

**A Proposal for**

# **GUTS**

by Janet Buttenwieser

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## Overview

GUTS is a memoir that exposes the challenges of facing a mysterious illness as a young adult. At age 24 I moved to Seattle with a resume devoted to public service and fantasies of single-handedly ending poverty. But within a year I'd developed an intestinal illness so rare I wound up in a medical journal. I navigated misdiagnosis, multiple surgeries, and life with a permanent colostomy. Like many female patients my concerns were glossed over by doctors. I was young and insecure, major liabilities in my life as a patient. How would I advocate for low-income people when I couldn't even advocate for myself?

My model for assertiveness was my friend Beth. She was the kind of friend who'd accompany you to the doctor when you got dysentery in Ecuador, nonchalantly translating the graphic details of your symptoms into Spanish. Throughout my illness she took care of me; then she developed brain cancer and our roles reversed. Eventually I recovered, but Beth's condition worsened. At the age of 38, she died. To cope, I competed in endurance events, becoming a triathlete with a colostomy pouch.

125 million Americans, nearly half the U.S. population, suffer from a chronic condition. They need books like GUTS that demonstrate how we manage to thrive despite our incurable statuses.

GUTS contains 57,000 words in 32 chapters. Selections from GUTS have already appeared in 7 publications, been nominated for a Pushcart prize, and won honorable mention for several awards including *The Atlantic* Student Writing contest and the *New Millennium Writers* award. Author Brian Doyle says of GUTS: “Blunt, eloquent, piercing, honest, witty, heartaching, startlingly funny, and beautifully, refreshingly unique.”

## Market Overview

GUTS is a memoir about living with chronic illness, which the University of Michigan Center for Managing Chronic Disease defines as “a long-lasting condition that can be controlled but not cured.” 125 million Americans suffer from a chronic condition. Within this group:

- 60% are between the ages of 18 and 64.
- 25 million live with a rare disorder.
- 1.4 million are affected by Inflammatory Bowel Disease.
- Over 1 million have an ostomy.
- By 2020, the number of people with chronic conditions will increase to 157 million, and by 2030, approximately 171 million Americans will be afflicted by chronic illnesses.

In addition to the physical experience of chronic illness, an incurable condition takes an emotional toll. Navigating early adulthood with a chronic illness presents a particular set of challenges.

- 500,000 chronically ill teens enter adulthood every year.
- Despite having similar high school graduation rates, chronic illness patients are only half as likely to graduate from college as their healthy peers.
- The divorce rate among the chronically ill is over 75%.
- Depression is 15-20% higher for the chronically ill than for the average person.

- Physical illness or uncontrollable physical pain are major factors in up to 70% of suicides. More than 50% of these suicidal patients were under 35 years of age.
- 7 of every 10 deaths in the U.S. are caused by chronic conditions.

Support for chronic illness patients and their loved ones exists in a variety of ways. Centers that study chronic illness and improvement of the lives of chronic illness sufferers include:

- Center for Managing Chronic Disease, University of Michigan
- Improving Chronic Illness Care at Group Health’s MacColl Center for Health Care Innovation, Seattle
- Center for the Study of Chronic Illness and Disability, George Mason University
- Center for Research on Chronic Illness, University of North Carolina
- Partnership for Solutions, Johns Hopkins
- Rest Ministries, a Christian organization devoted to serving the chronically ill. Among other services they organize an annual “Invisible Illness Awareness Week.”

A multitude of support groups, conferences, and discussion groups exist regionally, nationally, and online for chronic illness sufferers. Most chronic conditions have their own associations that include regional chapters within a national organization. For example:

- The Crohn’s and Colitis Foundation of America (CCFA) has a constituent base of over 2 million people and serves 300,000 patients annually. They maintain a website, a telephone hotline, and an active online community with several message boards. They

host the endurance/fundraising events “Team Challenge,” “Take Steps Be Heard,” and “Get Your Guts in Gear” at several locations across the country.

- CCFA has 40 regional chapters. The Northwest Chapter, headquartered near Seattle, serves 5 states. They host several regional conferences for patients and their families, as well as 10 monthly, in-person support groups.
- United Ostomy Association of America has affiliate support and advocacy chapters all over the country, including 4 in the Seattle area alone. They host 10 online support groups and an extensive message board. They publish a quarterly magazine, The Phoenix, and host an annual national conference. They host endurance/fundraising events, including “Get Your Guts in Gear” along with CCFA.

An article titled “13 Things People With Chronic Illness Wish You Understood” by Deepa Lakshmin is one example of the current popularity of the subject. Lakshmin’s article was posted on MTV’s website in March 2015. The article had 24,000 Facebook posts within 24 hours of going live and 113,000 posts within 7 days, suggesting that people seek empathy about their chronic conditions.

## Comparative Titles

People with chronic illness and their caregivers crave stories told from their perspective. *All in My Head* author Paula Kamen calls this subgenre “sick lit” and describes it as “women fighting shame and isolation through telling their stories about ‘invisible’ illness.” The isolation Kamen speaks of is a large factor in the chronic illness experience, where patients are frequently confined to their homes and hospital rooms. “Sick lit” memoirs like GUTS thus become essential guides to life with a chronic condition. GUTS complements the following titles:

- *Brain on Fire: My Month of Madness* by Susannah Cahalan (Free Press, 2012). Susannah Cahalan is 24 and a reporter for the *New York Post* when she wakes up in a hospital room with a mysterious illness that has left her unable to move or speak. A *New York Times* Bestseller, a *Booklist* Top 10 Science and Health Pick of 2012, on *O Magazine*’s list of “Ten Titles to Pick Up Now.” Cahalan has appeared on The Today Show, the Katie Couric Show, and NPR’s *Fresh Air*. A feature film based on the book will be released in 2016.
- *Misdiagnosed: One Woman’s Tour of – and Escape From – Healthcareland* by Jody Berger (SourceBooks, 2014). A detailed account of misdiagnosis and a navigation of the labyrinth Berger terms “healthcareland.” A *New York Times* bestseller by a journalist whose articles have been published in the *Los Angeles Times*, *Sports Illustrated*, *Outside*, and elsewhere.
- *Two Kinds of Decay* by Sarah Manguso (Farrar, Straus & Giroux, 2008). Tells a story in fragments of suffering from CIDP, an autoimmune disease, in early adulthood. Named an

Editors' Choice by the *New York Times Book Review* and a Best Book of the Year by the *Independent*, the *San Francisco Chronicle*, the *Telegraph*, and *Time Out Chicago*.

- *Limbo: A Memoir* by A. Manette Ansay (William Morrow, 2001). Details the journey of a young woman whose career path shifted from pianist to novelist when she developed a muscle disorder at age 19 that eventually confined her to a wheelchair. Ansay's best-selling books include *Vinegar Hill*, an Oprah Book Club selection, and *Midnight Champagne*, a National Book Critic's Circle Award finalist.
- *Sick Girl* by Amy Silverstein (Grove/Atlantic, 2007). Demonstrates how being a so-called "angry" patient could actually save your life, as well as what life is like after a heart transplant. Honors include the Books for a Better Life award, finalist for the Borders Original Voice award, *Good Housekeeping's* "Good Reads" pick the month of its release. Reviewed in *O Magazine*, *People*, *Elle*, and elsewhere.
- *All In My Head: An Epic Quest to Cure an Unrelenting, Totally Unreasonable, and Only Slightly Enlightening Headache* by Paula Kamen (Da Capo Press, 2006). Highlights the common experience of a woman who is told that her chronic, 15-year headache is "all in her head." Kamen is a feminist activist who writes and lectures frequently on the topic of women's treatment within the realm of pain care.

GUTS builds on these complementary books by:

- including the caregiver perspective;
- exploring themes of illness, friendship, and athleticism;
- providing an up-to-date view of living with a chronic condition;
- listing current resources for patients and their families in an appendix.

## Marketing and Promotion Plan

**Promotion Through Prominent Authors and Physicians:** Janet has existing connections to the following people whom she will contact for a foreword and quotes:

- Cheryl Strayed, author of *Wild: From Lost to Found on the Pacific Crest Trail*
- Atul Gawande, MD, Professor at Harvard Medical School and Harvard School of Public Health, *New Yorker* staff writer, and author of *Complications: A Surgeon's Notes on an Imperfect Science*
- Rafael Campo, MD, teacher and physician at Beth Israel Deaconess Medical Center and Harvard Medical School, and author of *The Desire to Heal: A Doctor's Education in Empathy, Identity and Poetry*
- Perri Klass, MD, Professor of Journalism and Pediatrics at New York University and author of *Treatment Kind and Fair: Letters to A Young Doctor*
- Nicholas A. Christakis, MD, PhD, MPH, Director of Yale University's Human Nature Lab and author of *Connected: The Surprising Power of Our Social Networks and How They Shape Our Lives*
- Elissa Ely, MD, psychiatrist and *Boston Globe* columnist
- Danielle Ofri, MD, Editor-in-Chief of *Bellevue Literary Review*, Associate Professor at NYU Medical School, and author of *Incidental Findings: Lessons from My Patients in the Art of Medicine*
- Robert S. Lawrence, MD, Professor at the Johns Hopkins Bloomberg School of Public Health and the Johns Hopkins School of Medicine.
- Gail Caldwell, author of *Let's Take the Long Way Home: A Memoir of Friendship*

**Promotion to the Writing Community:** Janet is a former teen services librarian and current writing teacher. She is active in Seattle’s literary community through her roles as a teacher at Richard Hugo House, a board member for the Bureau of Fearless Ideas (a writing center for kids), and an alumnae of the Northwest Institute of Literary Arts. Janet will apply to 15 organizations, including local and national writing conferences and writing programs, to give seminars and workshops on the topics of memoir and writing about illness.

**Promotion to the Ostomy Community and others with Chronic Illness:** Janet is an active member of Seattle’s community of people with ostomies, belonging to both the Seattle chapter of the United Ostomy Association and Ostomy United, a group of individuals with ostomies who participate in endurance events. To promote GUTS, Janet will contact the following organizations for readings and speaking engagements:

- Improving Chronic Illness Care & the MacColl Center for Health Care Innovation
- Crohn’s and Colitis Foundation of America (CCFA), Northwest Chapter
- Patient support groups at Seattle-area hospitals (Swedish, University of Washington Medical Center, Children’s Hospital, Virginia Mason)
- United Ostomy Association of America, Seattle Chapter
- Columbia University’s Narrative Medicine Program
- Global Alliance for Arts and Health Annual Conference
- Omega Institute
- The Examined Life Conference
- Ostomy United
- Get Your Guts in Gear: The Ride for Crohn’s and Colitis

- Team Challenge (endurance events held nationwide through CCFA)

**Promotion to the library community:** Janet, a former teen services librarian, served on the Young Adult Library Services Association (YALSA)'s Michael L. Printz Award committee (2007) and the Popular Paperbacks for Young Adults committee (2005-2006) and has connections at public, school and university libraries across the country.

**Promotion through a reading/signing tour:** Janet will set up a reading/signing tour at bookstores, libraries, and community colleges in the following Pacific Northwest cities: Seattle, Portland, Boise, Eugene, Bellingham, Spokane, Leavenworth, Lopez, Eastsound (Orcas Island), Sitka. Janet will set up a reading/signing tour in the Boston area, where she has family with connections to Boston's literary community, including Carol Horne, events coordinator for the Harvard Bookstore and Deborah Porter, Executive Director of the Boston Book Festival. Janet will contact newspapers and radio stations in advance of her visits to solicit interviews and reviews.

**Promotion through Janet's website and social media accounts:** Janet will set up a blog tour and contact podcast hosts for interviews. Janet maintains a website and blog at [janetbutterwieser.com](http://janetbutterwieser.com), where her most popular blog posts have been about GUTS. She will also promote GUTS on her Facebook and Twitter accounts.

## About the Author

Janet Bittenwieser's nonfiction work has appeared or is forthcoming in several publications, including *The Rumpus*, *Bellevue Literary Review*, *Potomac Review*, *The Pinch*, *Under the Sun*, *Literary Mama*, and *Los Angeles Review*. Janet was nominated for a Pushcart and was a finalist for the 2014 Oregon Quarterly Northwest Perspectives Essay Contest. She won honorable mention in *The Atlantic* 2010 Student Writing contest, the 38<sup>th</sup> *New Millennium Writings* contest, and the 2011 Artsmith Literary Award. She has an MFA from the Northwest Institute of Literary Arts.

A former teen services librarian, Janet now teaches writing at Richard Hugo House in Seattle, as annual visiting faculty at the Northwest Institute of Literary Arts, and elsewhere. Janet has been an avid volunteer since she was a teenager. She has served in a variety of positions in low-income communities, including ESL and homework tutor, teacher's aide, soup kitchen coordinator, and more. From 1995-1997 she worked as a VISTA (Volunteer in Service to America) creating a family resource center at Solid Ground, a Seattle-based social service agency. Her work with the Seattle Foundation earned her their 2006 Chairman's Award. She has been a longtime writing tutor at the Bureau of Fearless Ideas (formerly 826 Seattle), a writing center for children, and now serves on their Board of Directors.

Janet lives in Seattle with her husband and their 2 children. She has raced in 8 triathlons (and counting) since her colostomy surgery in 2004.

The published and award-winning essays listed below are excerpted in GUTS in a slightly different form:

“Out of Order.” *The Rumpus*. Summer 2016

“Laws of Motion.” *Under the Sun*, 2015. Nominated for a Pushcart Prize

“Pins and Needles.” *The Pinch*, October 2014

“Personal Record.” *Stymie*, October 2014

“Chief Complaint.” *Potomac Review*, Issue 54, Winter 2013

“Running Out the Clock.” *Mason’s Road*, Issue 6, Winter 2013. Honorable mention, 38<sup>th</sup>

*New Millennium Writers Contest* (2015)

“Approved for Occupancy.” *Shark Reef* Issue 20, Summer 2012. Honorable mention,

Artsmith Literary Award (2011)

“The Colostomy Diaries.” *Bellevue Literary Review* Vol. 11, # 2, Fall 2011. Honorable mention, *The Atlantic Student Contest* (2010)

## **Contents**

### **1. Diagnosis**

I move to Seattle with my boyfriend Matt at age 24 with ambitions of eliminating poverty, but my energy deflates when I become ill. After a year of doctor's visits and diagnostic tests, I'm shocked to learn I have Crohn's Disease. I soon realize my unassertive nature will be a liability.

### **2. A Good Patient**

I decide I will get through my illness the way I've done everything else: by being good. A family friend offers to connect me with a big-shot gastroenterologist he knows in Seattle. I want to be self-sufficient in Seattle rather than relying on personal connections as I did at a younger age. I decline his offer. Matt and I try to go on normally, hosting our friends Beth and Kevin for Christmas dinner. While Beth and I set the table I think of Matt's marriage proposal from 2 years before and my negative response, an event I haven't disclosed to anyone.

### **3. Replicas**

Beth's gregarious and assertive nature draws me in, and she becomes my closest friend in Seattle. She starts collecting pewter replicas and I become obsessed with finding one for her. I worry about how strong the thread of our friendship is, and whether or not I will break it with some blunder.

#### **4. Abscess**

I develop an abscess, a common complication of Crohn's. I make a visit to the E.R. and narrowly avoid emergency surgery.

#### **5. The Princess Bride**

Just as I am beginning to figure out life with a chronic illness, Beth and Kevin announce plans to move to Ecuador for a year. How will I cope without her?

#### **6. Truco**

Matt and I travel to Ecuador to visit Beth and Kevin. My medication-stuffed backpack contains Prednisone steroids. I seem to have every side effect listed on the prescription insert: acne, buffalo hump, weight gain, chin hair, and swollen cheeks from "moon face." To add to my lower-region troubles, I contract amoebic dysentery on the trip.

#### **7. The Goddamn Grand Canyon**

A few months after we return from Ecuador, Matt and I raft through the Grand Canyon with a group that includes the family friend who recommended the big-shot Seattle doctor 2 years before. The friend and I talk about the big-shot doctor again. I've become bitter about my illness and I take it out on Matt during the trip. The situation isn't helped by the fact that we can only access the portable toilets at camp in the morning and the evening. I clench my way down-river.

## **8. Out of Order**

When we return from the Grand Canyon I visit the big-shot doctor. He tells me he doesn't think I have Crohn's. The problem is a tumor on the outside of my intestine. I need surgery. I consult with a surgeon whom proclaims himself "the best colorectal surgeon on the west coast." In the hallway outside his office he tells me I'll probably need a permanent colostomy. My surgery day arrives. In the pre-op area, with Matt and my parents by my side, the enormity of it all hits me. They don't know what they are going to find when they open me up. I could wake up with a colostomy, an ileostomy, a tumor still inside me, unable to be removed.

## **9. Chief Complaint**

The operation is successful and I have a temporary ileostomy. The day after the surgical staples are removed my incision opens up, necessitating a trip to the Emergency Room via ambulance.

## **10. Proposal, Revisited**

My wound heals slowly, along with the rest of me. With a renewed sense of energy and health, I ask Matt to marry me. He says yes.

## **11. Rules of Engagement**

Matt and I announce our engagement to family and friends, including Beth and Kevin. Beth reacts as though we'd said we were planning to breed children and eat them. Matt

and I marry, then Beth and Kevin, and gradually Beth and I drift apart. We have our last conversation for 8 months at Beth and Kevin's wedding reception.

## **12. Grand Mal**

Beth has a grand mal seizure in the middle of the night. A brain tumor. A mutual friend calls to tell me the news. I reach across 8 months of silence and write Beth a letter asking what I can do to help.

## **13. Driving Miss Peterman**

Beth and Kevin phone in response to my letter. Because of the seizure, Beth is not allowed to drive. Can I help with rides? Before surgery, and after, I drive her to her appointments. We never speak of the rift in our friendship. We simply pick up where we left off. I have started seeing a fertility specialist, a fact Matt and I keep mostly to ourselves.

## **14. Recurrence**

My 2<sup>nd</sup> IVF treatment results in a pregnancy. During the first trimester, I have a miscarriage. A few weeks later I feel a too-familiar pain down by my tailbone. After a CT scan my surgeon phones with news that the teratoma is back. "You'll need to have a colostomy for sure this time," he tells me. "Permanently."

## **15. Trash Can**

The administration at the library where I work takes my request for a lidded trash can for the staff bathroom a little too seriously.

## **16. Olympus**

In the weeks leading up to my surgery, my usually confident doctor expresses anxiety about the procedure and wonders if I will need to have a hysterectomy and part of my spine removed to get rid of the entire tumor. In the end, I have the colostomy but my uterus remains intact and only my tailbone requires removal. Eating dinner with Matt, my parents, Kevin, and Beth on my last night in the hospital, I notice there's a positive aspect to the surgery and the closeness it creates between the others and me.

## **17. Waiting Season**

In the aftermath of the miscarriage and surgery, Matt and I decide to adopt a baby. We find an agency we like that specializes in local, open adoptions, where we will have ongoing contact with the birth family as the child grows up. We fill out heaps of paperwork. I decide to compete in a triathlon in order to maintain my sanity during our wait.

## **18. Caleb**

More than a year after we complete our adoption paperwork, a pregnant woman chooses us to be her baby's adoptive parents. Matt and I are present for the birth and stay in a hotel near the hospital. Making a follow-up appointment with a pediatrician we chose a

year before Caleb was born, I get into an argument with the clinic receptionist. I realize I might finally learn how to be assertive now that I am a parent.

### **19. Cancerversary**

Beth passes her 5-year anniversary of being cancer-free. When Caleb is a year old I participate in my 2<sup>nd</sup> triathlon. The afternoon of the race, Beth calls with news. “It’s baaa-ck,” she says, her voice high, Poltergeist-style. I don’t have to ask what “it” means. Her tumor. Her cancer.

### **20. Lavawoman**

Shortly after Beth’s surgery, I learn of Team in Training, where endurance race participants raise money for cancer research. I sign up to do Lavaman, an Olympic-distance triathlon in Hawaii, planning to race in Beth’s honor.

### **21. Murder of Crows**

A few months into my training Beth and Kevin come over. I tell a long story of a recent bike crash before learning that Beth’s latest round of chemo has failed. I see her cry for the first and only time in our 14-year friendship.

## **22. The Call**

The phone rings one evening. It's our adoption agency. We've been picked. The baby is due in a week, the same day that Matt, Caleb, and I are scheduled to leave for Hawaii for my triathlon.

## **23. Helen**

I cancel my race plans and our trip. Seven days after the adoption counselor calls, Matt and I stand in the delivery room to witness our daughter Helen's birth.

## **24. Down in the Hole**

Helen develops acid reflux at 2 weeks of age, making sleep and feeding a challenge. Home full-time with a high-octane toddler and a fussy newborn, unable to spend time with an increasingly sick Beth, I become addicted to HBO's "The Wire."

## **25. Attitude is Everything**

Beth comes over before a doctor's appointment. I call Beth and learn that the chemo isn't working. She's applying to participate in a clinical trial, a fact that fills me with alarm. Aren't clinical trials a last-resort option? With Beth's worsening condition on my mind, I decide I need to do my Team in Training event as soon as possible. I sign up for a fall race, though I am so sleep-deprived and busy with the kids that I cannot imagine when or how I will train. Beth goes to Europe. Within a few days of her return, she cannot talk or move her right side.

## **26. A Fissure in the Sky**

Matt, Helen, and I visit Beth on the last morning of her life.

## **27. Pre-Race**

I go to California for the triathlon. The night before the race I sit in my hotel room missing Beth and my family and fretting about the race.

## **28. Personal Record**

In the race, bad weather causes 4-foot swells on the swim course. I miss the time cutoff for the bike and am asked to leave the course before I can complete my final lap. I have an angry run until I see a Team in Training friend, who stays on the sidelines to cheer me on. I make a decision and my mind finally settles. After the bike course clears of racers, I do my final lap. My own private triathlon.

## **29. Sitka**

Beth's husband Kevin, now a widower at the age of 38, decides to move to his hometown of Sitka, Alaska to build himself a house. I help Kevin pack Beth's belongings. I keep returning to the house, thinking I am allowing myself to say goodbye to Beth, to process her death. But I am not letting go. I am clinging.

## **30. The Mountain**

Two years after Beth dies, I go snowshoeing to the place where her ashes were scattered in Mount Rainier National Park. While there I realize that I've developed the stamina to endure the weight of many things, including the loss of my dear friend. I return home and

dance to “Yellow Submarine” with the kids while Helen sings the words she knows, *we all live.*

## **Appendix**

I will provide a list of print and online resources for people with chronic illness.

## Sample Chapters

### 1. DIAGNOSIS

The first time I received bad medical news, I was 26 years old. I shivered in my hospital gown while I waited for the doctor to arrive, a gastroenterologist I'd never met. My boyfriend Matt was at his job a few miles away in downtown Seattle. He worked as a lab technician at a blood bank that served hospitals in a 5-state region, including the one that housed the clinic where I sat.

This was my first time in this exam room, but after a year of unexplained illness and half a dozen doctors' visits the trimmings felt familiar: crinkly exam paper underneath my legs, over-bright fluorescents humming from the ceiling. Sharps container on the dull-colored countertop, biohazard trash can by the wall-mounted blood pressure monitor. One framed print of a nature scene intended to be soothing – Mount Rainier at sunset, its glaciers painted in pastel pinks and purples.

With each doctor I saw, I had to fill out the paperwork anew. I did not yet know the habits practiced by the chronically ill. I didn't keep copies of past medical procedures or carry a notebook to record medications and their dosages. I didn't write a list of questions down ahead of time. I didn't take notes. Instead, I relied on the elephant memory I'd inherited from my mother to tell and re-tell my medical tale of woe. *Once upon a time, a 25-year-old woman had a pain in her butt.*

Up to that point, I'd thought of myself as fortunate. I'd grown up in 1970s suburban Boston, the third child of a psychiatrist and a social worker who had a happy marriage. I

inherited their liberal politics and desire to help disadvantaged populations. I had a boyfriend in middle school, my only dating experience until I went to college and met Matt. I rarely drank or did drugs, and didn't smoke. My biggest act of rebellion was to flaunt the advice of my prep school's college advisor and my parents and apply to a small liberal arts college in Colorado no one I knew had ever heard of, let alone attended. I got accepted and I went, declaring my first month of school that I'd never live in New England again.

In Seattle, the medical assistant measured my height (holding steady at 5'2" since 1984) and weight before bringing me into the room.

"120," she announced after the scale beeped. "That's good," the doctor would tell me later. "You've maintained a healthy weight." No easy feat, considering the year I'd had.

One afternoon the previous fall, I returned from a long car trip with an aching rear end. The next day I still felt pain, the sensation against my tailbone like an outlaw hunched behind a rock, waiting for his enemy to arrive. A few days later it was worse still, one man pressing the other against the rock, his lungs nearly collapsed from the pressure, a knife blade resting on his throat. Within a few months, I was pooping 15-20 times a day, my stools coated with blood and mucous.

I went to urgent care, the bone and joint clinic, internal medicine. They took stool samples, blood samples, prescribed Aleve and antibiotics. On one doctor's advice I bought an inflatable donut pillow at the pharmacy. Finally, in October 1997, a doctor scheduled a colonoscopy. For advice on how to prepare, I called the only person I knew who'd had one – my Mom. She was the least prone to worrying of anyone in our family, and possessed a social

worker's skill of listening and then dispensing wisdom in a way that made it seem like your own idea.

"Iced tea makes a good chaser," she said.

"Chaser for what?"

"For the stuff you have to drink to prep your bowel. She let out a nervous laugh. We did not talk of such intimacies, my mother and I. "It has a funny taste."

If by "funny taste" she meant a Drain-o-flavored liquid that, years later, would make me gag simply by appearing in my line of vision on the drug store shelf, she was right.

A few days after the colonoscopy I sat in the exam room, awaiting a diagnosis. In truth, I wanted there to be something definitive wrong with me. I'd grown weary of the inconclusive diagnostic tests, the condescending tone of physicians as they dismissed my symptoms.

The doctor came in. She stood at a medium height, slightly plump, with short black hair, frameless glasses, and a raised mole above her right eyebrow that I tried not to focus on as she spoke. She wore pearl studded earrings; a tan silk blouse peeked out from underneath her white coat.

She introduced herself, giving her first and last name. I'd never had a doctor tell me their first name before, and I lingered on it, Carol. My cousin was named Carol, and my father's sister, who died of complications from anorexia long before I was born. It was my aunt Carol whose image I conjured in the clinic, clutching a bouquet of roses in the wedding photograph that hung on my parents' kitchen wall.

Dr. Carol gave me a limp handshake, and got right to her point.

"We received the pathology report from your colonoscopy. You have Crohn's Disease."

Even though I didn't know what that meant, I felt panic course through me. I wanted to go back in time and remove my desire for a diagnosis. I didn't want one after all. Not if it had the word disease in it. Not if it made a doctor I'd just met give me such a pitying look. She began to explain what it meant to have Crohn's, but it was as though a ringing had started in my ears as soon as the word "disease" emerged from her mouth. Information came through in fragments – inflammation. Treatments improving. Chronic. Incurable. My mind snagged on this last word, then jerked forward when she asked me a question.

"Are you Jewish?"

"Half," I said. "On my Dad's side."

"Ashkenazi?"

"What?"

"The disease is more common among Ashkenazi Jews," she explained. I didn't know if that's the type of Jews we were; I'd never heard the term before. Apparently I was the kind of Jew who doesn't know anything about being Jewish.

She asked if I had any questions. I didn't. I felt the way I did when I walked into a music store to buy CDs, where all thoughts of what I was there to purchase dissolved as soon as I walked through the metal detector at the entrance. It seemed like I should have a question, ought to say something, anything. But I was unused to asserting myself; instead, I relied on my family and friends to do it for me. Usually this method worked well, though sometimes it had dire consequences. Once I'd gone rafting with a group of inexperienced people. When we arrived at the river and I saw how high the water was, I thought it was too dangerous to raft. I said nothing. Three of us fell out of the boat and nearly drowned.

Still, the idea of asking more of Dr. Carol felt both inappropriate and impossible, as though the chain had just derailed on the bicycle in my brain. She wrote something on her prescription pad, tore it off and handed it to me.

“This should lessen your symptoms,” she said. Lessen, not eliminate. “Come back in a month and we’ll see how you’re doing.”

She seemed a little stern, but I didn’t think to be put off by this behavior. I’d never been under ongoing care of a specialist before, and I didn’t know that it was important that I like her, not just as a doctor, but as a person. We’d be seeing a lot of each other, Dr. Carol and I, though I didn’t understand that yet.

“You need to store this in your refrigerator,” the woman behind the counter told me when I picked up the medication at the hospital pharmacy one floor above the clinic. “Insert one each night at bedtime.”

“Insert?”

“Yes. Into your rectum.”

In the parking garage, I sat in my car, listening to the screech of tires and the rumble of engines as other patients entered and exited the spaces around me. I fiddled with the strap of my watch, a 21<sup>st</sup> birthday gift from my parents. Though it looked like fancy jewelry, with a wide piece of silver encircling its face, I wore it every day along with the baggy jeans and monochromatic t-shirts that made up the majority of my wardrobe.

In the passenger seat a paper bag bulged with my prescription and the four-page handout of side effects, contraindications, instructions for medication administration. I should be crying, I thought. No tears came, though, just a tight, heavy feeling in my chest. I tried to let the Bad

Medical News sink in, but it was like car oil pooling on the surface of a puddle. My brain couldn't make sense of the information I'd just been given, couldn't even remember most of it. This was 1997, the pre-Google era of the Internet. I couldn't instantly look up everything I needed to know about the diagnosis I'd just received. I only had single words thudding in my ears along with the roar of my heartbeat: Disease. Lifelong. Incurable.

Where was the brochure I was supposed to be handed, bolstering me with facts? Therapies were improving all the time; there were support groups I could join. Over a million people in the United States suffered from Crohn's or its cousin illness, ulcerative colitis, many of them young people like me. My Crohn's seemed to be limited to my rectum, but the disease could affect any portion of the digestive tract, mouth to anus. Patients sometimes experienced "flare ups," a worsening of symptoms for a distinct period of time.

But I didn't know any of this yet. It felt as if there was one true thing, which was that this was not supposed to be my fate. Bad things did not happen to me. I was 26 years old. Every single person I knew under 40 was in their prime of health. The previous summer some friends from Colorado stayed in our apartment on their way to summit Mount Rainier. It felt like a cruel contrast, the 3 of them going to rent climbing gear while I stayed home with the phone to my ear, on hold while the nurse looked up my latest test result. This would be my vantage point now, navigating adulthood from the waiting room chair instead of the mountain top.

Being ill for the past year had made me feel lonely, and the prospect of living the rest of my life with a chronic illness lonelier still. It was as though all my life up to that point I'd been walking a trail through the woods with a group of family and friends. We sang songs and paused to observe mushrooms and wildflowers, the way the leaves and branches above us were shot with sunlight. The route was obvious, signaled by bright yellow blazes painted on the trunks of

the trees that lined the path. Sitting in the hospital garage, though, it seemed to me that my trail had veered left, away from the others. No more markers, no more companions. The way ahead brambled and dark.

I needed to talk to someone, immediately. It was late afternoon. Matt worked the swing shift, and calls were difficult to take at the lab, so phoning him was out. My college friends Amy and Penny, to whom I confided everything, lived in different states and would also still be at work. I could call my best friend in Seattle, Beth, but I'd rather tell her in person. My sister in New York was probably eager for a distraction. She was a week past her due date for her first child, no doubt pacing the apartment double-checking the contents of the duffel bag she'd bring to the hospital. My brother, in his first year of medical school, would surely have some up-to-date wisdom to pass along.

I decided on my parents back in Massachusetts. They'd be home from work by now, my mother preparing dinner while she listened to *All Things Considered*, a glass of wine on the counter next to the cutting board. My father, in his study, would be responding to emails while he drank a Diet Coke. I took a shallow breath. I started my car, exited the garage, and pointed towards home.

The apartment I shared with Matt sat 20 blocks from the clinic, and 3,060 miles from my childhood home in Massachusetts. My parents moved into the house a few months before I was born and still lived there twenty-seven years later. The western-most edge of Interstate 90 began a few miles from my home in Seattle, and ended approximately the same distance from my parents' house.

"One road from my house to yours," I joked to my mother over the phone when I made the discovery. Then it had felt true, a thick rope that stretched from one side of the country to the

other, shrinking the distance between us much the same way the telephone line did. Nonstop flights departed Seattle for Boston every day, and I could travel from one house to the other in less than 6 hours. But as I exited the hospital parking garage and drove past the university campus, it was my childhood home I longed for. For the first time since arriving in Seattle, I was overcome by a wave of homesickness so strong my vision blurred for a moment.

I'd moved to Seattle with Matt two years earlier intent on eliminating poverty. It was a goal I'd had in mind since high school when I interned at a child care center for abused and neglected infants and toddlers. I continued along my public service path by spending every Tuesday afternoon in college tutoring kids at the Red Cross homeless shelter a few miles from campus. After graduation I spent four months in Kathmandu working for a Nepali women's rights organization.

My role model was my grandmother, who as one of the first female attorneys in the country had dedicated her career to helping disadvantaged people. Her briefcase was a 1960s-style rainbow-striped Technicolor affair. Grey-haired and 5'3", she would walk calmly down the courtroom aisle and set her briefcase down on the counsel table with a confident *thwap*. I wanted to be her.

I pulled up to a red light and rolled down my window. It was early October and the maples and dogwoods that lined the university campus were just beginning to change into their autumn wardrobes. On either side of the boulevard students and faculty transported themselves from building to building by foot, bicycle, skateboard. To my left, Lake Union appeared to be painted in gunmetal with a matte finish, churning as the wind picked up. To my right, the Burke-Gilman, a rail-trail that bisected campus and continued north for some twenty miles. I jogged on the

Burke-Gilman regularly, crossing the drawbridge near our apartment to run along the path. I hadn't gone running in months, though. I'd been too sick and in too much pain. Maybe the medication would help me feel well enough to resume running. Did people with Crohn's Disease exercise, I wondered?

I parked in front of our apartment and sat in my car for a moment before gathering my prescription and my backpack from work. Inside the house I kicked off my shoes and shucked my rain jacket, hanging it on the over-full coat tree. I flicked on light switches and walked straight to the phone, eager to hear my parents' voices and share my news. My father, Harvard-educated in English Literature and medicine, would surely have something erudite to say. He answered and the words "Crohn's Disease" had barely escaped my mouth before he gave his response.

"Oh, shit."

## 2. A GOOD PATIENT

Crohn's was my biggest problem, but it wasn't my only problem. I was shy and unassertive. These hadn't been obstacles when I was healthy, but now that I would be spending a lot of time at the doctor's office, they would be liabilities. As a young woman, if I didn't speak up my symptoms and concerns would be glossed over by my doctors. I would need to become my own advocate.

No one told me this. If there was a guide to being a patient, I didn't know of its existence. My usual methods – read about the issue, talk to family and friends – yielded little useful information. Everyone was supportive, but I was a pioneer in the Land of the Chronically Ill.

In the month following my diagnosis, I continued to take the nightly steroid suppositories, as well as an oral medication. My stools were now absent of blood and mucous. The pain continued, but with less intensity; I no longer required the donut pillow at work. I pooped at least ten times a day, less than before, but still too often.

If the shift in my physical symptoms seemed moderate, they became eclipsed by the dramatic change in my outlook. Before Crohn's, I felt frustrated by my protracted illness and motivated to find a cure. After the diagnosis, though, I felt deflated. Crohn's was incurable. Crohn's lasted forever. How was I going to get through it?

I realized that I would have to endure my chronic condition the way I'd managed everything else: By being good. I'd been a good daughter, taking the strait-laced path in the wake of my sister's rebellious adolescence. I'd been a good student, friend, girlfriend. And now I would be a good patient. I took my medications dutifully, and followed all of my doctor's instructions to the letter. My brother, immersed in his medical school coursework, had advice.

My father, several years past his med school days, had more. I took all of their suggestions, just as I had my entire life. And then one day, at the very wrong moment, I'd had enough.

My father called one evening with a recommendation from Bob, one of his closest friends from college and medical school.

“Bob knows a gastroenterologist in Seattle,” my father told me. “He was a year behind us in school. I don't remember him.” He was the head of a clinic associated with one of the large hospitals, though not the one where I was getting treatment. “Bob can put you in touch with him if you like.”

“I like my doctor,” I said. This was true and not true. She'd treated Crohn's patients for years, and seemed like a good doctor who knew what she was talking about. I found her manner condescending, though. She had a stand-offish tone that, years later, made me wonder if she preferred the research part of her job to patient care. But the clinic had a good reputation, part of a state-of-the-art hospital with access to the latest treatments.

I chose the clinic for reasons that made sense to a 26-year-old who'd never had a serious illness: It was close to our apartment and covered by my insurance. When my first symptoms – the tailbone pain -- cropped up I didn't have a primary care physician. I went to urgent care hoping they'd prescribe some heavy-duty pain reliever and send me on my way. Instead, they took an x-ray and referred me to the bone and joint clinic. From there I bounced to a general practitioner, who took some stool samples and tried a few rounds of antibiotics before sending me to a specialist. The g.i. clinic was where the buck stopped, and my doctor seemed as well qualified as anyone else would be to take care of me.

Throughout our lives my father's well-connected status had yielded gifts for his children – front row seats to the Eric Clapton concert when I was in high school, or a space for my sister

in her college dorm even though they were purportedly full. We had to earn the important things - jobs and school admissions – on our own. It was his way of taking care of us, a character trait I saw as generous from the vantage point of older adulthood.

In those early years in Seattle, though, I wanted to feel I'd made choices that were both wise and my own. I'd opted to settle on the west coast, not the choice my parents would have made for me. Now I was choosing to stay with the doctor I'd found. No matter that the one my father knew was one of the top gastroenterologists in Seattle, and likely had a long wait list I could hop with a phone call from Bob. Maybe my father was simply encouraging me to shop around, that I didn't have to stick with someone I didn't love. But I didn't see it that way. I saw it as judgment. His choice right, my choice wrong.

“She's a good doctor.” I told my Dad. “Tell Bob thanks anyway.”

Throughout my childhood my shyness had kept me from speaking up in the classroom, which in turn had a negative impact on my grades.

“You come up with the right answer, then talk yourself out of it,” my father told me once while helping me with my math homework. Perhaps that was true, but knowing this didn't help me find my voice. My teachers tried to draw me out, but it wouldn't be until late in college that I spoke in class without prompting.

My timid nature extended to romantic relationships. When Matt and I met in college, I was the less confident one. We lived two floors apart in our all-freshman dorm, where I viewed him as part of the boisterous group of guys who lived on his hallway. Sophomore year, as our groups of friends merged with one another and I had my first conversations with Matt, my opinion of him changed. He seemed interesting and smart. And cute. He wore his red hair in tidy ponytail

that framed his slender, high-cheekboned face. At six-foot-two inches he slouched – to remain at the same height as his best friends in high school, he said -- and his shoulders sloped at steep angles. I liked looking at his arms, the ropy veins and sprinkling of moles covered in a thin layer of strawberry-blonde hair.

One winter night during our sophomore year, I encountered Matt in his dorm lounge and we decided to go to 7-11 for a midnight snack. We walked diagonally across campus, the thin layer of snow on the quad crunching under our shoes. Behind the student center we could make out the faint outline of Pike’s Peak and the surrounding foothills, darker shapes backgrounded by an indigo sky. It was the first time I’d ever been alone with Matt. My heart thrummed. Does this count as a date? I wondered. Did he want to be my boyfriend?

My boyfriend. The words sounded strange inside my head. I could tick off my romantic interludes on one hand: a boyfriend for the entirety of 6th grade, and a couple of one-night fumbblings with boys during my first year of college. Matt had turned twenty the previous month; I was nineteen. If we became a couple, we’d do our growing up together. Either that or we’d grow in different directions, and the relationship would fail. I’d seen it happen to friends, the melodramatic breakups or the fizzling connections. The awkward encounters waiting in the keg line at a party, the old boyfriend standing shoulder-to-shoulder with a different girl.

If Matt felt nervous too, he didn’t show it. He pointed out the course of his new favorite sport, Frisbee golf. Extending his arm into the darkness, he pointed towards the bronze statue of a school trustee that stood in front of the library.

“Ten points if you hit Charles Tutt’s head.”

At 7-11, under the fluorescent lights, we contemplated our options. We rejected beef-and-cheese burritos, Snickers bars, microwave popcorn, before settling on our snack: A large bag of

Cool Ranch Doritos, and two sixteen-ounce bottles of Sprite. We returned to Matt's dorm and climbed two flights of stairs. Everything in his room sat on the floor: mattress, stereo, overstuffed red laundry bag. We leaned against his unmade bed, our fingers coated with Dorito essence as we listened to Fishbone and Michael Hedges. Matt showed me his Ronald Reagan shadow puppet trick on a section of blank wall. We talked and talked through several albums. Sometime after three a.m. he finally turned to me.

“Can I kiss you?”

We'd been a couple ever since. It wasn't long before I gained self-confidence and a sense of adventure. After graduation, I changed locations almost as often as I changed my sheets: a ski resort town, Denver, ski town, Nepal. I spent several months working in Kathmandu and traveling before I returned to Matt. While I spent two years zigzagging around Colorado and Asia, Matt lived with friends in the ski town, working at a paint and decorating store and perfecting his telemark turns. I wrote long letters from Nepal on air mail stationary and he sent short ones back via fax machine. *Justin drove your car into a ditch, but no damage. Miss and love you always.* He sounded like he thought I wasn't coming back.

But I did come back, slightly shrunken from near-constant intestinal illness and ready to stay put. At some previous and un-definable point in time I'd become the one who called the shots. I wasn't interested in staying in the ski town.

“Let's move to a city,” I said.

“Okay,” Matt said. He was mild-mannered and agreeable, products, he told me, of growing up in Iowa. “We Midwesterners are an easy-going bunch.” My mother, raised in Cleveland, certainly exemplified that style; she was the most relaxed person I knew and had brought up three children without ever raising her voice. I was turning out to be like my father, a worrier and

an over-thinker. But I liked planning a future with Matt. On hikes we discussed our options. San Francisco. Washington, D.C. We had friends in both places, and had visited each city as children, before we met.

“How about Seattle?” I asked. Seattle sat on the water, a feature I’d missed since leaving Boston, and near the mountains, which we’d both grown to love. There was a university, in case we wanted more schooling. There would be jobs and apartments aplenty, so we could arrive in town with neither secured.

“But I’ve never been there,” Matt said. “We don’t know anyone.”

“We know two people,” I said, naming classmates who were distant friends. We’d both entered college knowing no one, I pointed out. “This time, we have each other.”

“That’s true,” Matt said. “Seattle sounds cool. Should I join a grunge band?”

Just like that, it was decided. I felt excited at the uncharted territory of living together, just the two of us. Up to that point we’d spent our entire relationship as part of a larger group. Outside of the bedroom, we rarely spent time alone. Meals, ski days, outings to the bar always took place with some combination of friends. I imagined candlelit dinners for two at the dining room table we planned to bring with us to Seattle, formerly used as a ski-tuning surface by a local rental shop. I envisioned exploring Washington’s evergreen-covered mountains together, sleeping in the turquoise backpacking tent Matt bought when he joined the college outdoor recreation club.

After I got sick, the actual scenes were decidedly less romantic – we walked to the pharmacy together to pick up my prescriptions, then ate Thai takeout on TV trays in front of the television. Before my illness, it felt like we’d been play-acting at being grown ups. Our first year in Seattle, our explorations of the city and surrounding natural beauty left me feeling almost

tipsy. But it was as though my Crohn's diagnosis had sobered us up. We were grown-ups too soon, dealing with an adult-sized problem before we were ready.

Sometimes the scenes from my imagination came into reality, though slightly altered from the fantasy. Our first Christmas in Seattle, two months after my diagnosis, I stood in our kitchen making dinner with Matt. We played our usual roles: Matt at the stove, stirring and seasoning, me at the counter slicing and dicing. Our closest local friends, Beth and Kevin, were coming for dinner. The only meat they ate was fish so I'd planned an all-vegetarian menu adapted from the holiday issue of *Martha Stewart Living*: pumpkin soup served in miniature pumpkins, honey-glazed carrots, wilted chard salad. A loaf of crusty bread from the neighborhood bakery sat on the counter, waiting to be warmed. The night before I'd made apple pie - my mother's recipe, not Martha's - and a pint of Ben & Jerry's World's Best Vanilla sat in the freezer. The fridge held our lunch leftovers: dips and salads from the deli at the overpriced co-op grocery store. All the delicacies for the holiday. It had been that way my entire life.

In my family, food stood in place of religion. We had two refrigerators perpetually crammed with grapes in a ceramic colander, leftover lasagna, half-full jars of spaghetti sauce, three different kinds of mustard. My favorite childhood chore was unloading the food delivered from the local grocery store. While the delivery driver shot baskets with my brother in our driveway, I'd dart around the kitchen, using my blossoming organizational skills to find a space on the shelves for each item.

How soul-crushing, then, to be diagnosed with a disease that would forever impact my food choices and my digestion. In 1997, the idea of eliminating foods to control intestinal distress was still avant-garde, even in a mecca of alternative medicine like Seattle. I performed

my own experiments, and came up with an anti-shopping list of foods to avoid: beans, lettuce, corn, nuts. Tomatoes proved difficult to digest, more so to give up, so I kept eating them.

Matt opened the oven door to check on the roasting pumpkins. He poked one with a fork.

“Five more minutes,” he said.

“I’ll set the table,” I said. Matt moved from the stove to step in front of me as I headed to the dining room, wrapping his arm around my waist and dipping me, ballroom-dance style. He righted me, then bent down for a kiss. I kissed him back, then pulled away when he started to move his hands down my back.

“Beth and Kevin will be here any minute,” I said in a mock-scolding tone. “Besides, didn’t you get enough earlier?” We’d had sex that afternoon, the time of day when my intestines were their quietest and intercourse held its highest appeal for me. Not that it did very often in those days. This made me different from other women my age, or so I assumed. In college, my friends and I talked openly about sex. But in Seattle, the rules were different, or maybe I was. I felt more private about my relationship with Matt than I had back in Colorado. All couples go through fallow periods, I told myself. They must. But wasn’t it a little early in life to lose my libido? We weren’t even thirty yet.

I went into the dining room and dug placemats out of the built-in hutch that covered one wall. The apartment took up the main floor of a two-story Craftsman house. Our neighborhood was covered in turn-of-the-century homes like this one, houses originally built for employees of the Seattle Lighting Company who worked at the coal gasification plant down the hill on Lake Union. The house was drafty, with lead pipes, knob-and-tube wiring, and asbestos siding. We loved it for its hardwood floors and light-filled living room. Our cat had already made a habit of

climbing into the unlit fire place and up the chimney's interior, emerging in the upstairs neighbor's living room sooty and proud of his cleverness.

As I set placemats on the table, the doorbell rang. I walked through the living room, pausing to turn down the volume on the *Ella's Swingin' Christmas* CD before I opened the door. Beth and Kevin stood on our porch. He held a six-pack of beer and she held a flat present wrapped in plain brown paper – a recycled grocery bag, her signature - and a bright red bow.

“Ho, ho, ho!” Beth said, stepping into our entryway to wrap me in a hug.

“Merry Christmas!” I said, hugging them both.

“Pardon our moisture,” Beth said as they removed their shoes and shed rain-covered jackets. “We just walked around Green Lake. We had the place to ourselves.” She beamed. Beth was always pleased when she could pursue unpopulated activities in the city.

“Wet but happy,” I said. Their cheeks were flushed and Beth's eyes caught the light from the fixture above our heads. “Matt's in the kitchen,” I said and Kevin headed to the back of the apartment, the six-pack still in his hand. Beth stepped into the living room and put the present under the Christmas tree.

“For later,” she said. “What can I do?”

“Help me set the table?” We went into the dining room, Beth chattering about her visit to her aunt and uncle's house the night before as I handed her napkins, silverware, glasses.

“Dominic is home from Notre Dame,” she said, referring to her cousin. “He loves it. Of course he loves it. I'll bet his classes are full of guys just like him – smart Republicans who love to hear themselves talk.”

“Did you get into a political argument?”

“We refrained, for Aunt Maryann's sake.”

“I thought it was all good-natured bickering.”

“Well Dominic and I enjoy it, but it drives her crazy.” I set a stack of plates on the table, ivory-colored with fat yellow birds painted onto their centers.

“Wow,” Beth said. “The good china.”

“The Queensbird collection,” I said, waving my hand in a little flourish.

“Fancy. Is it new?”

“New and old,” I said. “Some of the pieces were my grandmother’s wedding china.” The rest, I explained, were part of my sister’s registry from her wedding five years before. After the wedding she and her husband decided they didn’t want it. Ever since, the dishes had sat in my parents’ storage room, unused, until the month before when, while Matt and I visited for Thanksgiving, my mother had offered them to me.

“Why now?” Beth said. She widened her eyes in mock horror. “Is there something you haven’t told me? You’re getting married?”

“No,” I said, laughing to cover the lurch in my stomach. “My Mom was just tired of them sitting around unused.” That was a partial truth. My mother had also been lamenting our lack of dishes since we’d moved to Seattle. Before the Queensbird arrived, we had a total of six plates, four bought at Goodwill, two stolen from our college dining hall. But there was something I wasn’t telling Beth about marriage, something I hadn’t told anyone. Thinking of it as we set the table, I had to turn away from Beth so that she wouldn’t see my flushed face or hear my hammering heart.

It had happened in our first apartment, a few months after we moved to Seattle. Matt and I were watching *E.R.*, a favorite show before my illness and after. A commercial came on. Matt picked up the remote, lowered the volume, and turned to me.

“Will you marry me?” he said. I thought he was kidding, and I laughed. His face fell. He was serious. Shit.

“Um,” I stalled.

It wasn't that I didn't want to marry Matt. I did. Just not right then. None of our friends were married, and I didn't want to be that kind of trendsetter. Moving somewhere together had been the biggest commitment I felt ready to make. It would be years before we'd be ready to have kids, or discussions about the rest of our lives. That was how I felt, anyway.

“Not right now?” I said it like a question. There was a silence, but not the comfortable kind between two people who know each other intimately. We watched the rest of the episode without speaking. I felt embarrassed, as though someone had been there to witness Matt's question and my refusal. A proposal while watching television? It didn't fit the image I'd held in my head since childhood of that milestone moment.

Sometime later, I had a proposal of my own: “Let's wait.”

Where does assertive give way to bossy and controlling? Some time in our past I had crossed that line with Matt, though I wouldn't notice until years later. Maybe I had assertiveness inside me that I only felt safe to demonstrate with him. But it was like the water stored in a fire hydrant; it couldn't come out in a moderate quantity. It never occurred to me to worry about whether or not Matt would stay with me. I took it as a given.

Some men would have fled when their girlfriends shat blood and mucous or required nightly steroid suppositories. Not Matt. He didn't get grossed out. He didn't alter his behavior. He stayed right by my side. I should have married him right then, for that reason alone. But I felt

too worn-down to consider marriage or a wedding. I didn't feel celebratory. I felt as though I was perpetually at the tail-end of a flu I couldn't quite shake.

That Christmas night, though, I felt okay. By the time Beth and I had finished setting the table, dinner was ready. The four of us bustled around the kitchen, ladling soup into the little roasted sugar pumpkins and carrying vegetable-filled serving bowls to the table. Soon everything was in the dining room and we sat down.

I raised my cider-filled wine glass to make a toast and the other three lifted their beers. I hesitated. Except for when I lived in Nepal, this was my only Christmas not spent at my parents' house. My father always made the toast, quoting the last line in *A Christmas Carol*, "God bless us everyone." It was a tribute to Dickens, one of my father's favorite authors, and had long since lost any religious connotations for our family. But still, it was too much God for Catholic-turned-atheist Beth. She didn't even like to say "bless you" after someone sneezed. Instead, she said the Spanish word for health, which is also what you say in Spanish when you toast. So that was my toast. "Salud."

"Salud," everyone chorused. We clinked our glasses together. We laughed. And then we ate.

### 3. REPLICAS

I met Beth two months after I moved to Seattle, on my first day of work. I'd been hired by a large social service agency to create a family center that would be housed down the hall from the agency's food bank. The family center would hold free classes for clients and other members of the community on topics like budgeting, cooking, parenting, English as a Second Language. I would be part of VISTA, a national service program that was a domestic version of the Peace Corps.

A few days before I started at the agency, I traveled to a Seattle suburb to attend a state-wide VISTA training. The retreat center where we spent three days had a swimming pool. One evening, despite the crowd in the water and the lack of lane lines, I attempted to swim laps. Once my goggles fogged over, the result was inevitable: a head-on collision with another swimmer. My nose bled on impact, and by morning I had a pronounced black eye.

The following Monday the department director at the agency greeted me in the lobby with a warm smile and a booming hello. His grin faded as he examined my face.

"Should I ask?" he said, pointing to my eye. I told the swimming pool story and he worked it into my introductions as we went from office to office, each a small room jutting out to the right of a long corridor. A tall, broad-torsoed man with a red beard he kept well-trimmed, he had to walk in front of me so we could both fit down the narrow hall.

"This is Janet," he would say. "She's our new VISTA. Another VISTA gave her a black eye during their training session." I got looks of pity, or laughter if I laughed. Most of my new co-workers looked like me: White women in their twenties. The director was talkative, and it took us a long time to make our way down the hall. Two doors up from the conference room, a

redheaded woman sat at a desk, her back to the open door of her office. She swiveled in her chair when we knocked, then stood when she saw us.

“Hi!” she said in a tone of familiarity, like we were old friends. This was her in-person greeting, I would learn later, a drawn-out, two syllable *hi-i*.

“This is Beth,” the director told me, then delivered his lines.

“*That’s* how you’re introducing her?” Beth said.

“I didn’t want people to get the wrong idea,” he said defensively. “Start slipping her brochures for our women’s shelter program.” Beth, a former domestic violence counselor, narrowed her eyes at him. Then she turned to me, and smiled.

“It’s really nice to meet you.” she said, reaching out to shake my hand. She wore cropped khakis and a short-sleeved button-down. Her thick hair, a shade oranger than Matt’s, hung past her shoulders. I’d soon learn that she changed hairstyles frequently – cutting it short, growing it out, tying it into a ponytail during a staff meeting and then removing the hairband a few minutes later.

A brightness extended from her smile outward, as though the light above her head was a theater stage light instead of a buzzing fluorescent. Her blue eyes sparkled like she couldn’t wait to see what would happen next. She smirked, a friend sharing an inside joke.

“Don’t pay any attention to him,” She said as she gestured towards the department director, her boss’ boss. “He doesn’t know anything.”

“It’s true,” the department director said, smiling at Beth like a proud father. “That’s why I hire such great people, to do my thinking for me.” The three of us laughed and I watched Beth, thinking, she’s brave. It wasn’t long before I returned to her desk, or she to mine, to sit and talk. Or I’d lean in the door of her office, asking, “is it lunchtime yet?”

Two major events marked Beth's childhood: a move from Chicago to Seattle when she was ten, and the death of her mother from brain cancer when Beth was sixteen. She rarely spoke about her mother's death, but it seemed to have shaped her adult self. Despite her light-bulb personality, Beth had a wide cynical streak. Perhaps that came with the territory of losing a parent when you were a teenager, old enough to have memories of a happiness ground to a halt by disease and death. After her mother was gone, and even after her father remarried, Beth took on a caretaker role for her two younger brothers. She fit into the mother hen role naturally, standing up to their would-be aggressors on the school playground and advocating for a more generous dessert policy at home.

Even though we were only four months apart in age, Beth seemed older than me, and wiser. She behaved towards me the way my older sister did, giving her opinion about how I should act with a fervency that left no room to do anything except obey. Beth stood up for herself and spoke her mind, two traits I lacked. In choosing her as my friend I employed a strategy I'd used since my ultra-shy childhood: Find an extrovert and stick close to her. I had to be careful, though, not to mimic her gestures too closely, or someone might get hurt.

The first time it happened was in the swimming pool at summer camp when I was six. During free swim at the end of lessons I usually hovered on the pool deck, hesitant, like a teen driver afraid to merge into traffic. Then I met Jody. She'd skipped Kindergarten and wore her curly hair short, Little Orphan Annie style, and talked and chewed gum constantly.

One day when the whistle blew for free swim, Jody grabbed my hand and we ran together, laughing. What a relief not to linger at the edge of the pool, worrying. I did not look before I

leapt. I just jumped. Another girl was already in the water, practicing her back float. How peaceful she must have felt in the moment before my feet hit her stomach.

In two breast strokes I was at the ladder, scrambling up, hoping a swift exit from the pool would somehow undo my actions. Nearby, the swim coach turned and blew his whistle, his extended arm and finger pointed at me.

“Watch where you’re jumping!” he yelled while a counselor helped the girl. “No running on the pool deck.” My eyes filled. I’d never before been scolded by a stranger. Walking back from the pool, I saw the girl vomiting onto the grass. I can still picture her bathing suit: a blue-and-red lattice pattern with a frilly skirt at the waist.

By the time I met Beth I’d learned that it worked better if my outgoing friends made their grand gestures on their own while I watched. Beth wouldn’t have taken well to a close imitation anyway. She was her own person, strident in her beliefs even if they didn’t match those around her. I’d never met anyone my age with such strong convictions about her future.

“People assume that because I work with mothers and babies, I want kids of my own,” she told me shortly after we met. “I don’t. My mind is made up.” No children? The idea was foreign and the opposite of how I felt. I was surprised by the finality of her statement. As I got to know her better, I learned that Beth did not make decisions with ease. Most actions -- from choosing the right clothes to pack for a long trip to who to vote for in an upcoming election -- required deliberation. She’d often call me or come into my office for a consultation, giving a long list of pros and cons before asking my opinion.

Not that she did not have one of her own. She had strong views about everything, and a long list of favorite items: green tea ice cream, Gruyere cheese, a chocolate-coated, chopstick-

shaped cookie called Pocky. Several stuffed zebras – her favorite animal -- dotted the bookshelves around the tiny house three blocks from our office that she and Kevin shared. Most of their other decorations were art pieces friends had made or items Beth bought while traveling in Latin America. Their house had an uncluttered feel – Ikea furniture, small television, the slimmest model stereo available. Still, there were splashes of style: A purple couch that Beth bought from a co-worker for \$50.00, a lichen-colored Zen alarm clock that made a gentle chime like a gong at a Tibetan monastery.

One day while standing in her living room, Beth surprised me with an announcement.

“I’ve decided to collect pewter replicas.” A few months before, she and Kevin had taken a road trip to Chicago to attend a wedding. On the way there and back they’d detoured to the most Americana places they could find – Mount Rushmore, Wall Drug, the world’s largest ball of twine in Cawker City, Kansas. While browsing the gift shops, Beth had delighted in learning about people who collected the same kind of souvenir from every tourist attraction – bells, spoons, coffee mugs.

“Pewter replicas are harder to find,” Beth told me, picking up the one she’d bought at her favorite site, the Corn Palace in South Dakota. She cradled it in her palm for a moment like a hamster she’d just brought home from the pet store, then handed it to me. It was impressive, a sort of a Taj Mahal with tiny kernel-shaped beads comprising the pillars and minarets.

“It gets redecorated every year,” Beth said as I handed the replica back to her and she returned it to its spot on the bookshelf. “They use thirteen different shades of corn, and nail it up ear by ear. Isn’t that amazing?”

She was pleased by the smallest things, and thus made me eager to please her.

I'd begun to notice a trait in myself that I didn't like but couldn't control – the need to be not just a friend, but an *important* friend. To me this meant solving some kind of problem no one else could solve – connecting someone with a great car mechanic or fixing a faucet that had leaked for years. Since I was new to the city, and not the least bit handy, the services I could offer were harder to conjure in my mind. But then Beth provided me with one.

“Next time you go somewhere touristy, will you look for replicas?”

Matt and I went to Colorado to ski in the town where we'd lived before moving to Seattle. While getting an après-ski snack one day I said I wanted to go into F.M. Light and Sons, the most touristy of the tourist shops.

“I need to find a pewter replica for Beth,” I told Matt. I searched every corner of the store, which was full of anything you might need to outfit a cowboy – ten-gallon hats, pearl-buttoned plaid shirts, spurs, chaps – but no replicas.

“It's just a tacky pewter thing,” Matt said when I emerged from the store looking dejected. “Why do you care so much?”

Why *did* I care? I couldn't say. I only knew that Beth's attention was like that theater light that seemed to hover above her head was shining on me. It felt nice, that focus, and different from the way most of my friendships in Seattle seemed to work, with a barrier between me and the other person you could almost reach out and touch. With Beth it was more like the connection I felt with my friends from my pre-Seattle life, like there was an invisible thread that connected us.

But how strong was that thread? Would it hold under pressure, or would some event sever it, a blunder made in a moment of clumsiness? Beth would not be the one to blame. Her insights about people and relationships seemed generated from a long and storied past, as though the Beth

we knew was the reincarnation of a less self-assured person. She had life figured out, it seemed to me, and my best strategy would be to stay close in hopes that some of the grace with which she moved about the world might rub off on me.

If a problem lay ahead, then, surely I would be the cause of it. I needed to be careful not to mess anything up. I wouldn't allow myself to be the source of any pain.

#### 4. ABSCESS

Most of the time, I could focus on friendships, on Matt, on my job. Sometimes, though, the Crohn's symptoms would take over. In March I experienced my first disease complication: a flare-up. My pain and bowel movements increased suddenly, and the medication didn't help. Dr. Carol performed a sigmoidoscopy, a procedure in which she inserted a small scope into my rectum, displaying the inside of my colon on a color monitor in the exam room. I lay on the exam table in a fetal position, cramping from the air blown up my anus to allow the scope interior access.

"What's that?" I asked, gesturing to an angry red lump on the screen.

"That's just a polyp," Dr. Carol said. "Lots of people have those. It's unrelated to your Crohn's." The exam didn't reveal anything conclusive, so she ordered a CT scan for a Friday afternoon. I wouldn't be allowed to eat anything until late afternoon, a state that sounded worse to me than the scan itself.

"It's a routine procedure, not as uncomfortable as the sigmoidoscopy," Dr. Carol said, smiling her mouth-only smile. "I'll call you with the results."

My third bite of dinner, my only food all day, had been on its way to my mouth when the phone rang.

"You have an abscess," Dr. Carol said, breathless, like she'd read the radiology report and run up a flight of stairs to call me. I thought I detected a note of excitement in her voice: Finally my mild, hard-to-treat Crohn's Disease was asserting itself in some identifiable way.

"You need to go to the hospital. Immediately."

Landing in the E.R. at the age of twenty-six would have terrified me if Matt hadn't been there. During a crisis, he behaved like I imagined a Buddhist monk at the scene of a car accident would act.

I'm certain my pulse slowed as we sat opposite one another, me in the bed in a curtained-off area and Matt in a vinyl-cushioned chair.

Down the emergency room hall, machines beeped and gurney wheels bumped along the scratched linoleum. The smell of disinfectant covered every other scent I imagined might be present at any given time: vomit, feces, blood, booze.

In order to stay warm, I'd put my jeans back on underneath my hospital gown like a three-year-old who wanted to wear pants and a twirly dress to school. After four failed attempts to find a good vein in my arm, the nurse inserted a port into the back of my hand where an IV would be placed when I went upstairs for surgery. If I went upstairs.

"I thought it would be busier," I said.

"I thought it would be faster," Matt said.

"We should have brought something to read."

"I'm hungry."

"I'm starving."

"I bet." He paused, then reached over to rub my leg. "I hope you don't have to have surgery."

"Me too."

Two hours after we arrived, the surgical resident stood in the curtained-off area, peering at my CT scan on the film reader.

"I *guess* that's an abscess," he said. He was handsome: short, early thirties, with a shaved head and frameless glasses. He turned to me, taking in my gown-and-jeans ensemble, my arms crossed for warmth.

"You look too good to be here." It sounded like a pick-up line, and I blushed. But it wasn't flattery, it was doctor-speak. He meant: I'm not much older than you, but I've been

through four years of medical school, and six years of residency, and now I'm the Chief Surgical Resident of a busy urban hospital and in my experience when someone needs surgery they look like they need it, if you know what I mean. You are too far from death's door. You don't even have a fever, for Pete's sake.

I decided right then that I liked the resident better than my regular doctor. In my growing survey of medical professionals, I'd begun to notice a trend. The younger the doctor, the more he or she listened to me. They asked questions and in their responses to my own, conveyed both confidence and a willingness to admit when they didn't know the answer. They seemed more like peers with special knowledge than experts making a distant pronouncement. More like my brother, in other words, our family doctor-in-training. In talking to people like my brother, I felt more comfortable giving my opinion.

"I don't feel like I need emergency surgery," I said.

"You don't," the resident said as he pulled my scan off the film reader and turned back to me. "We can track the abscess through weekly CT scans. I'm giving you antibiotics and sending you home."

The next week I sat in the radiology department waiting room, drinking oral contrast from a wax paper cup. If you drank it slowly, as I did, the wax disintegrated, tiny flakes like fish food floating on the surface of the yellowed liquid. They mixed it with Crystal Light to sweeten it; I thought it tasted like Crystal Light long past its sell-by date.

Of the substances I'd had to consume to prepare my intestines for medical procedures, oral contrast ranked in the middle, taste-wise. Slightly worse than the milkshake-like Barium, far better than Phosphosoda, the near-toxic liquid I had to drink before my colonoscopy. Phosphosoda tasted like bathroom cleanser, and required a Root Beer chaser. It made me sputter

and gag and come close to vomiting. If I had to drink something in front of an audience of other waiting-room sitters I'd choose oral contrast over Phosphosoda any day.

By my third scan, they knew to get their best vein-finder when they called me back to the scanner room. One nurse had written *difficult stick* on my chart. I resented the adjectives used to describe me, *pleasant 26-year-old*, or the way the specialists signed their notes: *thank you for referring this interesting patient to us*. If you have a chronic medical problem, for goodness sakes don't be boring, or unpleasant, or possess tiny veins.

While waiting in the hallway for my fourth scan, I saw a classmate from the Spanish class I took on Monday evenings at the university extension.

"Hola doctora," I almost called out, a reflex, but then I stopped myself. What would I say after that? That I had an abscess that may or may not have been shrinking in size, depending on which radiologist read the scan. That the antibiotics they'd had me on all month had given me a yeast infection. That in addition to the oral contrast I drank ahead of time, during the scan I had contrast running through an IV into my arm, and through an enema bag into my rectum. That no one, including me, had raised concern about the larger problem I might have – cancer - if I went through the scanner too many more times. It didn't matter. My classmate, deep in conversation with another doctor, did not notice the half-naked patient sitting in the corridor. He walked right past.

At my follow-up appointment six weeks after my E.R. visit I lay on the exam table while the shaved-head resident felt my abdomen for lumps.

"Finish this round of antibiotics," he said, "and then you're done. No more scans."

"Why hasn't the abscess gone away?" I asked.

“I don’t know. But it’s not getting bigger. We shouldn’t keep making you come back here. Go on and live your life.”

He reached out his hand and I put mine in his, thinking he meant to shake it. I was still lying down. Instead of shaking my hand, he pulled on it until I was sitting up. Helping me, not because I was pleasant or a difficult stick or because I did or did not have an abscess, but just because. I’d never had a doctor do that before, and it felt oddly personal, this extending of his arm, like we were teammates and I’d fallen on the soccer field. Maybe we’d all meet for beers later and laugh about the game, or the abscess, or the fact that I’d had so many scans that month it was a wonder I didn’t glow in the dark.

He reached his hand out again, and this time shook mine.

“Good luck,” he said, and left the exam room. He pulled the door closed slowly, marking his exit with a faint click of the latch. I got dressed and placed the hospital gown unfolded on top of the wrinkled exam paper. I left the door ajar. Before I’d rounded the corner I could hear the medical assistant crumpling the used paper and smoothing a fresh sheet across the table as she readied the room for the next patient.

## 5. THE PRINCESS BRIDE

Life with a chronic illness, it seemed, was an obstacle-filled endurance race. I'd overcome one barrier, then brace myself for the next. I went to bed each night not knowing how I'd feel when I awoke. The uncertainty and inability to plan drove me crazy. I developed a jaw disorder from grinding my teeth in my sleep.

In the Spring of 1998, several months after my diagnosis, Beth made an announcement that threw me off-course once again. She and Kevin were moving to Ecuador. They'd lined up jobs, housing, visas, passports.

"For a year, give or take," Beth said. "We might come back to Seattle, we might not. The future is uncertain." She grinned. She enjoyed the anticipation of the unmapped journey, craved it even. In this way, we were opposites.

"Wow," I said, forcing a smile back. "You're brave." I said other things too: *How exciting! What an adventure you'll have!* Wasn't this what you said when one of your best friends realized her dream of living and working abroad? Not the truth: I'm jealous. I'm hurt.

The envy came from the fact that I'd once been that person, the one who craved that kind of adventure -- living and working in the developing world. My time in Nepal had been a realization of that desire. Even the VISTA job, domestic though it was, had filled me with a sense of purpose and pride. I'd created something from scratch that would continue after I'd left. I'd had a positive impact on peoples' lives. I'd made a difference.

But that feeling had long since gone. My VISTA position had ended around the time that I got sick and I felt too worn out to make a big move, job-wise. So I made a small one, becoming

the agency's volunteer coordinator. Now I plodded along. I processed applications and attended volunteer recruitment fairs. I planned the agency's first-ever volunteer appreciation party. I missed working directly with the clients. I wasn't fulfilled, but I felt too sick to muster the energy to do anything about it. This was what Crohn's did, I thought. Sapped. Leached the color out of everything.

And the hurt feeling about Beth and Kevin's departure? That was more complicated. We had other friends, of course, most of them co-workers or friends of college friends who were also recent Seattle transplants. But Beth and Kevin were our first couple friends, our closest friends. Beth, who'd lived in Seattle half her life, served as my unofficial ambassador. She was the one who told me about the best breakfast spots and bookstores. She helped translate the music section of Seattle's independent newspaper, The Stranger, each week and decide which bands to go see. Though standing around smoky bars listening to bands I'd never heard of wasn't my favorite pastime, I still did it regularly. We all did, as though going out to hear music was part of our job description.

Ditto for large parties, which I attended whether I felt in the mood to socialize or not, lest I miss out on something. I preferred more intimate gatherings where we each brought food to share or took turns crowding into someone's kitchen to prepare dinner together. Beth and I co-hosted a monthly dinner where everyone spoke only Spanish. She was the principle player in my social life, second only to Matt. I saw her every day at work and most weekends. I couldn't imagine my Seattle life without her.

I shouldn't have worried about losing touch. Like me, Beth remained close to friends from all parts of her life, surmounting geographical barriers and harried schedules to make time to see them. We'd even talked about Matt and me going to Ecuador for a visit. But I did worry.

Maybe I had a hunch, buried deep and barely detectable. When she moved back to Seattle, if she moved back, things would not be the same between us.

One evening that Spring I perched at the foot of Beth's bed as she zipped back and forth from bedroom to bathroom, getting dressed to go to a karaoke bar. The outing would be our mutual friend's send-off from urban life; she'd recently married and would be moving to the suburbs. While Beth searched for a scarf to match her blouse, we talked about our friend.

"We won't be seeing much of her anymore," Beth said.

"What do you mean?" I asked.

"That's what happens. People get married, move to the 'burbs. They'll pop out a couple of kids and then forget all about us childless un-marrieds." She would make new friends, Beth said. It was hard to imagine. The friend was a central figure in our group of co-workers that got together on the weekends for dinner parties or outings to the bar. Was she really going to become one of Those People?

"Are you going to get married?" I asked Beth once, early in our friendship.

"Did my grandma tell you to ask me that?" Beth's family was Catholic, and Beth took pleasure in eschewing the traditions of the religion she found distasteful. Beth thought marriage was patriarchal, oppressive. Since gay people couldn't marry, straight people shouldn't either. Marriage was an institution, she said. The only institutions she was interested in being part of were ones that would assign her papers and award her a degree.

Beth always liked a good debate. Probably she wanted me, or someone, to argue with her, to host a Point/Counterpoint episode in her living room. Or else I should sign an oath, pinky-

swear that I wouldn't get married. But I was ambivalent. Whenever the topic came up, I'd nod my head noncommittally. We got ready to leave.

“Okay,” I said as I patted myself down, making sure I had everything. “Okay. Okay. Okay.” I performed this routine regularly, an imitation Peter Falk in his role as a narrating grandfather from *The Princess Bride*. We'd all seen the movie enough times that its dialog got worked into our conversations, becoming the language of our friendship.

“Stop rhyming now, I mean it!” Beth said from her doorway.

“Anybody want a peanut?” I said as I stepped past her and down the steps. Beth flipped the porch light on and locked the door. She paused at an anemic-looking bush by the front step, two pink flowers struggling to bloom.

“Come on, Ms. Camellia,” Beth said, stroking the broad green leaves, her face close to the plant. “You can do it.”

We climbed into my car. I took a medication that came with an alcohol contraindication, so I'd become the group's designated driver. I'd never been a big drinker and I was used to cheerfully accompanying my friends on bar outings. On that evening, though, as I circled the blocks surrounding the bar looking for parking, then wedged myself into a chair at the too-crowded table in the too-loud bar, I wondered whether or not I should have come. Who participates in an evening of karaoke sober?

We ordered (club soda for me, pitchers of margaritas and tequila shots for everyone else) and then I sat at the table while the members of our group took turns getting up to sing. Beth and our friend preparing to move to the suburbs browsed the binder of karaoke songs.

“The Eagles!” our friend shouted. Beth burst out laughing.

“At any given time,” Beth liked to say, “somewhere in the world, an Eagles song is playing.”

“We have to do The Eagles,” our friend said.

“Clearly,” Beth said. “No other choice.” So they sang a duet of “Take it to the Limit.” With Beth’s encouragement, most of the bar joined in on the chorus, and they received the evening’s largest round of applause.

On the way home, Beth chattered drunkenly while I navigated the dark streets, fighting to stay awake.

“What’s Ecuadorian food like?” I asked. “Will you be expected to overthrow your vegetarianism?” She wrinkled her nose.

“Under no circumstances will I eat cuy.”

“What is cuy?” I asked.

“Guinea pig.” She lifted her arms up to her chin and bent her hands down in an imitation. “Cuy!” she said in a soft squeal. She went on to describe other food she was more excited about: fresh-squeezed juice, a fried plantain dish called patacones. She told me she planned to eat an entire avocado every day.

“For the whole year?” I asked.

“Yes,” she said. “365 avocados. And then I’ll come home.”

“Don’t go,” I said, mock-distressed.

“To Ecuador?”

“Yes. What will I do without you?” I forced my voice an octave higher than usual so I’d sound cartoonish and insincere.

Beth laughed. “You’ll coordinate some volunteers,” she said. “You’ll see some bands.”

Matt and I had agreed to store some of Beth and Kevin’s belongings while they were gone.

“I’ll watch your TV and eat all of the canned pumpkin.”

“And then you’ll come visit,” she said.

“And then we’ll come visit.”

It was well after midnight, and bright lights emanated out toward us from buildings that lined the street: the movie theater marquee, the 24-hour supermarket’s neon rooftop sign, the customer-choked parking lot of the burger stand. I turned off the arterial onto Beth’s street and pulled up in front of her house. She unbuckled her seat belt and opened her door.

“Thanks for driving so I could drink,” she said. “Lunch Monday?” Unless one of us had a meeting, we ate lunch together every weekday, trading bites like middle-schoolers. She’d introduced me to quinoa, and I’d converted her from mustard-hater to mustard-lover.

“Of course.” I said. Beth climbed out of the car and walked up the path. Just as she’d done when we left the house, she paused at the camellia plant and brushed her hand over it. As she stepped up to unlock the door and go inside, one pink petal dislodged itself from the bush and fluttered onto the rain-slicked pavement. I sat in my idling car looking at the doorway that had framed her body just a moment before.

*Lunch Monday?* A phrase from *The Princess Bride* floated into my mind, the one Westley uses to substitute for “I love you” when wooing young Buttercup. The rain and the clack of the windshield wipers and the night swallowed my words as they moved from my brain to my vocal chords and emerged from my mouth.

“As you wish.”

## 6. TRUCO

Beth's laugh announced her presence from the other side of the immigration desk at Quito International. As I scanned the crowd I heard the familiar bubble of sound rising above the din of greeters welcoming passengers. Once Matt and I reached the front of the line, Beth was easy to spot. In Ecuador she stood tall, her long red hair and pale face even more distinctive than at home. It had been eight months since she and Kevin had left Seattle. Beth's eyes found mine, and she started waving like a kindergartner on stage at a school play.

"You're here!" she said when we came across the customs line at last. She wrapped me in a hug, her arms pressing into my shoulders and my overstuffed backpack. We crossed diagonally, Matt and Beth hugging as I hugged Kevin, his smile radiating from beneath his baseball cap.

We headed outside into the humid midnight air and climbed into an awaiting taxi. I watched Matt's eyes take in the chaotic scene with a combination of wonder and fear. Prior to our trip he'd only left the U.S. by car. He felt uncomfortable in unfamiliar surroundings, and didn't like anyone to know his tourist status. When we visited other cities, he would study the map at night in the hotel room so that he didn't have to pull it out on a street corner. His posturing as a local wherever we went seemed to work, as people often asked him for directions. As the taxi wound its way through Quito's dense outskirts to our hotel, I imagined Matt's thought process as he looked out the window. How will I ever find my way around? What happens if Janet gets sick while we're here? I reached over and squeezed his hand.

In the morning I transferred my medications from Matt's and my carry-on bags to our duffel. For nighttime, cortisone in both liquid-enema and suppository form. In the mornings I swallowed twelve pills that varied in appearance and pronounce-ability: Sulphasalazine, Asacol, Imuran, Mercaptopurine. Chalky, amber, tan, white. Round, oblong, tiny, the length and thickness of a baby's pinky.

In the aftermath of my abscess my doctor won a months-long campaign she'd been mounting and convinced me to take steroids. By the time I arrived in Ecuador, a few months after I started the Prednisone, I displayed nearly every side effect listed on the prescription insert. Acne covered my neck, chest, and upper back like a rash. Dark hairs appeared on my chin and in a spiral around my navel. I experienced daily headaches, low libido, irritability. A layer of fat termed "buffalo hump" appeared at the nape of my neck. My metabolism got thrown out of whack; I felt hungrier than ever and began consuming portions worthy of an Olympic athlete in training. I gained twenty pounds, fifteen of which seemed to be on my face, balloons inflated in each cheek and under my chin. *Moon face*, the prescription insert called the swelling. On forty milligrams, my initial dose, my cheeks swelled to the point that my eyes almost disappeared. I looked like Violet Beauregarde in Charlie and the Chocolate Factory, inflating into a giant blueberry.

"Do you want to visit a faith healer while you're here?" Beth said as the four of us rode a bus north to the mountain town of Otavalo later that morning. "You'll have to bring him a carton of cigarettes and a can of Sprite," she said. "He uses them as diagnostic tools."

"No thanks."

Beth and Kevin lived atop a steep hill a mile above Otavalo. Kevin worked in a variety of roles: English teacher, environmental educator, construction worker. He built the tiny house

where they lived, learning Spanish from the local men as they stood side by side, spreading mortar on cinderblocks.

Beth worked as the administrator for the town's only medical clinic. She took the position to a new level and trained locals to promote the concept of preventive care. She worried that the clinic would cease to function after she left, so she provided mentorship to the locals, hoping they would advocate for themselves in her absence.

When we arrived it became immediately clear that there, as in Seattle, Beth and Kevin were cherished members of the community, already at the center of its orbit. They were Godparents for two different families, and the un-Ecuadorian name "Kevin" was bestowed upon three babies born during their stay. I envied so much: Beth's language fluency, her obvious comfort in this foreign place, her health. She beamed as she walked around town. I wanted that beam.

In the evenings, we went out to hear music or play cards. Beth and Kevin taught us an Argentinean card game called Truco. I observed that it sounded like an epithet, and it became our word for the trip. The bus was late – *truco!* We lost our way on one of Otavalo's back roads – *truco!*

The four of us stayed overnight at a resort in Chachimbiro, soaking in hot springs and playing cards by candlelight during the rainstorm-induced power outages. While the electricity was off, I imagined bacteria gathering on the chicken carcasses lining the refrigerator case at the front of the restaurant. The menu offered one meal for dinner: chicken soup. The next day, it took its revenge on me.

My symptoms were more acute than my regular Crohn's manifestation, and it felt like my energy drained further with each restroom visit. Developing countries each have their own way

of managing inadequate plumbing. Ecuadorians throw their toilet paper into a plastic mesh trash can that occupies every bathroom. For days, our hotel room smelled like shit. I worried. Matt worried.

“Any better today?” he said every morning when I woke, sun already pouring through the windows of our all-white hotel room.

“A little,” I said. I felt hung-over even though I hadn’t had anything alcoholic to drink the entire trip. I tried to be game, staying at the budget hotel instead of the fancy one on the other side of town, travelling to a hot springs by bus and returning when I felt so sick I could barely stand. We were able to afford a more luxurious vacation, a five-star hotel, a hired driver. I could have taken naps in the afternoons instead of sight-seeing. But I felt embarrassed about my illness and ashamed of needing special accommodation. It wasn’t like a broken leg or a case of chicken pox. It was messy. It was private. It was shit.

Three days after our return from the hot springs, Matt and I rode a taxi up the hill from Otavalo to Beth and Kevin’s house. My nausea had abated, but the diarrhea hadn’t stopped. It didn’t seem to matter what I ate, so when Beth suggested we come to her house to make *llapingachos*, potato pancakes topped with thick dollops of peanut sauce, I agreed.

We arrived to find Beth standing at her stove frying potatoes in a pool of oil. Sunbeams reached through iron-barred windows to splash on the concrete floor. In the middle of the high wooden table, a bunch of bananas rested in a white ceramic bowl painted with orange flowers. I sat on a stool and worked on mustering an appetite. Beth looked across the kitchen at me. She cocked her head to the side, a trademark tilt.

“What’s the matter with you?” she said, blunt as ever. I described my symptoms, the ways in which they were different from my usual state of being. She listened and nodded. Here she was on her day off from her role as medical advocate for the community, performing the same role for me.

“Okay,” she said when I finished my explanation. “Here’s the plan.”

The next morning she took me to the doctor who worked at Beth’s community clinic. She had an office near our hotel in Otavalo, not a tourist clinic, but as a friend of Beth’s I got special treatment. I handed her the letter Dr. Carol wrote, translated by my neighbor, a doctor who spoke fluent Spanish. Beth and I sat across the desk from the doctor while she read the letter, like a married couple signing papers at a lawyer’s office. I started out responding to her questions in Spanish, with Beth correcting my grammar. I was low on brain capacity, though, and after a few questions, I responded only in English. Beth translated matter-of-factly, relaying the details of stool frequency and color.

“Amarillo y café,” she told the doctor, giving me a sideways smile that said both “you knew that one” and “I’m sorry your shit is yellow.”

The doctor sent us to the pharmacy to buy a sample cup, and Beth and I wore a triangular path between pharmacy, doctor’s office, and analysis lab, me carrying an open container with my own feces inside. Capturing bodily waste in specimen containers was an action I performed regularly at home, though this was my first time walking my own sample to the lab. The cup, the kind used for urine samples, fit easily in my palm. I clung to the rim of the container, careful not to spill its contents on the street. It was three blocks from the clinic to the lab, and the route was a minefield: tourists, locals, taxis, food carts, souvenir stands, dogs, musicians all competing for space on the narrow dirt road.

It was Saturday, which meant Otavalo's street market was in full swing. Booths lined the town square, fanning out from the center for several blocks. Tables showcased a riot of colors: serapes, sweaters, jewelry, and tapestries. In one corner, black soapstone and Tagua nut carvings of all shapes and sizes, in another, products from the nearby towns Matt and I had visited with Beth: leather from Cotocachi, weavings from Ambato.

An hour after we dropped the sample off, Beth and I returned to the lab to get the results. We sat in hard plastic chairs in the hall. Through the doorway, we saw the technician sitting at the microscope. She held a mango popsicle as she analyzed a slide, holding it protectively away from the scope as she pressed her eye against the lens.

"Won't the popsicle taint the sample?" Beth whispered to me. We laughed, first under our breaths, and then louder, the laughter echoing in the hallway. The technician snapped her head up at the noise and wrote something on a slip of paper. She folded the paper into an envelope and called out something in Spanish that I didn't understand. Beth got up and walked over to retrieve the envelope from the tech's free hand. We went back to the doctor's office, and she read the results. Her eyes widened in surprise. *Truco*.

"Amoebas!" she said. "Es increíble!" I felt twin emotions of anger and relief. Everyone else ate the same bacteria soup at the hot springs; my compromised immune system and my defective intestines made me the sole victim. But a specific diagnosis offered more direct options than a vague one. More pills to ingest, yes, but unlike the others I took, these would provide a cure.

One more trip to the pharmacy, where, waiting in line, we speculated as to whether or not the popsicle also had amoebas, and what its treatment might have been. On our way back to my hotel Beth took my elbow and steered me toward a market booth.

“Let’s get you something to go with that case of amoebic dysentery,” she said. She walked me to a table covered in the ubiquitous bracelets I’d admired since we arrived in Otavalo. Tiny, bright, seed-shaped beads ring the wrists and necks of most of the women there. Beth told me to choose a bracelet, and I selected a cobalt one. She fished some sucres out of her purse, and after bargaining a price, wrapped the bracelet around my wrist. I slid it up and down, rolling the beads around with my fingers, an action I would perform every time I wore it. I felt surprised at its beauty, how it dressed up my arm, my diseased and dysenteried body.

“There,” Beth said. “Feel better already?”

I did.

## 7. THE GODDAMN GRAND CANYON

Every evening of our raft trip through the Grand Canyon, the desert heat dissolved into a chilly evening and the guides built a fire. I liked to sit directly to the side of the blaze, feeling its warmth while the flames stood on the periphery of my view: the steep canyon wall covered in shadow, the sandy bank giving way to the Colorado, indigo in the evening light. I wrote in my journal, or read, or stared into space while the rest of the group bustled around me – the guides preparing dinner, the other guests standing in clusters, beers in hand, talking and laughing.

One of our last days on the river, while I sat fireside in my pre-dinner reverie, Bob dropped his camp chair on the sand next to mine.

“Mind if I join you?” he said.

“Please do.”

Bob and his wife Cynthia were among my parents’ closest friends, dating back to Dad and Bob’s college and medical school days. Bob was the friend who’d suggested I go see the g.i. specialist in Seattle that he knew, the offer I’d refused at the beginning of my Crohn’s treatment. Their middle son had organized the raft trip as a celebration of his medical school graduation the following month. My mother, Matt, and I joined the group halfway through, hiking from the canyon’s South Rim to Phantom Ranch to take the spots of three people who’d hiked out that morning.

Bob folded his six foot-plus frame into a sitting position. He wore the same horn-rimmed style glasses and thick moustache he’d had since the 1970s. We chatted for a few minutes.

“So,” he said finally, and a long pause followed. “How are you feeling? How’s your Crohn’s?”

What emotions must have stirred within him the first time he saw me coming across the suspension bridge at Phantom Ranch, a person he'd known since birth, a healthy, active girl? I had a flare-up every time I tried to wean myself off the Prednisone, so I was on a small maintenance dose indefinitely. I still had all of the medication's side effects. I weighed 150 pounds, a substantial load to bear for my five-foot-two-inch frame. My wide-brimmed hat accentuated my weight gain and swollen face like a fun-house mirror.

To make matters worse, I'd tripped coming out of the port-a-potty at the top of the trail on the south rim the morning we hiked in, and sprained my ankle. My mother lent me her hiking pole, and I hobbled down seven miles of steep trail, slipping often, worsening the sprain every few steps. No wonder Bob had walked right past me as I limped across the bridge, his eyes scanning the trail behind me for the petite, vibrant young woman of his memory.

The ugliest part of me, though, resided somewhere inside of me. Not my diseased intestine, but the shadowy matter that made up the fibers of my soul. I'd become bitter about my illness, resenting the healthy status of those closest to me.

The person who bore the brunt of this, of course, was Matt. We'd quit our jobs in February and were both scheduled to start school the following month, June – Matt for civil engineering, me for library science. Four months to travel and play had sounded luxurious when we planned it the previous fall. Spending every waking moment together, though, had started to take its toll, at least on me. By the time the raft trip arrived, I felt tired of Matt's company. Or rather, I thought I needed a break from my kind, patient boyfriend instead of understanding the obvious – that it was life as a Crohn's patient I wished to escape. Having a chronic illness had started to feel like an endurance race and I didn't know if I had the stamina for it. Of course, I could no more part ways with my lifelong, incurable disease than I could have left one of my limbs back in Seattle.

Matt showed no signs of relationship fatigue. On our hikes into the narrow side canyons he would come up behind me.

“Look Janet,” he would say in my ear. “It’s the goddamn Grand Canyon.” He was quoting a line from Thelma and Louise. I’d always laugh, but the phrase stuck with me through the trip. Maybe it was the shit-colored glasses through which I viewed life, but I didn’t feel a swell of gratitude for getting to see one of the seven natural wonders of the world and going on a trip many dream of but fewer actually take. Instead, I felt surprised by how much brown existed there. On its flat stretches, the Colorado looked less like the western rivers I’d grown to love and more like a farm pond full of pesticide-coated mud. The rock varied in color, some red and white mixed in with the tan. I tried to absorb the guides’ explanations of the different canyon layers and types of rock, Kaibab, Supai, Tapeats, Vishnu; sandstone, limestone, shale, schist.

Something remained more prominent in my mind about the earth that surrounded us, though: it was too rigid to dig a hole. I panicked when I learned that we were only allowed to poop in the portable toilets the raft company provided. They got packed onto their own passenger-less raft every morning, not to be set up again until evening. If we had an emergency we could use the container reserved for such purposes, a plastic tub that once held margarita mix. Stamped diagonally across the front in perky blue script was the message, “tastes great with tequila!” I did not use the emergency toilet. Instead, morning to evening, I clenched. Goddamn Grand Canyon, indeed.

I developed a crush on one of the raft guides, and harbored fantasies of following him to Utah after the trip to go climbing. Matt registered my flirtations internally, he told me later, but said nothing while we were rafting. He was trying, had been trying all these years, to look past my illness, to not let it take a toll on me, on us. But I couldn’t ignore it. It felt as though I was in

a raft all by myself, trying to negotiate the mansion-sized boulder that had plunked itself down in the middle of the river after the rest of the group had already made it further downstream.

I'd rafted the Colorado before, on the stretch that ran close to the ski town where I lived after college. I went on a day trip with my friends and our next-door neighbors, three men whom we'd met the day before. The only one of our six-member group who had more than a couple of raft trips under his belt was the boat's owner, Doug. His two housemates, who'd moved from New Jersey to Colorado the previous month, had never been in a raft.

As I stood at the put-in watching the higher-than-average river rush past me, one thought bubbled to the surface: this is a very bad idea. But my extroverted friend wasn't protesting, so I kept my mouth shut. We set off with me in the back, opposite Doug. Soon enough, we heard the rush of water ahead, louder than our voices. We came around the bend and saw a large rock dead-center of our first rapid.

"Paddle right, hard!" Doug screamed as we headed left, and straight over the top of the rock. We tipped vertically onto the hole the water formed around the rock and the boat stayed in that stuck position, wedged between the hole and the rock as if with Velcro. Doug and I were forced to our feet, and I heard him say "shit" as I launched out over the boat and into the water.

The underside of the rapid was the opposite of its surface. Cold, quiet, and dark, it was like being in a slow, mute washing machine. I knew almost nothing about whitewater rivers, but I did know this: a hole can hold an object a long time, longer than the average human lung capacity. It releases you when it feels like it. The river flowed over, under, all around me. Time slowed almost to a stop as water pushed me backwards into the hole. I thrashed wildly, to no effect. Nearly out of breath, I had no choice but to submit. My limbs went still, and almost immediately,

I spat out of the hole. I popped to the surface, my feet pointed, mercifully, downstream. I imagined bouncing off rocks, first with my feet, then with my head. I thought of my helmet still fastened to the raft. Bad, bad. Stupid, stupid, stupid.

But the impact never came. The current slowed. I remembered I could swim and did so, landing in an eddy further downstream. I scrambled onto the bank, a thin swath of dirt abutted by large rocks. Doug and one of my friends had fallen out too they climbed onto the bank alongside me. Somehow the other three managed to get the boat to the eddy and hold it there. The water flowed by at some forty thousand cubic feet per second, a herd of buffalo charging past. The river had a lesson to teach me that day, but it would take me years to hear it: If I didn't learn to assert myself, I might die.

Sitting with Bob in the middle of the Grand Canyon, I wasn't sure how to answer his simple question – *how are you?* Had he seen my wordless exchanges with the head guide each night as he fished my “refrigerated” medicine out of the water at the bottom of his raft. Did he know about the liquid enemas I squeezed into my rectum each night while lying in the tent I shared with Matt, the used bottles I stored in my a Ziploc in my duffle, folded against themselves like empty beer cans. Maybe it was all obvious to Bob: my flirtations, my moving around in my body like it didn't belong to me. He had five children, after all, including two daughters around my age.

The dinner preparations grew louder – a clatter of pots on the four-burner camp stove, the *chopchopchop* of the knife mincing cabbage and carrots – and I saw my opening, a moment where my words would be inaudible to the rest of the group.

“It’s been frustrating,” I said, finally. And then the rest came tumbling out. I told him about the attempts to manage my symptoms, the long list of medications I’d tried, the bi-weekly visits to the acupuncturist, the tea. I’d started seeing a naturopath, who planned to put me on an elimination diet as soon as I got back from Arizona. It was like a child-constructed rock dam giving way; once I started talking, I couldn’t stop. Finally I got to the Prednisone. My gastroenterologist still seemed unconcerned about my side effects; I found them worse than the disease itself.

“I think we’ve come to an impasse,” I said. “She says there are no other medications for me to try.” This wasn’t totally true; there was one more option, a medication recently approved by the FDA. It was only available intravenously, though. I’d have to go into the clinic for regular infusions, like a chemotherapy treatment. No thanks.

“You know about the clinic director,” he said, referring to him by a nickname. “Your Dad told you about our connection?”

“Yes,” I said. “But won’t my doctor be offended if I go somewhere else?”

“It’s your right as a patient,” he said. “People do it all the time.” He asked me if he should give me the phone number.

“I’ll look it up,” I said.

“How about I call you in a month,” he said, “to make sure you’ve found it.” It was a therapist’s move, the deadline-setting. I took my first deep breath in months, letting it out in a long exhale. I felt like I’d lost weight since sitting down.

“Sounds good,” I said. “Thanks for asking.”

“Glad I did,” Bob said. Matt joined us on the sand and I scooted my camp chair closer to his. I rested my hand on his knee. Matt pointed to the top of the canyon.

“Look,” he said, and Bob and I tilted our heads in the direction of his finger. On the uppermost ledge sat a tiny arch. Through its miniature frame you could see a few inches of sky, and a star framed in its exact center. How many of those sights had I missed on this trip, busy brooding?

“Good eye,” Bob said. I thought he might launch into the long explanations he was prone to, something about the geological history of the canyon. But like Matt and me, he was quiet. Behind us, one of the guides banged on a pot behind us three times in rapid staccato.

“Hot soooooop,” he yelled, drawn out, like a shepherd calling his flock home for the night.