Much to Be Grateful For

By Lynn Royster

The story of a mother's effort to help her son
and a family's struggle to cope with
chronic fatigue syndrome.

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When CFS strikes your child it impacts the entire family. CFIDS Association board member Lynn Royster knows this firsthand. Her memoir tracks her family's journey through the complex landscape of this debilitating illness.

It is 10:30 on a March weekday evening in 1987. I climb the wide, green carpeted staircase to the second floor landing and cross to Patrick's room. A sweet high voice comes from Brett's room across the landing to my left. She is singing to her dolls, a collection of cheery-faced munchkins that she chats to, invents adventures for, chastises and loves—like she loves all the people in her life. I hear the bed bounce and imagine her hopping about, propping everyone up on the pillows, tucking them under the pink and white comforter, then fitting herself into a space among them, all of them round cheeked and rosy, smiling even in sleep.

I glance to the right where the open door reveals my own bed, pale green and peach comforter, thick pillows. The bedside lamp glows warm and inviting. There is laundry on the chaise longue still to be folded—maybe there will be time to get to that. A cough-like bark from Monty echoes up the back stairs from the kitchen. I hear him circle and flop heavily into a new sleeping position.

At the door to Patrick's room, I lean briefly against the door jamb with one hand, feeling the tiredness in my back and arm. There is a rustle of pages in the master bedroom. Bart is reading. He gets up to go to the bathroom. I feel as much as hear the covers pushed aside, his heavy steps. The toilet flushes. Steps vibrate in the floor again. The bed creaks. Then suddenly, the light goes out. I feel a little shock, then translate the silent disapprobation to a tenseness in my stomach. I will be left to creep into bed in the dark like a criminal, guilty of not being a good wife.

"Come to bed," Bart says impatiently most nights. "Patrick will be ok." And even when he doesn't speak, which is more often lately, that is what I hear. He wants that to be true, and he is very good at convincing himself that truth is what he wants it to be. Desperation catches at my heart. I must go to bed. I might still catch Bart before he goes to sleep. There might yet be a connection.

"Mom," says Patrick weakly, sensing my presence. "Mom?"

"Yes, honey." I step into his room. The wood floor is cold on my bare feet. There's a stillness in the room—not the peaceful kind, but the kind that hangs in a yellow air before a battle or during the eye of a hurricane. Patrick is lying on the bottom bunk under the old green quilt. At thirteen, he is tall, most of the growth having come in the last year, so I am still adjusting to the length of him. "You're still awake," I say.

"I can't sleep," he says. I hear the desperation hanging on the edges of his words.

We both know what is likely to be the night in front of him. He will lie awake alone, staring at the ceiling, too ill to read, thinking about the schoolwork he hasn't done, the fun that is passing him by, the little things awry in his room that annoy him but that he has no energy to fix. Then, trying the dark, he will drift off briefly into nightmares that rouse him in a cold sweat. Frozen with fear, but not wanting to wake us, he will turn on the light again. After a few hours, misery will settle over him like fog in a valley. Toward morning he may sleep, though it will not be enough, not even if he doesn't wake until noon.

And I will go to bed and sleep soundly through the night, jump out of bed in the morning, brush my teeth and dress in a matter of moments, heading into my day with confidence. He never experiences that—not any more.

"Can you read?" I ask a question to which I know the answer, just so he can know I care.

"I tried. I can't see around the spots in my eyes."

"Well, maybe if you turn out the light and think of something peaceful, like a waterfall, you'll be able to sleep."

He doesn't say anything. Then,"I'm afraid."

"Afraid of what, honey?"

"The nightmares."

'Well, if you get one, you wake me up, ok?"

"What good will that do?"

"It helps to talk them out."

"But you'll be asleep."

"It's ok. I feel better helping you than thinking of you lying here feeling awful."

He doesn't say anything for a minute. Then resignedly, matter-of-factly he says, "Even if I don't have nightmares, I feel terrible."

There is nothing to say. And he won't wake me up. Even though his needs are overwhelming, he asks very little.

Patrick had been sick for nine months at that point with what we now know is chronic fatigue syndrome. It began suddenly, six weeks after we moved to Illinois from New Jersey. One morning he didn't come down to breakfast. I found him in the playroom leaning on the back of one of the old orange sectional chairs. He looked up at me, bewildered.

"I feel terrible, Mom."

The look in his eyes has haunted me ever since. Something had happened to him, something terrible, and at some level he knew it. I took him back to bed, tucked him in, and told him to stay there until I got Brett off to school. It was so unusual for him to be sick that I had to make a point of saying that. I went back up later with a tray. After four days during which he didn't improve, I took him to the doctor, and then began an odyssey of doctors and diagnoses and medications and diets and all that goes with chronic illness. I was naïve. I used to believe you went to the doctor when you were sick and she made you well. But medicine, I discovered, has only nibbled at the edges of human disability. Vast arenas remain where nothing can be done.

Not that they tell you that. No, instead, each specialist has an answer, a program of recovery. It may be strep or postviral fatigue or allergies or TB, they opine. We test for all of that—an ongoing game of yes and no and maybe and let's see and try this medication. But he doesn't get better. So we do it all again. Then one doctor says pompously to me, "It's a school phobia. I've seen this before. Send him back to school. Insist."

I look at Patrick He's so frail. How can I? And he never missed a day of school before he got sick. Never even got sick before. But maybe they are right. It could be psychological. After all, we've just moved. It's hard to start a new school near the end of sixth grade. And though he was an outstanding student, he had never liked school much. "I think school is interfering with my education," he had informed us solemnly when he was seven.

So I insist.

I don't really know what occurred at school, but I imagine that if you had followed him, you would have seen him walk down the hall, hugging the wall in case he should stumble. He would have lifted his feet carefully, like a drunk person navigating a line drawn by a policeman, totally focused on making it through the crowd, not really seeing the other students, though he would have known they were there and known they were whispering about him. He is nearly at the door to class, when someone puts out a foot. A short, sharp giggle, and he trips, falling against the tiled wall before righting himself stiffly. Too tired to hunt out his tormenter, he resumes his focused walk and finds his seat in seventh grade English.

A year before, he had shone in this world. Spelling bee champion, straight A student, deeply thoughtful analyzer of ideas, funny poet. But now he is behind in the homework. He struggles to follow the discussion, adopting a variety of stiff poses to keep himself alert. Inadvertently, he drifts off from time to time. Tears prick the back of his eyelids, but he will not let them show. He lets nothing show.

One day, he comes home and falls in the entry hall and can't get up. That is enough for me. No more dragging him out of bed, leading him in a zombie state to the car, driving him slumped in the seat to school, seeing him come home ashen faced. How can I be participating in this torture? So we work out a modified program in which he is home most of the time, but still he is always behind, always left out, and never free of something hanging over his head. He is always guilty.

Education was important in our household. Education was the route to success, and success, particularly to Bart, was the goal. He has tried relentlessly for years to motivate Patrick, assuming somehow that with the right phrase or the right incentive, he could wake Patrick out of this living death and galvanize him into action. But Patrick's illness has thwarted Bart at every turn. And what was meant as encouragement, as a prod to achievement that would, in normal circumstances, bring self-esteem, value in the marketplace and currency in life, instead left Patrick doubly ashamed, feeling himself an unworthy son and less than a whole man.

I have wondered how Bart can maintain this fiction that Patrick's performance is optional, that it can be changed by anything short of a medical miracle, how it is that he can't see that what Patrick needs is not motivation but acceptance and appreciation for who he is. But Bart can't, I don't think, get past the idea that a man is what he *does*. To shift to a mindset in which one can have worth without doing is not thinkable. It would call into question all Bart has done and said throughout his fifty-eight years. I am sad about this, not only for Patrick, but also because Bart has missed out on the pride he could have taken in his son's kindness, his honesty, his compassion and especially his courage in facing, without any of the resources available to the average man, an adversary far more powerful than any I have seen in the business world.

"Even David had a slingshot," I wrote once, trying through poetry to express what I could not say otherwise.

But I carry my own guilt as well. I pressured Patrick, too. I wanted him to have the pleasure of success; I wanted *me* to have the reflected glory that comes from having a successful child. It is not only to please our children that we decorate our car windows with college logos: Harvard, University of Michigan, Stanford.

It has taken time to get past those cultural icons, to ignore societal expectations, and to learn to just love him.

It is 1989. Patrick sleeps twelve hours a day, sometimes sixteen. He wakes up exhausted. His face is puffy, his throat is sore, acne makes his face look like raw meat. He has terrible headaches. There is something wrong with his joints. His temperature is very low. Then he runs a mild temperature for several weeks. Epstein-Barr, the doctors say. Then no, sorry, that hypothesis has been disproved. Overactive killer T-cells (or underactive—I couldn't remember). And what does that mean? No one knows. I notice a lump at the base of his skull. A swollen lymph gland, they say. Allergies, they say.

We enter into the world of allergy diets: rotation diets in which one removes all the foods anyone would want to eat and substitutes only rice and potatoes, then slowly adds back in things like lettuce and bananas and almonds. Patrick is fourteen now and needs a lot of food, but he is determined to follow the rules religiously. He will do anything to get well. We order exotic foodstuffs: lion, cassava, quince. I dislike cooking in the best of circumstances, but this is impossible. And what if he is allergic to potato? We go back and start over. He gets thinner, almost wraithlike.

He cannot tolerate mold. We take the plants in his room away from him (a sad thing, since he loves them), get air cleaners, keep him away from the basement, put filters in the windows. He has chemical sensitivities. I discover that formaldehyde hangs thickly in clothing stores, that gas stoves can create havoc, that laundry softeners are dangerous, that pesticides are killers.

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A new focus emerges. Perhaps it was lawn chemicals that made him ill. I check the dates. There had been a spraying of the school grounds the day before he got sick, and the children were sent out to play on them. I check school records for absences. Definitely more absences after spraying time. I complain. I am ignored. I let them know that I'm a lawyer. I get a meeting with the superintendent of schools and speak to the village council. I join anti-pesticide groups, devour reams of material, write letters, talk to community groups. After a year of continuous lobbying on my part, the school district agrees only to cease spraying during school hours and to post notices of recent spraying.

Patrick has blackouts. This gets a brief flurry of attention, but mostly the medical professionals are bored with us. Nothing is less appealing than a patient who keeps returning week after week with the same complaints. In defense of their methods Patrick is labeled: a hypochondriac, uncooperative, developmentally maladjusted. When that fails to produce a successful outcome, I am labeled: an enabler, overprotective.

But regardless of treatment or lack thereof, label or not, Patrick, now fifteen, does not get well. I find him one afternoon sitting on the landing, head against the banister. "I might as well be dead," he says.

Depression becomes our focus. I leave to teach a couple of mornings a week, an early version of a cell phone with me, praying that he will sleep the entire time I am gone—that I will not have to come into the driveway with my heart in my mouth wondering if he might, no, it is not possible, might have, no, I will not think it. I open the door and hear nothing and run upstairs and look in his room, and he is there, alive, and I am so grateful that I am almost cheerful even though he has been suffering unbearably now for more than three years, and my cheerfulness is brittle and tense and probably grating to him.

And while this goes on, we try to maintain a "normal" life. I go to my daughter's soccer games, host birthday parties, make Halloween costumes. My husband and I play tennis, go out to dinner. I volunteer in the schools and teach a course in business law. I tell people Patrick is "doing better." But being away from home carries a tenseness with it, and at home I numb myself so I cannot feel the pain any longer.

I used to see people pushing a son in a wheelchair down the street or handling a daughter's epileptic fit at a ski lodge and think that somehow they were okay with this, that they had adjusted to it, that they were meant to be in this gray life while I was not. But I have learned that there is no difference between those who have chronically ill children and those who don't. They weren't born to live a sorrow-filled life any more than anyone else was, and their pain can be just as fresh after years of coping as it was in the first few weeks of revelation—worse sometimes because at the beginning there is denial and more hope.

One day Bart tells me he'd like me to join him for a lunch with a doctor he has met who might be able to help us—a man who isn't practicing but who has some role in the medical world. So I meet them at a conference they're both attending. We sit at tables set up in the open space outside the breakout rooms, and the doctor tells me over box lunches that there are a lot of quacks out there and that I am too "involved."

I remember how the fury rose in my throat, and how I hated him—how I left the table with my spine rigid with anger and held in grief, and how I looked at Bart, and he didn't say anything. I remember the sun blinding me as I pushed open the glass door, wanting only to go home, go home, go home.

What did he want me to do, I asked Bart later. Take up bridge, play more tennis perhaps while my child died a slow death alone in the cavernous house? How could I not be involved?

"He's depressed," said Bart. "Tiredness is part of depression. He needs psychological help."

"He's sick," I said. "He's very sick. There is something physically very wrong. And Id like to see how happy *you'd* be if this was happening to you."

It was our ongoing argument: mental versus physical illness, depression versus chronic fatigue syndrome, lack of motivation vs. overwhelming fatigue, obsession vs. multiple chemical sensitivities—all irrelevant except as it related to treatment, which was, after all, not irrelevant.

Time passes. Brett reads *Wren* and *What Katie Did* over and over. Patrick becomes obsessed with the devastation of the environment, watches endless programs on global warming and deforestation, becomes an expert in toxic waste dumps and alternative fuel sources. I read books on thyroid function and organochlorines. Bart rips out bushes in our sunken garden and communicates via article clippings: "AIDS patient continues to run company," and "Overprotective mothers found to weaken immune system of children." We all watch the Simpsons together on Sunday nights over rutabaga and hippopotamus steak. It all begins to seem normal.

At Bart's urging, we take Patrick to a psychiatrist who prescribes drugs. Patrick does as he is told. He takes medications that give him hallucinations and sleep problems and brain fog and weight gain and weight loss—none of which do anything to make him better, but all of which confirm to him that he is mentally unstable and somehow to blame for all that's happening.

Finally, at my urging, we try the geographic cure, go all out, move to Arizona and build a nontoxic house. Are we crazy? But I know from Patrick's face that if there is no hope, he will die. He has to have hope. I have to have hope. I think if we can give his immune system a rest, he may be able to heal himself. A doctor recommends it. With that stamp of approval we go. Bart commutes.

The public schools there are not good. Brett, after a try at being driven to a private school as a day student, says she wants to board. I don't realize it right away, but I have lost her. She is angry and sad and keeps it to herself. She doesn't want to come home, even to visit, not for a long time. Something else I don't know: Bart is angry, jealous and hurt. I am going to lose him, too—not for some years yet, but the seeds have been sown.

It is 1991 and Patrick is seventeen. We have landed in a white tiled, white walled place on a hill overlooking a hardscrabble town. The color scheme is my choice. I have mused since on why I chose it. Purity? Health? An effort at cheeriness? The white intensifies the blinding Arizona sun that drives through the windows. Even with the sun, though, the tile is hard and cold. Numbing.

The nightmares and floating spots before his eyes have ended, but he now has intense pains in his head and deep depression that fills the whole house with its blackness. The fatigue is unrelenting. I wait for a knight in shining armor, for a hand to reach down and pull us up to safety, for a miracle to help us escape, but no knight comes, no hand reaches down for us, no one is there. No one. I remember thinking once during the pain of childbirth that I had no idea one could experience such agony and still remain conscious. It is the same kind of feeling.

The year is 1999. Much has changed. My father has suffered through six years of Alzheimer's disease and died. My mother has come through a series of devastating illnesses and reclaimed life. Patrick has completed the GED, first out of the17,000 who took it the year he did. “Maybe that's as good as valedictorian,” he says, not really believing it.

Bart's father has died. Bart has divorced me and married his new love. Brett has stopped singing. There is an empty hollow where her lilting melodies used to be. She has gone to college in Colorado, learned to fly a plane and survived a brutal attack. I have acquire a Ph.D. and run some triathlons.

And Patrick is still ill. I cannot believe it. It is impossible. But it is true. Even though everything has changed, nothing has changed. It is still me struggling with *what is it* and *why* and *what to do*, Brett still avoiding it, and Bart retiring and moving a thousand miles away to New Mexico.

I remember watching the movie Lorenzo's Oil with Bart four years before as we lay in bed on the edge of divorce, wishing he had acted like the father in that movie and devoted himself to finding a cure. I think he might have done it. He always managed to solve the problems he took on. I used to feel quite useless by comparison. But he didn't, and maybe it wouldn't have made any difference, except, of course, in the message it might have sent to Patrick about how important he was in the scheme of things.

By this time, I felt like I had been living in an ever-downward spiral, one trauma creating another, with no time to recoup between challenges. Illness is not the romantic thing some movies and novels make it out to be. It destroys people; wrecks not only bodies, but families, careers, plans and hearts. I used to believe what people told us about tragedy making you stronger if it doesn't kill you, being a lesson one needed to learn, etc., but I don't anymore. Patrick has more courage than anyone I have ever met, he is honest to a fault, caring and

Did you know?
A 2006 study found that nearly 2 out 1000 American adolescents meet the diagnostic criteria for pediatric CFS. If accurate, that makes pediatric CFS more widespread than sickle cell anemia (1:3573), pediatric heart disease (1:1000) or Down's syndrome (1:1000).

compassionate to all the world's creatures, and he has learned lesson after lesson. No, there is no reason I find acceptable that can tell me why Patrick, who could bring so much to the world, lives a 5 percent existence while the violent thug who attacked Brett can continue on his unholy path.

It is March, 2001. Patrick is a grown man now, tall and handsome. The depression has largely abated, whether due to his diligent efforts to rethink his life, the counseling help he has received, the cessation of all medications or simply the erratic path of this illness, we don't know. However, the fatigue is worse than ever, dragging him down, aborting all his plans, laughing at his attempts to create some sort of social life.

"I know I'm smarter than 99 percent of the people I see on the street with their briefcases and fancy cars," he says to me. "And I would work so hard if I had the chance." He looks away out the window. "What is going to become of me?"

I have what I believe is a fairly strong spiritual life (developed in tandem with the progression of the illness), but it is hard to have faith in a universe that permits such suffering. Isn't it bad enough that he is so ill? Does he have to be deprived of career and friends and love as well?

I used to think that if I could only love enough, I could cure Patrick and fix everyone's pain. Every time I felt resentment, numbed out, complained or was short with him, I would feel terrible guilt.

I used to think that if I could only love enough, I could cure Patrick and fix everyone's pain. I had read stories about people who could do that. Every time I felt resentment, numbed out, complained, was short with him—or anyone for that matter—I would feel terrible guilt, feel that somehow I was not rising to the challenge that God had set for me. At the very least, couldn't I be strong enough not to add to his pain? I prayed to become more compassionate and less selfish, more serene and less tense. But I remained flawed, human, without special powers, an ordinary mother like so many other mothers who cannot help their children.

Sometimes when I'm thinking this way, I wonder what would have happened if, on that long ago night at the top of the stairwell, I had gone into Bart's room and roused him, not let the light that had gone out in Brett's room stay out, not let Patrick be alone. What if I had found sleeping bags and pillows, dragged us all out onto the landing to camp out together, to say by my actions we are all in this together. Would they have laughed, would Patrick have felt enough love to carry him through all this pain, would Bart and Brett have felt less angry and rejected, would I have had the support I needed? Could love like that have cured him? Cured all of us?

But some things have changed without my being perfect.

One day a few years ago, when Brett was staying with me, I heard her singing in her bedroom, a muffled sound, but still, it was singing. I didn't say anything, terrified that my noticing would cause her to clam up again. A week or so later, it happened again, a haunting sound. Then one day, I heard the words clearly:

Please no more therapy.

Mother take care of me.

Piece me together with a
Needle and thread
Wrap me in eiderdown .

I stood in the hall outside, feeling totally helpless.

For years, as my way of coping, I had gone inside a bubble. Inside the bubble, I could sit in stillness and silence. The rushing sounds of voices raised in anger or grief were distant, like traffic noise from the top floor of a hotel room. The pain I carried under my chest sat like a brick, mildly uncomfortable, but not unbearable like the hot liquid that used to run round my body sloshing agony everywhere. I could drift through the house, tending to chores, dealing calmly with crises. I was functional. But I wasn't there. Not really there. Not like my daughter needed me to be there.

Denial is easy when there is no one we care for. Without someone to love, we live life on the surface—we can push away anything awkward or negative about ourselves. Marriage has been called a mirror of our own shadow side, but love for a child can be an even stronger force for seeing our imperfections.

I'd like to say that the epiphany of that moment changed everything, that we ran into each other's arms and she was healed by my love, but that didn't happen. Still, the moment of such intense desire to be different for my daughter seeded a determination to retrieve my feelings and start to live again in technicolor. Her venturing to sing again and my being able to hear gave us a new space in which to begin to heal.

Patrick, too, has landed in a new place, still not a destination, but a stop on the long journey that he has been called upon to make. He said to me today as he lay on the couch looking out at the sky, "I've been thinking about how I can get obsessed with not having something, and it will overshadow everything—like the manuals for my old stereo system that came available on the Internet and I didn't bid enough for—but, you know, I have a lot to be grateful for. I don't want to get caught in the trap of letting what I don't have dominate my life anymore."

I feel so proud to know him; proud to be the mother of someone who has such strength; proud to share part of a life that is so huge that it cannot be assessed in any ordinary terms.

I don't really know how their father feels. He has escaped the dailiness of the pain by distancing himself from Patrick (and from me), and choosing his own interpretation of the past, though what he carries in his heart, I don't really know. I do know that despite the daily sword I feel piercing my heart, I would rather be me than him.

For I have landed somewhere, too. No final resting place either, but a wide and comfortable enough ledge for the timebeing. I have largely ceased caring about what others think and ceased to measure life by accomplishments. Instead I think more in terms of depth: depth of gentleness and authenticity, depth of compassion and honesty. I have stopped thinking of Patrick's illness as something to conquer and more as something to tame. Small gains, perhaps, but a thread to follow out of the Minotaur's cave, a place to stand in the middle of nowhere. ▮

Author's note: This memoir was written in 2001. Since then, more things have changed. I have found ways to translate my pain into work in the world by starting the Chronic Illness Initiative, a program at DePaul University that helps chronically ill students to succeed, and *by joining the Board of the CFIDS Association. I have remarried—to Michael, whose patience and support have helped me to heal. Internally, I have moved to another place that perhaps I will find words for sometime.*

Brett, now 30, despite struggles of her own, has put away her anger and become her brother's champion.

Patrick, 33, is still ill with chronic fatigue syndrome. Unable to have a life that most young men take for granted, he has developed levels of compassion and understanding that people who face lesser challenges won't come to for many years, if at all. His courage is amazing.

Lynn Royster and her two children, Patrick and Brett.