

can you make hair for me?

A memoir in strands *eileen powers*





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Eileen Powers

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“Hello!”

“Hello!”

“Do you like my hat?”

“I do not!”

“Goodbye!”

“Goodbye!”

— P.D. Eastman, *Go, Dog, Go!*



Pictures of Speeding Cars and Other Pursuits

Miss Understanding

My Body, My Rock

The Subject was Kale

Hair

In Remembrance of Me

Monovore

Running

Subway Tile

Aftermath

Walking with Sam



*For my cancer caddy and best
photography student ever, Tom.*



Introduction

Make, Learn, Teach, Heal

My work as an artist is about the lives of others. The human portrait is an intimate medium, a shared choreography between the subject and the photographer. The photographer's nature is voyeuristic. As a maker of images, I seek to capture the understated gesture of a hand holding a set of keys, or the curve of a slender finger twisted around a lock of hair.

In 2018, I was diagnosed with lymphoma and underwent months of chemotherapy. My body changed. I lost my hair. I longed to go out and make portraits but was prevented by my compromised immune system. Alone at home I examined my physical self, a person I no longer knew, and found myself becoming oddly obsessed with my hairless head.

After my diagnosis, I noticed friends and well-wishers would offer affirmations to me, words that were supposed to provide comfort like: "F____ cancer, you're a warrior!" "You can beat this!" and "You're a hero!" These phrases sounded off-key, slogan-like, and pitted me, the patient, against my own body in a kind of dogfight. My experience was at odds with the sporty and militaristic metaphors that are bandied about by the well. I was firmly in Susan's Sontag's camp when it came to cancer metaphors: they were discordant, outdated and in no way reflected my profound loss of sense of self. As an artist I knew my disease would be material for art making, and hopefully healing, but I didn't have the slightest idea what form it would

take. I only knew it wasn't going to be a battlefield, ballfield, or Elysian Field. I wanted it to be joyful.

The months of treatment wore me down. I became lonely, fatigued, and unrecognizable. We're all judged by others on our outward appearance, consciously or unconsciously, and the adjustments we make to that presentation can affect us in myriad ways, including our viability in the world. When our appearance is altered, our personal relationships suffer, career mobility flattens, and friendships seem distant and strained. I experienced both negative and positive reactions to my personal changes: weight loss, hair loss, aging. Through chemotherapy, I had become a tabula rasa. I was blank slate, a non-appearance. I didn't realize for months the opportunity it presented.

Once I accepted my cancer and my bald head, I became fascinated by the changes. I spent weeks experimenting. I tattooed the word "Blonde" on the right side of my head, and "Brunette" on the left. I placed food on my head. I shot self-portraits in various states of baldness and covered in metallic silver. I bought prisms and reflected rainbows off my head and made more pictures. But none of it felt true.

I began reviewing the work of other photographers who made art from cancer. Some used huge view cameras with black and white film, others shot with iPhones, many documented the decline of others or themselves. I learned quickly that wasn't the avenue for me. I was presented with a creative and conceptual problem: how can I express my cancer through my art positively?

The simplest idea ended up being the most effective. I was dealing with change and loss on both the inside and the outside of my body. Why not try to replace what was physically missing in a collaborative way by asking people—who all wanted to do something for me but didn't know what to do—to help me fill that void?

It turned out people were excited to be asked to participate and looked forward to having a hands-on project. A project that required a different kind of thinking from cooking pot roast and casseroles that I couldn't eat anyway.

My goal for this project is to show loss is real, but our ingenuity in dealing with loss (in this case identity) is what makes us stronger, more compassionate humans.

The project is also about both giving up control by mimicking the disease treatment process—where patients give their minds and bodies over to a team of others—and gaining control back through collaboration by making and directing an art project.

The activity of making "hair" created a bridge of conversation, activity and creativity between my healthy friends and myself and, surprisingly, added a very different point of view to the final images. For me, the performative aspect of the project is the artwork—the hair—and the photographs a record of that activity.

I don't know anyone who hasn't experienced cancer in one form or another. I can name 15 people who have cancer right now. What I've learned from this project is that others have much to say to us about disease and death; they have wisdom to impart but may not be able to say it with words. Language is limited when it comes to cancer, and the "heads," as I refer to them, provided an alternate way for others to express themselves.

Each head has a story. Each is made by fingers, hands and bodies. I am awestruck by the thoughts and processes of the hair makers and how they came to make their individual creations.

This project has been a catalyst for family dinner table conversations about health, for creating art with a friend or a stranger, for trying something new, for freeing ourselves to make something completely beyond what we might have created before, and for teaching ourselves there are many sides to a problem. I now have over 80 heads. I'm grateful to all my collaborators who happily took on this challenge, some making multiple pieces.

We can heal our bodies with treatment. We can heal our souls with activity, expression, and the help of others. *Make, learn, teach, heal.*



one

*Pictures of Speeding Cars
& Other Pursuits*

Cancer is all about scheduling and testing and the repetition of those schedules and tests. Cancer is never punctual, but you must be. At Massachusetts General Hospital (MGH) CAT and PET scans are performed with the same machine. I was normally summoned to the hospital at an ungodly hour to avoid the viscous Boston traffic. This was both a courtesy and a bane. I've had appointments as early as 6:45 a.m. Coming from Cape Cod, that means leaving the house around 4 a.m. As a result, ease of transport becomes an essential theme in the patient's overall treatment plan, as does knowledge of the whereabouts of public restrooms.

I estimated that I spent over one-hundred anesthetizing hours in the car driving from home to MGH and back again. The possibility of treatment side effects curtailed my driving, and my partner Tom gave up hours of work time to caddy me from appointments to procedures to biopsies to surgeries and back home to recover. Repetition has always been a theme in my art practice and cancer treatment offered that repetition in real time, and in mega doses. I responded by taking snapshots of my medical commutes from the Sagamore Bridge to the Longfellow Bridge. Images shot with my

iPhone, which I printed and arranged around my dog. All the photos were as repetitious and as desensitizing as my hours in the passenger seat.

I could no longer go out and photograph strangers on the beach, tourists and lovable odd ducklings, as before. I made piles of pictures of traffic in blue light, tractor trailers emblazoned with gargantuan EggMcMuffins, and, my favorite, rows of streetlights that appear to be bursting like zingy photons. Through the monotony of treatment, I kept making images. Like other muscles, I believe we need to keep exercising our eyes and brains lest they become dull and too lazy to respond. I forced myself to smile and kept scanning headlights, keeping in the back of my mind the fantasy that “the happy man would not get the plague (Sontag, 55).”

As Susan Sontag reminds us “psychologizing seems to provide control over experiences (like grave illness), which people have, in fact, little or no control (Sontag, 55).” Creative expression also provides a semblance of control, and assigns meaning to mundane activities like photographing parking lots, documenting waiting areas and “working the scene” of a hospital room.

When I left Lesley University after the June 2018 MFA residency, I had no idea I wouldn’t be coming back. I was soon to find out more than I ever wanted to know about malfunctioning lymphocytes, the rituals of stem cell transplants, the blunting effect of chemotherapy on memory, and the quiet uneventfulness of CAR t-cell immunotherapy. Throughout my cancer treatment I continued my art practice in clinics, hospital rooms, and home. When one becomes ill, banal objects take on exalted roles: clocks become gods, grilled cheese sandwiches manna, and a walk in the woods a feat of superhuman endurance.

In June of 2019, my cancer gave me the finger and decided to expand its stay in my small intestine. This was the first of three refractory episodes. My cancer wasn’t leaving without a proper smackdown. The day before I was scheduled to return to school I had a PET/CAT scan.

At each appointment, the patient’s vital signs are taken. Every visit involves blood work of one kind or another. I had been given a port-o-cath

early on. Tucked just under my skin and inserted into an artery, the catheter makes blood work a clean ordeal and creates a physical and psychological barrier between you and the phlebotomist. It becomes both an entrance and exit ramp for blood and drugs. It’s one of those banal common items of cancer treatment that becomes exalted, metaphoric, turning the patient into a cyborg, part human, part mechanism. At one point, I had two ports; the second, a heavy-duty version used for stem cell transplants called a triple lumen catheter., which I renamed it Cerberus.

Before a PET scan, the patient fasts for eight hours then downs a radioactive elixir. There is a waiting period of about an hour as the isotope circulates through the body, then into the barrel of the beast she goes. The PET scan detects high concentrations of sugar, i.e.: cellular activity. I imagined my thorax lighting up like a crystalline Las Vegas as my body seesawed in and out of the giant donut-shaped scanner. It was at this point that I began drawing pictures of donuts. (At the time, I didn’t know why.) Once inside, the donut the scanner sounded like a be-bop drummer playing inside a tomato can. There were signs on all the doors indicating high radioactivity. The technician hands you a card when you leave that you can present if you set off a scanner at a store or airport.

The CAT scan comes next. A small bit of contrast is injected into the port, and as it travels it carries a wave of heat the patient feels from head to toe. The next sensation is that of a full bladder, but you’re stuck on a table and need to remain motionless. The contrast is a dye that helps to highlight the parts of the body being examined; my scans were of the thorax and neck. The CAT scan was quiet and I often fell asleep, once the urge to pee passed.

In medical parlance, a recurrence of disease is referred to as refractory. I had refractory lymphoma. After six rounds of chemo and major abdominal resection surgery, there was still a small, stubborn tumor deep in my intestine that was thumbing its nose at treatment. My oncologist, Dr. Barnes, was optimistic. He urged me to join a research study which would ultimately lead to the newest, most effective treatment: immunotherapy.

In the summer of 2019, I was heading back to MGH for three additional

rounds of in-patient chemotherapy. I'd just started the Can you make hair for me? project. I was in the process of inviting friends and family to make hair for me, and had already created a number of images. I taught Tom how to use the camera and he began photographing me each weekend. I art directed and set up the shots, and dug deep into my memory for people, places and happier times. Knowing that cancer could return is always in the back of my mind. I decided to try to not think about it and concentrated on making hair.

The process for making the body of work was simple. Due to my compromised immune system, I was confined to home most of the time, except for walks and trips to the thrift store to purchase clothing for the project. A "head" would arrive (or I would make one) and I'd create a personality based on the materials I had around me. We used a blank gray wall as a backdrop and shot with a Speedlite flash set to bounce off the ceiling. As the series began to emerge, I noticed striking similarities to what John Berger, the British art critic, called publicity images. Images that must be "continually renewed and made up-to-date...yet they never speak of the present." (Berger, 130) I had transformed my life of repetition into a series of renewed publicity photos, absent from time, yet somehow familiar and rooted in mass produced advertising images and popular culture. I had attended graduate school for advertising many years earlier, but never finished my degree. I now realize it was because I was in love with the illusion of advertising, but not the day-to-day grind of working in a faux-funky-artsy-office as falsely hip as the creative it produced.

The summer progressed and I began to notice lapses in my memory. Similar to my eighty-three-year-old mother, I would lose words mid-sentence, or completely forget what I was talking about or doing. I asked Tom and my family to take pictures of me hooked up to IVs, flat out on my back in the ER, and injecting myself with Neupogen, a drug that encourages white blood cell growth but causes extreme bone pain, nausea and headaches. I was afraid that the painful memories of my treatment would be dropped

by misfiring neurons, like fireworks exploding on the ground, before being safely stored in my cerebral cortex. I was right. If I didn't have those snapshots, I probably wouldn't be able to write these essays.

New technology, especially the smartphone, "allows us to produce a narrative of our lives, to choose what to remember and contribute to our own mythos." (Renner) With the Can you make hair for me? project, I was able to create a narrative and alternate selves; a made-up pantheon of ragtag characters to replace the memories and the me I had lost to chemotherapy. I no longer remember the abject disdain I had for my design job, the terror I felt at being told I had lymphoma, the crushing disappointment of cancer returning not once but twice, or the relief of finding out it was gone. But I do remember working on the Hair project and trying to solve the visual problems I gave myself.

I recall glimpses of my life in the year before my cancer diagnosis, but I can't remember the details. I've completely lost what it felt like to be myself, what I did in the course of a normal workday. The project has become a parallel scape of fictional memories, a carousel of made-up characters and colors that spins and blends into a personality I now call "myself." The images are references for time, activities and space. They help me to unearth long-term memories through associations with colors, fabrics, and materials, but do little to recover the feeling of what it was like having cancer. The images seem still to me "eternally young, fixed forever at beauty's apogee" (Barthes, 15) and an undeniable indicator that death will one day come. Beauty is superficial, and the images, artificial.

That July, the oncologist in charge of the research study flipped a coin and it landed on heads. I like to imagine it was taken from under a corpse's tongue on an unsuccessful bid to cross to the River Styx, but it was probably just an ordinary quarter. Heads meant I was in Arm A of the study. After two positive PET scans, lucky Cancerians who got Tales went straight to immunotherapy. The unlucky, like me, had to start with a stem cell transplant. At this point my creative life came to a standstill. I entered the hospital on

October 5th 2019, and left a couple of days before Halloween. When I got home, I was quarantined for six weeks.

A stem cell transplant is a bit like having your oil changed on a cellular level. The first step, stem cell collection, happens about a month ahead of time. The patient is hooked up to two jumbo sized IVs and all of her blood is ushered away and whirled through an attached centrifuge. The pinkish liquid that rises to the top, the stem cells, are collected and the blood is put back into the body through an IV in the other arm. This process should take six to eight hours, it took me three days to make enough stem cells to be used in the procedure. I barely made the cut-off of two million cells.

A month later, the patient is admitted to the hospital and given a high dose of conditioning chemotherapy. These drugs are highly toxic and designed to erase the immune system so the process of building a new one can begin. The idea is that by injecting the patient with their own healthy stem cells, the cells will recognize the cancer and start an all-out attack. The day the patient receives the new cells is called “Day One” in research circles. A team of medical professionals comes to the room and begins double and triple checking that the patient is indeed the correct patient, and the cells are indeed the correct cells. The cells return in a small come into the room in a wheeled fridge that holds the several frozen IV bags.

There is a ritualistic quality to the transplant as each nurse and doctor repeats your name, medical number and birthday multiple times as the bag is thawed. I confirmed each query. I had the option of having my cells blessed by the hospital chaplain. I’m not particularly religious, but I figured it couldn’t hurt.

As the IV was hooked up, a team of twelve or so nurses, researchers, and students stood around the foot of my bed. The chaplain, a young man fresh from Harvard Divinity School, said a prayer and we all bowed our heads. At the end I could hear the motor of the IV churning and many of the staff wished me a “Happy Birthday!” while toasting bottles of water to my new immune system. The process was not without its drama.

Two of my bags ripped while thawing and needed to be reconstituted and manually injected into my port through an object I can only describe as an oversized turkey baster. My mouth tasted like garlic and flounder. The room smelled like rancid pasta and raw fish.

When the last bag was injected, I became very sleepy. The team left my room and I dozed. I remember opening my eyes and seeing a stranger looking over me. He was heavy browed and dressed in medieval attire. He had on a burgundy and purple tunic with a matching roundlet hat. In his hand was a black silk cord. He cut the end with a scissors and gently put the cord around my neck leaving it untied. He placed one end of the cord on top of the other making the shape of a cancer ribbon. I felt at ease with his presence; all was peaceful in my room. He held a Catholic thurible from a long chain. Incense rose up and curled around my bed. I looked over at him, but he was gone.

A month or so later, I was at home and in quarantine. My brother, an avid paranormal enthusiast, took me to see a psychic medium against my better judgement. I was not supposed to be outside, but he wanted to do this for me and I agreed. The reading lasted nearly two hours and was stunning. At the end of the session, I mentioned the man in the medieval garb, and the medium became very still.

“That was Danté,” she said. “He wants you to read his work.”

I chuckled to myself, agreed to pick up a copy of *The Divine Comedy* and then forgot about it.

A week later while Googling at bedtime, I came across a Wikipedia page about Danté and rapid clicked. The famous Botticelli painting of Danté began to load. I recognized that nose! It was the same figure I saw had seen beside my hospital bed. Now, I’m sure I’ve seen the painting before, it’s probably cached somewhere in my memory, but the incident was startling, nonetheless.

In November, my cancer came back and my final stay at MGH began on December 26, 2019 and ended about ten days later, after the new year. I got

a special cupcake to celebrate the holiday in my hermetically sealed room. This time around I was getting a CAR t-cell treatment, touted as the miracle cure hermatologists had long waited for. I had managed to read *Inferno*. I wanted to see if it was somehow connected to me. In Canto I, Dante is lost in a dark wood at the advent of the darkest night of the soul. He cannot find a straight path; his way is blocked by three beasts: a leopard, a lion, and a she-wolf. I read this passage spoken by Virgil:

“It is another path you must take,”
 he answered when he saw my tearfulness,
 “if you would leave this savage wilderness;
 the beast that is the cause of your outcry
 allows no man to pass along her track,
 but blocks him even to the point of death”
 (Danté, line 91)

Cancer can make sense of things that once seemed abstract: birth, death, and direction. In February of 2020, I learned I was cancer free and got to go home.

two

The News

We all have a way of beginning. A visual artist may take out a blank sheet of paper and start scribbling. A writer might open a new Word document and start thinking. The commonality lies in the fact that all beginnings are the result of an action. A life unwound can be seen as a string of related actions and events that in some way impact our behavior and shift our direction. Our actions are what compel us to move forward. We can be motivated by interactions we barely remember: a phone call from a stranger on a summer day. To speak to us, change takes various forms. The exact content of the communication we may forget, but the essence remains, as does the stark divide between before and after. Just before Labor Day Weekend 2018, I was standing in the sunroom when my cell phone buzzed. It was a local number so I picked it up. Change had arrived.

I remember the geometry of the day; the shapes of the trees, the rectangle of sky, and the soft ovals of clouds above the L-shaped yard. A silent shock jolted me like an electrical current, followed by moments of stock-still disbelief. I still feel it in my dreams—the shock forms a meandering fuse of tension, actions and words that threads through my gut. But when the spark reaches me, I can’t explode. It’s my first experience with cancer limbo, a void every patient passes through. From that point forward, I can never go back to how life was before. Altered, I’m forced into a new version of myself. She’s not a person I’ve seen before. She’s indecisive, confused, afraid. After that

moment dreams turn into sweaty night terrors and conversations become circular. I remained undetonated for the next year and a half.

That day in the sunroom I spoke to an endoscopist calling with colonoscopy results, a test I'd taken a month before. I had no idea what he looked like. All I could remember of the procedure were the individually wrapped Lorna Doones I downed with apple juice upon waking. I tried to pay close attention to his sentences but caught only every third word. I heard biopsy, atypical, malignant, suspicious, oncologist and chemotherapy. I was given instructions in the form of an apology. He said he'd never made this kind of call before. He urged me not to dally. I had appointments to set. "Call your G.P. immediately," he said. I would need to see an oncologist.

I felt like a goldfish flopping on the floor. There was an absence of air. The endoscopist asked if I had any questions. I said "No," and thanked him. He said goodbye. I didn't catch his name.

It was very sunny and reminded me of the 9/11 sky. I stood there for a while; maybe, the whole afternoon. The sun eventually dimmed.

Cancer is all about scheduling and testing and the repetition of those schedules and tests. Cancer is never punctual, but you must be. At Massachusetts General Hospital (MGH) CAT and PET scans are performed with the same machine. I was normally summoned to the hospital at an ungodly hour to avoid the viscous Boston traffic. This was both

three

Miss Understanding

My medical miseries began on August 10, 2018, when I had a routine colonoscopy. I drank the pretest bowel-clearing liquid every fifteen minutes until my colon sparkled. I rode my bike to my test, fell asleep, woke up, ate cookies, and got a ride home from my mom. In June, Tom and I had purchased a new home, and at the end of July we moved in. I spent one night in the house and drove up to Maine to spend a week taking pictures and eating ice cream cones with my friend Marion. Upon return, I had the colonoscopy. We were still unpacking boxes. Come to think of it, we're doing that three years later.

We bought the new house before selling the old one, but I was confident I could sell it myself without a real estate agent. We'd been looking for a house for several years and had stopped searching. It was by happenstance that Tom saw a listing not far from where we run on Saturday mornings at Johnny Kelley Park. I didn't want to look at it, but Tom thought it might be worthwhile. That day I put in an offer on the house, and started preparing the marketing materials for selling the old one. It was a stressful, yet happy time. The work on the old house was nearly done, the septic had failed and a new one installed. We did everything we needed to make the house marketable and move-in ready: new neutral paint, clean carpets, insulation, stainless appliances. We held our first open house in the beginning of September. Then I threw up.

During the previous year I'd been treated for shingles and a nasty bout of Lyme disease. I took no regular medications except an asthma pill. I was sleeping more. I started noticing that certain foods made me sick to my stomach, especially alcohol. I went to a free-drinking Christmas party with my running pals in December 2017, and afterwards stayed in bed for two days. I postponed Christmas. I think back now and believe something had started brewing in my blood way back then. It just wasn't making me sick enough to pay attention.

When I got my cancer diagnosis in September, Dr. Wellport, my GP, was on vacation. All Cape Codders take time off in September, so this wasn't a surprise. I was left to stew with my overactive imagination for two weeks. The day after my diagnosis, I was certain I was going to die. I stopped unpacking my cheap dishes. What's the point? I banned myself from Google. I stretched out on the lawn and stared into the sun. Why was I always so cold?

When I finally met with Dr. Wellport, no information was confirmed or denied. I got the sense she had sicker patients than me and was happy to hand me off to Dr. Nussbaum, a local hematologist. I waited another week for that appointment. It was now mid-October and I was sleeping half the day and eating copious amount of cottage cheese.

I met Amy in the summer of '97 while working at the Inky Mirror newspaper on Nantucket—she was a reporter and I was a production assistant, otherwise known in the newsroom as a “Betty.” We cleaned houses for extra cash, lived in a keyless ramshackle apartment, and shared several cats, including a large, cantankerous gray tabby named Ox.

And now we shared something else: blood cancer.

Amy has multiple myeloma, a chronic form of cancer that forms in plasma cells making it harder for the body to form antibodies and fight infections. As of now, there's no cure for it.

Amy stills lives on Nantucket, and while on her way to MGH for a blood

fusion, she stopped by to see the new house. We took Sam, my pryador (half Great Pyrenees, half Labrador), on a walk around the bog behind my house. She'd been witnessing my decline. When we were roommates, we'd go to yoga on Sunday mornings for a hot hour and a half, then I'd go out and run five miles. I often went into the studio after that to get some work done in silence. My energy level had always been high. I likened myself to a small dog that jumps and yips until it practically pees on the floor.

At the midpoint of our walk I asked Amy to take the leash. My back and my stomach ached, my pace and breath slowed. My movements were sluggish and labored. “You shouldn't feel this way. I think you need a second opinion. I'm going to find you a doctor.”

We should all be so lucky to have a cancer buddy like Amy; someone who asks of lot of questions with a cool head and a pad and paper at the ready. I agreed that my care wasn't optimal. She told me she'd get back to me with a name in the next few days.

In the meantime, I'd seen my local oncologist twice and spoke to her by phone after a lymph node in my groin doubled in size over a weekend. Dr. Nussbaum explained she didn't really need to see me, but kept the appointment anyway. During our visit she squeezed my hands and said, “You're going to be fine. I know it's nonintuitive, but we don't treat follicular lymphoma. We watch and wait. It's nothing to worry about at this point.” She made me feel at ease, but she didn't ease my pain.

So I fired her.

I wanted to clean house and fire Dr. Wellport, too, but I couldn't find a suitable replacement. When you live in a small community, finding a doctor is nearly impossible. As my cancer exploded I was simply not up to the task.

By mid-November the pain had become unbearable. I called Dr. Wellport's office and asked how soon she could see me. I went in late in the afternoon and waited nearly an hour past my appointment time. By now I was so uncomfortable sitting, I shifted waiting room chairs so many times that other patients started staring at me. I probably looked as if I was having

a manic episode. Even the receptionist eyed me with suspicion. When my name was called I bolted up and dragged my slothy-body down the hallway to the examining room. I sat on the table for another twenty minutes. When Dr. Wellport finally arrived, she looked at me sternly and told me the pain was all in my head. The cancer I had didn't need treatment at this point.

What?

Every night for weeks I'd writhed in pain in front of the propane stove. I'd wake in the middle of the night to take steaming hot showers. Nothing dulled the agony and no one seemed to care. Each day I sat in my office chair with a heating pad and an electric blanket. Now I'm a liar, a fantasist hallucinating about pain?

Dr. Wellport maintained a misplaced, condescending tone. "Well, the best I can do is refer you the pain clinic. If you're in so much pain I don't know why you came here. I can't do anything for you. You should go to the ER."

What exactly is your job? And does it include the Hippocratic Oath?

I had seen those pain clinic vans motoring around my neighborhood. The passenger all looked like addicts. I wasn't getting on that van. I sat in my car and cried.

Just when I thought the pain couldn't get any worse, it did. I could feel a hard ridge like a surfboard under my breastbone. My stomach churned and roiled. I could barely sit up. I finally asked Tom to take me to the emergency room on a cold Friday night the week before Thanksgiving. I groaned louder and louder until the ER team pumped me full of dilaudid, an opioid analgesic used to quell extreme pain (and moaning patients). I was too nauseous to drink the contrast, so I went into the CAT scan without it. My scans wouldn't be as detailed. I didn't care. This was my first drug-induced haze and the best rest I'd had in weeks.

Lying on the gurney, wrapped in warm blankets I dreamed I saw the Big Dipper on the ceiling of the lab. After the scan, an astute radiologist tapped me on the shoulder and asked if I had more than one kind of cancer. "Not

that I know of," I replied. I went back to looking at the stars and forgot all about it.

I'd heard back from Amy. Team Multiple Myeloma recommended Dr. Barnes, and Dr. Wellport granted my request and referred me to MGH. I was relieved until a snippy administrator in her office called back and told me Massachusetts General Hospital didn't accept my MassHealth insurance plan. For the next two weeks, while trying to work and keep my business afloat, I researched health insurance. By now I could barely eat and had lost twelve pounds. The cottage cheese wasn't cutting it; my appetite had disappeared. I took daily naps at 2 p.m. and by nightfall was crying in agony on my dining room floor. No sick person should ever have to review health insurance plans. I finally got some help and chose a plan that was twice as expensive as my old one, with a \$5,000 deductible. As a freelancer, I pay all of my healthcare costs. (When I finished my 2019 treatments, I had spent well over \$24,000. But, I was able to go to the cancer center of my choice. I suppose it was a bargain. Thank you, American healthcare system.)



four

“Good news, your cancer’s worse!”

That’s how my first conversation with Dr. Barnes began in December 2018. Jovial and puckish, Dr. Barnes smiled and explained, “What you have is very aggressive but highly treatable. C’mon guys, this is lymphoma!”

We sat in the exam room as he compared and contrasted a stack of scans from the autumn of my discontent. He listened intently to intimate details about pain, emergency room visits and offered me his professional opinion. It ended with an affirmation that I was neither psychotic nor delusional. I was a cancer patient in need of immediate treatment. He handed me his business card embossed with a Harvard logo. My trust in corporate graphics was renewed.

It had been three months since that phone call in the sunroom. Three months since a faceless endoscopist referenced a biopsy by an anonymous New Jersey pathologist and told me I had follicular lymphoma. I was now learning I had been carelessly misdiagnosed.

Dr. Barnes explained it was a matter of agreement, and he didn’t agree entirely with the pathology report or the diagnosis.

“Looking at these scans, it’s my opinion that you don’t have follicular lymphoma. What you have appears to be Diffuse Large B-Cell lymphoma. In fact, I’m not sure you ever had follicular lymphoma. But we’ll need to run more tests.”

“Dr. Wellport thinks the pain is all in my head.”

Dr. Barnes turned to his computer, tapped on a few keys and was silent for a few seconds. “Yes, she did put that in your medical records. Well, I believe you.”

My body sagged. I think I saw an angel in the fluorescent lights. I heard bird songs from the vents. After holding my breath for three months, I exhaled.

“So, do you want me to be your oncologist?”

Dr. Barnes became my new oncologist. During the next couple of weeks on some of the darkest days of the year, I had another set of scans, a biopsy, a gaggle of appointments, blood work, an EKG, and a pulmonary function exam. I can’t remember what else they measured. Ultimately, in January 2019, I was admitted for a 5-day R-EPOCH (rituximab, etoposide phosphate, prednisone, vincristine sulphate, cyclophosphamide, doxorubicin hydrochloride) regimen of chemotherapy. It was my first stay in the hospital since birth. I was 51 years old. I thought if I ever became a front man for a band I’d call myself Vin Christine. I had similar oddball thoughts throughout my treatment. To my chemo brain, singing in Twisted Sister tribute band may have been unlikely, but held a certain plausibility.

Twenty-nineteen was a banner year. I had six rounds of R-CHOP/R-EPOCH chemotherapy, three rounds more after my cancer returned, two rounds of conditioning chemo, emergency abdominal surgery to remove tumors wrapped around my colon, two apheresis (cell harvesting) sessions, a stem cell transplant and finally, experimental CAR t-cell immunotherapy. I can’t even begin to estimate how many injections and IVs coursed through my limp veins. The port-o-cath, I once considered a bodily intruder, was now my other cancer buddy.

Weeks after I learned I was cancer free in February 2020, my sister and I baked blood-cell-shaped cookies for Dr. Barnes and Team Lymphoma. For fifteen minutes I was the toast of the cancer center Instagram.

In my head, I see Dr. Barnes passing out cookies and saying:

“C’mon guys, this is lymphoma! Have a lymphocyte!”



five

My Body, My Rock

I've always been an early riser. When I was little I would wake up before the rest of the family and sit in a corner just outside my bedroom. Lying on my side I'd look at my stacked knees and thighs. In my skin I saw a canyon. In the curve of my hip, a hill. And in the brown mottled carpet I saw the Great Plains. My stretched-out body reached across the hallway to the top of the stair. I imagined it a rocky outcropping in a vast pile that ended in a sea of green carpet at the end of the hall outside my parent's bedroom. I named my hands with sounds I liked to say. My right hand was Rigel, my left Googie. I curved them into horses and cantered them behind my knees. I then galloped them back around my rolling calves and sent them disappearing down to the soles of my feet; a few seconds later, finger-hoofs would appear from behind my big toe.

As far back as I can remember I played this game. My body was a mountain, a dune or a sloping lawn. The hills in our urban suburb were crowded with lines of two-story houses like cereal boxes on the shelves in the supermarket. The first green hills I ever saw were on the local golf course. In comparison, my body was flesh-colored like the rocks of Sedona, but infinitely more pliable. In a motion my knees could form the foothills of the Appalachians, then be squeezed together to form into the Matterhorn. My body was clay, water, and road. I could sit for an hour molding it until

the rest of the family woke up and it was time for cereal and milk.

My father's mother, Big Gram, supplied the family with an array of home-knitted afghans. A marathon craftsperson, she would sit in her olive-green TV chair and watch the nightly line-up from Wheel-of-Fortune through to Johnny Carson and The Tonight Show, knitting the commercials away. When she woke up in the morning, she start all over again with Good Morning America. As a child I was shocked to learn she didn't sleep in a bed. Each night she would doze off with her knitting needles in hand and a half-finished blanket draped across her lap.

When an afghan was finished, it was tucked inside a plastic bag, and then stuffed behind the green chair next to a bottle of Robert Mondavi red. There, she kept her stockpile of bed coverings for nieces, nephews, grandchildren and anyone she liked. Big Gram was a tough bird. Afghans were currency in the Powers family. Like a twenty-dollar bill inside a graduation card, you had to earn one or have the good fortune of being born during a surplus.

Big Gram used the yarn she had on hand or got free from the church, and as this was the 70s, there was a lot of rust, orange, avocado and brown in her color palette. She then knitted the rag-tag skeins into large, migraine-inducing zig-zag patterns that would dominate the decor of any room. My parents had an orange-shag carpet which presented quite a design challenge for Big Gram. The family afghan was zagged with burgundy, yellow and a yarn version of burnt umber.

But my afghan was different. It was a series of small multicolored squares linked together with strands of white yarn that formed a scalloped edge around the entire rectangle. It was smaller than the other afghans, and girlish. This was a prize among the home-knits. I'd won big—not a stripe, a zig or a zag, or a fringy finish.

My grandmother had small, nimble, onion-skin hands. She was speedy at knitting, but wasn't flexible enough to touch her toes and she often needed help with basic hygiene. One Saturday my mom and I stopped by for a visit. My grandmother's living room was like a bank lobby with a revolving

door of cousins and distant relatives coming and going. They took whatever they could pick up and pocket: Hummels on the credenza, small-framed family photographs, spare change, single earrings. They treated my grandmother's keepsakes like free pens.

While my mother clipped my grandmother's toenails, Morris, a big yellow tabby and an intrepid TV viewer, watched the Creature Feature, the weekly horror movie that came on at 1 p.m. The selection was the The Blob. My mom switched it off as the volume was louder than a heavy metal concert.

"I was watching that," said Big Gram.

"Gussie, I can't hear anything but screaming," said my Mom in her Bronx accent. My mom, always the compromiser, switched the TV back on and turned the sound down. Morris jumped off the chair and disappeared into the kitchen.

When my Mom finished the trim, Big Gram reached her papery arm around the back of the chair and pulled out an afghan.

"That's for you," she said, waving her outstretched finger at me. My grandmother was not sentimental and receiving a present was more of a command than an offering. So I grabbed it, rushed out the front door, and stuffed it in the cubby hole of my mom's VW beetle just as a second cousin strode up the front steps. No relative was going to get his grifting hands on my afghan.

When I got home I spread the afghan out on my bed and counted the colors: eighteen. I slipped under the squares and pulled the whole thing over my head. Light came through the spaces in the knit and the colors reflected onto my bare legs. My skin was dappled with colored light and reminded me of the psychedelic day-glo posters hanging in the bootleg record store I'd walk past on my way home from school. I poked my head out and rocked my knees from side to side. My legs were icy mountains with square patches of flowers poking through the snow. My head, a house, high above a white

meadow, and the horses cantered and jumped over the flower beds two at a time.

When I opened my eyes, everything was white. I didn't have my glasses on but I could see the blurry outline of my knees and legs outstretched to the cliffs of my feet. The drop at the end of the bed blurred into a grayish-white abyss. It looked far away and blank. The overhead light was too bright, and I could hear a slight beeping sound. When I moved my arms to free Rigel from his stable-covers and trot him down to the snowy paddock on my thighs, I realized I was tethered. I pulled Googie out, same thing. I looked down for the colored flowers and snow trails crisscrossing my body, but they were gone. A person came in, wrote on a whiteboard and asked me if I was in any pain. I said, "No."

"Do you need any more ice chips?"

"Yes, please."

"Just remember to push that button if you need anything." She hung the button up on the wall and left the room.

I found my glasses. It was February 16, 2019, 2:08 p.m. I fell back asleep.

No one came back to my room until 7 p.m. It was dark. My cup was dry and I had peed all over my hospital blanket. I couldn't reach the call button. I was unable to get out of bed on my own. I found out I was being sequestered from the other patients as I was neutropenic (which means having an abnormally low white blood cell count) and immune compromised. Someone leaned over my bed and told me I'd had emergency abdominal surgery. My lymphoma tumors had wrapped around my small intestine and the surgeon had removed two feet of tissue. I had four IVs, two in each arm. My memory slid back into place: a walk in the woods, crippling pain, vomit in the car, the ER, and an ambulance ride to Boston with the sirens on.

I looked down. There were no hills or horses. My skin was flaky and wrinkled. A nurse showed me how to roll out of bed. There were chunks of hair on my pillow like fur from a cat. The room smelled of disinfectant and urine. A man came in and mopped. I looked at myself in the mirror and vomited.

I rinsed my mouth and went back to bed. Somewhere in another room a gameshow was on. I texted Tom and asked him to bring the hair clippers.



six

The Subject Was Kale

Down near where my grandparents lived on the south side of Yonkers on Kimball Avenue was an IGA Supermarket. It was a brutalist cement building; a kind of forerunner to the beauty-be-damned-I-want-money big box store architecture of today. It was squat, beige, ugly, and proudly proclaimed itself a “Foodliner” in giant red san-serif type that ran along the front exterior. I pictured a Titanic-sized ship overflowing with a rainbow of vegetables, meat, milk, and my personal favorite, cheese. The vessel had donuts instead of life preservers and the deck was planked with pretzel rods. A flag billowed proudly from its stern emblazoned with a logo that was part cauliflower part container ship.

“Ahoy, Foodliner!” I’d shout from my mom’s red VW Beetle, waving furiously as we drove by.

Curiously, I have no memories of kale from childhood. My mother didn’t sneak it onto the plate like she did with beets, or disguise it with cheese sauce as she did with asparagus. Our table was a kale-free zone; out of sight, out of mind.

Kale wasn’t even a brand then; it was just a mere second cousin of cabbage. If a product didn’t have a zingy jingle, I knew nothing about it.

At age five in 1972, I was a bit of an advertising wunderkind. I could

memorize TV spots by the end of the second viewing, mimic radio ads with parrot-like aplomb, and sing popular jingles over and over, driving the entire family nuts. Perhaps I was just acutely susceptible to ad messaging, but I preferred to think of my ad sense as a superpower.

Once, in desperate need of an intermission from my singing, my older brother tackled me and put me in the dryer. Wily even in my preschool years, I kept my leg hanging outside the hatch so he couldn't close it all the way. I repeated the McDonald's classic "You Deserve a Break Today!" incessantly, until he gave up on the dryer and locked me in the basement. I sang louder.

I learned products like letters and made up my own songs, jingles, and words. A practice I still entertain myself with today. For Nixon's 1972 reelection campaign, I generously contributed the repetitive yet catchy "Vote! Vote! For Nixon" sung to the tune of "She'll be Coming Round the Mountain:"

Vote, Vote! for Nixon when he comes,
Vote! Vote! for Nixon when he comes,
Nixon went to China, McGovern never did!
So Vote! Vote! for Nixon when he comes!

A staunch supporter of voting rights as early as kindergarten, I went on to pen numerous political jingles before the sixth grade, but none equaled the early success of my anthem to Tricky Dick. I made up songs up about naked neighbors, showering cats, and sharing a submarine with a cocker spaniel named Bee. I sang most of the way through elementary school. I rarely wrote songs about produce, though, but if I had, I certainly would've chosen bananas over kale, for the obvious reason that "banana" is a lot more fun to say.

Can you make hair for me? is heavily influenced by advertising campaigns. I have a fond memory of a 70s commercial featuring actress Angie Dickinson (TV's Police Woman) touting the health benefits of domestic avocados, while reclining in a drum-tight white bathing suit. She held a fork perpendicular to her body skewed with a perfect avocado slice, and

spoke to us through teeth as white as her swimwear:

"California Avocados. Only 17 calories a slice and no cholesterol. Would this body lie to you?"

Driven by the hypnotic power of the female form in advertising, I imagined droves of hungry men leaving their tv sets and beelining it to the Foodliner to buy every last avocado. I later found out that 17 calories equal approximately one-fourteenth of an avocado. Angie may have been compelling, but was not entirely truthful. The copy had to be rewritten at the request of the National Advertising Division of the Council of Better Business Bureaus. Sales still soared.

I have no issues with avocados, or broccoli, string beans or Brussel sprouts, which I happily consumed in our kale-free zone. I even ate cabbage. No kale crossed my lips until my sister grilled up kale chips on the barbecue and served them with dubious amounts of assorted cheeses. Kale is only as good as the edibles surrounding it; the greasier and cheesier its neighbors, the better.

Around 2014, kale began soaring in sales and celebrity. Hailed as a superfood and the second coming of the avocado, kale went from being the last vegetable at the farm stand at midday to having a major shout-out in a Beyonce video. Overnight, kale was heralded as the modern-day superhero of the produce world. No one cared that no matter how you cooked, roasted, sautéed, or baked it, it always tasted like a pile of free-range grasshoppers. It didn't need an ad campaign with smiling, gleeful kale plants dancing in the fields of California. People were buying two heads at a time and, somehow, they were duped into thinking it tasted good: meet herd consumerism.

Then more good P.R. arrived from the science front! Not only was kale dense with vitamins K, C, B6, potassium, copper and manganese, kale was chock full of cancer-fighting antioxidants. Somewhere along the way, kale became the answer to America's nutritional ills, the green panacea of our current era. As a leafy wellness ambassador, it became particularly irksome to the cancer community. When speaking to the malignantly maligned,

the message became: “C’mon you cancer slack asses, EAT MORE KALE!” As if all one needed to rid oneself of lymphoma was more kale smoothies supplemented with organic yogurt enemas.

Let’s get two things straight: I didn’t give myself cancer and I can’t cure myself of it. And the same goes for you. Although many good-intentioned well-wishers still believe, consciously or unconsciously, that if you had only eaten enough organic produce (code: more kale!) you could’ve avoided this whole cancer thing.

And while most people don’t say that audibly, as a cancer patient, I experienced the Blender Phenomenon firsthand. Cancerians receive much unsolicited nutritional advice (both passively and aggressively) in the form of healthy soups and casseroles left anonymously on the back step: expensive blender gifts (emblazoned with photographs of unnaturally green vegetables), self-help books, clean recipes, and smoothie how-to videos.

Throughout my cancer treatment I continued to work. I was so afraid of losing my design business, I constantly checked my work emails, even during the three weeks I spent in the hospital for a stem cell transplant. I tried my best to keep up with the workload but eventually cancer caught up to me. I ended up giving away thousands of dollars of work, as there was no way I could keep up with the deadlines. My stress level began to climb, and panic attacks became a daily occurrence.

I was sitting in my home studio staring blankly at the computer screen, bald and nauseous, when I heard a car in the driveway. Seconds later Tom came in with a large rectangular box, a brown bag of vegetables, and a card.

“This just came for you.”

I looked at the bag chock-full of produce. I thought of the Foodliner and my ship of vegetables and dairy cruising up Kimball Avenue.

“Aren’t going to open it?” Tom asked.

I unwrapped the box. It was a glimmering new bullet-shaped blender. Compact yet practical, powerful yet healthful. I placed it on my counter

and it mocked me with its serving suggestions and eco packaging. It was a Honda dressed as a Tesla. On the front was pictured blender jammed with lemons and limes (rinds on), tomatoes, strawberries, cucumbers, something reddish I couldn’t identify, blueberries and gigantic leaves of curly kale. It snarked at me: “Be best.”

“I hate you,” I said to it.

I stuffed it back in the box and shoved it into the closet between the skeletal remains of four broken laser printers and a crate of rewritable CDs. Remember those?

“Soon you’ll be obsolete, too,” I said to the blender. “Make yourself at home.”

Angie would’ve crammed it with a swinging load of avocados and made One-Minute Guacamole for everyone on the Police Woman set, while holding a pistol and a curling iron. I slammed the closet door closed and ripped open the card; out fell a two-page letter. I exhaled and practiced my mantra three times:

Try and be nice

Try and be nice.

TRY and BE NICE.

It was kindly written, thoughtful, and filled with as much promise and kale-good wishes as one could puree in a new blender. Inside the brown grocery bag beneath the avocado was an enormous head of organic kale.

I was mad. I was sick. Niceties and bullet blenders couldn’t change that. Not to mention that gifts are often for the giver. When you do something nice for someone, it makes you feel good. When you do something nice for a cancer patient, you grow a halo.

Then I started singing:

Two all-beef patties

special sauce

lettuce cheese

pickles onions

on a sesame seed bun.

Nary a kale leaf has crossed these lips. I donated the blender to the food pantry and tossed the kale into the yard, which incited a rabbit riot.

Chemo: it does a body good.

seven

Hair

In the years before I became sassy, my father would take me to our local barber. I accepted the sensible buzzcuts until I discovered gender. When one too many pink ladies in push-ups and pumps patted me on the head and told my father what a cute little boy I was, I protested. I still wanted to eat dirt bombs and play army man with my brother, but what did that have to do with gender?

My mother wanted nothing to do with little girl hair. The accessories alone were a nuisance. On the occasion when a barrette got inhaled into the vacuum my mother would release a string of “God dammits” that made all of us kids run for the backyard. After I graduated from barber shop cuts, mom drove me one town over to Mount Vernon for a visit with her own hairdresser. Jimmy was either Italian or Greek and wore a neat little blue jacket with a scissors emblem embroidered on the right breast. Like most stylists at the time, he was a chain smoker and could be found standing outside the entrance of the shop, even in torrential rain, puffing away and humming a top-forty tune.

“Hello, Leeny! You’re turning into such a big girl! What grade are you in now?”

“Second.”

“Second grade! Well then! I’m going to have to give you a second-grade haircut. Would you like that?”

“I want to look like I’m in third grade.”

Mom would pinch me and remind me to thank Jimmy for his thoughtfulness.

Jimmy cut my hair from second grade to fifth grade. The third-grade cut resembled the second-grade cut with less ear showing, and the fourth-grade cut resembled the third grade cut but was shaggier. The fifth-grade cut was a modified version of the second-grade cut with bangs. By the time sixth grade came around, I decided I wanted a seventh-grade cut and headed out on my own to a beauty parlor in the strip mall. It had a pink neon sign that read “La Donna Salon” and was agreeably located next to a bakery that featured a genre of pastries Big Gram called “Gooey Louies.”

Richard was my stylist for the next few years. He was kind and attentive, enthusiastically reviewing torn out pages from magazines with absurdist hair styles. He had a penchant for polyester Sansabelt pants in powder blue, and he, like Jimmy, spent more time stamping out Marlboros near the salon entrance than cutting hair.

One Saturday I called up and to make an appointment. I was looking forward to my eleventh-grade cut and a post-style napoleon. The receptionist always answered “La DonNAH!” (like when people say “Ralph LauREN with accent on the last syllable, instead of the correct pronunciation “Ralph LAUren.”) I felt posh.

“I’m sorry honey, Richard died last week. I can set you up Carmine. He’s a Houdini and he loves the girls.”

I had no idea what to say. Richard was dead? Was Carmine going to make my hair disappear?

“Yeah, he had lung cancer, sweetie.” I heard her inhale. “We all miss him. Antonette is here, would you like me to set you up with Antonette? We’ve got some new Cellophane colors just for you girls!”

Cellophane was the hair rage at the time. It was transparent color that made hair glow blue, purple or pink when backlit. All of my friends had it done. I hung up the phone. I had no point of reference for death or Antonette. I let my hair grow out for a few weeks then headed to Astor Place in Greenwich Village, known at the time for its extreme style. I got a buzzcut. My history of hair had come full circle.

I’ve never seen my mother with hair below her ears. In her high school graduation picture she sported an expertly-coiffed 50s-style bob and a crisp Peter Pan collar. My mother was stunning in her wide smile and dark-gray lipstick. All of the headshots in the yearbook were black and white, and as a child, I thought her make-up was dully monochrome. My mom was, and is, neat and unadorned. Her style is one of utility and convenience. A beauty regime I now ascribe to, with the exception of my high school years, which I now refer to as “baroque.”

Sophomore to senior years came with a parade of hair products and appliances formulated for excess. Gels and balms, curling irons and blow driers were the instruments of follicular torture and a token of 1980s superfluity. My girlfriends and I followed secret rituals and sacraments turning tresses into mile-high skyscrapers plastered over steely structures of spritz hairspray. I worked in a drug store and dragged home bags of products in a spectrum of shapes and sizes. When lined up in the shower window, the bottles resembled the NYC skyline. Like city life, the products offered fantasies and possibilities. Included in the product boxes were elaborate instructions for creating flips and acrobatics, one more daring than the next. My head was fed more chemicals than our Yonkers lawn. My best friend Stacey became an engineer, no doubt due to her remarkable understanding of fibril physics. We were architects, we were.

Thus coiffed, my friends and I entertained strings of suitors, dazzling as Christmas lights, with vertical-standing, coiffed hair of their own. We were

horrified at the thought of Woodstock—where were the electrical outlets? Not even the most robust product can keep a strong hold in the rain, every ninth grader in my school knew that. I once dropped a hot curling iron in my lap. I slathered on some Bacitracin and got back to work. As it turned out, I had third degree burns on my inner thighs and had to wear sweatpants to class for three weeks. I was undeterred. I washed my hair with baking soda once a week to remove build-up.

When the 80s blended into the 90s, I took the tamer route and let my hair grow long and glossy. This look required eco-friendly products wrapped in brown-kraft paper, an appearance that belied the chemistry within. I spent hundreds of hours shared only with a blow drier gun, round brush and reflection. With the time I spent preening and grooming, I could've written a Ph.D. dissertation on narcissism as a cultural practice. I was an easy mark for advertising. Savvy marketers micro-targeted varying waves of hair and feminism from Mary Tyler Moore to Julia Roberts to RuPaul. The more options I had, the more fixated I became.

My hair grayed throughout the 2000s, even though I was only in my 40s. I sought out semi-permanent solutions. Every five or six weeks I'd drop half my rent on a cut, color, blow out. I took selfies with my digital SLR and posted them on match.com. Strangers would come up behind me and stroke my hair. "It looks as good as it smells," they'd say. Then I stopped blow-drying it completely and wet-set it with tangle tamer and products I picked up at the pharmacy.

For a year in between jobs, I was the night cleaner at a high-end salon on Nantucket. Each styling station was covered with about thirty product bottles shamelessly claiming to create "sexy beach hair" or "the bedhead look." "Spray evenly and liberally (you can't use too much!)" one package directed. At night, while washing the black and white tile floors and listening to breezy salon music—the mix was heavy on Astrid Gilberto—I'd dream of getting a \$100-hairstyle and a \$200 color. At some point, the owner stopped calling me to work. I think it was because I accidentally washed the floor

with oil soap. I heard a client came in the next morning and slid clean across the floor into the stereo system, putting the kibosh on the Astrid. It didn't occur to me that Christian Louboutin shoes don't have much tread. I always wore running shoes to work.

Over the span of a few weeks in the winter of 2019, between chemotherapy treatments, my hair fell out. More like snow than rain, the strands so loved and coddled silently let go, gathering on pillowcases, in shower drains, and on the collar of my favorite shirt. The techniques meticulously honed over thirty odd years faded with obsolescence. No one prepares you for the shock of bald. There's no neat brown bottle for that.

During the Valentine's Day 2019 hospital stay, my room faced a cement building. There was a tiny square of gray sky at the very top of the window. Occasionally a plane would come into sight and quickly disappear behind a giant vent on the roof next door. The view was a cacophony of drab. The bratty patient in the bed next to me complained that I snored too much. I was intubated, catheterized, and punctured with four IVs; one in each arm and one in each hand. My right hand was wrapped around a PCA pump (patient-controlled analgesia). The incision in my stomach was three inches long and throbbed with the slightest shift of my hips. The room was freezing. My movements were restricted to what I could reach. With my left hand I picked up a pink crocheted cap on the side table that sat next to a pitcher of ice chips. I recognized it from the free hat donation box in the infusion lobby at the cancer center. It was shaped like a baby bonnet. When you have cancer, people want to give you free stuff, quality and style notwithstanding. I placed the hat on my chest and rubbed my fingers over my scalp. The feeling was unfamiliar and lunar.

My roommate asked to be moved. I concurred. She had a full head of hair and a rare form of cancer. She was the talk of researchers, each one vying for a wafer-thin slice of her tumor to test and retest, analyze and scrutinize. When Team Rare Cancer came in that afternoon, they flocked about my

roommate like birdwatchers on a Blue-Footed Booby. Speaking in hushed tones that did little to contain their fervor, I blocked them out and turned my head to the window. It was snowing. An orderly brought me bone broth and more ice chips.

eight

In Remembrance of Me

Baldness, as a state, can offer great possibilities as my experimental hair can attest, but there are some secrets. The first secret: losing your hair is painful. Placing your head on a pillow after it falls out can sting and buzz. My scalp felt dangerously thin and unprotected. And there's the constant chill. Amy told me early on to buy lots of hoodies. She asked the library knitting circle to make me a mohair hat. I wore it to bed every night for eight months. I smell it sometimes. It smells like sickness.

The second not-so-secret secret is that nothing says cancer like a port and a bad haircut. I remember visiting a local thrift store in between chemo sessions in the summer of 2019. This was my second set of treatments; I'd already had six rounds in the spring, but the devil returned. I was looking for something garish and seventies to wear with the kale leaves I planned to glue to my head. Tom and I were searching the racks when a petite senior tapped me on the shoulder. She was elfin. I was wearing a sleeveless tank top and she pointed to the bump on upper right side of my chest.

"I couldn't help but notice you have a port. My husband had a port. What kind of cancer do you have?"

I took off my bandanna and mumbled something that sounded like non-Hodgkins lymphoma. She took my hand and looked me flat in the face.

"You're going to be fine, dear. Everything is going to work out. God bless you."

She squeezed my shoulder and left the shop. As per usual, my response was to just stand there. It took a confirmation from Tom to convince me she was real.

The third secret about being bald is that people will talk to you about God. It's best to think about this in advance so you have several responses at the ready. You'll find angels in your Hosta garden; red-faced strangers will give you St. Luke medals. People want to help you because it helps them. Smile and say something gracious.

There's a plastic Ziplock bag in the top desk drawer in our dining room. Occasionally, I'll open the drawer to retrieve a pen or shuffle through the contents searching for a lost object. I'm shocked for a second, when I see it. The bagged hair looks like a scalp in an evidence bag. It's dark brown and soft, and feels vaguely forensic. As with any part disconnected from its whole, our minds try to fill in the missing piece. My imagination comes up blank, though. The presence of the hair suggests an ending, or the tangled mass of an ill-plotted story. The personal connection I had to it is missing. It's not mine anymore. It's an object; a form divorced from its function. I'm reminded of Victorian mourning jewelry I've seen on Antiques Road Show. Rings and brooches with skeleton motifs created by long-dead artisans and fashioned with threads of a deceased loved one's hair. Victorians were prepared for death, as they knew it lurked just on the other side of the gazebo. As someone with cancer, I lived in the gazebo.

On the top of the desk is a Jesus candle someone gave me, along with a stack of books with inspirational titles like *Healing Beyond the Body*,

You Can Fight for Your Life, and Head First. I never read the books. I'm not interested in regenerative energy. I always say, "Hello Jesus!" and give him a hearty wave.

I'm not a particularly religious person, but hidden in the subtext of a cancer diagnosis is a strong spiritual message: Go and find your god. Then comes the not-so-subtle religious imagery from friends: cards with sunrises and donkeys; prayer candles. The material for future art projects.

In the 70s, my family attended a small Dutch Reformed Protestant church on Crescent Place in Yonkers. The vestibule smelled like lemon Pledge. A gaunt man who reminded me of Charon, the ferryman of Hades, would glide us down the red carpet to our place in the pew. High on the altar, a silver chalice sat atop a mahogany table inscribed in 600-point (jumbo) Roman letters: "In Remembrance of Me." Christ died on the cross for our sins, in case the twelve-foot, multi-colored stained-glass window of the crucifixion complete with stigmata doesn't jog your memory.

Part of me was dying of lymphoma; dying for my own sin of unbalanced nutrition, the Kalies (kale zealots) would say. We should all be drinking superfood smoothies with extra acidophilus and virgin bee pollen from that chalice, for Christ's sake. I still find Christian iconography creepy. Why does Jesus always have a lush head of hair? I prefer Greek statues. Athena had a fabulous nose and would've looked fabulous with a bare head.

Hair is tactile and visual; our fingers and eyes interpret the way we experience it. When I hold the bagged hair, I'm holding a modern reliquary. I sometimes unzip it and feel each strand with the tips of my fingers. When I pull the bag up to my nose, I smell lavender shampoo. I'm instantly taken back to the hair washing ritual at the salon. It was my last appointment before my hair started falling out. I asked Christina, my friend and stylist, to give me a boy cut. She took my long, thick ponytail and cut it at the nape of my neck, then wrapped me in a thick gray towel. She fastened the back of the black gown and I leaned my head back onto the sink headrest. Her

fingers smelled like cigarettes and coffee. The steaming hot water streamed over my scalp. The ponytail was smaller than I expected.

At that moment I decided I would never have long hair again. I don't know why. I eschewed the mass marketing of brushes, combs, conditioners, and expensive, over-packaged products. I told people I was going to keep my hair short to honor the chemo patients that came before me, those who gave their bodies to science in early clinical trials. The hero children whose parents put all their hopes in the newest experimental drugs, agreeing to have their kids injected with mysterious, toxic mixes; hope is the salve of the desperate. Hundreds of people died so that I, in 2020, could benefit from the immunotherapy they tested. I keep my hair short. It belongs to someone else.

Cancer is about a lot of things, but for me it's mostly about memory and loss. The slightest whiff of Italian cookies or bus exhaust transports me to my old neighborhood. My thinking changed during chemo; my short-term memory is still compromised. There are a thousand days in the early aughts I can't account for. If someone says "2004," I can't tell you a thing that happened in my life during that year. I can't name a single pop song. I'm not sure where I was living. I know I had a cat.

The changes in my brain have affected my language and visual acuity. It takes me longer to solve problems involving both words and images; numbers are impossible. The time spent looking at white screens and empty notebook pages has quadrupled. I think back to those Sunday mornings at the church. If Charon were here today, I'd give him the bag of hair and a penny. Bon Voyage, old friend. Cancer makes the mythic commonplace.

nine

Monovore

At the time of my stem cell transplant, I was encouraged to go for daily walks around the hospital floor. Each time I'd lace up my shoes, I'd smell hummus. I was convinced that every nurse on the floor concurrently consumed it during raucous hummus parties in the staff lounge before the 7 a.m. shift change. The smell induced queasiness, which curtailed my morning constitutional. Shuffling back to the room, I'd close the sliding door of my hermetically sealed space in an attempt to keep the stench out. But the odor railed me like dog crap on a Nike. It was everywhere I was. The smell was coming out of me.

Sleep was elusive and stench-filled. The bed was so uncomfortable, I used it as a table and slept in a mound of prewarmed blankets on the vinyl sofa every night. One evening I ate nothing but popsicles and slurped myself to sleep with dreams of a long-ago barbecue. I often strolled through the distant past, as the recent past consisted mostly of drab macaroni and cheese garnished with hamburger parts.

In the summer of 1997, I was working thirty miles out to sea at a small island newspaper, The Inky Mirror. It was July, and we were all urged to attend the optional Employee Appreciation Day /Cookout, or risk losing our pay for the day.

The turnout was great. Picnic tables and grills were set up on the

crabgrass outside of the pressroom. The smell of ink was stronger than the smell of hotdogs, but everyone smiled after a few slogs of punch dispensed from a bowl hidden behind the collating machine.

For those who might not have been born in the time of Big Print, paper newspapers were printed in sections and collated either by hand or by machine. The Inky Mirror had a minimum of three sections: News (A), Arts/Living (B) and Sports (C), with an occasional (D) section in the summer filled with fun seaside fare for the tourists, or absurdly expensive cottages-by-the-sea.

The News section (A) was always the first section and began with the front page. The collating machine folded each printed signature (large pieces of paper with multiple pages printed on them) and arranged them by section. More often than not, the collating machine would misfire and reorder the sections non-alphabetically. I heard that once the front page was mis-collated and replaced with a full-page ad for a kitchen store advertising their annual liquidation sale. Not only was the page in the wrong place, but it had a typo. The headline read, "Is your panty empty after a long winter?" That edition sold well, and the ad reps told clients it was a new premium ad space. But after numerous alphanumeric blunders and pagination mishaps, the collating machine was deemed cursed and put out of commission for good.

From then on, the paper was hand collated by an elite team of senior citizens and work-challenged adults. The Collation Sensations worked every Wednesday afternoon and arranged all the sections in neat piles on top of the collating machine. A skeleton crew waited around until midnight to finish the final collating of the all-important (A) section. It was once suggested by a cheeky editor that the tagline under the paper's banner read, "Hand-collated for Your Pleasure," but was later edited to the more authoritative, "The Island's Newspaper of Record."

Staffers were encouraged to bring their families to the Inky's summer picnic and a side dish to share. I brought along macaroni and cheese and sat

at a table with coworkers from the production department: The Bettys. The Bettys were a group of staffers between ages twenty-eight and forty who, for one reason or another, found themselves poorly paid, working on an island, and slinging out newspaper ad design like hash. While the Bettys all hated their jobs, there weren't many other places to make a living on the island. Of the six Bettys, four had cats, three had children, one was a man, and one had psychosis plus some combination of cats and kids.

Psycho Betty, a mom of two, never missed an Inky event. It gave her a forum to complain. The picnic table served as an impromptu podium from which she would spew her medical history complete with diagnosis, treatment, prescriptions, refills, and dosages. On more than one occasion she ended up in tears discussing a particularly perplexing child-rearing situation. On that day, Psycho Betty was alone. Her daughter, Celery, refused to come to the picnic, and her husband was rumored to be hunkered down in the island's only dive bar, The Chicken Box.

"I asked her to come, but she's going through a phase," Psycho Betty sniffed. She's stopped eating meat, she won't eat vegetables or cereal. She won't eat anything that isn't white."

The moms at the table sighed in solidarity, followed by a collective nod. The Mom Bettys had experienced the same phenomenon with their own children. All of these finicky children were the offspring of graphic designers, after all, and had innate knowledge of color theory that affected their palates. Psycho Betty didn't want Celery to end up on the menu-abuse spectrum requiring a lifetime of art therapy. Her daughter's madness sated only by stuffing her trap with mozzarella sticks and heaping tablespoons of self-rising flour. It was a colorless destiny that no child deserved. The Bettys knew Psycho Betty needed their help.

"Just don't feed her at all. That's what we did with Joshie. He finally came around and now he eats white food and hummus," said Busty Betty, adjusting her spaghetti straps.

"I always make Morgan her food separately. We discuss the elements

of the menu each week and go shopping together. Morgan is very focused on balanced nutrition,” said Suburban Betty.

“How old is Morgan?” I asked.

“She’ll be four and half in August.”

“There were eight kids in my family. My mother would just throw a roast in the middle of all of us. We tore it apart like hounds,” Burt Betty recalled. I once saw him skipping to work while picking his teeth with a pink plastic toothpick.

Bargain Betty grew up in Pennsylvania and told us, “My mom smoked skinny cigarettes and drank iced tea. She made chicken cutlets every night for fifteen years. I was twenty when I found out chickens had legs.”

“Will she eat celery or is that considered cannibalistic?” asked Boozy Betty.

And on it went.

Psycho Bettys cried harder until Boozy Betty handed her a thick black drink.

“This is from Chuck.”

Like the liquid panaceas purportedly endorsed by doctors and advertised in our paper during the Whaling Era, the “Collation Cosmo” was a cure-all for the common mom. It was created by our own jack-of-all-trades in the pressroom, a guy from Dedham named Chuck. Mystic mixologist Chuck knew just what the moms needed: a mysterious elixir three parts hard liquor, one part newspaper ink. It was black and turned your lips gray. I was later to find out it was made with a combination of grape, lime, and raspberry Jello-O, and sundry hard alcohol, a secret Halloween recipe from Suburban Betty. We all preferred the ink myth.

The Bettys settled in and partook of the island’s second oldest tradition: drink. As every islander knows “In the summer we drink and fish, in the winter we don’t fish.” We were all floating thirty miles out to sea in the hot summer sun, sipping and swigging, relieved we didn’t have to stuff macaroni

and cheese down Celery’s delicate throat. This was our time, goddammit. To hell with the spawn.

This was my first exposure to a monovore, defined as a child or adult with an irrational fixation for monochromatic food, or a person who’ll only eat one kind of food, for example, lettuce. I’ve always been a picky eater, but cancer treatment can turn the most omnivorous of us into a monovore after just one hit of rituximab.

Chemotherapy made it difficult to eat anything. I had three different drugs for nausea and made good use of them. My body couldn’t tolerate spicy food or bland food or red food or green food or orange food or gray food. It could only tolerate white food, and in small quantities. I lost thirty pounds. I now refer to this time as my cuisine blanc phase. My basic form of sustenance was a prepackaged vanilla protein shake infused with enough fake sugar to induce a fake coma. Chemo patients need absurd amounts of protein to heal damage tissue and fight infections. On most days, I’d have four or five twelve-ounce drinks and excrete double that amount in liquid form.

While I was depleting my stock of baby wipes in the hospital toilet, I thought of Celery and wondered if she was still eating cuisine blanc. Perhaps she’d grown up, gone to culinary school, and opened a four-star Michelin restaurant in the Loire Valley that served nothing but organic, local, hormone-free fromage de chèvre. “Celine,” as she is known in France, smoked while cooking and drank duck fat. I had many such thoughts while toxic chemicals were pumped into my bloodstream and I was huddled on the couch in my sterile room. Memories that once made me shudder replayed over and over. I’d view them as if I was seeing the film of someone else’s life and kept rewinding my favorite parts. As it turned out, my brain had fewer needs than my body during treatment.

After another round of Collation Cosmos, Smoking Betty chimed in with

a memory of a summer intern who ate only carrots. She started working at the paper in June and by Labor Day, her skin had a distinct orange hue. It looked like a canned tan. They called her the Thintern because she disappeared when she turned sideways and could only be viewed from the dorsal side. She went to Harvard and left our humble paper to find veritas and a very rich husband in Cambridge. She now lives off his dividend's dividends. All the Bettys clammed up. We were doomed to setting type, drinking Chuck's inky cocktails, and watching the ferries filled with beautiful people returning to their beautiful lives with their gorgeous kale-eating brood.

Boozy Betty looked down at her cup.

"This stuff is chowder. Let's go to Town and get some real cocktails. I'm buying and I'm driving."

Bargain Betty followed Boozy Betty to her jeep. I took a quick detour to the newsroom fridge to pick up my leftovers. In my cheery intoxication I pulled a swatch book from the art supplies cabinet. Leafing through it, I tried to find an exact color match for the mac and cheese. It was very light yellow, nearly white like New England cheddar. I found one of Suburban Betty's Tupperware Rock n' Serve containers and spooned up a load of noodles and put it in Psycho Betty's side desk drawer. It was Wednesday. She was off until Friday.

ten

Running

I hear my feet padding down a frozen path. My friend, Coach Joe, is running a bit ahead. We're in a frosty meadow and the sun sits just below the horizon. I'm in an Ansel Adams photograph. The grasses and leaves have an icy glow. Joe's shoes make a crunching sound with each stride. We're talking about where to have coffee. I ask about Joe's wife Ellie. Joe remarks how well I'm running. My body is weightless and I float above the trail with only my big toes touching the ground. There are others running behind us chirping and chatting. Joe and I disappear down a hill into the woods. We know they can't catch us. We run towards the park.

Delmore Schwartz wrote, "In dreams begin responsibilities," and yes, I believe we are wholly responsible for the content of our dreams. But along with cancer come profuse amounts of pharmaceuticals, compounds that act like a giant soup spoon, stirring the subconscious until the damndest things rise to the surface. In the dark of my hospital room, shapes and colors shifted behind my eyes, forming and reforming like clouds into days and dogs and distances. A noun becomes a verb becomes an adjective, and words a limited means of communication.

On the first day of the stem cell transplant, I received large doses of conditioning chemo called BEAM (carmustine, etoposide, cytarabine,

melphalan). The goal of which is to entirely erase one's immune system. The days before the transplant are marked with negative numbers, so the day I was admitted, October 5, 2019, was recorded as "day -6." The day the stem cells are administered is day zero, and the day after that becomes "+1." Each morning the nurses would change the date on the white board. By this time, I was a frequent flyer in the cancer center and knew most of the nurses on sight. I had a mental punch card and noted each stay with notches, like on a coffee card. "After twelve stays, I get a free massage therapy session," I would say to the nurses. No one laughed at my old-man humor.

The melphalan, the last letter in my chemo alphabet, turned out to be a pharmaceutical grand finale. Thirty-minutes prior to the infusion, my nurse came in with popsicles and ice chips, and explained that ice can prevent a condition called oral mucositis, a common side effect of high doses of melphalan. Cryotherapy, sucking on ice or holding cold water in your mouth during the infusion, decreases the exposure of the mucous membranes to toxic agents. No one likes popsicles more than me. I easily ate nine of them in a half an hour (grape and cherry!), along with four cups of ice chips. As with everything else in life, I like to be over-prepared. I considered my popsicle consumption a badge over achievement.

When it came time for me to receive the melphalan, it was about 11 p.m. My nurse Katie hooked up the bag to the IV and a second nurse double checked all the numbers on the bag. One of the rituals of chemotherapy is the repetition of your name, date of birth, and hospital database number. Each time there's a significant event involving drugs, the nurses and the patient repeat this sequence multiple times to make sure you are indeed you, and the drug is indeed, for you.

The infusion was scheduled to take about an hour. After the hook up I curled up on the couch. The staff always asked why I didn't sleep in the bed, many offered to wheel in a new one. The central metal bar anchoring the bed was like a steel spine. After having lost so much weight I was sensitive to every lump and bump. I became the princess in "The Princess

and the Pea." No matter how I tossed, I was jabbed with metal. After several sleepless stays, I gave up on the bed. Each night I put sheets on the brown vinyl couch, asked for a hot blanket, and covered my head with pillows. This night was no different. I set up myself up and away to dreamland I went to the sound of a dripping IV.

Tom and I are running in the woods heading towards Johnny Kelley Park. As we move down the trail the sky gets darker and darker. It's going to rain. We see an abandoned office park and run inside to avoid the downpour. We find ourselves in a warehouse packed with hundreds of floral sofas, each with a built-in mini-bar. Tom wants to keep one. I say "no." We start to argue, then a bolt of pain like an electric current, shoots across my face. Then another, and another. I start screaming. I fall to the floor.

"Eileen, wake up, wake up! Are you OK? One a scale of one to ten, how is your pain?"

"Eleven!!!!!!" I shout. The word and my tongue stuck to the roof of my mouth.

Katie disconnected the IV, and ran out to get a pain killer. She swiftly connected it to my port and in seconds I felt a numbness traveling through from one side of my head to the other. I had no idea what drug it was. I settled down, breathed, and chewed on some more ice. This was the first time I was frightened of the IV. I had never been this scared before. But we had to try again; without the full chemo, there can be no stem cell transplant.

Katie hooked me up again and waited. Nothing happened. The painkiller made me drowsy. I leaned back on the couch and closed my eyes.

It's raining. Tom and I have stolen bikes from a closet in the warehouse. Someone is following us. We start racing down a hill and duck into a grove of trees. "We need to keep going," I say. I fall off the bike, my face hits the sand. There's a root growing out of my face and it's soaked in sweat.

“Eileen! It’s Katie, are you OK? I’ve unhooked you. I’m going to call the doctor.”

My face was on fire. It was a pain worse than anything I’ve ever experienced. A resident rushed into the room and flooded my port with another drug. Morphine, I think. I felt it coursing through my body like a storm cloud in my veins. I could hear my heart beat. It was erratic. The tip of my nose tingled.

“Eileen, I know you can do this, we only have about twenty more minutes of the melphalan. I’m going to wait right here.”

Waves of fear rushed over my body. I would have been shaking, but I’m teeming with morphine. The IV started to click and I could see the melphalan going into my arm. I held my face. Katie sat next to me and put her hand on my knee.

A hot pain jolted my trigeminal nerve, the largest of the cranial nerves, and I cried out in pain. The resident rushed in one more time and flushed my port with even more morphine. This time I could feel it when it reached my heart, everything slowed down. I pressed ice packs to my face. Katie hooked me back up to the IV and we rode the melphalan wave together. Finally, after two and half hours, the infusion was over. I folded myself into three heated blankets and dozed off in a heavy, opioid-induced slumber.

It’s a sunny day and I’m running on the trail around the park but everything is muddy. I run up to the ball field and I see Tom is tossing a ball to a white horse. The horse canters after it, picks it up in his mouth, and brings it back to Tom. I get closer I realize my dog has turned into a horse.

The park in my dreams is Johnny Kelley Park, named for the famed marathoner. It’s the starting point for our out-and-back Saturday morning runs. I’ve run with Coach Joe, a friend of the late Johnny Kelley’s, and the rest of the running gang at the park for over thirteen years. In that time the group has grown, diminished, aged, dispersed, and reunited. A core group of us remains, and while the runs get shorter and slower, the camaraderie

expands. I looked forward to Saturday mornings, even when all I could do was plod.

As Johnny Kelley got older, his running (and ladies) less frequent events, he would say, “Running for me is about beating the girls to the finish.” After my runs, I’d walk up to Johnny’s bronze bust, greet him and ask how I could beat Sarah Palin. Her race times were always a sliver faster than mine. The answer was always the same. “Bird bones, you need bird bones. Light as sea foam.”

Johnny was a bit of a sphinx.

There were many months when I couldn’t run at all, and many weeks when I could barely walk due to resection surgery. For years, I ran half-marathons and an occasional marathon. My body was a tank, then. Before I had cancer, I’d drive down the road, see a runner and say to myself with a tinge of guilt, “He lands on his heels. I should be out there.” Later, I’d go for a run and all would be well with the world.

We take many things for granted in life, like a good night’s sleep, a hot stack of pancakes, and coffee with friends. When I got sick I yearned for these things with a sadness I could feel in each limb. I dreamed about running. From the ninth-floor patient lounge I watched runners go through their paces on the Boston Esplanade. Cancer creates vacancies and if you’re not careful, you’ll fill those spaces with self-pity and hopelessness. Whenever I was out of the hospital and up for it, I tried to run or walk. The simple repetition of knowing others would be at the park on a Saturday morning motivated me to get out of bed, lace up my sneakers, and move my body. Tom was always a willing participant, even when his morning face said otherwise.

In the hospital, I was a fixture in the hallways much like an exit sign or crash cart. I walked so much during one stay that my blood thinners were suspended. I considered making myself a bib number with the paper, markers and scissors that Kelsey, the art therapist, gave me. On the tenth floor there is a panel that states 1,238 loops around the floor equals one Boston Marathon. I saluted the sign each morning and kept my pace even. I teared

up each time I saw the plaque. I've run the marathon twice and knew I'd probably never run that distance again.

The stem cell transplant ultimately failed, but luckily, CAR t-cell immunotherapy was next up on my menu of options. In January 2020, after ten miserable days of IVs and drugs, I was back at home. My prognosis was very good. The first scan after immunotherapy was clean. My family cheered, my friends hoorayed, there were high fives all around. I felt no such joy. I remained steady, resolute, and in my mind, realistic. Cancer is an uninvited guest and my body a hostile host. You never know who's going to show up, or if you'll have the strength to toss them out.

A year and a half after having everything thrown at me but radiation, I started to recover. My visits to the park became more regular, and I began to notice things. Yes, it was still a friendly meeting place, but now I paid more attention to the benches scattered along the gravel path.

If disease gives us permission to think about mortality, recovery gives us an unrestricted license to obsess.

On my cool downs, I'd walk the circular trail around the park's perimeter and read the benches. To make some extra cash, the town sold commemorative benches at \$2500 a pop. The donor supplied the text and the town emblazoned it on the back rest.

For Suzy and Squeaky. I miss you every day.

—Louise

For John "Bud" Crowell and his wife Pam.

Sit awhile.

A morning walk is a blessing for the whole day.

HOW PERFECT IS THIS

HOW LUCKY WE ARE

Live with No Regrets

Roger Jennings

Dog Dad and friend

1932–2003

This is a place to dream things that never were—and not ask why.

The markers paid little heed to grammar and spacing, which was irksome, as I suspected they were intended to last an eternity or at least until the next millennium. I made a mental note to enlist a copyeditor (or at the very least a proofreader) when writing my epitaph.

The pithy sentiments on the benches made me rage. The last thing I wanted was to be memorialized on an object on which a dog could freely pee. And no fake flowers with my adios. I wanted, I wanted—I stopped.

I had no idea what I wanted...and I didn't have a will.

Like most people, I knew what I didn't want. There would be no peel and stick bumperstickers recording my demise in Zapf Chancery script, or cheaply printed poly-blend t-shirts advertising a "Run for Eileen!" embellished with a cheesy logo of a lymphoma cell on the side of a running shoe. I'd have none of that.

I thought of my dad. He was eighty-five and visited the park daily. He used to have a dog, now he walked with a cane and a healthcare aid. I hadn't spoken to him in over ten years. I facilitated my parent's divorce after he beat my mother and made her drive herself to the hospital with a broken leg, while he slept off his drunken rage on the couch. He was seventy-four at the time.

I assumed he spent his days alone. I spent my days alone, as Tom had to get back to work. I might be eighty-five one day, tooling round the park

with a walker.

My greatest fear all those years before cancer was that I'd get sick. My second greatest fear was that I would die alone in rat-cat-mold-infested-second-floor apartment where I'd remain until my decomposing body smelled like Liederkrantz cheese. My dad seemingly wasn't too far off from that scenario, sans the second floor.

Thinking about death isn't pleasant, but if you're a planner, it can relieve anxiety. The passive aggressive plan would be to die and leave all the decisions up to the next of kin. Not having any children, I had no idea who that would be.

The simple solution was to ask Johnny Kelley. He seemed to like his bust and presided over the park in death as he presided over the Boston Marathon in life—with a sharp wit.

"Johnny, what do you think I should do?"

"Skip the sticker and the 5K. Tell them to make you a water fountain. Always stay hydrated."

Not so easy to do if I'm cremated, I thought.

I went back to the parking lot to find Coach Joe. He'd want to get some coffee. My dad's car was parked in the handicapped space. The water fountain sounded useful. I remembered the melphalin, but my brain wouldn't let me remember the pain. I kept walking.

eleven

Subway Tile

Our first-floor bathroom has a shower stall lined with subway tiles. I've never been a fan of subway tile, as I grew up with the real thing. My grandfather was a tile setter, who adorned the Scarsdale homes of silent screen stars with intricate geometry until the Depression put him out of business. As children, my mom shuttled my sister and me on big trips downtown to Manhattan. She'd parallel park the Beetle on Jerome Avenue in the Bronx and we'd ride the #4 train down to Grand Central Station. My mom, always the adventurer, took us to the Automat. A hallmark of the age of convenience, the Automat was a cafeteria where all food, sandwiches, soups and the like, were obtained from vending machines. By the 70s, it was an exercise in nostalgia. Afterward, we'd sail around Manhattan on the Circle Line and then take the subway back up north to the Woodlawn station and head home. I love trains to this day and become a zombie while aboard. Watching the stations fly, by my eyes focus on the tiles. I watch until the rectangles disappear into a white blur and then to black. Symmetry has a somniferous effect on me.

Our first-floor shower didn't get hot enough. It didn't need to be lymphoma hot, but self-care warm would have been acceptable. Early in my cancer ordeal during the limbo between Dr. Nussbaum and Dr. Barnes,

the pain in my lymph nodes became so intense that heating pads and electric blankets weren't enough. Searing hot water and lie downs in front of the propane stove in the dining room were the only way I could relieve the pain. Near the end of treatment, I accepted the limitations of my hot water heater and showered in water of less than optimal temperature.

In the stall I'd place my palms down on the tiles and pull my chin to my chest and let the water run down my neck. So much had changed. The excruciating cancer pain was a memory. I'd close my eyes and watch a Super 8 of my misery with scenes accented with empty brown bottles of Oxycodon. Reinvention is the future, I kept telling myself, clueless as to what that meant.

One time in the shower, I saw a single hair stuck to the subway tile. It formed a swashy letter "C." I gasped and dragged my hand across my bald head. My palm was clean. I checked again with both palms to be sure; still clean. I scraped up the lone hair with my nail and rolled it on the end of my fingers: ash brown. A quick scan of the floor revealed a weave of single strands twined around the drain. The hair was longer and lighter than mine. How long had Tom's hair been falling out? I've heard of sympathetic breast cancer, but sympathetic chemo seemed extreme.

I was starting to grow my hair and Tom was shedding his. Now we were really starting to look alike.

I'd met Tom thirteen years earlier when I joined a running group at Johnny Kelley Park. Coach Joe separated us into three groups: beginning, intermediate and advanced. Tom had been held back and was taking the intermediate session over, and I was assigned to the same group. Intervals and speedwork were the backbone of Coach Joe's method. We all took turns running around the trail, speeding up, slowing down, speeding up. We were mediocre but competitive. Trying to outrun each other one sedate 9-minute mile after another. During our final session, Tom showed up in plaid pajama pants and a wool sweater. He became clammier with each lap. At the end of

class, he stood in a stream of sunlight. The steam shot off him, swirling and disappearing above his matted head.

"Cotton kills," said Coach Joe.

Tom and I have been together ever since.

The MGH interior design team has an inclination for subway tile. I think of my grandfather every time I wash my hands. Emerging from the ladies' room after my latest CAT/PET scan, I looked around the waiting area for my boyish, ash-headed beau. I saw an old guy with bad posture huddled over his phone. Where's Tom? I looked again and saw my graying man look up at me with a big, wide smile.



twelve

Stockholm Syndrome

Amy has a theory. Not only are patients lulled by the predictable rhythms of cancer therapy, they also come to form strong bonds with the medical staff who stick poison in their veins and hold them captive. Like zombies, we willingly let nurses hook us up to IVs teeming with toxic chemicals and cheerfully ask about their kids' summer camp.

Months into treatment and confinement I started to identify with my kidnappers-doctors. When I returned home after my final hospital stay, I was unmoored without a clear regimen to follow. On some level deep inside my brain I yearned for the repetition of my care plan. I hated hospital food, but missed the routine of filling out the menu forms. I dreaded each stay, but looked forward to mornings when the nurse entered my room with a smile and wrote down my daily agenda on the white board. I sat on the bed and obeyed. The caregivers I met in the cancer center seemed like part of my social circle. When I didn't see them anymore, I became lonely and depressed. Amy theorized that we were both suffering from a kind of cancer-treatment induced Stockholm Syndrome. I think she's right.

In 1973, four hostages were taken during a bank heist in Sweden. Over time the hostages became attached to their captors and refused to testify against them in court. The irrational emotional and psychological bonds

the hostages formed with their kidnappers is now known as Stockholm Syndrome. Its name a shout-out to the city in which the robbery occurred.

Even after a full year of cancer freedom, I still think about the hospital every day. In a recent conversation with my friend Lynne, she told me she felt dumped by her oncologist as he never returned her calls. More than once I've found myself having imaginary chats with Dr. Barnes about what to make for dinner or which Cape Cod beach has the best snack bar (it's Kalmus). The hospital was a purpose, a job, and a familiar, steadfast friend. It bustled with activity and hope. My post-treatment life was empty and aimless. No one sent cards anymore. I'd crossed over to the "well" side, but my brain remained stuck on the ninth floor of the Yawkey Cancer Center.

At home I waited for my studio phone to ring and checked email every five minutes. Team Lymphoma had moved on to other patients and the intricacies of their own lives. I was still in the same crappy office chair with a new set of circumstances to navigate. I wasn't the star patient anymore. I was an out-of-work, middle-aged dinosaur at the outset of a second life. Gratitude was replaced by fear and nagging anxiety. My new schedule is punctuated with appointments with the oncology social worker and the psychiatrist.

The transition to patient was easy: I was told where to be and what to expect. Adapting to life without directives has been one of the most difficult challenges of the post-cancer world. Every day I get dressed, and work on the construction of a new self. There are times when I want to stay in bed and let the day pass over me. I try to shift my focus from loss to renewal.

It's time for Sam's walk.

thirteen

Walking with Sam

In late August on Cape Cod the mornings become cool and gray. I wake up early. In the dark I put on long pants and a fleece vest. I cue up my medications, fumble around the kitchen for Sam's leash and out we go into the stillness. We walk through foggy bogs, along offshore roads, and down quiet side streets. August is a month of transition, when the college students return to ivy and brick buildings, and their parents return home to neat lawns, suits and salaries.

The swallows fly south. I tread in place.

Each September I die a little with the summer. It's a soft death, atomic. Tiny pieces of the younger me shed and float away. As an artist I reinvent myself through pictures, found images, objects and collage. The self needs constant reinforcement and the company I keep confirms my existence. Sam jangles his collar and points his majestic nose toward the view trail. We adjust our direction. My dog knows where he wants to go.

During the first two weeks of September, I mourn the flight of the sweet season and the summer girl in flip flops I used to be. I'm gray. I'm bone. I'm Lazarus.

In my ideal death, I quietly float away. I exhale and dissolve into the sea breeze. It's bright and I finally get to see my house from the air.

Hunting season opens in October. Sam and I will be wearing orange.

Forgetfulness is a daily occurrence for me, now. I lose keys, forget my shopping list, I make multiple visits to the store. Last week I went back three times, once for bread, once for bananas, and once for laundry detergent I already had. Recuperation is humbling.

Amy says cancer made her old. On the two-year anniversary of my diagnosis, I now understand what she means. On the Cape, the new season arrives in the nights just after Labor Day. Like a light switch summer is off and autumn is on. The summer becomes a collective memory of pictures of our younger selves and the fall, our future, nudges us one season closer to death. Those pictures don't exist yet. But we rise on that blue day. We meet our natures and our fates, and work with the materials at hand: shorter days, falling leaves, an indifferent ocean. The years of treatment have made me flat, unaffected. I laugh less, worry more. My voice is slowed by a brain dowsed with chemicals, drained and left to dry on the clothesline next to the garage.

Sam and I stop and listen to the wind.

Our time is marked with unpredictable shifts and migration, and the Cape is no different. The tourists see us as an outpost of quaintness, not the land of unrest we really are. In our towns, small seaside cottages are torn down and monstrous trophy homes emerge from the broken ground. Native plants, pines and scrub, not to the liking of seasonal owners, are razed and high-maintenance lawns and privet take their places. Every weekend in my neighborhood we are subject to an hours-long cacophony of weed wackers, mowers, trimmers and blowers; an asynchronous symphony of dissonance. We have opioids and heroin. We have daze. We have clarity.

The native grasses and flowers loved by summer visitors become green menaces, once they purchase a year-round, seaside home. As a lymphoma-free person I find this curious. The yard must be managed, cataloged, raked, and bossed around until it becomes the twin of the yard left behind in Duxbury, Scituate, Greenwich or Westchester. The Cape has become a floating suburb by the sea. On our walks, I inspect the damage that's been

done, scowl at discarded nip bottles on the side of the road and turn my nose away from the smell of fertilizer and Round-Up.

The yards grow contradictions and I see statements in the plantings: we want what we don't have. We want what others have. We want what no one else has. Or we have no idea what we want and plant a shrub and put out a lawn chair. The tedium and time put into landscaping is one the great perplexities of the seaside home. I read yards like tea leaves and foresee my neighbors' dreams of green grow into purposeless plants and leafy ornaments: needy, useless and utterly unsustainable.

Not unlike myself.

This is a nostalgic time of year when every loss becomes more pronounced. I'm now cancer free and suddenly without intention. When you become sick the disease is your job and like most Americans, we become what we do. I'm a patient lacking a diagnosis. Sam and I turn a corner and walk down another street of empty gray houses. I count my losses. Numerous. I count my coins. Few. I count my pills. Many. I count the children I never had. I tally those who are dust. My new body, the latest model, is a gift. It gets hungry, it sleeps, it craps, it cries, and it loves. It listens to me most of the time. It does everything the old model did but not as well. It feels like I'm wearing a pair of three-legged pants.

We head down a woodland trail, the last leg of our walk. The new model rumbles and grumbles and I duck behind some scrub oak. I've prepared myself for these moments, as they've become frequent. My breakfast behind me on ground, I double scan for poison ivy and scoop up my mess with an extra dog bag.

This is the body I have now. It throws the baton but misses the catch. It forgets the words to songs and names of good friends. I well up with guilt over the unspeakable things I've done to it. I hated you, but I loved you, too.

A man walks toward us on the path. He's smoking. Who smokes anymore? And who smokes in the woods? He stamps the butt out in the middle of trail and bids us a good morning.

Dumbass, don't you know those things will kill you...and me?

I pick up the butt and put it in the poop bag. It's nearly 7:00 and time to get home and figure out who I'm going to be today. Which hair am I? Which character? What personality can I vacuum into my own. I'm an actor, a shiny new understudy. But there's possibility in loss, activity and reinvention. And the inevitable growth that springs from filling a void. Every day I take the empty and fill it with something new, and you must do that, too. Like a shark I keep moving forward. I run faster, now. I'm a bald opportunist and tell my story to anyone who'll listen.

A landscaping truck passes us on the crest of hill, and like that, we're on the other side of our loop. I can see brownish tops of the hydrangeas in our front yard. Sam quickens his pace.



