

which combines, by turn, naiveté among the newcomers and knowledge from the veterans, helplessness and can-do spirit, despair and humor. Feeding Eden brings all that together. For all the stories I have heard, all the mothers I have listened to, I have never gotten so thoroughly into the experience of a child, the effects on a marriage and a sibling, and above all the mind of a mom as I do with the Weissmans when Susan throws herself into the unexpected health challenges of her adored son.

Susan also holds a mirror up to medicine (and alternative medicine) in ways that ought to give all of us pause. Among the many strengths of this book is the way Susan describes her frustration with a succession of practitioners, necessitating her acquisition of the skills and knowledge to evaluate the care Eden had been getting both inside and outside the medical mainstream. This is a journey that many others have embarked on and many more unsuspecting parents will have to take. They will all benefit by reading this book.

—Dr. Paul M. Erhlich

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## INTRODUCTION: CRAZY

**THE JANUARY SKY SHED WAFERS OF SNOW** onto our coats during the short walk home. By the time we reached our building on East 87th Street in New York City, the descent had quickened. My four-year-old child, Dayna, and I pulled at our watery boots outside the front door of our apartment while she offered a detailed report on yet another birthday party. Too full of pink frosting and sugar doughnuts, she decided to forgo lunch and hurried off to her dollhouse as if an event had begun without her. I headed straight for the kitchen, where I saw my younger child, one-year-old Eden, fussing, his faint eyebrows knitted vigorously. My mother-in-law, Eden's "Nana," who had baby-sat for the last hour, announced as soon as she saw me, "He needs to eat. But I waited." As she hurried him into his high chair, I imagined her anxiously eyeing the covered bowl on the counter, suffering the slow minutes I was out.

It was getting harder to watch Eden eat these days, even for me, and so instead of hovering over his tufted round head, I decided to use the time to sort through my designated drawer, which was comfortably close in the adjoining dining room. Whereas the top drawer of the

credenza was reserved for Eden's stroller enhancements such as key chains and scraps of Velcro, and the middle drawer was for the generic junk of my husband, Drew—checkbooks, wallets, keys, eyeglasses—mine was more revealing and held subtle clues to my current life. There were handwritten notes of phone conversations with Eden's doctors, old unsorted photos, half-squeezed tubes of Eden's rejected skin lotions, an invitation to a come-and-gone alumni event, a sparkly hair elastic purchased for Dayna that I kept forgetting about, and a flyer from a United Jewish Appeal Women's Committee that I kept without any intention of joining but which served as a warning that I might be in danger of becoming one of those mothers who are all about their children—or child.

I was only a few feet behind Eden's high chair, clutching handfuls of paper, when Nana called out to me, "He's scratching his neck."

Before I could turn and walk the three feet of wooden floor, she added with uncharacteristic insistence, "Susan! Susan, look *now*. He's *really* scratching his neck."

Eden wasn't so much scratching his neck as clawing at it. His nail streaks had raised red flesh. Above them, one cheek was oddly lumpy, as if he were a squirrel storing food. He began to cry as I reached down and unstrapped him.

"What is it? What was it? He was fine . . . he was fine, wasn't he?" Nana asked.

I pitched my words over hers: "Nothing! What could it be? The doctor said because of his vomiting and that stupid milk thing we did, we should just stick with lamb and rice or maybe bananas . . . that's what's in the bowl . . . that was it . . . rice and lamb. What *could* it be?"

Nana silently blinked her questions at me as I paced the parquet. "I'll call the doctor—where's the phone? What's the matter, Baby? Okay, no more, no more, I'm calling . . . Yes, hello?"

As I was explaining his symptoms, the phone crooked under my neck, Eden's forearms started flushing. I got off the phone and put a syringe of Benadryl in Eden's mouth as Doctor Bennet had just suggested. It didn't help. It was supposed to slow it, but suddenly Eden's hands were puffing like two tiny baseball mitts. While I picked up the phone to call Doctor Bennet again, Eden's other cheek expanded into equilibrium. Doctor Bennet ordered, "Don't wait."

Eden was wailing as I tossed his navy coat over his back. He pawed at himself harder, more. He couldn't get at it. He couldn't satisfy the itch. I ordered my mother-in-law to call my husband at his office, and after she hustled Dayna into her bedroom and out of the way, Eden and I were in a taxi to the Lenox Hill Hospital emergency room. In the backseat Eden panted slightly. When I pulled up his shirt, his stomach was decorated with patches of rounded rectangles and smaller circles and streaks, a random topographical skin mosaic. As Eden's eyelid started swelling and his lips inflated, I was already on autopilot, running through a tunnel of panic into the hospital.

We were lucky.

The doctor said we were lucky because the emergency room was practically empty that day. "So unusual . . . Things were slow this morning . . . Maybe the weather . . . This way, this way." No stretchers racing down long halls, as I might have imagined, just walking fast and carrying Eden into a white partitioned area. There, Eden's red-and-white body was stripped, flipped, and reflipped, and then shot with liquid epinephrine.

And then the exquisite pale pink of Eden's relief after the epinephrine took effect. Everywhere his flesh seemed to exhale. Those soft hues whispered into me like warm mist: *he's safe*. Then it was quiet. He needed to rest.

I was sitting on the side of the bed, Eden's head cupped in the crook of my arm, when the doctor came back with his clipboard. He asked

me questions. It seemed so important to try to keep that beautiful calm inside our space, so at first I practically whispered about Eden, about how I hadn't been able to produce enough breast milk to sustain him and had fed Eden a formula, which he had vomited for months after he was born. It wasn't until a specialist, a pediatric gastroenterologist (GI), diagnosed Eden as allergic to his milk-based formula that we understood he had an allergy. But wait. Then, a few months later, the same doctor suggested that we find out if Eden had outgrown his allergy. So just a few weeks before Eden's first birthday, I fed him some dairy foods and it didn't go well. He had been vomiting regularly ever since.

Louder now, I continued. But there wasn't any dairy in Eden's lunch. Eden's GI had cautioned me to feed him digestible foods such as ground rice and lamb. Those foods were supposed to settle his stomach, to restore him. Not do this. "What *was* this?" I asked.

I'm sure that the doctor answered me, but I don't remember exactly how he responded. I remember what he said later. Later, Eden and I were waiting to be checked out and I was thinking about Nana back at home and her split-screen images of that day—her grandson inflating from all angles while her granddaughter busily ruled the geopolitics of her dollhouse miniatures. The doctor spotted me in the hard plastic chair, silently staring out, clutching Eden, and he beamed at us. "If I might offer you some advice . . ." He looked pleased because he just saved my son's life, yes? He looked so pleased that it took a minute before I realized he was telling me an anecdote about his first child's health problem.

His opening: "My mother always used to say, you act like a meshuggener, they'll act like a meshuggener."

I'm a Jewish New Yorker and know my tribe's vernacular. *Meshuggener* is the Yiddish word for "crazy"—not the clinically insane kind of crazy, more like the hyper wild-child kind of crazy. As he spoke, the doctor's face gleamed with confidence in his advice.

And so my lifesaving emergency room doctor moved on from this introduction to tell me, in far more words, that he and his wife had been a bit overprotective of their first daughter when she had a little colic. But the real problem was that they continued their solicitous and slightly crazy behavior even after their baby girl was long over said colic. As a result, he believed, his daughter became demanding and capricious, causing his mother to ask them why their little one always acted so crazy. That was when he and his wife had their epiphany about modeling behaviors for their child.

He finished his story with these lines: "So, just because you've been to the emergency room, you don't want a meshuggener on your hands later. Don't let his allergies make you crazy."

Here's what I think. I think the emergency room doctor, who had probably seen more than his share of it, surely didn't want me to go forth feeling crazy. But in fact, according to the Asthma and Allergy Foundation of America, food allergies account for 30,000 visits to the emergency room each year.<sup>1</sup>

Crazy. But did that doctor have any idea how crazy Eden's allergies seemed? He wrote Eden's diagnosis simply: anaphylaxis. Cause unknown. Anaphylaxis is defined as a "a serious allergic reaction that is rapid in onset and may cause death," and you need to have only one of these sets of symptoms to be diagnosed with anaphylaxis: the first, skin symptoms (such as hives or swollen lips) and either difficulty breathing *or* signs of low blood pressure; the second is possible exposure to a suspected allergen plus two or more of the following: breathing problems, skin symptoms of any kind, low blood pressure, and symptoms affecting the gut (such as vomiting or cramping); the third, exposure to a known allergen *and* signs of low blood pressure.

The trigger for Eden's anaphylactic reaction that day was never identified. Most likely, it was caused by an allergy to something in his lunch. The possibilities ranged widely:

1. I had unwittingly used a dairy-free margarine that contained “soy protein isolate” and Eden, we would learn later, was allergic to soy.
2. There were traces of butter, a dairy food, on the surface of my frying pan or other cooking utensil.
3. There were traces of something besides lamb in the ground lamb.
4. Eden had a lamb or rice allergy, both of which are uncommon (disproved after testing).
5. Eden reacted to the combined exposure of the margarine containing soy, possible trace amounts of butter tainting the frying pan, and/or other unidentified proteins contained in the ground lamb.

The possibilities may not have been endless, but within a week of that visit Eden’s allergies seemed that way. Could the ER doctor have foreseen that we would go to an allergist who would perform skin, blood, and urine tests and pronounce Eden allergic to soy, eggs, dairy, tree nuts, peanuts, beans, fish, shellfish, plums, peaches, and cherries? If he had known about Eden’s long list of foods, would he still have told me not to be crazy?

What if that same doctor knew that in four years we would intrepidly visit a new peanut-free diner that opened in our neighborhood and witness one of Eden’s worst reactions? We didn’t know that Eden’s French fries had swum in a vat of oil with some buttermilk-coated chicken. Those fries were such a rare treat, so authentic and crispy, that even after his bottom lip swelled out like a saucer, Eden tried to keep eating for a few frenzied minutes until we pulled them away. Two minutes later, after his first dose of Benadryl, as I was pulling on my jacket, EpiPen poised, Eden’s head rolled forward toward the shiny red diner tabletop. But he was just exhausted, thank God, not faint.

Would the famed spilled coffee afternoon have changed that doctor’s mind? My anguished babysitter dripped three measly drops, at most, out of her lukewarm coffee cup and rinsed it all off Eden’s arm before continuing on to his Tae Kwan Do class. It was Eden’s turn to get a new stripe on his belt that day. But as his eyes began watering during the sparring exercises, she panicked and broke into a rare jog back to our apartment. When they burst inside, Eden’s hives were growing upward out of his starchy karate uniform and into his right ear. One hour and one dose of Benadryl later, Eden got up off the couch and asked me, “Can we go back now? I want my new belt.”

How wouldn’t I know Crazy? Let me count the ways. Despite the doctor’s counsel, Crazy and I became as intimate as lovers. Crazy became my stalker, my unwelcome houseguest, and even my muse. I see Crazy in the shadows of other parents, the parents with children like Eden. When I try to tout my sanity to teachers and friends—“Oh, and I try not to get too crazy”—Crazy laughs its ass off in the corner and continues to flit and fly all around.

After that day in the emergency room, Drew took Crazy everywhere too. He has brought Crazy to work, even to board meetings, the image of Eden’s haggard eyes or rasping breaths remaining with him long after he closes our front door. Even our “well child,” Dayna, has caught more glimpses of Crazy than we ever wanted. Just a few months ago, the three of us stopped off at a prepared foods store on the walk home from school. I shopped there so often that the owner, Lorenzo, knew all of us. Of course I asked twice about the potato Eden and Dayna wanted, and Lorenzo assured us that the potato was just potato. All of us heard him. So at first I didn’t fully believe Eden when he pushed his plate away and repeated with a six-year-old’s insistence that “something is in that potato.”

Half an hour later when his wheezing began and his hives sprouted, I believed him. Dayna’s eyes went wide as I pulled off Eden’s shirt and guided him to the couch, away from any mirrors. That night Dayna

squeezed herself in between Crazy and Eden on our red sofa while I rubbed cortisone and ice on his torso and dosed him with Benadryl and ice water. Dayna wouldn't acknowledge his swollen body and face as she challenged Eden to endless rounds on their handheld electronic game. In fact, Dayna stood up to Crazy better than any of us. Except for Eden.

Drew and I know that Crazy is our Achilles' heel: we have a child whose illness, since his eczema is under control, is rarely visible. Worse, food allergies are sometimes stigmatized at every level, from the school cafeteria to the mass media. We cringe every time we read or hear a media pun on allergies and nuts. I am perpetually surprised at how much energy I use explaining to new camp counselors, teachers, and other parents what we must do to keep Eden safe. Alive.

Before that trip to the emergency room, I looked forward. *When she is in grade school, in a few years when we travel more.* But after the emergency room, I began mothering in circles. During the upward loops, I was certain I had Eden's allergies under control. "This is it," I would reason with myself before finessing my latest strategy with Drew. "I know what to do for him so we can all feel normal again." Every time one of Eden's doctors reevaluated his diagnosis, tweaked his list of forbidden foods, offered up a new course of treatment for living with his life-threatening allergies, I would edit the narrative of our lives. Anaphylaxis? We'll tote an EpiPen! Feeding therapy? Uhh, sure! Cross-contamination? I'll make food from scratch! Asthma? Let's get inhalers! Okay. Now can we go back to our normal life?

Crazy is the hairbreadth between health and illness, intimacy and pretense, festivity and panic. With every blunder, every significant allergic reaction, my brain catapults back to the emergency room where Eden showed me how he might look before he dies. The precipice. Sometimes the mere suggestion of an accident—"Hon? Would you look at his eye? Was that kid over there eating peanut butter?"—was enough to freeze my thoughts in the middle of a crowded playground. Those were the

downward curves, my numbing vision of a life with maximum safety and little joy.

And now, seven years after I met that doctor, Crazy still tries to distract me from building our big and beautiful life, one that embraces Eden's allergies. But I stay focused. Everyone else can blow off Crazy with the same tiring assumptions: "But they outgrow it, right?" or "Surely they will find a cure." Most people want to hear promises.

Now, of course I want Eden to outgrow a condition that offers him a swift and potentially unpredictable death. Of course I want him to outgrow it all: his multiple food allergies and then the asthma he developed when he was three. I want Eden to have a cure. But in the meantime, I live with Crazy, and it won't let me tell tales of deflective optimism. Instead, like many other parents, I've educated myself about my child's medical condition to find ways to live with it. I've joined a larger community of individuals and organizations devoted to developing a body of knowledge about food allergies.

As I search for my own solutions for Eden, time is on my side. There has been a statistical rise in children with food allergies and a responsive groundswell of resources, products, and general awareness. As for the parents surfing this wave together, once in a while one of us falters; we slip up. We might forget the medicine just when they need it most or fail to notice the other, nonallergic child. Often we read a label too quickly or simply buckle under the sheer effort of constant vigilance. Sometimes one of us loses pace and gets caught in his or her own undertow of despair. When that happens to me, I pull myself back up to tell the tale. So I've written what I know. Though I learn more about allergies every day, I know how life is when food makes you feel crazy.