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Zebra: An Autobiography of a Medical Mystery

By Abby Baird

DIAGNOSIS AT TIME OF REGISTRATION

13 yr old here for c/o severe lower abd pain.

White sailboat hulls, dirty with sand, were stacked six high in the boathouse. Sunfish are perfect sailboats for beginners. They are tiny, and hard to sink. I pulled my legs up onto one of the upturned hulls, folded them under me, and turned to face out the boathouse door. The summer sun shone through. I kept my sunglasses on.

Lake Michigan stretched out in front of me, its sandy beaches reaching all the way to the city.

I watched my friends out on the beach. They were easy to spot, in their bulky orange lifejackets, pushing their Sunfish into the water. As they sailed away, the boats got smaller, and smaller and smaller, eventually disappearing beyond the edges of the doorway that framed my view of the outside. I had a life jacket on too; the black plastic buckles still clasped together across my chest. I'd put it on that morning, when I'd arrived at the sailing day camp. I had forgotten I even had it on. But instead of wearing it on the water, I was here, in the boathouse, bent over my knees, digging my nails as far into my thighs as I could, raising bright red welts. I was biting down on my lower lip. My mouth tasted of blood. My stomach hurt.

I sat like that and stared straight out the door. It was just a stomachache. I could make it a few hours. I didn't need to bother my mom.

Three hours later, the first Sunfish sailed back into view, returning to the beach. Boat after boat ran ashore. The new sailors grabbed the boats' hulls and hauled them onto the sand, out of reach of the lapping waves. Orange blurs whizzed around, furling main sails, coiling ropes, taking the boats apart. Each Sunfish had to return to its place in the boathouse stacks before its crew could leave.

It was July 7, 1998. I was 13 years old. It was the opening day of sailing camp. I never made it onto the water.

Now I am 26, living in Oakland, California, and writing about what happened next, about everything that was to follow the day I began my life as a zebra.

A famous medical professor named Theodore Woodward, who taught at the University of Maryland School of Medicine in Baltimore in the 1940s, used to tell his students, "When you hear hoofbeats behind you, don't expect to see a zebra." 70 years later, the medical world still uses the word "zebra" to describe a patient with a perplexing and rare diagnosis--the mystery illness, the answer that never occurs to anybody at first.

On television, zebras usually guarantee an entertaining plot line, with the doctors confounded until some quirky brilliant diagnostician swoops in, solves the case, and saves the patient, all before the last commercial. (Law and Order's 1990 pilot episode involved a "zebra hunt," with the detectives hoping to charge an ER physician for murder after a missed zebra diagnosis led to a girl's death.) But the life of a zebra, everything leading up to that elusive diagnosis, is repetitive and frustrating. Weeks, months, and years are spent being passed from hospital to hospital, department to department, doctor to doctor. Most appointments don't even move you forward in understanding. Some push you back.

Zebras walk out hospital doors with no answer to those who ask what's wrong. When a zebra finally gets a diagnosis, when the obscure zebra ailment gets a name, helpful people--sympathetic people--don't recognize it. More importantly they don't know into which category the condition falls: annoying, life altering, or terminal; hay fever, diabetes, or cancer. People don't know how to react, and this makes them uncomfortable, especially if your ailment is not visible on first glance even though it beats you up as badly as something requiring bandages or a cane or a big scar. "Honestly, I sometimes wished my kid had had cancer," said the mother of another zebra I know. "They look sick. And it's got a name."

My mom sinks back into the dark green couch in the living room of my parents' house in Winnetka, a suburb just north of Chicago. Her arms are crossed tight over her chest, and her bare feet are propped up on the large dark wood coffee table in the center of the room. Her toenails are painted a deep red – classic.

It's November 2011, and I am home to see a new neurologist.

My body often feels the need to go off on funky tangents, but it usually straightens itself out within a week. But this time, the fainting, migraines, and severe muscle spasms in my legs have lasted for months. My doctors are stumped. My last specialist – after prescribing me five times the average dosage of a new medication, leaving me unable to recognize my own car, put on my watch, or remember my name – is no longer in the running.

The neurologist came highly recommended.

CLINICAL INFORMATION

26 y/o RH F w/POTS, possible Ehlers-Danlos, mast-cell activation disorder, migraines who presents for further evaluation of dysautonomia/POTS diagnosis – it appears that this appointment was made as "second opinion"

The appointment was two days ago. When I arrive, a nurse asks for my current medications and takes my vitals. A resident and medical student, seemingly no older than 12, take my history – 13 years boiled down to a 15-minute summary. I'm practiced at this. They ask for my current medications. I list them: Lyrica for all over nerve pain, Adderall XR for extreme fatigue, Pyridostigmine Bromide to counteract blood pooling in my hands and feet, Singular to help me breathe, Fludrocortisone to keep my blood pressure up and stop my fainting. Potassium Chloride to replenish the potassium leached out by the Fludrocortisone. Lexapro for pain. Zovia 1/50E to stop my periods, because my body can't handle the hormone fluctuations. Nitrofurantoin after sex to keep me from getting kidney infections. Imitrex for migraines, Zolpidem for insomnia, and Diphenoxylate/Atropine for nausea, as needed.

They follow with the usual. *Changes in your appetite? Headaches? Changes in your vision? Ringing in your ears? Lightheadedness? Problems swallowing? Stiffness or pain in your neck? Shortness of breath? Chest pains? Abdominal pain? Weakness? Depression? Anxiety?*

The interview takes 45 minutes. The resident and medical student disappear to confer with the doctor. I put on a hospital gown; I'm also practiced at this. Five minutes later the doctor shows up, resident and med student in tow.

Her first two questions to me are: Who sent you to me? What kind of doctor did he tell you I was?

Shit.

I was so damn used to this. Getting sent from hospital to hospital and doctor to doctor. This is what I do.

underscore the tone of that whole scene--you're so damn used to this. This is a deeply familiar routine for you. This is what you DO, in your life--you get sent from one doc to the next.

She asks for my current medications and performs a standard neurological exam. Ten minutes, max. They leave. I change back into my clothes. Four minutes later they return.

The doctor sits down in the chair next to mine. "I'm a neurologist," she says. "I specialize in neurological disorders. I do have a very small population that has autonomic problems, but I do not manage their care."

In other words: I can't help you. Thanks.

OK, fine. I'm practiced at this, too.

The next night I borrow my mother's car to pick up my boyfriend Michael from the airport. Yes, I'm 26 years old, I take nine zillion pills every day, and I have a boyfriend. Extraordinary man. We met on the train platform in Berkeley. I was sick and heading to my godparents' house in downtown San Francisco. He thought I looked beautiful anyways. At 9 pm, as his flight is supposed to be landing, I have merged from the highway onto the airport's access road, a route I've taken a thousand times, slowing from highway pace to 25, I know exactly how to do this, and then my eyes snap open. A giant white air bag explodes from the steering wheel. It smashes into my chest. I manage a glance out the windshield. The front of my mother's car is currently becoming the accordion it will end up resembling. The air bag deflates just as fast as it appeared, and I'm jerked back in my seat. The car has stopped. I can only see out the top half of the front windshield as the hood has folded up, blocking the bottom. All I can see is white, which is the white of a Cadillac Escalade, aka a brick wall.

I've been in a car accident. I hit the back of another car. I fainted while I was driving.

I sat out eighth grade. My mother and I spent our days watching movies; daytime television gets old really fast. We rented so many movies that we were awarded a special Blockbuster card allowing my mother to pick up Tuesday's new releases on Monday nights. If I was feeling stronger, she would drop me off at school for a few hours. I never lasted a whole day.

My best friend then and now, Rachel Wike, was thinking recently about what she remembers. "It was surreal at times," she said. "Hearing about all the different tests and all the different crazy stuff that they were making you do. To hear that and not have any idea what that's like. I've never done that."

Once, strong enough for a few school hours one afternoon, I arrived between class periods. Before I could take off my coat, my friend Dinah ran up and threw her arms around me. She was sobbing. "I had a dream last night that you died," she said. "And then you weren't at school this morning."

I bounced between doctors and specialties. They had no idea what was wrong. But middle school is probably the most awkward few years in any person's life, and somehow it was okay that the doctors didn't know; for my friends, my classmates, it made it – whatever *it* was - less scary. If the adults didn't understand, no one would expect a kid to. We were still young enough to believe the adults were working hard and would soon just fix everything, as they had for everything else in our lives. Once the doctors gave me a diagnosis, they could give me a pill. PRESTO! I'd be fixed.

Everyone in my homeroom signed a get-well card for me when I had to spend a week at the Mayo Clinic in Rochester, Minnesota. At the time, my parents were given to understand, this was the one medical facility in the country whose experts had the knowledge to help me.

The Mayo Clinic didn't figure it out.

To graduate from eighth grade, I passed a test about the US Constitution, and filled out a 15-page trigonometry packet. I went to the ceremony: June 2, 1999. In the photos I'm standing, in my Jessica McClintock prom dress--light pink, satin, tulle poofing out the skirt. The Cinderella effect. I'm sick. My face is paper white, sheet white, rice white.

I remember that my best friend Jessie Knight put blush on me that morning. I had never worn makeup before; I was lucky if I was able to stand long enough to brush my teeth. Jessie sat me down on the edge of her bed, after my mother dropped me at her house, and dumped a mound of makeup and tools down next to me. It was a big day. I had done it. I had made it. Made it to the finish line.

I looked down, so she could do the eyeliner, and looked up for the mascara. She dusted my closed eyes with a pink shimmer eye shadow, to match my dress. Every move was so careful, so precise. When she was finished, her face burst into a huge smile. "You look so pretty."

Energized for the first time that day, I stood to look at myself in the mirror. I was crying, but the mascara didn't run. I looked beautiful. Jessie bounced in and hugged me from behind. "Time for pictures," she said.

The doctors told me I wouldn't finish high school in four years. They told me I wouldn't be able to go to college.

I'm completing graduate school as I write this. So far, I've seen 64 doctors in 23 specialties at 15 hospitals in six states.

Here is the best way of imagining the way I feel, on a day that really hasn't gone well:

1. Don't sleep, eat or drink for 24 hours.
2. Pack two messenger bags, each with 30 pounds of books. Sling one bag over each shoulder. Do whatever you would do on a normal day. Don't put the messenger bags down.
3. Upon returning home, turn your thermostat to 104 degrees.
4. Blow up 100 balloons.

But remember that you *look normal*. No one will see the pain or the fatigue. They will expect you to perform. They will not understand.

My mother hated watching my friends doing normal things; playing sports, going to the movies, going to school, because I couldn't.

"We worked very hard to keep the family as normal as possible," my mom recently told me. "To do all the things we would normally do and to ensure *you* had as normal an experience as you could with all the same opportunities. So we tried to keep it . . ." my mom trailed off, looking down at the floor.

It was the only thing my parents ever fought about. If I was home for a week, the wages of having done something "normal," it was my mom who had to sit home with me, not my dad. My dad liked to charge ahead, as if everything were perfect. He would book adventure vacations. He was determined to give me everything. "But they were the right decisions," my mother said. "We agreed on them in the end."

Now, at 26, I am in charge of my own medical care, but for a long time that was my, mother's full time job. So one day last August, I called her. She put all of her Abby Active records into a box -- that was her file label -- and overnighted it to me in California. I thought that if only I could get all the information -- medical research, studies, and my own medical records -- I could figure out what was wrong with my body.

When the box came, every inch was covered in clear tape. Someone had taped the heck out of it.

The box was full. I picked up the white binder on top, settled onto the ground and opened it across my legs. The first two pieces of paper were small, with an unmistakable rainbow trout across the top of each page--the stationery I used every day to write my parents from sleep away camp in Wisconsin.

Dear Dad,

Today I felt really bad when we were singing this morning to the flag, my stomach started to hurt, I felt real dizzy then everything when blurry and I couldn't hear except for a buzzing noise in my ear. 1 to 2 minutes later I could see and hear again. I slept the whole morning in the nurse's office, but now I feel OK.

This was two years before the day I got sick at sailing camp. At 11 I didn't understand what had happened to me, but now I do. I had blacked out.

I found a timeline my mother wrote, detailing the first six months after the sailing camp day.

I don't remember most of what I was now reading in the timeline, but I do remember the second entry, July 14, when I woke up at two am, slid my legs over the side of my bed, clutched my stomach and stood up. I swayed from side to side, unstable on my legs, but I needed my mother. I stayed conscious as far as the bathroom. I came to on my bathroom floor.

After that I have to rely on her account.

August 28: Pain builds significantly . . . she describes episodes as spikes from a steady plateau of pain during which she can't catch breath, shakes, sweats, sometimes has chills. Doctor puts her on Propulsid -- doesn't help. Upper GI ordered.

September 2: Upper GI done. Final report not in but radiologist says there is nothing there. Waiting for results of stool study I requested. I also requested another blood test due to her exhaustion. Extreme and unrelenting pain.

I had forgotten the extreme and unrelenting pain.

September 19: bad day – as always

I spent September and October rotating through Gastroenterology at Children's Memorial Hospital in Chicago, moving from one doctor to the next. I did the radioactive scrambled eggs test, the barium swallow, an endoscopy, a colonoscopy. Everything was negative. "It's not this," the doctor said. "It's not gastrointestinal. I can't help you."

My mother has a particular memory of standing in one of the nondescript hospital examination rooms. "And I'll never forget," my mother said. "I remember saying, 'Well what do we do next?' And he said, 'Well, I don't know.'"

CLINICAL INFORMATION

Young Lady with chronic abdominal pain.

Please page Dr. Davis with information after CT is done #0325

Here's a snapshot of me: big long messy blonde hair, green eyes; pale skin, average weight. This is what I've looked like since I was a teenager. A blonde teenage girl, walking into a hospital and complaining of stomach pain--nine times out of ten, it's all in her head. And doctors will always go with the safer bet.

"When we have a patient come in with headache, muscle aches and pains, brain fog, when multiple organ systems are involved, we tend to think about a psychiatric issue," says Dr. Todd Davis, the former head of academic pediatrics at Children's Memorial Hospital in Chicago. "So a lot of kids get misdiagnosed."

He's being charitable when he says "we." He's not part of the we. When every doctor you see is immediately skeptical of you, your symptoms, your illness, you can't help but start questioning yourself. Then one day at Children's, as I was quickly growing accustomed to being shuffled around the fluorescently lit halls, into an examining room walked a 6' 2" tall man with a cane and a smile. "I just want to tell you right up front that whatever this is, I'm not going to leave you till we solve it," he said. "We will do this together." My entire family remembers that first appointment with Dr. Davis. He was sent the Children's Memorial cases no one else wanted, the kids with strange symptoms. He was the zebra doctor.

He practiced medicine in a way I've seen no other doctor do, before or since. "He would physically walk to [neurologist] Dr. Zimmerman's office to talk about you," remembers Jennifer Winter, the nurse practitioner who worked with Dr. Davis. "He would walk to [cardiologist] Dr. Deal's office to talk. To [nephrologist] Dr. Langman. That is why Dr. Davis is so great. Most physicians don't practice like that." Most physicians are specialists and see what they are trained to see; to a hammer, everything looks like a nail. But Dr. Davis always acknowledged the possibility that any affliction could be something outside of his understanding, and thus would walk to the office of every specialist in the hospital to get their take on the symptoms.

But he still didn't know what was wrong with me.

The next two months are a blur.

My dad sent out a letter to his friends, personal and professional:

My daughter Abigail, age 13, is generally in constant pain. She has four to five spikes of pain per day. She turns very pale during these attacks, is extremely weak and has trouble walking a block. She shakes and cannot catch her breath. She is really unable to do almost anything except lie in bed.

I got better.

Then I got worse.

October 6 – notice lines on ankles where socks have bound skin – ankles swollen at end of day, complaining of pain from knees down – still having sporadic muscle spasms in other parts of body – still sensitive to cold – still tired.

I had pulmonary exercise tests done. My peak work capacity was 43 percent predicted for my age. My peak oxygen consumption was 50 percent predicted. They determined that I wasn't giving it my best effort. That my body could be pushed farther than I was pushing it. Later, it became evident that I *had* been giving it my best effort. It was just so improbable that I had gotten so sick in such a short amount of time; the doctors had initially discounted the possibility, the zebra possibility.

On October 30 I stopped going to school.

On November 15 the Chicago Tribune ran a story about a local zebra boy named Zac. "Meet Zac; He's Really Sick of Being Tired; A Mysterious Ailment Steals Two Years of Childhood, And Counting." After being sick for two years Zac had recently been diagnosed with Chronic Fatigue Syndrome (CFS). His father, a Tribune photographer, had written the article.

A number of my mom's friends called her about the article; a few emailed her a copy. Their notes all said the same thing: This sounds just like Abby.

The article described CFS in detail: "long-term fatigue, sleep loss, headaches, sore throat, low blood pressure, damage to the vocal chords, swollen lymph nodes, chest and lower abdominal pain, mild fever, cognitive difficulties, weight loss or gain, depression, dizziness, sensitivity to light, food or chemicals, and a sudden intolerance to alcohol and some medicines."

My mother knew then, she says: Whatever it was I had, it was going to be years.

Two days and a six-hour car drive later we registered for the first time at the front desk of the Mayo Clinic, internationally renowned for diagnosing difficult cases. They directed us to a waiting room where 200 people sat, listening for their name to be called. 200 *sick* people.

I didn't belong there. I wasn't sick like the others in that room. This was my conviction.

An old man in a wheelchair sat next to me, his gaunt head bent forward, his pale face staring at the ground, expressionless. His hand lay on his thigh, its wrinkled skin loosely draped over the bones. It was shaking. I looked down at my hand. It was shaking too.

They sent me to get a psychological evaluation first. "Before you went in they had already decided what you had," my mother said. The operative clinical word here is *somatization*, dictionary defined as "in psychiatry, the conversion of anxiety to physical symptoms," as in "basically all in her head."

Every subsequent doctor I saw first received a copy of the psychologist's report.

Clinical Information

Although further medical testing may be important, her presentation is consistent with that of a somatoform disorder.

After four full days of testing, we met my Mayo primary doctor. A resident did my initial examination and history, and then the doctor added a note at the end of the chart.

Although the history is not typical at all, I think it is somatization.

He believed there was no physical basis for my symptoms. "She's probably under pressure at school, he said.

My mother stared at him and said, "She got sick on July seventh."

He looked down at my chart in his hands. "Oh."

"What about the sweating?" my mother asked. "And the dizziness, and the facial flushing?" She turned toward me. I was bright red. "Look at her *face*," she said to him. "What about all these symptoms? Are these psychological?"

He was silent. He appeared to be focusing on me for the first time. Well then, he finally said, we should be running all these additional tests.

My parents looked at each other. "No. We are going home." As we walked out of the doctor's office, he said one last thing: "It sounds like it's autonomic." And we left.

So now, we again had a new word to master, a new addition to our vocabulary of weird illness: Autonomic. We went home. My mother mentioned it to Dr. Davis. Who nodded, then taking my mother's suggestion into account, said, "There's one more thing this could be." He sent us upstairs to the Heart Clinic, where they were conducting a study to determine if pediatric Chronic Fatigue Syndrome (CFS) patients exhibited signs of autonomic dysfunction. The test they ran on me was simple:

1. I lay on a table.
2. They took my blood pressure and my pulse.
3. I stood up.
4. They took my blood pressure and my pulse.

"That's when they diagnosed you with what they called Neurally Mediated Hypotension," my mom said. "They were doing a little study in the Heart Clinic, and they had found some kids who had this."

Nine months, 11 doctors, and four emergency room visits after that day at sailing camp in July, I had a diagnosis.

Or I seemed to.

Neurally-mediated hypotension – also known as the fainting reflex, neurocardiogenic syncope, vasodepressor syncope, or vasovagal syncope – is basically a miscommunication between the heart and the brain, which – upon standing – causes heart rate to drop, blood pressure to drop, and thus the person to drop. NMH is thought to be caused by a hypersensitive autonomic system producing an exaggerated response to outside stimuli – stress, injury, extreme emotion. Between episodes there are few, if any, symptoms.

If its daily functioning didn't affect every second of my life, I am certain I would know absolutely nothing about the autonomic nervous system (ANS). I know my friends in medical school aren't clambering to be ANS specialists. Oh wait. That's because the specialty doesn't exist. The ANS - one part of the body's larger central nervous system – maintains the body's inner balance by regulating blood pressure and everything else you don't think about: heart rate, breathing, body temperature, digestion, perspiration . . . Autonomic means automatic; the ANS controls everything your body automatically does. Without your ANS you are screwed.

autonomic nervous system

the system of nerves and ganglia that innervates the blood vessels, heart, smooth muscles, viscera, and glands and controls their involuntary functions, consisting of sympathetic and parasympathetic portions.

- Random House Dictionary

At the beginning, man walked on all fours, but then he evolved. So man is now stuck in a vertical body with a horizontal autonomic nervous system.

Comparatively little is known about the autonomic nervous system. It wasn't until October 1925 that it was even postulated that a malfunctioning ANS could be the cause of disease.

The ANS is complex and intricate. I monitor my own ANS every day, but I know very little. Here's how I understand it:

The ANS – or involuntary nervous system – controls most of the body's unconscious functions: heart rate, digestion, breathing, salivation, perspiration, pupil dilation. It plays a part in almost every major bodily system: circulatory (heart and blood vessels), respiratory, nervous, digestive, endocrine (insulin, adrenaline, glucagon, etc.), urinary, reproductive, and integumentary (skin, hair, nails). When the ANS fails, it takes everything else down with it.

The ANS is comprised of two subsystems – the parasympathetic nervous system (PSNS) and sympathetic nervous system (SNS) – that must function in perfect balance with each other. Think of the ANS as a balance scale, its left arm the PSNS and its right the SNS. Ideally, the sides are perfectly balanced. But for the right person, a certain kind of tap – a thunderstorm, getting hit in the head just a little too hard, even a girl getting her period – can set a malfunctioning ANS whirling into disarray. You would think the human body, after all these years, would have evolved into something more stable, but apparently it had other priorities.

For a while Dr. Davis narrowed down my ANS diagnosis even further, settling upon another acronym that seemed to bring everybody a certain satisfaction. There's a syndrome called Postural Orthostatic Tachycardia Syndrome, I learned-- rare, affecting less than 200,000 people in the US, although specific estimates are unknown. POTS is still not a diagnosis, but rather a specific group of conditions, characterized by a spiking heart rate upon standing. (I had one of those.) While a spiking heart rate

isn't necessarily a life-altering problem, a person with POTS suffers those because of the body's inability to keep its own blood pressure up – and thus keep the person from fainting. By pumping extra hard, the heart can compensate for the ANS's inability to regulate the body's blood pressure on its own.

But I was now 15 years old, a high school freshman, and I had bigger problems. I had to decide who I wanted to be -- sick versus well, odd versus normal. It's hard to be brave and confident when most teenage girls dream of one thing: to fit in. To be normal.

At New Trier Township High School, where Rachel and I spent four years (trekking around a 750,000 square foot building, hurrying up and down five flights of stairs, pushing through 4,500 other students to get to class), every girl straightened her hair. Girls would wake up at 5 am in the morning, pull out the iron, lay their heads on an ironing board, and get to work. I had curly hair and no energy, so I wore my hair curly. I stuck out.

I didn't have energy to put on makeup, or don the unofficial girls' uniform: the Steve Madden platform sneakers, the Seven jeans, the black North Face fleece, the black nylon Kate Spade messenger bag slung across the body. I went to school in drawstring pants. Sometimes I wore pajamas. I was always cold, and wore oversized sweaters and sweatshirts. I was too weak to carry my textbooks, so I had two sets, one for home and one for school.

Rachel pointed out that I didn't obsess about my weight the way every other girl did. “We're just trying for basic functions here.” That's how Rachel remembers me. Hierarchy of needs. Not all bad, right?

I was permanently excused from gym class, except for the three months of Health, which is where they wedged in nutrition and sex ed. On the last day of Health, my teacher said, “Everyone say goodbye to Abby. She won't be with us any longer.” Somebody burst into tears. No one knew what was wrong, then my friend Chris fessed up. He had thought it would be funny to tell everyone I had cancer.

No one thought it was funny.

Three of my major diagnoses – Neurally mediated hypotension (NMH), Chronic fatigue syndrome (CFS), and Postural Orthostatic tachycardia syndrome (POTS) – fall into the category of dysautonomia (autonomic dysfunction) related. Most forms of dysautonomia are caused by what is known as Orthostatic Intolerance (OI), the ANS's inability to adjust blood pressure upon standing. The lay description of this problem is pretty straightforward, and requires no acronym: You faint.

There is no medication or treatment for autonomic dysfunction, so each symptom gets treated individually. In the morning I take six pills, one at a time. Three are long and red, two are long and orange, and one is large, fat and white. Two of these pills keep me awake, so I won't sleep 18-20 hours a day, as I have often done to the extreme and unrelenting fatigue my condition caused. - three of them are for pain. Whether or not I have Chronic Fatigue Syndrome, which remains a matter of contention, I do have chronic fatigue – some of my doctors believe my sleeping issues are related to narcolepsy. Five of my morning pills are considered controlled substances, and two of these my mother ships from Chicago because both Berkeley and Kaiser – the main hospital in San Francisco – have a blanket policy not to prescribe the medications or dispense it at their pharmacies.

At night, still, I take ten pills. They let me sleep, cut the pain, help me breathe, keep my blood pressure up, stop me from fainting, replenish the potassium the previous medication takes out, and so on. I'm still supposed to prevent my own menstrual periods. Each month, the ANS helps regulate the dramatic rise and fall of estrogen levels in a girl's body. So for two weeks every month, I was bedridden with cramps, migraines, and hot flashes due to my dysfunctional ANS, unable to regulate my estrogen's fluctuation.

When I was first diagnosed in April 1999, the medical world was aflutter with a sudden barrage of newly recognized autonomic disorders – namely Neurally Mediated Hypotension and Chronic Fatigue Syndrome - many of which overlapped, making things just that much more *confusing*.

The medical community was starting to take notice, as dysautonomia was disabling a population previously not hit by disease – previously healthy, young, blonde, girls.

Autonomic specialists are not sure why such a high percentage is blonde. Their best guess would be some sort of genetic link between dysautonomia and those of Nordic decent. But finding those girls is difficult. Affecting the entire body, conditions of dysautonomia can manifest in a million different ways; the original complaint could be migraines, stomach pain, fatigue, fainting, or even anxiety. Disease severity also tends to vary widely with autonomic conditions. The majority of teenage girls diagnosed with POTS don't require medication – just increased fluid and salt intake, to help increase blood pressure, and an awareness and avoidance of trigger situations. 80 percent of these girls will also be symptom free by their early 20s. But I decided to pitch my tent on the other end of that spectrum; the severe end.

“Patients with chronic disabling medically unexplained fatigue have long been regarded as a conundrum,” wrote Dr. Michael Sharpe, a leading expert on CFS. “A quarter to a half of all patients seen by medical specialists have illnesses characterized by symptoms such as pain, dizziness, and fatigue that remain unexplained.”

Doctors usually are split on this issue. Half believe the patient's symptoms are physical, and thus look for a medical diagnosis, and half believe the patient's symptoms are mental and thus look for a psychiatric diagnosis.

Dr. Davis encouraged my parents to let me try anything, even if it turned out to be a huge mistake, even if it meant missing school the next day, or the next week. He also wrote regularly to my teachers and school administrators, telling them that a kid will get better faster if they have something to get better for. And that something does not include homework and exams. He explained that allowing me to be as regular a kid as possible, have a sleepover, go to a dance – even if that meant missing a couple days of school due to the fatigue and illness caused – would mean I would be able to put more into my academics in the long run. But every time a teacher spotted me at a dance, and not at school on Monday, there was a problem. I was always amazed at how hard I had to fight to *attend* school, essentially, in every sense of the word.

Somehow, through all this – managing to accumulate grades, write papers, take finals – I not only completed my work, but my health improved. I missed about half of my freshman and sophomore years but just one third of both junior and senior year. My doctors, parents, and I were all hopeful that I would only continue to get better.

The beginning of my senior year my dad and I flew east to look at colleges. It wasn't until then that – while I was still extremely sick – college seemed like a possibility, and even if I didn't head off the

following fall, it was easier to apply, when I was still in school mode, and defer admission then to fill out applications after lying around at home for a year.

I had always loved Harvard, but I didn't think I had a shot at getting in. I had been too sick. But my dad made me go on the official campus tour and sit through the admissions presentation anyway. I ended up applying early action.

When decisions went out in December I got good news and bad news. They weren't rejecting or deferring me, which was good; they felt it was only fair to give my application the same chance as every other, and they couldn't do that with my incomplete application. But they weren't quite accepting me, either. I had been so sick first semester senior year I hadn't received any grades yet, only incompletes. Harvard told me they would hold my application and make a decision upon receiving my first semester grades. I worked my entire winter break. I stayed up late. I got up early. I needed to get those grades to Harvard as soon as possible. I was finally able to send them the end of January.

Every day following I sat by the phone. On February fourth they called. I got in. I ran around the house screaming, but no one was home. So I danced around with my dog and two cats. I would defer admission for at *least* one year. I was not well enough to go now, but I would just wait till I was. And it didn't matter; I was in.

I finished high school in four years, on time, and on June 1, 2003 I stood in front of my high school class – 852 students – and accepted my diploma. My mother had the required full-length white dress custom-made for me.

It was the first time I had done something, finished something, that I had been told I wouldn't be able to do. It gave me hope. Hope that my life *could* be what I wanted it to be. I would just have to work a little bit harder.

And I was going to Harvard.

I took the next year off. The first six months I rested at home, and on the few days I felt up to it, I worked as an assistant buyer at a high-end boutique. My parents didn't want me to go crazy with boredom, and the boutique belonged to one of my dad's best friends, so I could work as much or as little as I was able to, he understood. Mostly I slept. Six months of sleep left me well enough to do something bigger, and I needed a dry run living away from my parents, and while it seems a horrid idea – sending a sick girl to Maui by herself – I managed to convince my parents to let me spend two months living on the Hawaiian island, researching Humpback whales. I lived in a house with five older researchers and one other intern. Every day we woke up at eight and were on our boat by nine. We stayed out on the water till five, just counting, photographing, and documenting whales and their tails. I was a long way from home and on my own, but I basically spent each day lying in the sun on a boat. I did extremely well.

Bust I was still going to have to make some serious adjustments at Harvard, where you can't lie on a boat all day – like giving up my passion for chemistry, since there was no way I could make it to labs; and picking classes in which doing the reading could substitute for attending lectures. But I was confident I could do it. College had to be easier than high school. There was *way* less required class time, which meant more time I'd be able to lie in bed.

So in April 2004, when Harvard was fast approaching, I felt good. I was happy. I hadn't stared an obstacle in the face in a long time. I didn't expect to face one now.

But the illness -- whatever it was -- was still there.

Labels turn out to be not nearly as satisfying as I thought they would be. The doctors went on arguing about whether it was or wasn't POTS, whether it was one condition at all, whether it was multiple overlapping conditions. The point was, I needed extra help. I needed a single room, a bathtub to help control my body temperature, and extra time and breaks on tests.

"You suggested that [Abby's] professors would prefer to know in advance when she cannot perform -- as would she," my mother wrote my Harvard Student Disability Resources (SDR) advisor, trying to explain what my college years were going to be like. "But she often does not know how she will do each day until she wakes up. What she can tell them and wants to inform them through you is that she *will* be sick. That is her disability."

I was already in disability defense mode when I arrived in Harvard Square, but I was not going to hide my illness and I was not going to let my illness become my identity. I was going to find that middle ground, and be me.

"I think I asked you why you had a room to yourself, when most other people had roommates," one of my college roommates told me recently when I asked him what he remembered about our freshman year. "You told us you had a medical condition. And gradually, as you grew more comfortable around us, you began telling us more about what it was and more about your symptoms. But you never told us any names."

There were four of these guys, my best friends and roommates. All boys. They became my big brothers. Every Sunday morning we would all get in my bed and gossip about that weekends' sexual adventures.

Let's face it; I had a weird relationship with my body. Every part of me -- and I mean *every* part of me -- had been poked and prodded by male and female doctors alike since I was 13. Also, every high school relationship I had was truncated by my breaking up with the boy as soon as I got sick. So this . . . weirdness . . . was just one more thing separating me from most 'normal' college students. I didn't want it hanging over me.

I know I'm being evasive. Ok, what I'm trying to say: I was a virgin. I decided this was a situation that needed attention.

I knew I was going to have to push my body the first few weeks of school in order to make those initial social connections, so I hit up a heavyweight crew party with one of my roommates, Jamie -- who was on the team -- picked out a guy and brought him home with me that night. Done and done. The next morning, when I told the boys, they gave me a standing ovation.

Gabe was my first serious relationship. Sometimes in the middle of having sex I'd have to stop, because I was too tired. Sophomore year brought kidney infections each month. My doctors realized that to stop the infections I needed to take an antibiotic every time I had sex. One of our favorite roommates jokes: I was allergic to sex! The roommates joked that I was allergic to sex.

Then the marriage conversations started with Gabe, but I didn't even understand whether I had a normal life expectancy. I didn't know whether I could have kids, or hold a job.

I focused on the present, and I knew I *could* finish college. So I would do that. My parents had already told me they didn't care how many years it took me to get that diploma. All they cared about was that I graduate.

Gabe wanted to make it work, but I realized it wasn't what I wanted. We broke up.

My parents never pressured me to do something I didn't think I could do, and they supported my decisions even when I decided to do something *they* knew I couldn't do. They let me learn for myself. But it wasn't until recently, sitting at home and talking with my mom, that I learned how completely my hardships--that's how I'd always thought of them--weren't just mine.

"To be honest with you, Ab," my mom said, and then she stopped. She didn't seem to know what to say. "If you have a child and something comes . . . if there is any sort of . . ."

I have only seen my mom cry a handful of times, but as she spoke, I could see her eyes begin to glisten. She took a breath, composed herself, and started again. "The agony of a child who is not well is just overwhelming," she said. "I don't think there's a mother of an unhealthy child who sort of doesn't beat themselves up."

I had been distracted by the petty problems of high school and college, and neglected to see that my mother had been left with the burden of my illness. Where to go next? What to try next? Who to see next? Refilling my prescriptions, following up with doctors, making appointments. It all fell on my mother, and she did it all without complaint.

If I needed all that from my mom, what would I need from a husband? And honestly, did that man even exist?

Michael's hand slipped out of mine as they wheeled me, still strapped on the gurney, through the doors of Resurrection Medical Center's emergency room. Romy, my dog, was in his arms. Michael had to stay outside.

I hadn't reached my parents. I left them messages, and Michael kept calling, but didn't know if they were coming. And suddenly it was July 1998 all over again. I was lying on my bathroom floor, believing I had ruined everything, and once again I was waiting for my mother to make it okay, and for a long time I lay there, staring at the ceiling, until I heard it: click, click, click. I knew it was my mother, her heels clicking across the floor.

"Mommy," I squeaked. "I'm so sorry. I'm so sorry." And I was sorry for ruining her car, but more than that, I was sorry for ruining my mom's life. She had given up so much to help me achieve my dreams, but what about hers? I knew they didn't include this.

For six years – with the exception of my off and on school appearances - my mother and I spent all day together, nearly every day. It's hard to pull back from that.

And now, if I ended up bedridden, it would be my mother sitting by my side, taking care of me. It wasn't her job to take care of me. I didn't expect her to. But I knew she would.

She pulled up a chair, and held my hand.

They needed X-rays of my head and neck. A nurse soon came to take me to get my scans. My mother never let go of my hand. She walked next to my gurney as the nurse rolled me through the halls of the hospital.

The nurse put us in a tiny room. We had to wait our turn.

"What if I wrecked everything," I whispered. I had just begun to believe that I could really do this: work, get married, have kids, have a life.

Michael and I had been dating for a year. For the first time in my life, I was taking a serious look at marrying and having kids. My gynecologist had sent me to a high risk OBGYN, who told me that pregnancy would be extremely hard on my body--that I would feel like crap, that for nine months I would probably be able to do nothing, that the possible interaction between pregnancy and most of my medications has not really been studied at all. Plus, the medical community is still split on whether or not my autonomic condition – whatever it turns out to be – is genetic or not, leaving the possibility of passing on my scum at the bottom of the gene pool DNA to a child, unknown. So I would just have to make an educated guess, cross my fingers, and hope for the best when it came to pregnancy.

Also, though: I had a new diagnosis. A few weeks after the crash, I received some of the medical records I had requested from my millions of doctors. One of them included a diagnosis I had never heard before, but there it was, another long name to master: mastocytosis.

It has another name, Mast Cell Activation disorder. Your allergy cells, which are more formally known as mast cells, go crazy and think you are allergic to everything. An exotic disorder. Some doctors think Mastocytosis can cause autonomic failure. It affects around 2,000 people in the US. One of them happened to be a friend of mine from college--crazy weird considering the insanely small number of those inflicted – a few weeks later she connected me with a Mastocytosis specialist in Boston, and yes, it turned out that specialist thought it was a definite possibility, and she needed 20 vials of blood and a 24-hour urine sample, and the tests came back February 24, one month after my January appointment.

Inconclusive.

There were indicators, the specialist told me, that I might have Mastocytosis,. But the results for the one test that would be the determining factor were still pending. So nothing can be done until these results come in.

They are still out.

When I told my grandfather about the Mastocytosis, he told me I needed to stop collecting diagnoses and find a new hobby. Maybe I should just mush them all together and call it ABI, Abby's Debilitating Illness.

Because maybe there is no answer. Maybe what I have is something new, or actually a combination of five different problems all going off at once. But I've finally realized that that no matter how hard I try, I will never be normal. I have finally come to terms with the idea that maybe how I feel right now, as

shitty as it is, is the best it's going to get. And I need to stop looking for something to make it better, because that something just isn't there.

And I don't want my identity to become my illness and I'm starting to worry about that for the first time in my life. In high school and college I had tremendous support systems in place – my family and then my roommates – who were always ready to prop me up when I fell. I didn't have to ask the outside world for help, so I didn't have to be as open about my special needs. But going to graduate school out here in California, I don't have that constant behind the scenes foundation. I have to ask others for help and I have to ask every day.

But as much as I want an answer, it's not worth spending all my time researching new treatments and new doctors, flying all over the country, searching for that one person who can make it all go away. I have other things I want to do in life, and I have to make just as much room for them as I do the disease. But I also have to accept that part of me is wrapped up in illness and I can't deny that part either.

So through all this – all these documents, articles, interviews, yearbooks, and old letters – I have come out the other side having learned a ton about autonomic conditions, the medical system, and disability, but even more, I have learned about myself.

I learned that you should always get copies of your medical records. I found numerous diagnoses I had received but didn't know about. Besides the Mastocytosis, I was diagnosed with both Osteopathia Striata and Osteopoikilosis by doctors at the Mount Auburn Hospital ER. Both conditions are incredibly rare – Osteopathia Striata only affects 1 in 10,000,000 people – and while aren't symptomatic themselves, are important markers of numerous other conditions.

I learned how easily and frequently mistakes get written on one chart and then continue to follow you in every subsequent record. Every single date is a year off in the notes of my initial interview with a gastroenterologist at the University of Chicago in December 2002.

I learned that doctors are human. And just like the rest of us, they make mistakes, and can be wrong. They don't have all the answers.

I learned how other patients are often better resources than doctors. Because just like me they have seen every doctor who might possibly be able to help, and tried every weird out-there treatment that promises relief.

I learned that being able to talk to someone else who understands, truly understands -- because they also have some mysterious disorder – is priceless. And having the chance to mentor younger girls facing the same upward battle – through Harvard and DYNA, the Dysautonomia Youth Network of America – is the most rewarding thing I have done in my life.

I learned not to feel bad or guilty about asking for help, from anyone. Recently, visiting a close college friend in New York City, I told her about my struggles to find a doctor. She was on the phone the next day to her aunt, who happened to be head of neurology at New York University. So next month, after three years of trying, I am seeing the doctor who leads the Dysautonomia Center and Dysautonomia Research Laboratory at NYU.

Last month, sitting in the last row of an airplane – 35,997 feet above the ground – I stared down at the Colorado Rockies. We were directly above Aspen, where I grew up spending my winters. I thought

back to when every morning I would buckle up my ski boots; sling my skis over my shoulder and bomb down the sides of Ajax, Buttermilk and Snowmass. No fear.

I'm flying direct from New York City to San Francisco. And at this point in my life I no longer know what I want. As now, after an emotionally confusing phone call, and a weekend to sort his thoughts, last Monday Michael left me with: "I think I am going to have to break up with you."

Why? I asked.

"I just don't love you in the same way anymore."

You don't love me?

"No. I do love you. I am just unsure of what kind of love it is."

My friends say he is just scared. That there is no conceivable way he doesn't love me anymore.

Because Michael loved me in a way I never thought possible for someone like me, someone with my baggage. He said things I'd only heard in my dreams:

"I want to be with *you*. So if this illness is what that means, then that is fine."

"Abby, you will never, ever, be a burden to me."

I called him back 20 times that Monday. Hysterical. Unable to understand. Unable to get any grasp on what was happening. The control I had fought to maintain for 13 years dissolved in front of my eyes. On that July day in 1998, I didn't cry or fall to pieces; my stomach hurt, that was all. I didn't know that from that moment on everything would change-- for me, my parents, my sister, my friends, anyone who would enter my life from that point on. In that moment I had lost control. I would never again be able to say with certainty that on any given day I would wake up and be able to get out of bed. But I wasn't able to mourn my loss, because every day since then has been spent playing catch-up, trying to gain back what was taken.

And I felt like I was almost there. Like that certainty was so close I could taste it. I had a boyfriend who loved me, took care of me, wanted to marry me, and who said he was prepared for the challenges that a life with me would mean. I was about to graduate and had national publications wanting to buy my work. I had found a great apartment in Cambridge. I was so close.

That Monday, my body broke out into hives. I continually gasped for air. I shook for 24 hours. My reaction could have been emotional, it could have been triggered by illness; it didn't matter. It was bad.

My parents were on vacation, my sister was in midterms, my friends were at work. I was alone in the suburbs. And it hurt so much.

But maybe this was finally my chance to grieve -- for the childhood taken from me; the hundreds of sacrifices I've had to make; the people I've lost because, as Michael seemed to be trying to say, it's just too much.

So maybe it's easier for Michael to just say goodbye now. People are creatures of habit, and one of the worst things you can take away from them is their trust in the predictability of the world. It often

forces them to question their fundamental beliefs, their faith. And often they decide I'm not worth it. It's too hard.

Back at the hospital after my car accident, still waiting for my X-rays, my mom brushed the hair out of my face and said what she always does when everything goes wrong. "Don't worry. We will do what we always do. We can deal with whatever happens. We always have."

So I guess that is what I come away from all this with. I can deal with it.

As a teenager, I used to lie on the floor of my room, stare at the ceiling and listen to music. It let me escape my broken body and dream. I'd imagine all the amazing things that might happen tomorrow, next week, next month, next year, in five years, in ten years. I dreamed of boys, love, success. I dreamed about writing a best seller and changing the world. I never dreamed about being well. I guess I just didn't think it was in the cards.

Today, I still lie on the floor, stare at the ceiling and listen to music. I often listen to my favorite song – Coldplay's *Fix You* - on repeat, for hours.

*When you try your best but you don't succeed
When you get what you want but not what you need
When you feel so tired but you can't sleep
Stuck in reverse*

*And the tears come streaming down your face
When you lose something you can't replace
When you love someone but it goes to waste
Could it be worse?*

*Lights will guide you home
And ignite your bones
And I will try to fix you*

To be disabled, to be sick, is to lose something irreplaceable. For most people, anything is possible, and even when some things may seem impossible, that glimmer of promise is still there. I try to be all kinds of things: smart enough, amusing enough, cheerful enough, tough enough.

Because I will never be the one thing I want the most: Well. Healthy. Whole.