

# D A M A G E



M A R I B E T H F I S C H E R

*The beautiful plate I cracked in half as I wrapped it in tissue paper —  
as if the worship of a thing might be the thing that breaks it.*  
— Laura Kasischke, “After Ken Burns,” in *Space, in Chains*

“I know my mom was really weird about your last novel,” my eighteen-year-old niece, Abby, said to me on New Year’s Day as we hurried through the grocery store looking for the ingredients to make a dessert involving cereal, pretzels, and M&M’s coated with chocolate. “But I’m so grateful that you wrote it.”

The comment stopped me. My novel had devastated Abby’s mother, my younger sister, in ways I could never have anticipated. Although I understood my sister’s pain, which was searing and nuclear in its bright, awful power, I’d been shattered by her reaction. On that day in the grocery store, almost six years had passed since the book was published. My sister and I had reconciled, but it was a shaky reconciliation based on the unspoken agreement that we not talk about the book again. Ever.

I glanced at Abby, thinking how much she resembled my

sister – the same thick blond hair, pale skin, petite frame. I also saw in her glimpses of my nephews, her brothers, bright funny boys who had died two years apart from a genetic disease. There was something of Zachary in Abby's solemn gray eyes, and as she turned to grab a shopping cart I saw in the upward tilt to her chin a flash of Sam's elfin mischievousness.

Loss unspooled inside me. And grief, a word that seems both ancient and timeless. I think of fossils, a seashell discovered on a mountaintop, the bones of dinosaurs buried beneath subdivisions. Maybe there's no such thing as healing. Life goes on, we move forward, but traces remain behind, the shape of grief pressed into a word, a memory, an ordinary moment. Abby's comment unearthed in me the understanding that I'd never gotten over what had happened between my sister and me, had never really healed. I knew my sister hadn't either. Perhaps because healing involves forgiveness, and there was no one to forgive because there was no one to blame – except that wasn't exactly true either, was it?

At first, I didn't know how to respond to Abby's comment. She'd been casually asking how I was, what I was writing, and I'd responded just as casually, I *thought*; things were good, but I was frustrated with my writing. This last part, about my frustration, was an understatement, like saying there's a small hole in the earth when I was talking about the Grand Canyon.

What I really felt was despair.

Had Abby heard this in my voice?

For nearly two years, I'd been struggling to write. I'd get an idea and begin, but within weeks, sometimes days, I'd feel the energy seeping away. The word *miscarriage* comes to mind, though I resist it. Not being able to write is *not* like losing a child; *nothing* is like losing a child. Still, when I picture those mornings of trying to write, of sitting alone at the antique table in the kitchen, I feel it in my gut: the sinking sensation of *oh no* and *not again* and the dread as I stay very still, trying to will words onto the paper even as another part of me knows that what was vibrant and alive just moments ago is slipping away.

In the past few months, I'd become almost afraid to write, for it seemed the minute I began putting ideas into words, I ruined the ideas. I think of butterfly collectors pinioning wings against black velvet, of John James Audubon killing the gorgeous birds he

longed to paint, and I wonder if it is always like this – we damage what we most love the minute we try to hold on to it.



Outside the plate-glass windows of the grocery store, the Wisconsin sky held a trace of light at the horizon, and I thought of it being an hour earlier here than in Delaware, where I lived. I felt far from my own life, and I was glad, hopeful that with the new year, I too could have a new start. I'd taken a leave from my teaching job so that I could have the spring to write. *If I just had more time*, I told myself. I wanted it to be that simple – the slammed-shut feeling inside, the sense that I was locked out of my own self – though I suspected it wasn't simple at all.

I was forty-eight that winter, had been writing all my life, and was terrified that I no longer could. I felt like a fraud in the fiction classes I taught, a has-been. Too young to be ending my career, too old to start over. But even if I wasn't too old, what else would I do? I had always written. From the moment I took an undergraduate creative writing class twenty-five years earlier, I had known with absolute certainty that this was what I wanted. I still recall the first story I wrote, the crushing disappointment at the B-, the dingy office where I met with the young professor. How hard I'd worked to improve – and I did! The next semester I received permission to take graduate writing courses, and I scheduled other classes, my waitressing job, everything so that I'd have one full day each week that was solely mine, to write. I moved through my life differently then, my writing day bobbing brightly inside me, a raft I swam toward all week.

That feeling never left me. I received a graduate degree in creative writing, worked adjunct jobs teaching creative writing, eventually landed a full-time job at the University of Maryland. I published a novel, gave readings, sat on panels at literary conferences. A long table on a dais; my name on a placard. I was grateful for this, but even then what I loved about being a writer was the writing, the winter mornings at my kitchen table with a mug of coffee that I'd reheat half a dozen times before finally giving up – the coffee forgotten the minute I lost myself in the words. Or afternoons in a café when I'd glance up, stunned that the sky had turned to dusk while I'd been writing, or that it had

begun to rain, headlights shimmering in wet pavement, the barista readying to close, setting chairs upside down atop tables. My life made sense when I wrote. It was that simple. Even on the bad days of rejections, news that my book was out of print, that my publisher was dropping me, even then, I had always, *always*, carried in me the unwavering surety that this was who I was: a writer.

That afternoon in the grocery store with Abby, I'd lost that confidence.

The store was mostly empty by the time we left, only a few cars in the parking lot. Snow began to fall; a thin layer coated the silver shopping carts. Across the highway was a lighted gas station and beyond that a tract development like the one where my sister lived, and beyond that, the cemetery where my nephews were buried.

The novel that Abby was grateful I'd written was about a child who had mitochondrial disease. Sam died of it at age seven. Two years later Zachary died. He was fifteen.



Mitochondrial disease is not only rare but mercurial, symptoms moving across the body like weather patterns, constantly shifting. Some mornings, Zachary was so depleted of energy he couldn't stand without his legs buckling. A week later, he'd be chasing Abby across the lawn with a water gun, laughing that Woody Woodpecker cackle we all loved. Because of these extreme ups and downs and because the boys looked so good – at least until the end of their lives, when they were swollen with steroids – we often questioned how sick the boys really were. *He seemed perfectly fine! He ate a huge bowl of ice cream!* Was my sister exaggerating, we wondered. Overreacting?

Unfortunately, medical professionals who didn't understand the disease either – and how could they? One minute the child's attending school, participating in sports; the next day, he's bedridden with pain – were accusing mothers whose children had mitochondrial disease not only of exaggerating their children's illness, but of *causing* it: giving their children Ipecac to make them vomit; injecting their own menstrual blood into the child's IV; suffocating the child with a pillow or Saran Wrap, then rushing him or her to the hospital and saying he or she had fainted. Supposedly, these

mothers did this for attention, like the arsonist who is also a firefighter, heroically saving what he has, in fact, damaged. In lieu of other answers, perhaps blaming the mothers for their children's illness made some kind of sense. How was it possible, after all, that in the richest, most technologically advanced country in the world doctors couldn't understand, much less cure or even know how to treat, this disease?

And so mothers of children like my nephews increasingly were accused of Munchausen Syndrome by Proxy (MSBP), a psychiatric disorder named after Baron von Munchausen, a notorious eighteenth-century teller of tall tales. Because it wasn't just an illness but also a crime – children were harmed – the FBI listed warning signs of MSBP on their website. If the child's illness was rare, if it baffled doctors, if the mother “doctor-shopped” in an effort to find answers, she might be suspect. If the mother was medically knowledgeable – my sister was a pediatric nurse – if she stayed overnight with her child in the hospital, if she dared to befriend her children's nurses or doctors, it was all part of a grand ploy, an elaborate lie, to prove her “devotion.”

It's clear where this is going, isn't it?

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On Christmas Eve the year Sam was two and Zachary seven, my sister learned that she had been accused of MSBP, and Social Services was investigating her. She never knew who made the accusation, and in the months and then the years that followed, she lost her trust in every single person in her life, always wondering, *Was it you?* The slightest criticism, the tiniest hint of disapproval, and my sister retreated behind walls that none of us – then or now – could find a way to scale. Once, at a doctor's appointment with the boys – I was there, for after the accusation she was afraid to go alone – the doctor left the room for something and my sister panicked. Where was he going? Was he calling Social Services? She gathered the boys' jackets, grabbed her purse.

“It's okay,” I said. “He's not – ”

“You don't know that!” Hands shaking, her face bloodless, she tugged Sam's arm into his jacket, and when he began whining, she panicked even more. “Stop it!” she pleaded. “I'm not hurting you!” She began to cry. “Maribeth, please, I need your help!”

It never stopped, my sister's fear: the boys' therapists, a kind nurse, another mother, *our* mother, my sister's husband, *me* – had *we* said something, she implored, perhaps not meaning any harm? Too thin, dark circles beneath her eyes, my sister would glance at the boys in the rearview mirror as we drove to another doctor's appointment or turn to me as we washed dishes. "How could anyone think I would harm them?" she'd ask in a small incredulous voice, something broken in her eyes. I told her I didn't know.

All I do know is that although nothing ever came of the accusation, the fact that someone believed, enough to call the authorities, that my sister was *making* her children sick; that this accusation still exists, years after the boys' deaths, in a file that by law can't be expunged; that my sister's name is in a registry of child abusers – *suspected but unsubstantiated* – robbed her of something she never got back. She'd always wanted to be a mother, and she was a good mother and proud of this, and maybe, *maybe* had this knowledge, this confidence, not been taken from her, she could have held on to it after she buried first one child and then another. *You were a good mother.* Such a simple thing. Maybe this would have comforted her, offered some impossibly small sliver of consolation.



I visited my sister shortly after she was accused. We sat in her family room at midday, the house quiet, which was rare. My sister couldn't cook or prepare medications or even empty the dishwasher. She was terrified. Yet another woman from the mitochondrial disease list-serve she frequented had been accused of MSBP, her children taken from her. The authorities had confiscated the woman's computer for evidence: participating in the list-serve, corresponding with other mothers of sick children, researching specialists – more proof of *her* illness, *her* obsession. "What if they take my computer?" my sister asked. "I'm always researching and . . ." Her face crumpled. "I wrote those letters. Do you think that's why someone thinks this about me?"

"No," I said. "*No.*" How could my sister question this? Years before – Sam wasn't even born – my sister wrote to eleven specialists across the country, begging for help. Zachary was four then, and none of his doctors knew what was wrong: eating caused him to sob in pain some days, and he was so exhausted he'd fall asleep

in the middle of his toys, a tiny rag doll of a boy. And so my sister researched – pediatric gastroenterologists, metabolic disease specialists – then wrote long letters describing Zach’s medical history. One of those specialists, halfway across the country, wrote back, got Zachary the necessary tests, and finally diagnosed him.

“Zach is alive because of those letters,” I told my sister, but she was staring past me out the sliding glass doors, the picnic table heaped with snow, the grass colorless and brittle looking. In her expression was something haunted that I’d only witnessed a handful of times when her guard dropped for just a fraction of a second and the awfulness of what was happening to her children tore through her. It hurt to look at, and so I followed her gaze. Even the air looked colder here than it was back east, as if it had frozen. After a moment, she said, “Maybe you could write about this, Maribeth. About Munchausen.” She sounded frightened. “Maybe it could help.”

It wasn’t the kind of story I knew how to write or even wanted to write, though. It seemed – it was – such a sleazy, tabloid sort of topic – women *faking* their kids’ illnesses, sometimes killing those kids, solely to get attention? This was a journalist’s story; I wrote fiction.

Still, I wanted to help my sister.

Even now I am clear about this; even now it is *my* consolation.



What I wanted to write about was the Salem witch trials. I was intrigued by the idea of repentance and atonement. How, I wondered, did a husband or a child ever forgive those who had falsely accused his wife or mother? How did the accusers ever forgive themselves? How did anyone ever trust again? How did they stop being afraid?

By the time of my sister’s accusation, I’d already visited Salem, had reread *The Crucible*, and was immersed in research. The more I read, though – about how the accused witches were often midwives and so had medical knowledge; about how the trials began with the unexplained illness of a child – the more I began to wonder if accusations of MSBP were just a modern name for witchcraft.

I felt a jolt of excitement and knew then that I would write the book my sister wanted me to. A novel. About a woman falsely accused of Munchausen. I would somehow connect it to the witch trials. No longer did it seem tawdry or tabloid. The story, I saw, was part of a much larger one.

Of course, I could have used any disease in my novel. Women whose children had “brittle bone disease” were accused of MSBP, women whose children had autism, cerebral palsy, Lyme disease. But I knew about mitochondrial disease. “And maybe,” I said to my sister on the afternoon when I told her that yes, I’d write the book, “maybe I can even bring attention to Mito disease. Maybe it will help.”

*Maybe*, meaning what *could* happen, what *might* be possible.

Isn’t *maybe* what fiction writing is about?

My sister and I were sitting in her kitchen, her daughters at school, the boys napping. She was wearing plaid pajama bottoms and a T-shirt, and she looked simultaneously young – round face, blond hair in a crooked pony tail – and exhausted – dark half-circles beneath her eyes, worry lines framing her mouth. “It’s not that I don’t want to bring awareness to the disease,” she said. “But . . . when I asked you to write about this, I didn’t mean it to be about me.” She glanced down. “What if people find out *I* was accused?”

“They won’t,” I said. “The character will be nothing like you. It’s fiction.”

She was sitting very straight, holding her coffee mug in both hands, like a child afraid of dropping it, and in that moment I saw how frightened she was of making a mistake, of not doing everything she possibly could . . .

And *what if?*

What if my book *could* make a difference? I saw that too – her hope, her enormous hope – and it made me ache. I knew even then that my novel would not keep Sam and Zachary alive.

“I guess it’s okay to use their disease,” my sister said, finally. She glanced at the ceiling, the boys’ room directly above us. Later, I would remember this: her glancing up. The fact that the boys were there. That they were still alive.

“But,” my sister continued, “I don’t want you writing about me

or my kids.” She looked at me, hard. “I don’t want you writing about my life.”

I promised her I wouldn’t.

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In the years since that novel was published, I’ve heard myself offer advice to writers who are basing a work of fiction on someone or something real. “Start by changing the little details,” I say. My sister was blond, so I gave the fictional mother auburn-colored hair. My sister drank wine; the fictional mother preferred Cosmopolitans. My sister had four children, the family in my novel had three. “The little details will affect bigger and bigger things until by the time you finish, your fictional character is nothing like the real one.” This is what happened with my novel, I tell them. Although based on my sister’s life, the main character was nothing like her. The plot was also complete fabrication. In the novel, the child is taken into protective custody by Social Services, something that never happened to my sister. But once I allowed it to happen in the novel, all kinds of other things happened as a result – court hearings and legal battles and arguments.

What I don’t tell people is that none of this mattered in the end.

Because in the novel a child dies of mitochondrial disease, and by the time I finished the manuscript, seven-year-old Sam had died of mitochondrial disease, and my love for him – my very specific love for that very specific boy – informed every word of the book.

In my sister’s eyes, I had broken my promise.

In the novel, I gave my love for my nephews to the character of the mother. My agent, editor, friends, even reviewers, all commented on this as one of the most compelling parts of the book: the portrayal of the mother’s immense love for her child. Although I’d worked to ensure that the mother in the novel *wasn’t* my sister, I hoped that she would nevertheless see what I had written as a gift, a testament to *her* parenting. “Everything I know about loving a child, I learned from my sister,” I often told people.

I still do.

But by the time the book was published, my sister felt not that I had given her anything but that I had taken *her* story, *her* chil-

dren, *her* grief and used them for my own purposes. While I was being featured in profiles, she was phoning the funeral home on rainy nights, needing reassurance that Sam's coffin was waterproof. While I was giving readings and signing books, she was planting orange flowers – Sam's favorite color – at the cemetery and sleeping on a chair next to Zachary's hospital bed as his condition deteriorated. That October, the year before Zachary died, I was giddily getting emails during the Frankfurt Book Fair – my novel had been sold to a German publisher! A Swedish publisher! An Italian publisher! – and my sister was buying Buzz Lightyear Halloween decorations to leave at Sam's grave.

I no longer recall whether she spoke the words over the phone or wrote them in an email, nor do I recall the exact words. I don't need to. The gist of what she said was “You used my child to sell your book,” and though it was the cruelest thing anyone has ever said to me, it was not wrong.



Of course, there were things I knew about loving a child and watching that child die that I could only have known from spending time with my sister. I picture Sam tossing down his SpongeBob backpack after a tough morning of kindergarten, grumbling about his coloring homework. My sister kisses the top of his head, smiling. Sam loves school, and that he's able to attend at all is yet another thing she fought for. I think, too, of Zachary, Oreo crumbs all over his chin and T-shirt, vehemently assuring my sister that he hasn't been eating cookies. My sister glances at me across the kitchen, both of us struggling not to laugh when he protests, “Why don't you *ever* believe me?” There was this too, I think now, and how – had I not spent all those weeks with my sister – how could *I* have possibly understood?

The joy even in the midst of grief.

All that amazing, ordinary joy?

My sister jokingly called me her wife when I visited. She worked part-time in Children's Hospital as a patient advocate for parents of sick children. On the days she worked, I'd hand her a mug of coffee when she came home and sank into a chair, still in her skirt and heels. Dinner would be in the oven, clothes folded on the dryer, the table set. The kids would clamor around her with

homework and arguments and projects, and the house would grow chaotic and loud, and I'd watch from across the kitchen. This is my younger sister, I'd think, the girl I shared a bedroom with growing up, the girl whose tooth I once knocked out, who let me try to glue it back with Elmer's, and now she was the mother of *four* children, her oldest daughter already a teenager. How had she learned to be this? And then she'd kick off her shoes, her mascara smudged, her eyes exhausted, and she'd stand at the sink and start drawing up the IV medications the boys would need during the night. Sam and I would make a salad, he ripping the leaves, while I, pretending to be the lettuce, whispered in a squeaky voice: "Stop ripping me! Ouch! Stop!" He'd throw his head back and laugh and rip more, faster, until the salad was ready.

On one of these nights, Sam started bleeding from his mouth – he received clotting factors and had weekly infusions, but they didn't always work. Afterwards, I was carrying the towels, soaked with blood, to the bathroom, where my sister, still in her silk dress, was wringing them into the tub. It was gruesome. So much blood, thick dark clots floating in the pink water. I had to look away. "It's okay," she said quietly. "No one should have to see this."

It struck me then, maybe for the first time, how lonely my sister was. Her husband helped, but she was the nurse, and so most of the medical care and responsibility was hers. I remember forcing myself to look at the bloody towels and water, remember thinking that to turn away was to somehow turn away from *her*; from this reality she lived with constantly.

I never wrote that scene or one like it. But my sister's matter-of-fact acceptance of what was happening? Her matter-of-fact acceptance because she had no other choice – I took that, didn't I? I used it: the way the horrific becomes normal, cleaning up blood as you would a glass of spilled milk. That's in my book.

And how lonely the mother is.

That also.

Another time, my sister was arguing with her husband about the outrageously expensive playhouse she wanted to buy Sam for his fifth birthday. I cowered in the family room with Zachary, staring at cartoons – *The Power Rangers* or *Pokémon* – battles and explosions and ordinary people transforming into something ferocious and undefeatable and superhuman.

*I can't believe you think money is more important –*

*That's not –*

*Oh, please, that's exactly –*

I waited for my brother-in-law to leave for work, then went to my sister, rage and righteousness and disdain and disgust radiating from her in waves. Her husband's logic was offensive to her, his practical considerations repulsive. "Doesn't he get it?" she sobbed, and the terrible loneliness seeped from her again, and of course I took her side, I always took her side. She was my sister and her children were dying, and against this, how could she possibly be wrong?

Later, we drove to buy the playhouse. "I know it's ridiculous to spend this much," she said as we pulled up to the warehouse-sized toy store. She stopped the car but didn't get out. Sunlight bounced off the windshield. Traffic rushed by on the highway. My sister looked at me. "It's just . . . What if . . ." Her voice broke, and she shook her head in frustration, then abruptly opened her door. "This is ridiculous," she snapped. "What if it's his last birthday?"

There's no playhouse in my book, no argument with the husband about money. But the fear that seeps beneath every moment of every day that this might be the last birthday, the last Christmas, the last time we play cars, the last time – it's there on every page. And who does *that* belong to? My sister alone? We all felt it. I remember sitting in my sister's kitchen grading papers and looking at the clock and thinking I needed to wake Sam from his nap, but if I could have just fifteen more minutes.

Immediately, I regretted the thought. In the not-so-distant future when Sam was gone, I would hate myself for even thinking that anything else mattered.

Who owns this?

The argument over the playhouse and the playhouse itself and the blood – these are my sister's details.

But the fear? The guilt?

Did she own them too?

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I sent my sister a draft of the book the summer after Sam died. Weeks went by before I heard from her. Time wobbled that summer, moved in fits and starts. All that registered was the third day

of every month, which marked the one-month anniversary of Sam's death, then two months, then three. When my sister finally responded, her email was apologetic. "I'm so sorry," she wrote. "I know this book is important." But ever since Sam died, she couldn't read more than a few pages of anything – she who loved to read. Fiction, nonfiction – she'd start a chapter, then skip to the last page. She didn't care anymore what happened to the characters or why. She just wanted to know how it turned out: Were the lovers reunited, was the murderer caught, did the child live?

With my book, she already knew the answer.

We were still on good terms that summer. By now I had a publisher, and when medical questions arose in the novel, I emailed my sister and she emailed back long detailed answers. There was no anger, no suggestion that I shouldn't be asking these questions, shouldn't be writing the book. Later I would use this to defend myself: "She *knew* what I was writing! She helped me with it!" By this time I had a publication date, advance copies were being sent to authors I admired who were writing blurbs, and (how do I say this?) I was thrilled.

My excitement was understandable. And yet, there was a black hole in the middle of everything, an awful truth that even now I don't know how to navigate. A real child – not a fictional one, but a very real boy with spikey blond hair and an impish grin who loved dogs and Buzz Lightyear and wanted to grow up to be a rocket – had been born with a devastating disease, and a very real woman, my younger sister, had been accused of actually *causing* this disease. Somehow, it no longer mattered that she'd asked me to write about this. All that mattered was that I had, that from the two most horrific things that had ever happened to my sister, I had written a novel that reviewers were praising, that my agent, publisher – our *family* – was celebrating. Forget the details of how or why it happened. Just lay the facts side by side.

The equation is devastating: *My child died and you have a book.*

In my sister's eyes, that's what happened. And though I wanted to protest, and I did – vehemently – another part of me knew that what she was saying was true: Had her children not been born with a terminal disease, there would have been no novel.

*My child died and you have a book.*



In my novel, the mother has an affair, and in part it's because of this that she is accused of Munchausen. The social worker in the book – also a fabrication – argues that the affair is proof that the mother isn't who she said she was, proof that she was duplicitous, that she wasn't *that* upset about her child's illness – all signs of Munchausen.

At the most basic level, the mother's affair in my novel was necessary to the plot. Although in real life, the accused mother might never know why she was accused or who accused her – and to this day, my sister does not know – in the novel the *why* had to be clear, I felt, so that there could be no doubt that the Munchausen accusation wasn't about a mother harming her child so much as it was about a woman who was flawed and human. Just as during the Salem witch trials accusations were used as a means to either silence outspoken women or punish them for their transgressions – learning to read, not attending church, committing adultery – so I believed that Munchausen accusations were being used similarly. I wanted this to be clear.

But herein lies the problem with using other people's lives in fiction: the boundaries blur; readers don't know what is true, what is made up. Perhaps readers who saw my sister in the fictional mother would start wondering not only if she had been accused of MSBP (she had) but if she had had an affair (she hadn't).

I knew this would happen. I also knew – didn't I? – that my sister would be upset. But this is what fiction *is*, I told myself. Made up! Pretend! Not factual! In some ways, you could even say – and I did say it in those brief flickering moments when I allowed myself to know that the book would hurt my sister – that in giving the mother an affair I was actually keeping my promise: I was not using my sister's life.

She didn't buy it.

"The mother in your novel is having an affair?" she asked quietly. I'd sent her a galley copy by now; the affair was there on page 1. "Why?" A tremor in her voice; she sounded bewildered. "People will think it's me."

"They won't," I told her. "So much is made up. Honestly, it's just one more thing." I started ticking off the list: the fictional mother's best friend was based on *my* best friend, the husband on my

husband; the teenage child was a boy not a girl; the child's doctor was an Indian woman, nothing like the man who cared for my nephews.

"The child dies of mitochondrial disease, Maribeth. *Of course* people will think it's me."

"But it's not," I pleaded. "Have you read the whole thing?"

She was silent. And then, "I can't," she said quietly. "But glancing through it, I happened to see a description of the little boy standing with his feet together and his arms spread out, telling his mother that he was the letter Y." Her voice broke. "That's Sam." She began to cry. "I thought you said you wouldn't use my life."

"But that's just a detail," I said. "One tiny detail! One tiny detail out of thousands!"

She didn't see it that way and I get this. I do. It wasn't just a detail. It was her child. And in truth, when I read the description myself, it's not a fictional boy I see either. It is Sam. He's five or six, and he's grinning proudly because he's learning his letters. I watch as he lowers his arms, holds them straight out from his body and announces, "Look! Now I'm a T!"

It's not just a detail to me either.

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The autumn before the book's publication, when I emailed my sister to tell her I'd like to dedicate the novel to Sam, and she phoned in response, her voice coiled with anger and said, "I prefer you not use his name in your book at all," I shouldn't have been surprised.

But I was.

I sat in the hard-backed chair at my desk, unsure what to say. How could I *not* dedicate the book to Sam?

Outside, it was a blustery beautiful day. *I prefer you not.* The words reverberated. I thought of an interview I'd once read with the writer Edwidge Danticat, who said that everything she ever wrote was practice, in a way, so that she could learn to tell the story of her brother's death of AIDS. That afternoon, I understood what she meant: I realized that everything I'd written in the past twenty years had been to teach me how to tell this story, the one about loving – and losing – Sam.

On the phone, my sister's voice was like something polished to

such a sheen that nothing remains but the glare on its surface. *I prefer you not* . . .

“I won’t use his last name,” I said.

“I would prefer you not mention his name at all.”

I can still picture where I was sitting that day, can still see how the bright yellow leaves of the tree outside seemed to heave themselves against the blue sky. *I prefer you not*. The colors blurred. I sat doubled over, clutching the phone and understanding in a place so deep I could barely acknowledge its existence that dedicating the book to Sam might have been the reason I’d written it to begin with.

I think I asked my sister why I couldn’t dedicate it to him.

She said something about not wanting people to associate my book with her child.

For a moment it seemed the leaves had turned blue, the sky yellow. Everything the opposite of how it was supposed to be.

*My* book.

*Her* child.

Even then, I registered the pronouns, the sharp blades of those two words against the thousands I had written.

I imagine I tried to reassure my sister – no one would think the mother in my book was her. It was fiction. Perhaps I reminded her that when our older brother read the manuscript, he felt relief, he said, because the fictional mother was so *not* like her. But I can also imagine that I said nothing. Sam was dead, and Zach was dying, and who cared if I didn’t dedicate my book as I wanted?

I asked if I could dedicate it to Sam by using the pet name I’d always called him.

*Hey, Big Goose*, I’d say.

*Hey, Little Goose*, he’d laugh.

And so the dedication page of my novel reads, *To my Goose*. It was the first page I looked at when I found it in the bookstore the day it was published. *To my Goose*. It’s still my favorite page. But I have never looked at it without recalling that conversation with my sister.

I hung up the phone, wanting to cry but not being able to, wanting to phone someone – my best friend, my mother – but not knowing what to say. I recalled the agreement my sister and I had made all those years ago. All those years ago when she glanced up

at the ceiling where the boys were sleeping, were still alive. I wouldn't write about her life; I wouldn't write about her children.

In many ways, I hadn't.

I had kept my promise.

The novel was not my sister's story.

But what I'd done was worse: I took her story and twisted it into something else. It was the same thing the Munchausen accusation had done. And whoever made the accusation? For whatever reason – call it profound misunderstanding of mitochondrial disease or profound misunderstanding of my sister, call it ignorance even – I suspect that this person imagined, hoped, *believed* that she (it was probably a she) was somehow saving my nephews, was helping.

I felt nothing but disdain for that person. *You stupid blundering fool*, I thought. And yet, I'd basically done the same thing. Had I really thought my book could help?

"It is all too natural for people who have been wronged or humiliated – or feel they have been," writes Janet Malcolm in *The Journalist and the Murderer*, "to harbor the fantasy that a writer will come along on a white steed and put everything to rights." In truth, "the writer who comes along is apt to only make things worse."

I'm not sure how long I sat on my couch that day. The sky grew dark. I didn't turn on the lights. Sadness and confusion knotted inside me, but more than anything what I felt was shame. A bright incandescent shame that made me glow in the dark.

Shame that what I had done, what I had written, was so distasteful to my sister that I was not allowed to use my nephew's name.

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I wish this had been the end of it: I don't use Sam's name, and my sister realizes that I never meant to hurt her. But it isn't the end. There's an afternoon shortly after Christmas when my mother goes to my sister's, excited about a review she believes will make my sister feel better about the book. I wasn't there, and I don't know which review it is, but I imagine it's one of those that comments on the mother's fierce love in the face of intolerable grief, her unswerving dedication.

This is the first Christmas without Sam. Eight months, twenty-two days. I wouldn't have known the number, but my sister does. I picture them in the family room: my mother, her husband, my sister and brother-in-law, my nieces, and Zach. The tree is lighted, piles of opened presents beneath it. Christmas music on the stereo. My sister sets out decorated cookies and bowls of nuts. There's something unfocused in her after Sam dies, the way she drifts into rooms, picking things up and setting them down, forgetting what she's looking for. Still, I imagine she's trying her best to enjoy the afternoon.

And then my mother mentions the book review and everything careens to a stop. A hole is smashed through the day. My sister freezes in the doorway of the family room, then lambastes my mother: *How can anyone in the family think it's okay what she has written in that – that book? It is so far from okay, it's . . .* I don't know her exact words. I only know that her tirade goes on. My mother tries to stop her, but this only enrages my sister more. *I'm sick of people defending her. It's disgusting what she has done.* No one looks at her. They stare at the carpet, at the unwrapped gifts. *What?* my sister demands. *You don't think I have a right to be angry?* She is in tears now. People who trusted her, respected her, now wonder, What's true about my book, about *her*, what isn't? The boys' doctors and nurses and therapists, her colleagues, people in the United Mitochondrial Disease Foundation, people at church, the girls' schools.

*Do you have any idea, she sobs, what it feels like to have your whole life questioned?*

My mother told me that Zachary in his wheelchair across the room was crying too.

I think of this often. Did he die wondering if I'd used him to sell books the way I apparently had his brother? Did he die questioning whether I'd ever really loved him?

What is fiction?

What is real?

Another day, I'm invited to give a reading from the novel at a high school near Children's Hospital, where my sister works and Sam and Zachary spent much of their lives. I'm given a choice of dates. I choose the one that falls on what would have been Sam's ninth birthday so I can be in Wisconsin with my family on this

day. My sister is furious. “You’re using his *birthday* now?” she asks me on the phone.

I change the reading date.

But it’s too late.

I stand on the stage of the school auditorium to read. When I finish, a student asks, “How do you know so much about that disease?”

I mention my “research,” give vague answers. The glare of stage lights makes it impossible to see anyone’s eyes, and I am grateful.

Another student asks who “goose” is. My nephew, I say, careful not to use his name.

Afterwards, I drive to the cemetery. Sam’s grave is crowded with Buzz Lightyear balloons and orange flowers and orange wind chimes and pinwheels, and I picture my sister coming here every day with these gifts for her dead child. Beside Sam’s grave is the grave of a little girl named Megan. My sister chose this plot because Sam would not be alone here, with another child nearby.

It is unfathomable that anyone can cause my sister more pain.

And yet I have. And I will. Every time I give a reading or someone reviews the book or an acquaintance of hers mentions having read it.

Does it matter anymore that my intentions in writing it were good?

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I watch a video of the novelists Richard Russo and Andre Dubus III. Dubus is recounting Russo’s advice from when Dubus was struggling with how much about his family to include in his memoir.

The novelists sit at a circular desk, coffee mugs in front of them, shirt collars open, their postures casual, relaxed. I notice this, perhaps, because I am sitting so straight against the hard-backed chair at my own desk. I am tense. I know, even before Dubus speaks, what Russo’s advice to him was because it’s advice I’ve heard writers offer time and again when the question arises: Is it okay to write about family and friends? I know, because it’s advice I have offered, time and again, advice that six years ago, I believed. This morning, though, it puts a knot in my stomach.

“You asked,” Dubus reminds Russo, if I was “trying to skewer anybody by writing this book and if the answer is yes, I either wouldn’t write it or I wouldn’t publish it. If the answer is no, if I’m just trying to capture as honestly as I possibly can through my subjective memory what it was like, then I go ahead and write it.”

I turn off the video and move to the window, where, although it is midafternoon, midsummer, the light is bleak and wintry, rain slamming down relentlessly in heavy sheets as it has been all morning. As long as you aren’t *trying* to skewer someone, it’s okay, even if that’s in fact what you end up doing? As long as you don’t *mean* to hurt the other person, don’t *mean* to violate her privacy? But *I didn’t mean to* seems childish and irresponsible, though I’ve said these words about my own book more times than I can count – *My intentions were good, I never meant, I was only trying* – and yes, these things are true. But equally true is that I knew people would assume that the mother in the book was my sister, I knew they would question what was real, and I knew that my sister, rightfully so, would be upset. That she was devastated, that she felt so horribly betrayed I hadn’t anticipated, but isn’t this just a matter of degree? I knew I would cause damage. I *knew*.

And I wrote the book anyway.

And yes, I thought that because it was fiction it wouldn’t damage her *as much*. How many times had I heard writers say *I’ll have to turn it into fiction* when contemplating writing a true story that might hurt someone they love? How many times had I said this to a student? *You can always make it fiction*. And for the *n*th time, I remembered that day in my sister’s kitchen when the boys were asleep in the room above us. *Don’t write about me*, she said, both of us believing, I see now, that I could protect her story *because* I was writing fiction.

But the distinction between fiction and nonfiction that I’d held out to my sister (and perhaps to myself) as a kind of promise was false. Because however we begin and in whatever form we are writing – fiction, nonfiction, poetry, memoir – and regardless of our good intentions, we are lifting from someone’s life an event or a story or a character or maybe just one detail (one tiny detail out of thousands!), and we are changing it, using it, twisting it for *our* purposes. And perhaps (we hope) it’s art that we’re creating – for

why else do this at all? – and perhaps it’s beautiful or disturbing or important, even, but it’s still someone else’s story that we’ve ransacked for the raw material.

As one writer says to another in Leslie Pietrzyk’s story “One True Thing,” “What happens – no matter how painful – it’s material for people like us. You know that. You chose it when you became a writer.”

People like us.

“Writers are always selling somebody out,” Joan Didion wrote in *Slouching Towards Bethlehem*. And “Don’t think you can write your way around hurting someone,” says the memoirist Patricia Hampl. “If you want to be a writer, somewhere along the way, you’re going to have to hurt somebody,” Charles McGrath, former editor of *The New Yorker*, once commented. “And when that time comes you go ahead and do it.”

I thought I’d feel less alone, maybe less culpable, knowing that other writers, writers I admired, had struggled with this issue. Instead, I was surprised by the sadness that rose up in me. This was not why I had become a writer.

“Congratulations,” a friend told *The Sun* associate editor, Krista Bremer, after her father threatened to sue if she ever wrote about her family again, “If you pissed your family off that much, you got it right.”

*Congratulations?*

No, I thought. *No*. These responses felt as disingenuous as the “I didn’t mean to’s” and the “as long as you don’t intend to hurt the other person” platitudes. One stance is all white lace and Mary Janes and *oh gosh!* naïveté and the other is a shrug, black leather jacket, cigarette-hanging-from-a-curled-lip nonchalance. But in between is a vast darkness filled with longing and hope and fear (*Maybe you should write about this, Maribeth, maybe it could help*), and it’s so much messier and more complicated and sad (*Maybe I can bring attention to mitochondrial disease*) than any – any – of those quotes suggests.

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Not long ago, I sat in my local bookstore listening to the poet Sue Ellen Thompson talk about *They*, her collection of poems about

her transgendered daughter. When someone in the audience asked how her daughter felt about the book, Sue Ellen's face crumpled. Her daughter was very unhappy, Thompson confessed, and refused to discuss the book. Shoulders squared, head held high, Thompson spoke of her efforts *not* to write about this subject for nearly a decade. She was staring at a spot just over our heads. "But this is what I do," she said. "This is who I am."

I recognized the note of pleading in her voice. Or maybe helplessness. It is a Sophie's Choice. And it is unbearable.

But not – as people are too quick to assume – *not* because Sue Ellen Thompson thought her poems more important than her daughter, though some made comments about her being a better poet than she was a mother, and *not* because I ever thought my novel was more important than my sister or what she was going through, although certainly my sister – and who knows who else – made similar comments about me. *You used my child to sell your book.* The truth is so much simpler. I wrote and published my book, knowing that it would cause my sister pain, because I believed that once she actually read it, she would understand: no matter what else the book was – a commentary on Munchausen accusations and motherhood and medicine and grief – it was also a love story to her and Sam. I truly believed she would eventually see this. I believed it when I sent her the galley copy, and I believed it the day she phoned to say that she didn't want Sam's name in the dedication – *I prefer you not.* I still believed it the December afternoon when my mother told me of her tirade, of how Zachary had been in tears. *Once she reads it,* I kept believing, until finally I stopped. I'm not sure when – perhaps that day at Sam's grave when I stared at the rectangle of new grass that had grown over the place where the ground had been dug open the year before and understood finally that my sister would never read my book; it would always be too painful. It would always feel like a betrayal.



My sister and I never talked about those months surrounding the publication of my novel. It is too raw, I think, for us both. We've never talked about the novel at all. Time passed and we moved on.

We had to. We marked the one-year anniversary of Sam's death, then two years. Zachary died. My oldest niece graduated from college; Abby graduated from high school.

At first I didn't worry about my inability to write. I was teaching too many classes, I thought, working too many odd jobs. I tried writing prompts, tried writing in new places. Still nothing. Increasingly, I felt bewildered, even angry, a tightness in my chest that reminded me of being pushed underwater as a child and trying to breathe. Not once, though, not ever, did I connect my inability to write to what had happened between my sister and me six years earlier.

Not until that moment in the grocery store on New Year's Day when Abby said she was grateful I'd written my novel, not until her words hit so hard at a place so deep I hadn't known it existed did I see the connection. I didn't understand it fully, and wouldn't until I wrote this essay. There was only the disproportionate gratitude I felt toward my niece and the sense that she'd handed me a gift, though I didn't yet know what it meant.

I can still see Abby that day – blond hair falling on her shoulders, her gray wool coat cinched at the waist, then flaring out in pleats, the high-heeled black boots. Earlier, the family had been sitting around my sister's kitchen table, asking Abby about her first semester at college – was it what she expected? Did she like dorm life? What about the guys? She described the sixth floor of the dorm where she lived and how the guys called her and her floor mates “The Chicks on Six” or “Sexy Six.” She blushed, dipping her head down and hiding behind her hair. It's easy to forget in those moments what Abby has been through, what she has lost.

That day, her boots echoing in the grocery store, Abby set a box of Cheerios in the cart I was pushing, then moved down the aisle. “It was awful,” she said over her shoulder, “but Christmas morning, I don't know, I just didn't miss my brothers or feel sad about them not being there.” She grabbed a box of Wheat Chex. “It really bothered me.”

I nodded. In March it would be seven years since Sam had died. Soon he would have been dead longer than he was alive. Abby was eleven then. A little girl. I remembered her playing a song at the

funeral that she'd written for Sam. The clinking tinny notes of the out-of-tune piano, tears dripping onto her hands.

"Anyway, after breakfast I started reading your novel and it was like they were there," Abby said as we set our things on the checkout counter. "God, I felt so sad! I missed them so much." She laughed nervously. "It probably sounds really weird," she said, "but I felt so much better." She paused. "You just, you captured them." And then she repeated her words: "I'm so grateful."

I told her I was glad, that it meant a lot to hear this. We were outside now, the light nearly gone from the sky, the snow still falling. I felt bruised inside. I thought of a friend who'd been in an accident that totaled his car. He walked away, seemingly unscathed, unaware that he was hurt until a day later, when he saw in the mirror the dark green and black and purple swath of bruises across his entire right side.

That we can be so damaged, I thought, and not even know it.



After my novel was published, I received a handful of emails from parents whose children had mitochondrial disease who thanked me for writing the book. I wanted those letters to compensate for my sister's pain, and maybe for my own — proof that what I had done mattered, that at least my novel had helped someone.

They were strangers, though.

She was my sister.

And nothing would ever compensate for her pain. She'd lost a child and within two years would lose another, and she felt betrayed by everyone and everything, and she had good reason to.

But Abby.

Abby is my niece, a very real girl who lost two brothers. And for five or ten minutes on Christmas morning, words *I* wrote over seven years ago brought her brothers back to her. This doesn't undo the damage to my sister; it doesn't compensate for it. What does that even mean? But Abby's words allowed me believe again that writing does matter, that stories do keep us alive, do allow us to *not* die. And not in the abstract.

A real boy. *Sam*.

A real boy. *Zachary*.

*I just started reading your novel and it was like they were there.*

And so I write again. Trying to understand what Abby gave me with her words, what I'd given her with mine, written all those years ago when her brothers were alive. I weigh my sister's experience, that in writing her story, I'd stolen it from her, and in a way I had, against my niece's experience, that I had somehow given her brothers back to her. In one version I have killed something; in one version, I have saved it.

Both are equally true.