now and she can't go on this way," Walter says. "This will be a test of both her and Harvard. We don't want her unhappy being there alone. And we don't want them to say she can't handle it, so goodbye."

As her first semester ends, Emily has a disturbing dream.

Her head is sunken in. She dials 911 to summon emergency help. But none arrives. The dispatcher, it seems, speaks no English.

And no one can understand what the emergency is all about.

The office of fairness

There are some 300 students with disabilities at Harvard. Blind students and deaf students, students in wheelchairs, students with emotional and learning disabilities. Some have disabilities that are permanent. Others can hope to regain full vigor.

Even in this universe, Emily stands out — the college's only math concentrator who is blind.

The students' needs are served out of a small office on Garden Street in Cambridge directed by Louise H. Russell, a no-nonsense woman whose patience quickly wears thin for those inclined to pity her charges.

"If people start the pity trip on our students, we interfere," she says firmly.

The spring semester is five days old. Emily has struggled through the final exam in her Warren Court class. But she missed her math final. Her headaches continue to punish her. If she is to continue at Harvard, she says, something has to change.

Russell knows this, too.

Her office is a bureau of exceptions of sorts. If it's doable and meets the needs of the student and the university, her office can

help make it happen. But, still, it is no place for soft hearts.

“Emily wasn’t admitted to Harvard because she was blind. She’s here because she’s like everybody else: otherwise qualified to be here,” Russell says. “We’re going to do whatever we can to make her programs accessible to her within the limits of what’s fair to everybody.”

And that’s what Emily wants, too.

The question for her and Harvard is: What is fair?

Emily acknowledges that she needs to be more organized. She needs to be more diligent about her diet and her regimen of therapies. She needs to find a campus life beyond the walls of her room.

And, finally, she decides, she needs to drop math until she can find a way to make it work for her.

“I can’t see the board,” she says. “I don’t have a way to take notes. Even if someone else takes notes for me, I can’t read their notes. ... I went to class on Wednesday and realized that I have no idea what’s going on. I really don’t.”

Her computer’s math-reading software, she says, speaks in a voice she cannot understand. And she laments, Sergio is not in her second-semester class.

“I’m definitely not giving up on my plan to be a math concentrator,” Emily says in early February. “I think there’s going to be technology coming out that’s going to make math a lot easier to deal with as a blind person.” But not now.

What follows is a delicate academic minuet. Emily needs a series of exemptions to Harvard’s administrative rules. And the university must balance Emily’s declining health with her requests to lighten her load.

The Administrative Board of Harvard College deals with administrative and disciplinary matters. Its work is confidential. Even before Emily’s first year began at Harvard, it approved her first-semester petition to take three classes, instead of the standard four.

Now, with the second semester underway, it hears from her again.

“Right now,” she writes to the board, “I am just trying to salvage as much of my education as possible.”

She asks for and receives permission to further trim her course load, this time from three classes to two. She is allowed to take a makeup for her math final after the final exam period is over. Later, she asks the administrative board to let her withdraw from the course altogether.

It is, at first, hardly clear that the board will accommodate her. James N. Mancall, an assistant dean for freshmen, asks her to have her doctor write him, and lays out a series of options, including accepting the equivalent of a failing grade for the course. That, he said, “would put you in jeopardy” of having to leave school “should you earn another unsatisfactory grade in this term.”

Emily’s school physician and her math instructor wrote to Mancall on Emily’s behalf. So did her father, grateful for the way

Harvard has tried to accommodate Emily, but very worried now.

“Harvard knew of her condition when it chose her for admission,” Walter Crockett wrote in late February. “Her combination of disabilities — brain tumor complications, legal blindness, one-handedness — is probably unique in Harvard’s history. But her abilities — strong intellect, excellent character, fierce determination, and deep compassion — more than make up for her disabilities.”

And on March 1, after Emily returned to her dorm room from a medical appointment, she found an e-mail waiting for her from Dean Mancall. Her request had been approved. “I hope that will be a relief to you,” Mancall wrote.

“I’m so happy,” she says. And, for the first time since early January, she sounds it.

Still, her headaches make even her remaining course load — a lecture in swing-era music and an expository writing class — a challenge. Her head hasn’t stopped pounding for more than two months.

And so Emily and her mother return to Heilman’s office at Tufts-New England Medical Center, searching for answers. Emily is now convinced her headaches are caused by low pressure in her brain. Her theory is that her shunt — a device that allows excess fluid to flow through a thin plastic tube from her brain to her abdomen — is overdraining when she stands upright.

The excess fluid is a legacy of her tumor and the surgery to remove it. Her brain’s ability to absorb the continually produced fluid has been impaired. So the shunt does that work for her. And now, it may be working too hard.

When she runs her fingers across the surgical scar on the right side of her head, it feels sunken in along the old incision line.

“I really want to finish this semester, but I’m not functioning,” Emily tells Heilman, a soft-spoken, sandy-haired Pennsylvanian with an almost boyish reserve.

Heilman says he can replace an existing valve with one that will work whether she is standing or prone. Still, for a moment, he hesitates, searching for other explanations for Emily’s head pain. Paint fumes, he has concluded, would be an uncommon cause for such prolonged torment.

“Do you think that stress may have anything to do with it?” Heilman asks Emily. “I mean that’s just an obvious thing to talk about.”

“No,” Emily replies instantly.

“Say some kind of paint fume set this off and then worrying about how it’s impacting your studies perpetuated it,” Heilman said. A new valve, he said, wouldn’t fix that.

But Emily and her mother believe firmly that the painkillers would have, by now, defeated a stress headache. Heilman agrees. Surgery is scheduled.

Two weeks later, on the Friday before spring break, Harvard’s campus exodus is fully underway on a cloudy and cool day in late March. Just 19 students attend Emily’s afternoon Swing Era class in the John Knowles Paine Concert Hall, some with carry-on luggage already packed and by their side. A Ken Burns movie is being screened and Billie Holiday’s “Pennies From

Heaven” echoes in the nearly empty auditorium.

As students drift across Harvard Yard, ready for trips back home or vacations in the sun, Emily is headed to Worcester and then for surgery she hopes will, finally, save her semester.

The 10th surgery

In the middle of the raw, drizzling morning of March 29, Valerie Crockett helps her daughter fill out her hospital admission form, reviewing a list of questions, and holding her hair back so she can lean in close to sign her name.

“Is it possible you’re pregnant?” Valerie playfully asks Emily.

“No,” Emily replies, and then bursts into a peal of laughter.

Presently, Emily is dressed in a hospital gown and lying in a pre-operative ward that is familiar to both mother and daughter. It is the same ward they were admitted to in November 1991, when Emily’s malignancy was first removed.

“I remember one of my big fears was not being asleep for the surgery,” the 19-year-old patient recalls of her fears as a 6-year-old.

By now, Emily has undergone nine surgical procedures — brain surgeries, shunt adjustments, biopsies.

And as her gurney is wheeled into operating room No. 8 at the Floating Hospital for Children at Tufts-New England Medical Center, her surgical team is ready for her 10th.

At three minutes after noon, Heilman makes his 5-inch incision in Emily’s scalp. Moments later the shunt leading from Emily’s brain is exposed.

Compared to her previous surgeries, both of which took hours, the procedure is modest. A small valve attached to the white-plastic shunt is removed and replaced. By 12:20, Heilman is using long pieces of black thread to secure the valve in place. And seven minutes later, dissolvable stitches and then a long, neat row of staples are used to close Emily’s incision.

Heilman leaves the operating room, climbs one flight of stairs, and finds Valerie Crockett in a waiting room. They step into a small, private room where he delivers his report.

“It went totally fine,” Heilman tells her. “I bet we don’t really know for a couple of weeks if this worked.”

As she is discharged from the hospital, her headache persists. She begins to imagine life back at home in Worcester. She faces an April 15 deadline to take a leave from school without academic risk.

“The one thing that’s always kept me going is that I don’t give up,” Emily says. “If I leave, I’m always going to be wondering: What if I could have made it? So I really don’t know what to do.”

But days later the clouds disperse.

When Emily awakes on April 8, a Friday, she notices the sunken spot on the side of her head is gone. And, for the first time in three months, so is the pain.

As she negotiates her way through the noontime bustle of the university's Science Center, there is a noticeable change in her demeanor. The tension is gone. Her smile is natural.

An hour later, she is upstairs in Paine Hall, where her music professor, Robert Levin, sits down at a grand piano and effortlessly bangs out an example of a swing arrangement. Emily leans forward in her seat and smiles.

"Isn't it awesome?" she whispers.

And by her tone it's clear she is thrilled to hear the music playing again.

By early May, as Harvard's well-tended quadrangles turn emerald, Emily has found equilibrium. Her grades are lining up in a straight line of B-pluses. Already, she's looking forward to her second year at Harvard. She and the university know a course correction is needed.

When she returns to math work in the fall, the university intends to have upperclassmen or graduate students help her take notes, review concepts laid out in her lecture, read the material, and record her answers.

Emily knows she'll have to do her share to make it all work.

Her tendency to procrastinate forced her to work harder than necessary this year, at times pushing her to the academic brink. It was so bad at the end that her parents had to pick their way around her, moving her dorm furniture out as Emily raced to beat the deadline for second-semester work.

That has to change, she knows.

She wants to savor what she has begun to sample about college life: stimulating debate, passionate causes, real independence from her old orbit in Worcester. And she wants to meet more people like Sergio, with whom a real friendship blossomed after they stopped solving math problems together.

On a warm May afternoon over lunch in Harvard Square, Emily and Sergio agree that they learned something from each other that can't be found in books.

In Sergio, Emily found an example of selflessness, and a reminder that important things, like family bonds, must not be taken for granted.

In Emily, Sergio saw courage and an unfailing authenticity — rare on campus or anywhere.

"That's not easy to find," Sergio tells Emily, seated next to him at a sun-splashed booth.

"It's been really great," she softly tells him.

The two freshmen compare notes about the courses they'll take, the houses in which they'll live, and the mistakes they'll avoid when they return to Cambridge in the fall.

And as they head back toward campus, where final exams await them, they make a mutual promise to see each other in September.

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