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The Iowa Review

Volume 34
Issue 3 *Winter 2004-2005*

Article 12

2004

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Laura S. Distelheim

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Recommended Citation

Distelheim, Laura S.. "On Leaving Normal Behind." *The Iowa Review* 34.3 (2004): 67-79. Web.
Available at: <https://doi.org/10.17077/0021-065X.S889>

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LAURA S. DISTELHEIM

On Leaving Normal Behind

I'm still here to tell you this story so, already, you know mistakes were made. Look: A conference room deep within the labyrinth of a large Midwestern hospital, its windowless walls the color of nowhere, its lights glaring like lidless eyes, its air leaden with the sadnesses it has swallowed. Over there, sitting side by side at the far end of the table, those are my parents, and, over here, at this end, the white-haired man with his back to us—opening his file, reading over his notes, taking a pen from his pocket, glancing down at his watch—is the doctor. No. As we had been told repeatedly when we were referred to him: The Doctor. And those white-coated people lining either side of the table—looking at their notebooks, at each other, at the ceiling, at the floor; looking anywhereanywhereanywhere but at my parents—are his interns, resembling jurors waiting to announce a guilty verdict. The Doctor clears his throat and they turn, in one motion, to face him. My parents disappear, leaving statues in their place. “It’s pancreatic cancer,” he says, not bothering with a prelude, and, up and down the table, the interns lift their pens. *Notes for December 23, 1974.*; they are writing. *How to tell parents that their child will soon be dead.*

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It’s four months before that moment and I’m riding in the back seat of a car on Cape Cod, returning to a rental cottage from dinner at a seafood restaurant, feeling sick. I press my forehead to the cool of the window and try to distract myself by listening to my family—my parents in the front seat, my two sisters with me in the back—talk about our plans to go sailing tomorrow afternoon and to drive to New Haven the following day to drop my older sister off for her first year at Yale. I sit back in my seat and look out the window and see there, hanging in the blackness, the ghost of my own image, looking back. It is right then, in the jolt of that instant, that I know.

What is it exactly that you know? my parents will ask me later, when I try to explain it to them, but I won’t have an answer to offer.

I won't be able to translate into words that hot shiver beneath my skin, or even to connect that premonition to the fact that eating dinner had made me sick. *That*, we'd all decided, was indigestion or a bad piece of fish, a touch of the flu, an allergic reaction, or some such thing. That I'd brushed away as unimportant. But *the feeling* lingered on, its breath close against my neck, no matter how fervently I tried to disengage it. It is only now, these many years later, that I have an answer to their question, that I understand what it is that my pounding heart already knew: The next four months would determine if I would go on living a normal life and the bell charged with starting the clock to trigger the countdown had just rung.

It's two weeks or so later and I'm sitting on an examining table in the office of the gastroenterologist to whom my internist has sent me, wishing I were at the tryouts for the school play instead, thinking that there's nothing like putting on one of these green, open-backed gowns to let you know you've fallen out of the world. Although I've started my senior year in high school, have resumed my lessons in piano and painting, have gone back to doing volunteer work at a local day care center and to spending time after school with my friends, I haven't yet resumed my *real* life. In this life that I'm now living, I bob and weave my way through my days, embroiled in a never-ending boxing match with pain. The discomfort I'd first felt on that night in Cape Cod has returned and returned and returned again and again, has progressed like a photograph negative placed in developing fluid, growing sharper, clearer, more distinct and more *there*, moving from the pale pink of nausea to the scarlet of a searing abdominal blaze which is reignited every time I eat, and then sizzles for hours after. "So," says the doctor—tall, bald, bespectacled, unsmiling—stepping into the room with a file in his hand, "You've been having some pain," and I nod. He asks me some questions, has me lie down, palpates my abdomen, says he'll order some x-rays and then adds—casual, offhand, as if merely making conversation before stepping out the door—"Your internist mentioned to me that your sister has just left for college. I'm sure you miss her an awful lot," and, without thinking, I say that I do. Without thinking, I say that I do, leaving me to forever wonder: Would things have turned out differently had I said that I did not?

By the time my mother and I are sitting across the desk from the fourth gastroenterologist six weeks later, I'm able to recite his lines

to myself verbatim before he speaks them, having sat across three similar desks in three similar offices, hearing them spoken by three other doctors in three identical tones. He's repeated the blood tests and the x-rays and has found nothing abnormal to speak of. He's read the notes the other doctors have sent him and agrees wholeheartedly with their unanimous conclusions. *It's time we start taking a look not at your body, but at your life as a whole, young lady. Your sister has just left for college and you miss her. In fact, you first started complaining of this discomfort just before leaving her there. I'd say that's a clue we'd be remiss to ignore. You've said that the two of you are very close and that this is the first time you've been apart. Not only that, but she's gone to Yale—quite an accomplishment, I'd say—and here you are, an A student yourself, from a highly achieving family. Your father's a doctor, isn't he? Could it be that you're hoping to be accepted to Yale as well? Would you not admit that you're dealing with an unusual amount of stress these days?* And, this time, with 25 of my 120 pounds having melted from my 5'7" frame, there is more: *I'm going to be frank with you because you can't afford for me not to be, his frown now aimed toward my mother instead. You don't have to have a medical degree to know, with one glance at your daughter, what's going on here. She fits the classic picture of an anorexic teen.*

This is when I leave the room. I don't stand up or even shift in my chair, but I'm no longer there, no longer allowing this to be happening to me. We will go home the moment his lips stop moving and I will be fine. We will go home. I will eat dinner. It will not hurt and I will be fine. I will put on my old life, zip it up the back, smooth down its skirt and head out onto the dance floor. *Remember that strange episode?* we'll all ask each other someday, looking back and laughing, shaking our heads in wonder. And I will barely be able to recall it. "But what about the *pain?*," my mother is asking, somewhere faraway. "She doubles up with pain every time she tries to eat. I've never heard of pain being one of the symptoms of anorexia. She's this thin because the *pain* makes it impossible for her to eat. She never even *talked* about dieting before this all began." And: *These girls can be plenty crafty* is his answer. *There's no way for you to know what they're thinking. They'll do whatever they need to do, say whatever they need to say, to avoid eating.* "And the weakness?" my mother pushes on. "She's so weak she can barely stand anymore. I've always heard that girls who are dealing with anorexia are mys-

teriously energetic." *Until it catches up with them*, he replies. *Look. It's as simple as this. Calories are energy. No calories, no energy. I'm not going to argue with you.* But my mother's going to argue with him.

"Can you just humor me for a moment, doctor?" she asks, deciding to interpret his scowl as a "yes." "She's *constantly* clutching her left side. Can you just tell me what organs are located there?" His answer rides the surf of a sigh—*There's her stomach. There's her pancreas. There's her gallbladder, but I'm telling you*—but my mother has already seen a life raft in that last word. "Gallbladder disease runs in my family and she *did* become ill that first night after eating fried shrimp. Aren't fried foods known to exacerbate gallbladder disease?" There is a half-beat of silence and then: *I can tell you right now that your daughter does not have gallbladder disease.* Even his voice is rolling its eyes. *In all my years of practice, I have never seen or even heard of gallbladder disease in a sixteen-year-old. I'm happy to order a gallbladder test to prove it to you, but, after that, I'm telling you that you had better start facing some hard truths here if you care anything about your daughter.* His face slams shut and he rises to dismiss us.

It's three days later and I'm lying in the back of the car on my way home from the gallbladder test, writhing. The test had consisted of my drinking a large cup of a fatty substance, after which my gallbladder had been x-rayed, but I had been only a few gulps into the cup when my world had blackened with pain and, by the time my mother poured me onto the back seat afterwards, I had bitten through my lower lip. I watch the tops of naked trees glide across the flannel sky and hold onto my mother's voice to keep from fainting. *Almost home now. We're almost there. Just a few more miles*, she is saying. And: *I know it doesn't feel like it to you at this minute, but your getting so sick from this test is the very best thing that could have happened.* And: *Now they'll have to get it, honey. They'll just have to. It'll be right there in front of their eyes the moment they read those x-rays.* And: *Didn't I tell you we'd find the answer if we just hung on a little bit longer?* Every few minutes, the back of her head becomes her face as she glances over her shoulder, still talking nonstop—talking even though she knows I cannot answer, because she can hear me stumbling around in the darkness and if there's one thing she's come to understand by now, it's that hope is the only night light we have left.

We're sitting at dinner the following evening—my parents, my younger sister and I—and my mother is feeding me so that I can

use both my hands to keep an ice pack pressed in place against my side. This is the system we've been using ever since the pain has reached the point where each bite I take sends the slice of a machete beneath my ribs. I'm focusing on the conversation with fierce attention, trying not to notice when the next bite of food is coming, and my sister is doing her part: talking without punctuation—without commas or periods or semicolons, with barely a sliver of a breath of a pause, and then and then and then and then and then and then about the going on in her seventh grade class—when the phone rings. My father gets up to answer it and the slam of silence across the kitchen is our only admission that we've been waiting.

"Oh, yes," he says, "thank you for calling. We've been anxious to know the results. Uh-huh. I see. But her response to the test was so violent that I was certain . . . I know gastroenterology isn't my specialty, but it seems to me that there *has* to be a clue there in the amount of pain she experienced after ingesting that fat. Even if the test showed no stones, don't you think there'd be some value in pursuing this further? Yes, I understand. Just as you expected. Uh-huh. Uh-huh. Okay then. Thank you for letting us know." He returns to his chair and picks up his fork and, although my sister's eyes have filled, she picks up her sentence mid-word, where she had dropped it. Outside, across the lavender dusk, I hear the whistle of the 6:06 from the city sliding into the train station at the center of town and, in my mind, I see a stream of passengers hurrying down its steps and rushing to their waiting cars; see them driving to their homes and pulling into their driveways, see them shaking off the day and slipping on the evening, sitting down to dinner and saying to their children, "So tell me, guys, how did things go for you at school today?" "One more bite," my mother says and I close my eyes and take it.

Early one morning last week, I drove away from my house in a fog so thick that the gleam from my headlights crashed against it, so disorienting that I had to turn back within a few blocks and inch my way home, crawling along roads I travel every day, now chillingly unfamiliar, their lampposts and street signs and hedges and trees looming into view and then vanishing again at random, so that, by the time I finally reached my garage, I was drenched in panic. It was only later, when I could breathe evenly again, that I realized that

those moments in my car had returned me to an evening I had lived all those years ago, a week after the gallbladder test: I'm sitting on the couch in my family room, feeling homesick. In the past month, I've watched my life fall away in layers like skin peeling from a body that's been badly burned and, sitting here now, I am suddenly realizing that I no longer recognize what remains. The first layer I'd had to slough off, late in September, had been made up of most of my extracurricular activities—the yearbook staff, the literary magazine, my work at the day care center—and the time I spent outside of school with my friends. And no more than a week or so after that I'd had to shed my piano and art lessons, too. By early October, it was the school layer itself that had begun to shrivel, with the principal arranging for me to consolidate all my classes so that I could go home every day by noon. And then, ten days ago, I'd sat in his office again, casting off the layer that had held my world together since I was five. No longer having the stamina to make it even through the mornings, with the pain now commanding my full attention every moment of the day, I had had no choice but to drop out of school.

The doorbell rings and I hear my father answer it. "Don't you girls look lovely," he says to the three friends who had called to say they'd be dropping by—his voice too bright, too cheerful, as if they've come to pick me up for the Halloween party instead of to *visit me* on their way there; as if I haven't turned into (when? I don't remember how it happened) *one of those kids* whose lives become the kind of TV movies that people watch to make their own troubles seem suddenly smaller. They come into the room already talking, dressed as the Brady Bunch girls and already talking, having prepared themselves for the fact that I've become too weak to help them out by talking back.

You won't believe it, they're saying as they settle into the three chairs my mother has arranged near the sofa. Nancy and Matthew broke up after all that time together and he's already asked Elizabeth to the dance. And did you hear? It's all over the school. Dan was kicked out of Leopold's class for the rest of the month for mouthing off again. Anna was there when it happened and she said that Leopold just about lost it. Oh, and listen to this! Jennifer decided to apply for early admission to Princeton? And if she gets accepted, she can just coast for the rest of the year. Can you imagine? I'm trying to keep up with the meaning of their words, but the pain in my side is keening and I'm having trouble remember-

ing what it feels like to be young. There is fog, the color of cement, everywhere I look, and the gleam from my headlights is crashing against it. There are lampposts and street signs and hedges and trees looming into view and then vanishing, looming and vanishing, whichever way I try to go. I no longer know where I am.

I'm lying in a hospital bed a week later, after my internist has had me admitted for three days of i.v. sustenance, to correct an imbalance in my electrolytes that has been caused by my lack of nutrition. My parents and sister have been gone for half an hour when the door swings open and an unfamiliar doctor steps into the room, trailed by a dozen medical students, who encircle my bed in silence. This is a teaching hospital and, at the moment, I am the lesson. *Sixteen-year-old Caucasian female, 5 feet 7 inches, 72 pounds, complaining of abdominal pain*, he reads from his notes and, then, handing them to one of his students, presses his fingers beneath my ribs. I inhale sharply and feel my eyes fill, but bite my lip and dig my nails deep into the flesh of my palms, determined not to let myself dissolve before this audience of twenty-six unblinking eyes. Tears, I have long ago learned, will be taken as conclusive proof of my instability. *As you can see*, the doctor announces to the air, *there's no evidence of pain here at all*. The students record his words in their notebooks and file out the door. I stare after them for a moment and then reach for the phone, but by the time my father picks up the receiver at his end, all he hears coming from it are my sobs. "Sweetie," he says, and, "I know," and then there's a pause in which I can hear his heart break.

Everything about our drive to the second hospital two weeks later beneath a charcoal sky bruised with November is shouting *last chance*. There is one month remaining before that clock, set in motion that first night in Cape Cod, will count down to zero. It has taken networking, connections, the pulling of strings, to be accepted as a patient by this doctor. The Wizard, some call him, or the Pope. The entire Supreme Court in a single white coat: The Doctor. There are rules we should know from the start, his office administrator has called to inform us, and the most important of all is that every test, every x-ray, every scan and every scope I have endured in the past three months no longer counts. The Doctor accepts data from no lab but his own. It is larger, this hospital, and darker and farther from home and there is a crevice somewhere deep in my memory

where I will store the images I am to gather there. They will be like snapshots taken on a battlefield and then tossed in a cardboard box to be stored in the furthest corner of a musty attic, too gruesome to look at again, too momentous to throw away:

There I am on that first afternoon, lying in bed in Room 763, meeting The Doctor. "Well, you're quite a puzzlement, young lady," he says and then, turning to my father, runs down a list of the tests that he has planned. "Will you be repeating the gallbladder test?" my father asks. "I've always thought her response to the first one was significant," and The Doctor laughs and shakes his head, turning to the resident who is standing behind him. "What's the profile of a gallbladder patient?" he asks and: "Fair, fat, fertile and forty," the resident recites. Later, when The Doctor leaves, the resident stays behind. "So this all began while you were taking your sister to college?" he asks, his pen poised to jot down my answers on an Intake Interview form, and, before I can answer, he adds, "I bet you really miss her, don't you?" He's bouncing the heel of his shoe against the wall behind him as he speaks and I can see a knot in my mother's jaw, pulsing in time with its cadence.

And there I am later that night, sorting and labeling the unfamiliar shapes that are interwoven in the darkness (there's the i.v. pole, the coat rack, the supply cart, the chair) and listening to the nocturnal rhythms of the hospital rippling around me (the tap tap of the nurses' rubber soles up and down the hall outside my door, a siren wailing to a halt in the street below my window, the ping of the elevator bell, somewhere off in the distance) when the air is rent by a moan so charged with grieving that it pimples my back with gooseflesh. "Mrs. Andrews," the nurse tells me when she comes in to check on my i.v. "You'd better get used to it. She does it all the time." It isn't until slivers of dawn have begun to slide between the slats of my shutters that I fall into the first of many dreams in which I'm struggling to swim my way through a river of moans.

And there I am, inching down the hall on a walk with my mother, my i.v. pole rolling between us. I stop to lean against the wall for a moment and my mother smiles at a man who has stopped to lean against the opposite one. When he smiles back, his face creases into a jagged terrain of angles and furrows, ancient with illness, though he must be only thirty or so. "I know it's not easy," my mother says and he attempts another smile. "I used to be a runner," he breathes,

his voice a whisper wedded to a plea. "I used to be a businessman." And then we make our slow way down the hall again, like underwater search parties hunting for signs of our remembered selves.

And there I am, lying on a gurney in the hall outside the radiology lab early one morning, waiting to be wheeled inside for a test, pressed flat up against the wall where the orderly has left me. I watch the torsos scurrying past—in lab coats, in surgical scrubs, in nurse's uniforms, in candy stripers' smocks—and listen to the threads of conversation that trail behind them, and I wait. And there I am, two and a half hours later: still waiting. My own voice has dwindled along with my body so that it's now a faint outline of its former self and, when I try to call out, to catch someone's attention, nobody hears. The nurse who had transferred me from my bed to this gurney had swaddled me within a nest of several blankets to keep me warm and I haven't the strength to pull my arms from beneath them to wave someone down. I have been lying here for two and a half hours. I have been lying here for a hundred years. I can't remember ever having been anywhere but lying here and I know now that I will never be anywhere else again.

And there I am, late one afternoon, lying in my bed, not moving, holding even my breathing still, focusing my full attention on The Doctor's voice outside my door. *It's been three weeks now*, I hear him say to the interns who I know have gathered in a circle around him and then, from a blur of words which I can't understand, I pick out *negative* and then *negative* and then *negative* again. My heart is pounding in my ears now but, before it blocks his voice completely, I hear a *no progress* and a *psychosomatic* and then the door is swinging open and they're filing into the room and surrounding my bed to evaluate me.

And there I am late on a Saturday morning, with my mother and sister having just arrived, carrying a box of doughnuts they've brought to leave at the nurses' station. The moment they step through the door, filling the room with its sugary perfume, I'm back on a Saturday morning last winter—*any* Saturday morning last winter—with my sisters and me still in our pajamas, at the kitchen table, our collie stretched out asleep at our feet; with my mother getting up to pour herself another cup of coffee, asking who wants another piece of French toast; with my father sticking his head in the door, saying, "Bye, all. I'm running late," and our laughing

because he runs late every day; with the branches of the maple tree peering in the window, jeweled with snow.

And then my sister comes to sit on the edge of my bed and I'm back on *this* Saturday instead, where, until they'd arrived, the air had reeked of antiseptic and medicine and airlessness and fear, where she has been sent to live at a friend's house and the collie to stay with my aunt, where my mother drinks watery grey coffee from a vending machine and my father spends so little time in his office, he no longer knows if he's early or late; where, at home, the kitchen sits silent and still, its air stale and cold and unmoving, and even the maple tree peering in the window is drooping, bewildered. "You want to run these down the hall?" my mother asks, handing my sister the box, and my sister says "Sure," but she doesn't move. She sits there instead on the edge of my bed with the box on the blanket between us and we stay there, the three of us, in the ashen winter light, inhaling the fragrance of *usedtobe*.

And there I am, lying on a table in the radiology department, trying to ignore the crush of my hot bones against the icy steel beneath me, about to undergo a duodenal drainage. "It's a test you haven't had done before," The Doctor has explained, "in which we'll draw cells from your bile duct." My father is standing next to me, his hand resting on my shoulder, talking to me to try to distract me from the sounds coming from the patient one table over, behind a curtain, who is choking and gagging. The lab technician hands me a long red rubber tube, a quarter inch in diameter, and tells me to swallow it down as quickly as I can. I look at my father, see him looking at me. "I'll have had enough practice to be a sword swallower by the time this is over," I say and we both laugh a laugh that is really a parachute. I put the tube in the back of my throat and start to gulp. My father squeezes my shoulder and smiles but, above his smile, his eyes are playing violins.

And there I am, lying in my bed a few afternoons later, waiting. My parents are meeting with The Doctor and his interns in a conference room somewhere deep within the labyrinth of the hospital and they'll soon be coming back to tell me what he's said, though I already know. I already know that, right this minute, he's telling them that I will be transferred to the psychiatric unit; that he's found that not a thing has gone wrong in my body, so something must have gone desperately wrong in my head. A pigeon lands on

my windowsill and stares in at me, an ambassador from the real world, and, as I watch him cock his head and then fly off again, I understand that there is no longer any road that I can travel to get back there. There are no more doctors to see. No more tests to take. No more chances. And no amount of talking to a psychiatrist is going to make this pit bull of pain loosen the grip of its teeth on my side. No one, not even my parents, can save me now and there is nothing I can do to save myself.

I try to raise my knees, to scoot up further on my pillows, but I'm too weak to move, to even turn over, without assistance. I am tissue paper muscles and spun glass bones knit together with needles and tubes and I know that all I have to do to leave reality forever is to stop all this fighting back and just let go. For an instant, I think that I will, but then I find that I cannot. A cart squeaks past my door. A nurse sprays words through the intercom. Mrs. Andrews releases a moan. And I lie there, unmoving, in my bed, alone inside the borders of my skin, not *letting* insanity wrap its arms around me.

Six floors down and four doors over, the echo of The Doctor's words—*It's pancreatic cancer*—continue to smoke in the air, even though the shriek of their initial explosion has now dwindled to a whine. He has since been tossing other words, like aftershocks, behind them—*The duodenal drainage culled cells which are malignant. We'll have to operate as soon as possible. We'll be doing the Whipple procedure—removing her common bile duct, part of her duodenum, 40% of her stomach and the head of her pancreas—but not until we can get her considerably stronger. Ten days or so of high-intensity nutrition fed into a vein near her clavicle ought to do it, I should think*—but it's hard to know if my parents are even aware that he's still speaking. My father has not moved, his body locked within a violent stillness, but my mother is staggering to her feet, her eyes scanning the walls for an escape route, her hands a vise on the table's edge. She is Jackie Kennedy in that convertible in Dallas, clawing her way back toward an earlier moment. And then she is suddenly speaking, reaching into the swirl of smoke and debris, finding a voice that isn't hers, using it anyway, saying: "No one in this room is to utter the word *cancer* to Laura. At least not until we get her through the surgery. Have I made myself clear?" The table is fringed with nods. It's the first time that any of us has been heard in sixteen weeks.

It is also the last. Somewhere in the haze of the next ten days—after the moment when my parents had come into my room from that meeting to tell me that The Doctor had finally discovered what was causing my pain, that I had a cyst in my pancreas that would have to be removed, but that then I would be just fine; after the moment when I seesawed between relief and vindication, pausing for an instant to wonder why no one was apologizing for having doubted me, but then collapsing into a euphoria of not caring instead, seeing the pathway back to the real world unfolding before me again; after the moment when I'd overheard a group of interns laughing outside my door, saying, *and we were all so certain she was anorexic*, but before the moment when 1974 bled into 1975 without our even looking up to take notice—there was *this* moment: My father, following The Doctor and his parade of residents out to the hall as they left my room one morning, asking The Doctor for a moment of his time, pulling him aside. He would like to have the slides sent to the Armed Forces Institute of Pathology for a verification of the diagnosis, my father said, having encountered numerous cases in his own practice when such results proved to be open to interpretation. And The Doctor said no. And The Doctor said no, reminding my father that we had been informed when I was accepted as his patient that he has no interest in the opinions of others, that he puts his trust in no labs but his own. And then he turned back to leading his parade of followers down the hall.

I've always wondered whether that conversation resurfaced in his mind during the instant, the following week, several hours into my surgery, when it became evident to everyone in the room that the diagnosis had been wrong. Outside the operating room, my parents sat as frozen and expressionless as a January prairie, surrounded by a protective fence of their sisters and brothers and cousins and friends, but inside, we would later learn, there was sudden bedlam as the first and then the second and then the third and fourth and fifth biopsies of my pancreas were being whisked to the lab and returned by the pathologist, labeled benign; as biopsies of my liver were producing the same report, as the surgeon was discovering a festering infection instead—in my gallbladder, now swollen and nonfunctioning, and, because it had been left untreated to spread for these four months, in my pancreas as well, whose cells, culled

in the duodenal drainage, had been so wildly infected they'd been mistaken for malignant.

...

If I were the author of this story, this would be where it would end, with a dulcet swell of music as a resident ripped off his mask and rushed from the operating room to release my parents from the grip of their nightmare, assuring them that the mistake had been discovered before the Whipple had been performed, while the surgeon closed me up and righted my world again, but, in fact, I am only its reporter and there was more: Somewhere in the chaos that followed the discovery of that misdiagnosis—unnoticed amidst the frenzy of snipping and slicing that ensued as the surgeon was asked to change his direction mid-course, at full speed, without warning; to remove my gallbladder, rather than follow his original plan—nerves vital to the functioning of my digestive tract were severed. In that instant, the clock that had been ticking off the moments since that night in Cape Cod counted down the final seconds to its shriek of alarm as the chance of my returning to a normal life slipped like a balloon from the clench of a fist, dwindling into the distance until it had been swallowed up into the jaws of an unyielding sky.