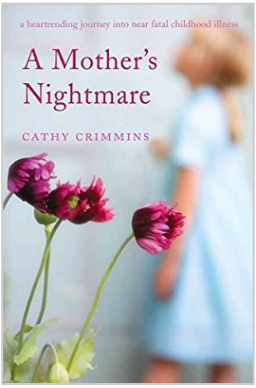

A Mother's Nightmare: A Heartrending Journey into Near Fatal Childhood Illness

By Cathy Crimmins

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In the tradition of Lorenzo's Oil, *a brutally searing story of one mother's quest to save her child's life.*

One day Kelly Crimmins was a happy seemingly healthy twelve-year-old; the next she confessed to her mom that she'd had blood in her urine for months. After a series of tests, Kelly was diagnosed with a life-threatening, potentially terminal autoimmune disease.

A Mother's Nightmare details Cathy and Kelly's three-year medical and emotional journey, which took them from Philadelphia to Minnesota's Mayo Clinic and back again. Cathy writes about the toll taken on a young girl who suddenly becomes a patient, and about a mom who in fighting for her little girl's life becomes sick herself with worry and fear. As she did in her award-winning *Where Is the Mango Princess?*, Cathy makes illness both personal and universal. It's an account all readers will find memorable and moving.

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Editorial Review

Review

Praise for Cathy Crimmins

"Simply amazing . . . an astonishing, alchemical story of tragedy and recovery."
- Anne Lamott on *Where Is the Mango Princess?*

"A portrait of family tragedy all the more poignant for mixing humor with blazing honesty."
- *Elle* on *Where Is the Mango Princess?*

"Transcends the subject of illness to become an inspiring meditation on the enduring nature of love."
- *Us Weekly* on *Where Is the Mango Princess?*

"Devastating yet unsentimental . . . Cathy Crimmins has enormous gifts as a storyteller."
- Mark Richard, author of *The Ice at the Bottom of the World* on *A Mother's Nightmare*

About the Author

Cathy Crimmins is the author of many books, including the memoir *Where Is the Mango Princess?*, which received the 2001 Outstanding Book Award in General Nonfiction from the American Society of Journalists and Authors and was made into a movie starring Julianna Margulies on TNT. She lives in Philadelphia, Pennsylvania. Visit her Web site at www.cathycrimmins.com

A Mother's Nightmare
1 . The Mystery Illness
The sick soon come to understand that they live in a different world from that of the well and that the two cannot communicate.

Jessamyn West

What if I had known all along that it was going to happen? What if Kelly's disease hadn't come as a total surprise?
I ask myself this often, since, in retrospect, it makes sense that our only child developed an impossibly bizarre autoimmune disease.
Of course she did get terribly sick, and why not?
Bad things sometimes come in sequence, and our family had been suffering through a storm of bad things for

some time. Based on the idea of bad things happening in numbers (threes?), I suppose I should have guessed that something was wrong with my daughter. At the time, all the signs were there that she was very ill, but I ignored them, maybe on the theory that lightning doesn't strike twice. I had my reasons to explain away anything bad--I had plenty of them, because denial had become my religion.

In the several years before Kelly became horribly sick, we had beenanything but lucky. When Kelly was seven, her father, Alan, was struck in the head by a boat on a family vacation in Canada. The accident pretty much changed everything, plunging us into a nightmare world in which Alan became a child again. He had to learn all over again how to walk, talk, use the toilet. He returned to work as a lawyer in a bank but was fired after the first year because he never regained his physical or mental stamina. He was strange afterward, "like a new daddy, like he is wearing new skin," as then seven-year-old Kelly told me.

So, when Kelly got sick, we had been riding what experts call the roller coaster of traumatic brain injury for almost five years. Even though I'm sometimes forced to use the roller-coaster image myself when I talk to audiences about brain injury, I've come to resent it because the simile is too benevolent. I *like* roller coasters, damn it! Brain injury is *not* like a roller coaster, because most people have fun on a roller coaster, and no one has fun after brain injury. For the families of people with brain injuries, the experience is more like riding an elevator that is speeding up to the thirtieth floor and then suddenly stops and free-falls eight flights. It's not fun; it's terrifying. The floor is knocked out from under you, and you lose your wind. The families of brain injury survivors try very hard to regain some sort of normalcy, and there is a pattern we all follow as we try to pick up the pieces of our lives. Like so many brain injury survivors, our family felt blessed that Alan had triumphed physically over his accident, but then, when the initial terror and euphoria passed, we began to feel persecuted. The realization of how much we'd lost started to sink in. At around the time Kelly got sick, people at her school had started coming up to me and asking how I was able to cope with my new husband. It was beginning to sink in,even to the general public, that my cynical, edgy husband had become more like a sweet, slow-witted teenage son I had trouble managing.

People outside our family had no idea of our daily struggles, of how I'd have to defend our kid against Alan's outbursts and give my own husband "time-outs" in order to keep peace in the family. Our marriage was gone, and in its stead was an uneasy relationship I couldn't quite define. I was desperately lonely and out of control. An affair I thought could stay casual became my only ballast as I clung to whatever could get me through endless days and nights of terror. I was afraid of what had happened to Alan, too afraid to admit that most times I *hated* what had happened to him, to acknowledge that I was consumed with grief for the life we'd once had. Worse, I'd continued my writing career with a book about his brain injury and recovery, which cast me into a role I never wanted: the Brain Injury Martyr, the loving wife who is an inspiration to everyone around her. In truth I was full of rage and fatigue, adjusting to a husband who was like a sixteen-year-old boy. Most of all, I felt I was living a lie and that maybe I would be punished for it.

Was I punished for it? Is that why my daughter almost died--or would have if we hadn't caught her imploding liver in time?

No, that's too crazy to think, even for me. I sometimes practice magical thinking, but I draw the line at believing that I was a bad person who somehow *needed* a sick daughter to teach me something new about life. Yes, I was feeling damaged and vulnerable when Kelly's illness came along, but I was still remarkably surprised by what happened next. When she got sick, it felt as if she'd gone off and done it behind my back. Moderately sick kids have always annoyed me, and unfortunatelyI gave birth to a hypochondriac. When it came to sickness, Kelly was the girl who cried wolf again and again.

Before her major illness, Kelly never really got sick, but she was always pretending to be, magnifying minor colds into major incidents. In those days she was a real character, not above putting a thermometer next to a lightbulb or sticking her finger down her throat in an attempt to throw up before school. How could I have ever guessed that I, a mom who got pissed off even when Kelly got a case of the sniffles, would spend the next two years taking care of a kid who would almost die?

Nowadays I see what a stupid waste of energy it was on my part to resent Kelly's minor illnesses. She only wanted to exaggerate them so that she could spend time with me at home, but I never played the doting mom who enjoyed bringing her chicken noodle soup. Who were those chicken soup women, anyway? Didn't they have deadlines?

Luckily, Kelly was basically healthy before her autoimmune liver troubles began. She'd never had all those childhood ear infections or endless viruses that kept her friends under the weather. In her twelve years on earth, she had taken antibiotics only once, and her only serious illness had been a bout with giardia, a weird stomach parasite we'd all picked up by drinking "spring water" in the wilderness of Alberta, Canada, when she was two years old. Kelly was so healthy, in fact, that she never got sick enough to have to languish in bed all day. Even with a fever, she was a terror. Her energy level always remained high no matter what other symptoms she might be suffering. As soon as she could walk, her illnesses became mobile: Leave her alone in a room, and she would tear it apart. Vomiting took place on the run. I hated taking her to the pediatrician because of the endless waits in the examination rooms--they encourage you to get your kid nakedand then leave you in a cold room with a naked toddler and no toys. It was all I could do to keep Kelly from destroying the medical equipment. The kid could be contained to bed only when I read to her or when I set up a portable TV to hypnotize her into a Sesame Street stupor. As a writer, I work at home, so having Kelly home sick from her preschool always meant a lost day.

Later, in the year that she was developing her liver disease, I was terrible about her requests to stay home.

"I feel tired, Mom," she'd whine.

"Of course you're tired--you never get enough sleep. Go to sleep early tonight, kiddo. If you think you're staying home because you don't go to bed early enough, you've got another thing coming."

"I have a stomachache," she'd say.

"Sure you do. It's from all the crap you ate last night. Get going, kid."

"I promise I won't bother you, Mom. Really. Please let me stay home."

"No way."

In the months before we found out that Kelly's liver was failing, she was getting skinnier by the week. (I just thought she was "thinning out," hitting adolescence with a vengeance.) And she was pale, but it was winter in Philadelphia, and everyone was pale.

So much for woman's intuition. I should have known! I should have known that my kid was on her way to dying. The evidence was mounting.

It only gets worse when I tell you about the Mystery Illness. How can I put the Mystery Illness out of my mind?

A year before Kelly's complaints of stomachaches and fatigue, we went to spend the millennium in Bangkok and Hong Kong, muchto my mother's chagrin. Mom subscribed to all the dire predictions about Y2K: The world was going to end amid riots and war. At the very least, we were going to be without flashlights and bottled water over there in mysterious Asia while the world turned itself to a new century. She was furious with us; she didn't even call us before we left. In truth, the whole reason we were going on the trip was because most people my mother's age were terrified of Y2K. The trip was being sponsored by ABC Tours, which catered to an older crowd. In the weeks leading up to the flight, seeing that hardly anyone was signing up for it, the tour company had dropped the price each week by a few hundred dollars. By the time we signed up, it was as if they were paying *us* to usher in the year 2000 in Bangkok.

Our friends thought we were crazy. I remember one saying to me, "You're taking a ten-year-old and a brain-injured man to Asia?"

"Why not?" I said, trying not to notice that the idea was a bit crazy. "I'm gunning for a sequel."

This book is not a sequel, so let me just say this: The trip was one of the best things I've ever done. It was a magical family time. Kelly and Alan and I forgot all the crap we'd been going through as we ushered in the new millennium on the banks of the River Chao Phraya, gazing up at fireworks and feasting on sushi and pad Thai. Yes, Alan frequently got lost and bought hundreds of dollars' worth of very bad souvenirs, and Kelly was cranky in that way kids sometimes get overseas, but it was all worth it when we climbed on and around giant golden Buddhas and watched fishermen steadily working and monks bopping around us on motorbikes. It is a memory we'll have forever.

We might also have Kelly's shot liver as one of those memories, though, because three months after we returned and a year before she became desperately ill, she developed her short but troublingMystery Illness, the one that served as a prelude to her "real" liver disease.

I take back everything I ever said about how resilient Kelly was when sick. This thing knocked her on her ass to the point where she couldn't move for hours. Her fever was high and her bladder was seemingly so damaged that urine dribbled down her leg. She completely lost her appetite, and as a consequence, more than twenty pounds peeled off her frame within three weeks. Kelly had never been fat, but at that time she would never have been considered as having the ultimate preteen figure. One day, when her friend Jennifer came to visit, she complimented Kelly's new look.

"You are sooooo thin, Kelly," she said in her best Valley Girl tone. "Like, it's so cool."

"My mom always said I'd lose the weight without knowing it," Kelly said with more than a bit of pride in her voice.

Had I really said that to my daughter about her weight? I felt chastened. I was prescribing magical thinking for her figure concerns. Worse, I was endorsing the idea that losing weight when you became a teenager was a good thing. I made a mental note to say something about it, one that I threw into my brain's recycling bin almost immediately, because as Kelly's Mystery Illness lingered on, the weight loss became the least of my concerns.

For one thing, the poor kid seemed to have a very wicked bladder infection. I'd been prone to those as a teenager, too, and I felt awful for her. She had the usual high fevers and the chills and lethargy. But her fevers were not consistent: One hour she would be up over 101 and then a few hours later she would be in the low-to-normal range. At the time, we were seeing a general practitioner's group I hated--her dad had fallen in love with a particular GP right after his brain injury andhad transferred all of us to his care. His practice was more like a public clinic than a private office, and what I particularly resented was that we often had to wait for hours to see a physician, and it was seldom the *same* physician. Alan saw it as a point of pride that we went to a clinic in West Philadelphia instead of to a "fancy" pediatrician in Center City Philadelphia--he even insinuated that I was a racist who didn't like waiting in an office full of black people.

I still believe that if we'd had a good pediatrician when this thing with Kelly started, we would have found some sane solutions much earlier on. It's another one of those things I beat myself up over. I often reflect on that time and wonder why I was so passive about our health care, and, besides laziness, I can say only that I often practiced passivity and opportunism when it came to child care. If I allowed Kelly to go to a doctor's office Alan loved, then he was more likely to take her there, and I could work longer hours. I'm nothing if not obsessive in my work, and I always hated all the routine child maintenance appointments--the school and camp examinations, the vaccinations, etc. Alan loved doing all that stuff, so I let him call the shots.

The first time Alan took Kelly to the doctor, they said she was suffering from a bad flu. The doctor on duty at the time wasn't concerned that she'd already been out of school for three days. These things take time, he said. I took her the second time and told the doctor about the fevers that came and went and her obvious signs of bladder infection.

The doctor, an attractive black woman with a nice bedside manner, suddenly turned to me and requested that I leave the room.

"Why?"

"I want to ask your daughter some things that she can answer on her own."

"I think I'll stay."

"I would prefer you didn't."

"I will stay."

The doctor was annoyed with me, and Kelly was getting fearful. The doctor moved toward the examination table and perched herself at the end.

"Now, Kelly, has anyone touched you who shouldn't touch you? Is there anyone in your house who hurts you?"

I felt my face get red. What the hell was this? My kid was eleven years old!

"No," said Kelly, looking at me quizzically.

"Kelly, have you had sexual intercourse with a boy?" said the doctor, gazing at her steadily.

"What?" Kelly looked even paler than she'd been. She looked over at me. I didn't know how I should arrange my face. I felt guilty when there wasn't any reason for me to feel guilty. I worried that the doctor would think I was sending signals to her, so I looked away. "I haven't even kissed a boy yet," Kelly blurted.

I giggled nervously, and the doctor smiled.

"Okay," she said. She sent Kelly out to a bathroom to get a "clean catch" urine sample and turned to me after the door had closed.

"You wouldn't believe how many kids we see who are sexually abused," she said, "and one of the signs is always the unexplainable bladder infection."

"Well, my daughter is not sexually abused, and she's not sexually active. It's horrible of you to suggest that she might be."

"It's standard practice," she said.

Kelly returned, got her clothes on, and we left for home, with me vowing never to see that particular doctor again. But how could I control it? I hated these big practices where you never made a personal connection with a caregiver. Worse, when I had told the doctor we'd been overseas in Asia, she didn't even note it down. Kelly's ailment had stretched on for days now, and I was beginning to worry that it was something more serious than a common virus or a simple bladder infection.

I don't know why they never cultured Kelly's urine. A week later I took her back to the office and got yet another doctor, who once again took a urine sample and said not to worry, that there was "something going around." By that time, Kelly had lost another ten pounds and was still spiking a 102 fever every other day. I complained to the male doctor that I'd been insulted by the previous doctor's questions about an eleven-year-old's sexual activity, and he also lectured me on the numbers of young girls who were abused. I wondered aloud if their methods really ever helped detect anything, and he just glared at me. Then we went home with a refill prescription for the sulfa antibiotic Kelly had been taking for almost ten days. When I called two days later to inquire about the results of the urine culture, I once again got the runaround. (Thinking about this infuriates me all over again, and I'm especially mad at myself: How could I have tolerated such a casual attitude toward my kid's test results? But life goes on--you know how it is. You make the phone calls, and you're upset, but then you have to let it go if you're going to get anything else done that day.)

About three days later, I'd had it with the Mystery Illness. Kelly, often too tired even to watch television, stayed in her room dozing on and off day and night. Her lethargy was what scared me most. She didn't even seem to have the energy to try to annoy me. It was a scarytime, made more so because her dad couldn't understand my concern. He didn't see this illness as any different from the standard bad colds or viruses kids have throughout their childhood. Alan, especially after his brain injury, was a doting dad, and he rather seemed to enjoy Kelly being sick and dependent on us. While he wasn't with her all the time, he was in and out to his part-time jobs and enjoyed combing the city to buy her candy and stuffed animals to make her feel better.

The candy went uneaten, and it was getting harder to concentrate on my work. It was ironic--I finally had a sick kid who kept to herself and let me write, but my concentration was shot. "We took her to Thailand," I kept thinking, "and now she's dying of something mysterious." Alan and I had a friend, an artist, whose sister had volunteered in Thailand for the Peace Corps. After only a few months there she'd been sent back to the States to languish at a federal hospital for infectious diseases. She never regained her energy, our friend told us--the mysterious illness, never defined, changed her personality forever.

But our friend's sister had been out in the wildest areas of Thailand. By contrast, our trip to Thailand had been very "vanilla," I kept telling our friends. Mostly tours of temples in Bangkok, a trip on a luxury boat to some ruined Buddhist sites down the Chao Praya River, and one guided tour of a floating market.

"She's always putting her fingers in her mouth," my mom said one day while talking about Kelly on the phone to me. "You know she still sucks her thumb sometimes, even at eleven. God knows what got into her mouth." Memories of Kelly sitting low in the carved-out canoe boats at the floating market came to my mind--I saw her trailing her fingers in the water, and then eating the market's mangosteens.

I stopped telling my mom that Kelly was still sick. She was getting better, I told her--except that she wasn't. One afternoon I camedown from my third-floor office to check on her. She was in bed, flat asleep on her back, a rare position for a girl who was usually casually tangled in the covers (we often called the sleeping Kelly "The Worm" because in the course of a night she could squirm around and steal a huge bed from any other sleeper). She looked corpselike, and when I touched her forehead, she was burning up. I freaked out and began tapping her.

"Get up. Get up! We're going to the hospital."

"Mommy? I'm tired. I have my pajamas on."

"That's okay. Stay in your pajamas. Wrap yourself in this blanket. Come on. I'm just going to put you into the car and we're going."

I'd been to the emergency room at Children's Hospital once before, when Kelly fractured her wrist at a soccer game, so I knew it was only ten minutes away. I couldn't get Alan--he was out wandering the city somewhere--but I knew it wouldn't be hard to get her there by myself. It was just a matter of finding our way from the parking garage to the emergency room.

Children's Hospital is filled with banners proclaiming that you're sitting in one of the top five children's hospitals in the country. I felt stupid as soon as we got there--was my kid really sick enough to justify an emergency visit? We had to park in the garage, which seemed a mile away, and I had to keep encouraging Kelly to move along in her pajamas and slippers.

The nurses didn't seem to think much of what was going on at the triage area, where they took Kelly's temperature and found it only slightly elevated. After charting her other symptoms, they sent us back to the waiting area's hard benches, where we cooled our heels for almost five hours before being called in. We'd arrived in the afternoonand now it was early evening. Alan had met us there and gone to fetch the junk food I would forever associate with Children's Hospital: McDonald's Happy Meals.

The waiting area for emergency at CHOP is in a huge atrium that was designed to be cheery but instead is very depressing: The high ceilings magnify every little sound, especially the pinging of the sadly abused interactive museum displays meant to delight the sick children waiting there. Every phone ring ricochets from the rafters, as do the computer printer sounds, the screams of unruly or vomiting children, and the annoying cash register sounds from the overpriced gift shop. And if the auditory delights don't get to you, there is the perpetual spectacle of very sick kids--hairless, emaciated, wrapped in bandages--being wheeled on gurneys from one procedure to the next, followed by anxious, hollow-eyed parents who haven't seen sunlight for weeks. That first day, waiting in that god-awful atrium, I thought of how lucky I was that Kelly wasn't an inpatient at the hospital. I had no idea that Alan and I would be following one of those gurneys only a year later, that the Mystery Illness would catch up to us eventually.

Eventually we were called in, and Alan and I recounted Kelly's medical history once again. I stressed to the interns our recent trip to Asia, and mentioned that she'd had the signs of a bladder infection but that our physicians had never gotten it together to culture her urine. The emergency team took a urine sample and then asked us to leave the room. Kelly was scared and said she didn't want me to go.

"We have to talk to this young lady *alone,"* the attending female doctor said.

"Not this again," I said. "I assure you that my daughter is not sexually active."

"We'd like to ask her about that ourselves. It's hospital policy."

"She's eleven years old."

"Old enough."

I don't know what they would have done if I had truly refused to leave Kelly alone with them. I was tired and, after waiting five hours for anyone to pay attention to us, I certainly didn't want to wait another five to go through some procedural committee.

"Kelly, you'll be all right," I said, and left. I stood right outside and then made a point of coming back in after what seemed like a long five minutes.

"I told them again, Mom, that I haven't even kissed a boy," Kelly said. The doctor smiled but shook her head.

"Honey, you're getting older. We just have to ask these things." She began pushing on Kelly's abdomen.

"When did you last go to the bathroom?"

"You mean poop?"

"Yes. Kelly, when did you last have a bowel movement?"

"I can't remember," said my kid, suddenly embarrassed.

"She hasn't been eating much of anything," I said.

"Well, Kelly, you've got a lot of hard poop in there. That might be why your stomach hurts."

They sent Kelly for an ultrasound, which did show accumulated fecal matter in her colon. "High level of constipation," said the doctor. Kelly's eyes watered as the technician pressed the Doppler wand, hard, on her lower abdomen.

But then a curious thing happened: Kelly's blood tests came back and her liver numbers were way off. Her AST number--for aspartate aminotransferase, a chemical the liver uses to make glycogen--was over five hundred (the regular reading is supposed to be under fifty). CHOPwas concerned enough to send around a liver specialist, who said it was highly unusual for a child to show such high liver numbers.

"Are you sure they're not *my* liver numbers?" I said, attempting a stupid joke.

It could be the fever, said the hepatologist--a high fever can sometimes make liver numbers go screwy--or it could be hepatitis A or B. He was the only doctor who seemed at all interested that we'd recently been to Asia. "But the window of time for contagious hepatitis is well past; you would have seen it before this four-month period," he said. Still, he ordered tests, and I was advised to tell Kelly's baby-sitter that she might have been exposed to some sort of mystery hepatitis.

We went home with a notepad full of instructions for giving our child over-the-counter laxatives and stool softeners. It had been more than nine hours, and all we'd found out was that our kid was constipated. It all felt silly.

Even though the CHOP liver doctor advised our following up the next day to see if Kelly's liver numbers had gone down, when I told our pediatric practice this, they said it really wasn't necessary, that there was nothing to worry about--it was definitely the fever that was elevating the liver numbers. They believed this even more after all Kelly's tests for contagious hepatitis came back negative.

I took comfort in what the liver doctor, the most communicative one of the CHOP team, had said to me: "I'm sure Kelly didn't pick up anything in Thailand or China. Remember, we have hepatitis breakouts here, too--there was that recent one in Michigan, for example, with the contaminated strawberries."

So I wasn't a bad mom, after all.

In the days that followed it was as if taking her to the hospital turned out to be the magic cure--her fatigue lessened, her fever letup, and she returned to school skinny enough to wear the shorter "tummy tops" she'd been eyeing ever since she'd started edging toward adolescence.

Of course, now I know that the Mystery Illness was just a dress rehearsal for the Big One. It had all the elements--surprise, frustration, hopelessness--that Kelly's later real illness would come to embody, and yet it seemed like a problem that had gone away. We had almost another year before Kelly got so sick that she almost died, and I can't help but feel that if I had been worth my salt as a mother, I wouldn't have been so complacent. I might have pressed my questions about why her liver was going kablooey. I might have wondered more ardently why a healthy, active kid had suddenly become lethargic and anorexic. At the very least, I would have insisted on the pediatrician taking urine cultures. But life is busy, and I had dozens of deadlines, and Alan and I were beginning to struggle toward a marital separation, so I had plenty of other things to occupy my mind. Right before the Mystery Illness, Kelly had gotten her first period, so I was even able to chalk up the incident to the onset of puberty. The loss of appetite, the fatigue, and even the weight loss all added up to one amazing and rather vicious lurch toward womanhood.

Recently, Kelly and I were sitting around talking to our new neighbors in Los Angeles about the subject of this book, and she remembered the Mystery Illness as just vanishing, too. But what I didn't know, until my sixteen-year-old daughter told me in front of our neighbors, was that the second phase of her illness started soon afterward.

"But right after that," she said, "I started peeing funny, and that's one thing I never told my mom about. I don't know why, but maybe I was embarrassed, or maybe I just thought it was normal. It wasn'tlike I had blood in my urine back then, it was more like, well, dark beer. The pee that came out of me was always really dark. Now, when I look back at it, I can't believe I didn't tell my mom, but I guess I thought I was grown up and wanted to be private, or that I thought it would go away."

Oh, how I wish it had gone away!

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