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Selections from Inventions in the Key of C

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FLORIDA STATE UNIVERSITY
COLLEGE OF ARTS AND SCIENCES

SELECTIONS FROM
INVENTIONS IN THE KEY OF C

By

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To the staff and my fellow alumni at the February 2003 Life and Living Program. I think of you often.

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ABSTRACT

Selections from Inventions in the Key of C is a collection of essays about cancer and issues related to cancer. Books on the topic of cancer are plentiful. There are a number of narrative memoirs including *The Red Devil*, by Kathryn Russell Rich, and *It's Not About the Bike* by Lance Armstrong. In the self-help/inspirational area are numerous books ranging from nutrition to positive thinking to navigating the practicalities of living with cancer; I believe I have noticed on the bookstore shelves *Cancer For Dummies*. Susan Sontag's *Illness as a Metaphor* looks critically at how cancer, and people with cancer are perceived, as do significant portions of some thoughtful memoirs, such as Arthur Frank's *At the Will of the Body*, and Ken Wilbur's *Grace and Grit*.

This work in its present state might be most closely compared to another collection, Anatole Broyard's *Intoxicated by My Illness*. Broyard, in a series of essays and journal entries, entertains a number of subjects related to his cancer: from the nature of illness, to relationships with doctors, his friend's reactions, and his thoughts on other illness-related literature.

While I believe that some of my essays will stand alone and be of interest to literary readers, it is my feeling that the eventual work will appeal to an audience that is in both broader—comprised of people who read popular literature--and narrower—those who have an existing interest in cancer. The essays in this collection range in style from the personal with small amounts of information embedded in the conversation, to the journalistic merely accented with a personal sensibility. This diversity was deliberate.

In terms of process, the “journalistic” pieces marked the greatest departure from my previous work and proved to be the most challenging, perhaps because in my preparation I did not find models specifically for this type of writing, which would perhaps have revealed strategies for balancing dense information and tone. For the future, I would like to spend more time reading authors who successfully present specialized material to a lay audience, especially with a first person point of view.

Further development of this work would definitely include a concluding section for “Sure it's Killing Us,” and I would also like add a few more personal essays for the purpose of balance. Here are some ideas:

A speculation (humorous) on how the 1960's television series, *Star Trek* might influenced my core beliefs about gender roles and the universe, and ultimately contributed to my “cancer personality” (“*Star Trek Gave Me Cancer*”).

A humorous/confessional essay about my “celebrity cancer curiosity,” perhaps incorporating results from an informal survey of other cancer survivors and their relationship to celebrity cancer in the news (“But I'm Not a Stalker or Anything”).

A personal experience/information piece about Buddhism, studies in mind-science and the pros and cons of meditation (“How Cancer Made Me a Quasi-Buddhist”).

INTRODUCTION

There is a point in the cancer journey, when the panic of being diagnosed has subsided, the initial frenzy of “treating” the cancer—in whatever form that takes—has subsided; a point at which the necessary focus on self--that has been an emotional reflex and also required for the myriad logistics of planning, scheduling shopping, meeting doctors and negotiating with insurance companies—can begin to soften. It was at this point that I began once again to look outward. I found in myself the desire to see my experience in a larger context, to examine how it fit in, question what it might mean, observe how it had changed my perceptions.

And at the same time, however that my mind enjoys following its flights of fancy, tangents about language and constructing my own narrative history, I am also ever aware that such entertainments are predicated first on survival. Thus I have a strong and ongoing interest in developing best practices to support that survival. Philosophical questions exist closely intertwined with practical considerations.

This is the case for me, and though I don’t imagine I speak for every cancer survivor, conversation and experience lead me to believe that my thoughts and reactions are not too dissimilar from numbers of people who have been faced with a similar experience. There are a lot of us just trying to find our way through a new, treacherous though interesting landscape. If I manage to wander down paths that are still largely unworn, then I’d like leave some markers, tie scraps of fabric around a few trees, in the hopes that those who come after will be able to look even further a-field.

In the end, I found that I have written these essays for myself, but I hope also for anyone who finds him or herself in similar places. I wish us all the best of luck on our journeys.

LUCK, STATISTICS, MAGIC

Luck

I must have been about eight when the toy store at the mall held the prize drawing. The large stuffed animals were displayed in the middle of the shopping center. Above, a plush gorilla hung from a green plastic vine. On the floor below stood a menagerie of almost life-sized creatures—lions, tigers, zebras and camels—in a jungle of paper grass and polystyrene trees, all cordoned off with velvet rope. This was the late seventies, before the advent of food courts, but during the heyday of a restaurant called Orange Julius. It was probably fear of sticky orange fingers that inspired the rope, which, combined with certain pictures from Sunday school, left me with the odd impression that I was looking through the guardrails to the deck of Noah’s ark, retro-fitted with fake grass.

When my sister, Moira, and I told my father we intended to win an animal, he said, “Well, sometimes you have to make your own luck.” Taking his words to heart, we talked our mother into bringing us to the mall three times a week. We left her by the sales racks at Sears or JC Penney’s while we moved methodically from Claire’s Boutique to Spencer Gifts to Merle Norman Cosmetics, asking for entry forms. Moira, in her yellow t-shirt with the shooting star appliqué, hair in messy red ringlets, tummy forward in an unselfconscious pooch. Me, already beginning to suck in my stomach, to sneak looks in every mirror, to constantly assess the breadth of my ribcage or the shape of my nose.

If asked, a clerk would sometimes give us more than one entry, and after a while, many stores simply left the pads of forms by the register. “Let’s take the whole thing!” my sister said the first time we encountered an unattended tablet. Although two years younger and shy with adults, she was more fearless than I.

“No,” I replied, “we can take two each, or three.”

“How about four?”

It was hard for me to break the rules, even those unstated, but it was also difficult for me to displease my little sister. Checking to make sure the shop attendant was helping

a woman in the dressing room, I slid my thumb under a larger portion of the stack and tore off a thick group of pages.

Back at the center of the mall, we sat on a bench filling out handfuls of entries. Our dad had explained folding the papers in half would form a V-shape that would float to the top of the others. Considering this, we decided it would be even better to aim for distribution throughout. We folded some into quarters, others into tight, small stones intended to entice someone's fingers if they grazed the bottom of the box; we folded triangles, rolled cigarette-sized scrolls, pleated paper accordions we hoped would lodge themselves at every level. Finally, we crumpled some into balls, though I worried this might be against the rules.

**

It's after five in the evening at the Familial Research Centre in Melbourne, Australia. It is February 2004. Two months have passed since my 34th birthday, my diagnosis of colon cancer, and subsequent surgery, all of which occurred in the same weeks of early December. The surgery involved removing a fist-sized tumor, along with a section of large intestine. The scar, still red, runs the length of my stomach, from the little hollow between my ribs to just above my pubic bone. I've coordinated this trip to Melbourne from our home in Alice Springs with a number of follow-up tests: PET scans, blood draws, and X-rays. The tests have come back clear, with no evidence of disease. Such results were expected, but still, in their wake I feel lighter, unburdened, almost powerful in the knowledge that the difficult part of my journey is behind me.

It is only by chance that the results from the genetics lab have arrived during my visit. Because I am flying back to Alice Springs tomorrow, the doctor has agreed to see me at the end of his day. The Familial Research Centre stands apart from the hospital and its twenty-four hour activity. Here, people go home at the end of the day, and most already have. The doctor, the counselor, and I seem to be the only people left and we remain in the lobby area, which is carpeted and furnished with cushioned chairs and a loveseat positioned around a coffee table as if we are in someone's living room.

Statistics

Our mall was the biggest in the area, a social center. People traveled from smaller towns on Friday nights to walk around: couples on dates, families, groups of teens. The animals, along with the ballot box, were on display for a month. If one of these weekly visitors had completed two entry forms each Friday, he or she would have had eight entries in the box by the Sunday of the prize drawing. A more frequent or ambitious shopper might have submitted as many as two dozen.

My sister and I had made three visits to the mall each week for four weeks, covering at minimum thirteen stores per visit, averaging three entry forms per store.

We had placed 3 x 4 x 13 x 3 forms in the box. So, approximately 548 entries. Each.

**

At the Familial Research Center, the doctor recaps the situation: Colon cancer in one's early thirties, if considered a random event, is statistically improbable. But, because my father has had cancer in the past, not once, but several times, we've suspected mine is not a random event, and so I had agreed before my surgery that my tumor would be tested. Now, he explains, they have searched the tissue for a certain protein usually emitted by a gene, labeled MSH2—one that plays a primary role in the body's ability to recognize and defend itself against cancerous cells. He says they did not find the protein, and that its absence indicates that my MSH2 gene is defective, probably the result of a mutation, probably hereditary. I have a condition called Hereditary Non-Polyposis Colorectal Cancer, or HNPCC.

The doctor explains how in the general population, a person's chances of having some form of cancer before the age of 75 is 5%. For someone who has HNPCC, these statistics differ.

Chances of having colon cancer: 80%.

Uterine cancer: 42-60%.

Gastric cancer: 10-20%.

Ovarian cancer: 10%.

Sitting on the sofa, the doctor tells me not to worry unduly—but since I’ve elected to keep a portion of my colon, I should have frequent testing, and if I’m thinking of children, I might want to get to it sooner rather than later, and once I’m finished, have a hysterectomy, which will significantly lessen my chances of having uterine cancer. He’s sorry but he needs to go. If I have any more questions, I can ask the counselor. I should have a nice weekend.

Luck

The drawing was on a Sunday. We had written the time on my mom’s Girl Scout calendar above the phone in the kitchen. Before he went out to get the car, our father kneeled down beside my sister and me. “Now, do you understand that one of you might not win? In fact, both of you could come home empty-handed. Are you going to be okay with that?”

We nodded our understanding, waiting for him to rise and go out to the car, waiting for the long minutes to pass between this moment and the one where we would be at the mall, winning.

At the mall, a small crowd of people stood around the platform as the man from the toy store drew slips of paper from the box. Each time I watched his hand, trying to see if he was holding one of our signature folds, but from several yards back they all looked the same. In the moments before he called each name I felt both the thrill of winning and a disappointment that was greater in my anticipation than in reality. Each time a stranger was awarded a lion, then a snake, then a one-humped camel, I simply turned to the future, to the next name, waiting. And then it was. My name. The centerpiece gorilla, hanging from his vine, was mine.

“Wow. She really won,” said my mom.

In the years since, Moira has told me that, at the age of six, she was so overwhelmed by the heart-pounding excitement of my win, she didn’t care if she received a prize. I, however, recall waiting for her name, if not with the same need as I had waited for my own, still with an instinctive conviction that if the world were fair my sister and I would share the same fate.

Walking to the parking lot after the drawing, my father carried Moira's two-humped stuffed camel that stood taller than she did. I had the gorilla over my shoulder, folded at the waist, its mitten-like feet knocking against my kneecaps.

"Well," said our mother, "You're certainly both very lucky."

**

Outside the Research Center, it is still rush hour in the Melbourne streets. February is summertime, and the sun has another hour before it will slide suddenly below the skyline. My husband, Paul, is still on a plane from Japan to Alice Springs, out of phone range. The evening is my own. Maybe I walk around. Maybe I eat, or see a movie. It seems for several hours that I carry the weight of my news gingerly, that I refrain from pressing on its mass, from exploring the shape of my fears. I don't think of my father whose periodic episodes of cancer have dotted the landscape of my family's life for thirty years. I don't picture his stomach, so crossed with scars he could be a roadmap—the unscarred flesh bulging like hills between the inelastic roads. I don't play the game where I weigh my fear of ugliness against my fear of pain. I don't contemplate lying in bed next to Paul without my uterus, without the feeling of it contracting when I have an orgasm. I sidestep memories of my friend telling me that after her hysterectomy, sex brought no pleasure, how she has periodic nightmares where her husband leaves her, waving as he is driven away on the back of a bus. It is not until much later that night, in my hotel room, that I burst into tears. My sobs activate abdominal muscles still recovering from being cut, producing a deep ache in my belly.

Statistics

For years, statistics were the bearers of love and self-esteem. I loved standardized testing like a competitive runner loves a race. There was a thrill to seeing the Scan-tron sheet hit my desk, filling in the ovals that spelled my name with a sharp number-two pencil, then waiting to begin section one. The computerized printouts that arrived in the mail a few months later brought good news. They told how many ovals I had correctly filled in. They listed the percentage of people who had not correctly filled in as many ovals as I had. I aced the Iowa Test of Basic Skills. My PSAT scores made me a National Merit Scholar, of which my father informs dinner guests to this day.

My only unpleasant encounter with statistics was my sophomore year of high school, when I had to take a required class on the topic. Fortunately, this experience was made significantly less painful because I was able to sign up with my friend, Amy. It was our only class together, and her family was moving at the end of the school year, so we dedicated ourselves to making the most of our time together. While the teacher drew a Bell Curve on the blackboard, underneath our desks we traded one of my olive-green socks for one of Amy's peach ones. Then we traded my left navy blue Chuck Taylor canvas hi-top for her black one, and wore our mismatched apparel for the rest of the day, drawing pictures for each other in ballpoint pen on the rubber toes of our shoes. The weekend I stayed over at Amy's house to complete our project on binomial probability, we invited our friends and drank *Hot Damn!* cinnamon schnapps while singing along with the Violent Femmes. In the early morning's purple glow, still awake and still a little drunk, we walked her paper-route.

Due more to test taking ability than skill, I managed to traverse the remainder of my academic career without ever taking another math-related class. I graduated from Indiana University in 1992, the same year that scientists discovered the human MSH2 gene at the Dana Farber Cancer Institute in Boston. As a polite and likeable girl, I would have nodded pleasantly had someone told me this fact; I might have feigned interest for a few seconds. I had a lot of things on my mind. I was packing my books and clothes into plastic Yaffa blocks. I was updating my résumé and taking my car to be serviced. I was calling friends, confirming a place to stay in Chicago while I looked for an apartment. My whole life was just beginning, and scientists in Boston had nothing to do with me.

Luck

In the Chinese story, a man has both a son and a horse. One day, his horse runs away, and his neighbors feel sorry for him. "Oh, what bad luck for you," they say.

But the old man says, "Maybe so, maybe not."

The next week, the horse returns, bringing another horse with it. "You are very lucky!" say his neighbors. The old man says only, "Maybe so, maybe not."

The old man's son likes this new horse very much and undertakes to train it, but one day, he is thrown from the horse and breaks his leg. The villagers tell the old man, "That is bad luck."

The old man responds, "Maybe so, maybe not."

Soon after this, there is war in the land, and all the young men in the village must join the emperor's army, but because his leg is broken, the old man's son does not have to go. "Ah, you are very lucky," the villagers tell the old man.

He says only, "Maybe so, maybe not."

**

In addition to winning the stuffed gorilla, I once found a dollar bill on the sidewalk; I have twice let the parking meter run out and not received a ticket (although three times I have been ticketed); and in the seventh grade, I was caller number eleven on the radio and won free passes to a Styx concert. Because I loved the song "Mr. Roboto," this was very lucky. However, the concert was on a school night, and my mom wouldn't let me go, which was less lucky. I put a sign on the bulletin board at the college where my dad worked and sold the passes for twenty-two dollars, so maybe that was lucky—though I would have preferred to go to the concert.

Magic

At the time of the stuffed animal give-away, Moira and I were both experienced practitioners of magic. We constructed impenetrable force fields around our croquet balls by circling our mallets over them and humming. Playing Monopoly, we incanted over the dice to prevent any number that would land us on Boardwalk, and if that happened to fail, we cursed the rent money before handing it over. When our little brother tried to hunt us down during hide-and-seek, we would cast spells, making ourselves invisible until, unable to find us, he started to cry, and our mom said it was unfair to use our powers against him, since he was only three.

At the mall, we put our skills to use. We blessed every entry and traced ceremonial shapes in the air with each slip of paper before dropping it into the darkness of the ballot box. We focused our powers on the animals we hoped would be ours—I had

my eye on a smooth black panther, sleek and graceful as I dreamed of being—until our mother came to meet us.

Statistics, Magic

During World War II when hospitals and battlefields suffered morphine shortages, medics substituted saline solution for the drug, and, as long as the soldiers were unaware of the switch, they reported a decrease in their pain. Many subsequent studies have shown that, depending on the illness, the placebo effect will take place in 30% of people tested, sometimes ranging as high as 70%.

The converse is also true. A “nocebo response” occurs when a person has a negative response or side effect based upon suggestion. In one experiment, when volunteers were told that a mild electrical current passed through their heads might give them a headache, two-thirds of them developed a headache even though there was no electrical current. In an unrelated study, women who believed that they were prone to heart disease were nearly four times as likely to die as women with similar risk factors who didn't hold such fatalistic views.

Much of modern medical science is based on the view, popularized by Rene Descartes in the 17th century, that the body and mind are separate entities. This would seem to rule out the possibility of healing through belief, yet, in experiment after experiment, the 30% who succumb to suggestion imply that this is not the case. Pharmaceutical companies testing new drugs make elaborate arrangements to control for placebo effect, and the successes of alternative health treatments are often dismissed for the same reason. *It only works because people believe in it.*

This begs the question, *if it works, then isn't belief enough?*

If a woman who believes she is prone to heart disease is four times as likely to die of that affliction, what about a woman who believes she is prone to multiple forms of cancer? By *believing* I am destined to have cancer, am I *increasing* the probability that this will be so? If I could believe otherwise, could I *lessen* that probability?

Magic

Magical Thinking: The conviction of the individual that his or her thoughts, words, and actions, may in some manner cause or prevent outcomes in a way that defies the normal laws of cause and effect.

In 1975, Ian Gawler, a 24-year-old man living in Australia, had his right leg amputated due to osteogenic sarcoma (bone cancer). He was told that if the cancer reappeared, he would likely die within three to six months. It did reappear, and by March 1976, his specialist thought he had two weeks to live. In June of 1978, Ian Gawler was declared free of cancer. What happened in the interim? He tried, by his count, twenty-seven kinds of healing techniques, including the Gerson juice diet, visiting psychic surgeons in the Philippines, and traveling to India to see Sai Baba. He meditated five hours a day. He never stopped believing that healing was a possibility. Bronwyn Stewart was a nurse who refused surgery for ovarian cancer. She embraced naturopathic methods and watched her test scores fluctuate for ten years before she was declared officially cancer-free.

In February of 2004, after receiving my clear test results, I drive from Melbourne to the Gawler Foundation in the Yarra Valley and spend a week hearing what Ian Gawler, Bronwyn Stewart, and others like them have to say about getting and staying well. They are convinced that how we think can affect our realities. They can hold out their lives as evidence, so I believe them. By the end of the week I am floating on a cloud of certainty that I can prevent my cancer from returning. But in the office of the genetic counselor, the cloud disperses with the dawn of a new realization: Believing in the power of belief and actually believing are two very different things. I fear I have lost the knack.

**

I recognize the little girl as my younger self. She is sitting on the front steps of our old house in Indiana weaving a potholder on a plastic loom. She seems to know me as I approach, asking, “Do you want to count love bugs? I get orange.”

I look out at vinyl-topped sedans and side-walled station wagons passing in the street. “Sure, I’ll take, umm...green.” Is this a good choice? I can’t remember the statistical preponderance of green Volkswagen Beetles compared to other colors.

“Why are you here?” she asks.

“I was hoping maybe you could help me do a spell.”

“Yeah, okay.” She squints to show she is thinking hard like her teacher does at school. “Hmm...what would be a good one?”

She leads me to the back yard, where we move the plastic wading pool, sloshing water over the sides as we go, uncovering a full circle of flattened yellow grass.

“Pick a bunch of these,” she points to some white clover scattered over the green lawn, “and tie them together. I’ll be right back.” She disappears inside the house.

I tie flowers into a chain until she returns. She lines the string of clover around outside of the flattened circle, tying the two ends together.

“We have a PERFECT circle. You have to sit in the EXACT center and not talk.”

I comply. She grabs fistfuls of clover heads, and brings them to where I’m sitting.

“First, the magical flowers!” She throws three handfuls of clover mixed with grass and stems onto my hair and clothes. “And theennnn...” she extracts from her pocket an oval perfume bottle wrapped in a red knee sock. She ceremoniously splashes me with faintly Jontue-scented water.

With all the ritual of a Japanese tea ceremony, she kneels and unwraps aluminum foil to reveal a mixture I identify as Cap’n Crunch Original Flavor, Fruit Loops, and Honeycomb cereals.

“Now you must eat three bites—and ONLY three bites, of this,” she commands. “It’s important to eat at least one of each kind—that increases the power.”

I dutifully chew, feeling the Cap’n Crunch scrape the roof of my mouth.

“You are now protected against cancer or anything else bad!”

“Thanks.”

She looks at me curiously. “Do you feel better now?”

I think I’m buzzing a little from the sugar in the cereal.

“Maybe.” This is the same diplomatic response I give after reiki, reflexology, numerology readings, and aromatherapy. I always want to feel different. I want my cells to tingle; I want visions. I want something to convince me that everything has changed and I don’t have to be so scared anymore.

“You have to super-believe,” says my younger self, as if she has read my mind. “I don’t think it works if you don’t believe.”

Statistics, Luck

As my doctor at the Familial Cancer Center pointed out, it is not uncommon for carriers of genetic variants of MSH2, or BRCA1/BRCA2 (the variant predisposing the carrier to breast and ovarian cancers) to have the suspect organs removed prophylactically. A friend of mine recently had surgery and treatment for cancer in one breast. If she is found to carry a BRCA1 or 2 mutation, her doctors are encouraging her to have the other one removed. Removing a healthy organ that may or may not ever become diseased might seem extreme, and yet, with a young daughter to raise and an 87% statistical probability of contracting the disease, can she afford to wait and see if she gets lucky?

Such a decision, on the surface, would seem to involve a simple weighing out of the numbers, a facing of the facts. But to even accept this method of making a life decision requires a number of underlying assumptions, the primary one being that where a person’s health falls in the statistical spectrum is random, unaffected by any number of potential variables. Stephen Jay Gould points out that statistical distributions apply only to a prescribed set of circumstances. Where is the statistical data that tells us something about the circumstances of the 13% for whom, despite their genetic predisposition, disease never occurs? Where are the numbers that identify what traits these people might have in common—factors such as diet, exercise, community, spiritual satisfaction, a sense of purpose? Is it possible that some combination of these could affect which numerical pile a person lands in, or is it all really just a matter of luck?

Magic(al Thinking)

One night during the writing of this essay, I enter the bedroom I share with my husband, to find, taped to the wall next to our bed, an index card with the words DREAM LOTTO printed in black Sharpie. This is Paul’s reminder when he goes to bed at night to dream of the winning lottery numbers.

Luck

A friend, who had a stroke when she was eleven, paralyzing one side of her body, tells me, “It took me a lot of years to accept it, but I don’t regret what happened. If I weren’t in a wheelchair, I wouldn’t be a writer.”

Many lottery winners have reported that their sudden wealth led to the dissolution of treasured relationships and even financial ruin.

The old man whose horse ran away knew it is impossible to see what chain of consequence might follow any single event. Yet, for most of us, it is hard to shake the conviction that the luckiest outcome, the one we should wish for, is the one that most closely conforms to our preconceived desires.

Had I chosen the results of the scan that diagnosed my cancer, they would have been clear.

My friend asks me “What about your cancer? Do you feel that because of it, you’re stronger and better as a person?”

**

Fun Quiz!

Do you agree or disagree with the following statements?

T / F: There is a mind-body connection.

T / F: A painful experience equals a “bad” experience.

T / F: Decisions should be made to minimize pain,
be it physical, mental or spiritual.

T / F: Life is chaotic and random.

T / F: Life has meaning beyond what we know.

**

I once attended a three-day lecture by the Buddhist teacher, Sogyal Rinpoche. In the course of the weekend, he mentioned that Tibetan Buddhist monks who were held prisoner and tortured by the Chinese afterward expressed gratitude, because in conveying suffering, their captors had assisted the monks in their journey toward enlightenment.

The Hindu mystic Ramana Maharshi said, “You thank God for the good things that come to you, but you don’t thank him for the things that seem to you bad; that is where you go wrong.”

Buddhist (and probably other) philosophers hold that there is little use in labeling our experiences good or bad, or ourselves as fortunate or unfortunate. What is important is that we use our circumstances, whatever they are, to practice compassion, wisdom, and equanimity, to become closer to our true nature. With practice, they say, we can learn to let go of our attachment to one outcome over another.

Statistics, Luck, Magic

Here is where I would like to wrap it up with some all-encompassing point, some formula for how it really works. But of course, there isn’t one—at least that everyone can agree on—and that’s why we’re always looking. And by we, I mean humanity: scholars, sages, scientists, priests, and as Kermit the Frog put it, the lovers, the dreamers--and me. We’re all addicted to causality. We’re all yearning for some control over our lives. So we look for meaning in the patterns—in the stars, the atoms, the numbers and the tea leaves. And if there is none, we impose it.

Depending on your source, people with HNPCC make up one to five percent of those diagnosed with colon cancer. I am part of that small percentage.

The five-year survival rate for people initially diagnosed with stage 3C colon cancer is 44%. Again, I am part of that lesser half.

At the Dana Farber Institute, a study of 850 people who had stage 3 colon cancer found that those who exercised most had a 55% higher survival rate than those who exercised least. Needless to say, I exercise.

A study of health insurance statistics of over 2,000 people practicing meditation over a five-year period revealed that meditators had fewer incidents of illness in seventeen medical treatment categories, including 55% less for cancer. So I meditate.

I also drink freshly made vegetable juices, eat certain foods and not others, abstain from alcohol, take enzyme tablets, and occasionally sing affirmations under my breath. For reasons statistical or anecdotal, I have chosen to do all these things, and in many cases, I have forgotten what my original reasons were, but I continue to do them.

My understanding of statistics has improved little since tenth grade. I can quote numbers, but I don't really know how being "X% less likely to get cancer than people who don't meditate, or exercise, or eat broccoli" factors into "80% more likely to get cancer than the general population."

Maybe I don't want to know.

Maybe that's because I like my illusion of control.

But there is more than that.

Not always, but sometimes, these rituals—originally performed out of fear of one outcome and desire for another—do actually transcend their original purpose. Some days I count my pills like prayer beads, stir my organic veggies with an awareness that I am honoring some connection between the universe and myself. The Buddhists might say I am coming closer to my true nature. Paul just says he's always known I'm a hippie.

I have even had fleeting moments of peace—a taste of what it would be like to let go of my attachment to outcome. Paradoxically, these brief moments do not lessen my resolve to beat the odds, but actually strengthen my belief that I can be one of the lucky ones.

Some might call that kind of belief magical thinking, but statistics show that it can make a difference.

October, 2003

Through the airplane window, the rust colored MacDonnell ranges came into view, alongside flat land peppered with small clumps of grayish-green spinifex and a few low trees. Almost immediately as our small craft touched down on the airstrip, both fore and aft doors were flung open, letting in the fresh desert air of Alice Springs, Australia, population, as one sign put it, 28,000 people, 100,000 sheep and 6,000,000 flies. Although Paul and I had just flown fourteen hours from our families and friends in Los Angeles, we were home.

THE C-WORD

“Well—I don’t like sayin’ the name if I can help it. No one does.”

“Why not?”

“Gulpin’ gargoyles, Harry, people are still scared. Blimey, this is difficult. See, there was this wizard who went...bad. As bad as you could go. Worse. Worse than worse. His name was...”

Hagrid gulped, but no words came out.

J.K. Rowling, Harry Potter and the Sorcerer’s Stone

Paul and I spent much of a year referring to my cancer as “the Voldemort,” after the villain in the Harry Potter books who is so fearful that even his followers decline to speak his name. It was just to be amusing, of course. In my family, where my father’s diagnoses with different cancers occurred with the regularity of presidential elections, I grew up using the word *cancer*, and had never noticed anyone else’s reluctance to do so. My first real awareness that anyone considered it a less-preferred word choice did not occur until high school, and even then not as a result of any event in my own life. While interning at the local summer stock theatre, I served as stage crew for Neil Simon’s autobiographical play, *Brighton Beach Memoirs*. Night after night I stood in the wings, holding plates of freshly fried Steak-umms which we used for liver and onions, as fifteen year-old Eugene eavesdropped on his mother and aunt talking. Each night, upon noting how their voices suddenly dropped to a whisper as they uttered the word, Eugene would turn to the audience and comment, “I think they’re afraid that if they said it out loud, God would say “I HEARD THAT! YOU SAID THE DREAD DISEASE! JUST FOR THAT I SMITE YOU DOWN WITH IT.”

But the play was set in 1937, and by the time I was diagnosed with colon cancer at the end of 2003, I assumed the world had moved beyond that. After all, thirty years had passed since *All in the Family*’s Edith Bunker startled the world by uttering the words “breast cancer” on prime time network TV. The popularity of pink ribbons had been on the rise since the mid-nineties; pink now adorned everything from high-end chocolates to household appliances. Numerous annual fundraising walks and runs had been established in the United States. In Australia, where we now lived, morning teas as cancer

fundraisers were common, accompanied by mugs and T-shirts encouraging us to “Have a cuppa for cancer.” Cancer was finally Sontag’s “just a disease,” no longer a fantastical villain such as Rowling’s “He-Who-Must-Not-Be-Named.”

So I thought until I noticed that acquaintances I ran into at the grocery store faltered midway through their sentences, “Hey I heard that, uh...that you weren’t feeling so well.” Now, when I look back to my childhood, I see that people were probably more circumspect than I would have realized. In the fifth grade when I said, “My dad has cancer,” the adults who approached me said, “I’m sorry to hear about your father,” not, “I’m sorry your father has cancer.”

As an adult now, I examine my actions and realize I do the same thing. It seems appropriate and respectful of people’s feelings to side step the specific nature of an illness. But what feelings, exactly, am I respecting in choosing an indirect approach? In dealing with a serious illness there is the sheer emotional weight of fear or sadness or anger or any combinations of these that someone might prefer to confront at certain times or confide to certain people. Treading lightly is a way to respect those wishes and to allow people who can’t control their illness to at least have some control over how they react to it.

At the beginning of my cancer experience, when Paul and I noticed how gingerly the topic was being handled, we assumed this was the only reason. We assumed people were acting in deference to our feelings. Since we assumed it was all about us, we felt we could set an example by being open about my illness, and unafraid—if not of the disease then at least of the topic. During our time abroad I was in the habit of sending an email newsletter to family and friends back home, and so before we traveled to Melbourne for my surgery I composed one titled, “Not Good News,” and sent it off. We wanted to let people know they needn’t worriedly whisper behind our backs while offering us only cheery words or fake smiles. We tried to counteract the reticence we sensed in our friends by being as open as possible, hoping to be part of the conversation, instead of just its subject.

I hadn’t yet taken into account how my illness and my “honesty is best” policy might affect other people. One friend confessed that receiving my emails had awakened all kinds of anxieties in her about her own health, resulting in several doctor’s visits and

even some counseling. Some friends I had been corresponding with occasionally for years before my illness I did not hear from again, whether through natural attrition that coincided with this time period, or because thought of being made witness to the possible progression of a serious illness, even via group emails, was too much. One group of friends I had known from working in event production in Los Angeles did not write individually, but elected a representative—Joe, a professional writer of skits and speeches for corporate events. I could easily imagine the conversation that provoked this, where my friends had doubtlessly chastised themselves for not responding and, at the same time, complained they “didn’t know what to say,” before arriving at the brilliant idea of having the company wordsmith compose something appropriate on their behalf. The email arrived some months after my announcement, at a time when I already considered myself well out of any immediate danger. But I could hardly blame them for their reticence. By then I had begun to recognize that although I was comfortable “being open,” not everyone shared my sensibilities. I had also realized that most of the details I’d written after the word “cancer,” had made little impression in the wake their predecessor. My upbeat optimistic tone had been interpreted as whistling in the dark. These friends were struggling with words because they thought I was dying.

I believe that most of my friends in Australia, who could see me looking fairly robust, were, in fact, happy to hear about my progress, but weren’t always quite sure how to broach the topic. The week after my diagnosis, we made the three-hour flight to Melbourne to have my surgery done at Peter MacCallum—a well-known cancer center. We spent our first night in the city with our friends Peter and Vida. Peter and Vida were neat and well-ordered people who seemed to sweat less than us on a dance floor and their home seemed to match them, tidy and artistically furnished with Roseville pottery and deco-era furniture. Their new white and brown Scott Terrier, Hildy, fit in perfectly. We passed some time allowing her to amuse us as we figured out how best to delve, for the first time in our friendship, into health-related topics.

“So you’re at hospital tomorrow. Which one? He leaned forward as Hildy reared to her hind legs and balanced. Up, up! There’s a good girl.”

“Oh! She’s so smart! Yes, Peter MacCallum. Have your heard of it?”

“Aww yeah! Peter Mac’s got an excellent reputation. Vida’s mum had a friend who went there...” Hildy dropped to all fours and rolled once. “yes she’s very clever, yes you are...” Peter gave her a treat. “so, um, what do you know so far?”

“Well, it’s cancer.”

W. E. B. Du Bois writes in *The Souls of Black Folk*, “Between me and the other world there is ever an unasked question: unasked by some though feelings of delicacy; by others though the difficulty of rightly framing it. All, nevertheless, flutter round it.”

In Peter and Vida’s living room, we had to take a few minutes to flutter round it. For them to ask too quickly, “Tell us everything about your life-threatening disease,” risked them looking like a curious vulture, while for me to say, “Want to hear about my cancer?” seemed rather presumptuous and self-involved. So we had to reach the topic round about.

Once we had we moved through the barriers of social niceties we ended up having a good talk, which continued as we met our friend Wendy at a restaurant for dinner later that evening. But then, when all our friends’ questions had been asked and answered, there was another lull. What do you say when you are thinking about something, but you’ve used up all the standard conversation?

“Gee, my food is really beautiful, how’re your curries?”

“Good. It’s a good restaurant. Service was a bit slow though.”

“Yeah.”

It was as if a lacquer of politeness had been poured over everything and solidified. I just wanted to puncture it. We moved to a nearby café, and decided to share a dessert. I pointed at a chocolate cake in a long glass display case. When Paul wasn’t entirely enthusiastic, I responded with a mock passive-aggressive tone, “Oh, well don’t feel like you should do what I want, just because I have CANCER!”

Peter rose to the occasion. “It’s true, since she has cancer, I guess we’ll *have* to help her eat the chocolate cake.”

At the table, as someone offered me the last bit since I would soon be fasting in preparation for surgery, Paul rolled his eyes, “Cancer, cancer cancer, why is it always about cancer!” an homage to the famous ‘Marcia, Marcia, Marcia’ line on *The Brady*

Bunch, when younger sibling Jan laments all the attention given to her older sister, Marcia.

Paul and I cracked ourselves up.

Peter, Vida and Wendy exchanged glances and smiled their appreciation at our antics, and we were pleased enough with ourselves not to notice if their smiles were real. I assumed their subdued reactions were probably due to lack of sufficient exposure to *The Brady Bunch* during their Australian childhoods. I didn't understand yet about gallows humor, how by its nature it is inherently exclusive. In the same way that most of us relegate the privilege of telling jokes that use certain racial epithets to black comedians, the realm of cancer humor is pretty much owned by those directly affected by it, and other people are unlikely to feel comfortable chiming in. As one comic with AIDS once noted, his jokes were not making fun of people with AIDS but laughing about his own life. Since that life is not mine, however, I might be reluctant to throw back my head and laugh if friends joked about it over coffee. It is ownership of hardship that gives you the right to laugh.

Scenes where people unwittingly make others uncomfortable make me cringe at the movies, and in memory. Looking back now at the five of us in the café, I wonder if it was more awkward than I realized, if our comedic forays held for our friends a tinge of frenetic desperation. I wonder if they enjoyed the evening, or gamely held on through it. But it was early days. We were only in our late twenties or early thirties, not an age that has normally provided experience with the social conventions of deadly diseases—so we just muddled through.

The next day at our pre-operation consultation, Paul asked the surgeon's assistant if I could have a scar on my belly shaped like a lightning bolt. The assistant smiled only wanly and returned to his notes. Why did everyone have to be so serious?

Another aspect I failed to consider, as I bandied the C-word about in coffee houses, was that despite fairly successful campaigns to make cancer a public issue, it is still a private matter. And like other matters that society has deemed private, there is a twinge of indelicacy in raising the topic. It could be the word's tendency to appear in conjunction with body parts we haven't entirely embraced in polite society. Cancer

happens in the breast, the testicles, the colon, the bladder, and other areas that we cannot help but associate with their vaguely shameful functions—lactation, fornication, defecation, urination. As I write these words they jump off the page, one editor, reading a draft of this essay, asks in the margins, “Do we need this specificity?”

But even when cancer is associated with a more neutral area of the body, we are unlikely to plop ourselves down next a sick person and say, “So, how’s that elbow cancer!” There is something about illness itself that evokes a sense of shame and we are sensitive to the fact that the sick person might feel embarrassed about it. When children vomit, they often begin to cry, intuiting there is something shameful in the event. We tell them, “it’s okay, it’s not your fault. You’re just sick.” In modern society, we’ve made a conscious effort through advocacy and advertising to strip cancer of its historical association with moral decay and sin. Even absent of moral sin, feelings of shame are hardly irrational. There is still aesthetic sin. Much of our everyday culture and commerce assigns value to our ability to own exact control over our bodies. Every magazine cover emphasizes the need to be thin, the need to look young. The commercials on television drive home the point that we should be embarrassed if our scalps flake, our skin sprouts a pimple or a stray hair, if we raise our arms and discover rings of perspiration. How is someone likely to feel about discussing her festering, devouring tumor?

Four years after my diagnosis, I still find myself occasionally grappling with matters of etiquette. Not long ago, Paul and I picked up a couple of new faculty who had just flown in from Paris. François, a bearded, professorial version of Luc Besson, had been hired to teach in the Humanities Department. We had met him once before, but his girlfriend, Ilaria, was visiting Tallahassee for the first time. Originally from Italy, she spoke to François in fluent French and to us in English that was clear, if occasionally hesitant. Despite the long day of travel, they accepted our invitation to dine at a local restaurant. At dinner, upon hearing that I was in the writing program, Ilaria, who I guessed to be my own age, asked what I was currently writing about. Still in the glow of having recently decided on what I considered a fascinating topic for a thesis, I did not sidestep the question. *I’m writing a series of essays about having cancer.* Across the table for just a microsecond, her face froze; she glanced at François uncertainly, spoke a

quick word or two in French that ended in a question mark. He responded with a nod, confirming my meaning. The moment passed quickly and they looked back toward me, recovered their looks of interest. But in that fraction of a second, I realized the awkward position in which I'd put our guests.

Saying, "I love you" on the second date, or proposing intimacy—physical or emotional—that exceeds normal expectation, is like raising someone twenty bucks in a penny ante poker game. Everyone else has to fold, or invest beyond their comfort levels. This is what I had done by dropping the C-word over the salad course with new acquaintances. I had, with no warning, pulled them to cliff's edge of more than one rather intimate form of contemplation. Not only does talking about disease evoke an image of the body underneath its social and material coverings—something we avoid conjuring outside of bars—and the affect of illness upon my body, but it also puts on the table the larger issue of my death. Indirectly I understand, but, like D follows C in the alphabet, in our culture the two concepts of cancer and death are inextricably linked.

When people say they have cancer, we feel a need to categorize, to ask, *Is it serious? What do the doctors say?* Those familiar with the disease and its parlance ask each other, *What stage is it?* These questions can all essentially be translated: *How soon are you going to die?* We need a box, some definition. If a person expects to live thirty or forty more years, it's one thing to be sitting across a basket of bread from her, if that life expectancy is two months, that's something else.

I did not put our new acquaintances through any of this guesswork. As soon as I saw their discomfort, I quickly reassured them that my health was good, my illness long over, that my writing was not so much about my personal experience as about perceptions of the disease in our culture.

Of course, by "our culture," I meant my own: populated by English speaking, middle-class, usually white and usually from the United States or English-speaking Australia. One study conducted by the Palliative Care Council of Southern Australia on the topic of multi-cultural care, pointed out that such topics as death, dying, and cancer—which are deemed all of a piece—are a greater taboo in immigrant Italian communities than among English speakers. Italian (and also Greek and Russian) families often request that the ill person not be told the nature of his or her illness, lest he or she lose hope and

the will to live. Likewise, the patient, who might or might not guess his diagnosis, feigns innocence as well, and there ensues a culturally required charade. Italians interviewed referred to cancer in general as “that terrible sickness,” while each specific case involving a friend or loved one was called “the situation.”

Times are changing, at least for Italians who had immigrated to Australia. The original study took place in 1995. By 1999, researchers were already finding that more of the Italian community involved in caring for those with cancer showed a willingness to speak of dying, cancer, and hospice. Some felt that using more direct wording could help to shift public perception, and make Italians less “over protective.”

I did not come across this study until after my conversation with Ilaria, but when I did, I realized how little I knew about her. I didn’t know where she was from in Italy or what cultural views she had been brought up with that would influence her feelings about discussing illness. . Even had she grown up in my home state of Indiana, unless we were friends, I wouldn’t know her family’s views or if she had experienced the loss of a close friend or relative to the disease.

I believe that everyone benefits from more societal openness regarding illness. It helps decrease stigma and fear and increases people’s willingness to investigate symptoms and seek treatment. A society’s willingness to acknowledge the illness opens the door for better advocacy and fundraising for research. It ameliorates the sense of isolation felt by those with cancer and encourages them to share information more freely. I am grateful that as I get to know someone better, I don’t feel pressure to conceal an experience that has played a part in shaping who I am. Still, I guess there are some things you don’t need to talk about on a first date. Note to self: When meeting new friends, refrain from discussing politics or religion...or *cancer*.

I was also surprised to find that even among those who have dealt with cancer, the word can cause discomfort. During my recovery from surgery, I became better acquainted with the other cancer survivors in Alice Springs. I was shocked one day when I said the word, and Sue Ellen, a breast cancer survivor, shuddered, saying, “I don’t like to use the word, I don’t like to hear it.”

“Really? You’ve already had with the actual disease—it’s just a word.”

“Words have the power to draw things to you, and I’m scared if I say it, it’s going to come back.”

An Australian social worker once told me that one of the most challenging aspects of working with Aboriginal communities located around Alice Springs was that whenever a member of a community died, everyone in the community would cease to speak his name. In addition, everyone in the community who shared the same name ceased to do so and chose new names, throwing everything from checks to hospital records into disarray. Later I read Ernst Cassirer, who describes the reason for such customs saying, “The being and life of a person is so intimately connected with his name that, as long as the name is preserved and spoken, its bearer is still felt to be present and directly active. The dead may, at any moment, be literally “invoked,” the moment those who survive him speak his name.” Sue Ellen’s cancer had been put to rest, but she lived with the fear that if called, it would come back to haunt her.

In contrast, I prided myself on being like Harry Potter, who made it a point to speak the Dark Lord’s name in defiance of the prevailing fear. For five books, readers applauded as Harry appropriated the language for himself and stripped it of its power. But by the sixth and last installment, *Harry Potter and the Deathly Hallows*, we come to understand that uttering Voldemort’s name is not without consequence.

Come on, Hermione, why are you so determined not to admit it. Vol—“

“HARRY, NO!”

“—demort’s after the Elder Wand!”

“The name’s Taboo!” Ron bellowed, leaping to his feet as a loud crack sounded outside the tent. “I told you, Harry, I told you, we can’t say it anymore—we’ve got to put the protection back around us—quickly—it’s how they find—”

But Ron stopped talking, and Harry knew why...

Harry, by uttering the Voldemort’s name with his habitual disregard for taboo, puts himself and his friends in peril. Voldemort’s power, at first dismissed as rumors and outdated superstition, is revealed to be capable of rendering real death and destruction.

In the end, Harry Potter survives his confrontation with Voldemort, and although there is no blockbuster movie upcoming, I seem to have survived my Vol—cancer. We’re both a bit older and more experienced. I’d say we’ve both come to understand that

the wiser truth-speakers consider time, place and audience as well a message. That being said (and I can't speak for Harry, though I think he'd agree), more regrets are born of truths unspoken than the other way around. For this reason, to my mind, message trumps other considerations. If a euphemism can get you in a window when the front door is locked, then that's the way to go. But if this is not the case, some things still warrant knocking down the door. Telling people you love them, sharing your feelings and information and helping people better understand a prevalent illness—these messages can backfire in your face, but are worth communicating anyway.

There were costs when Harry uttered the forbidden name. But, it could be argued that Harry's insistence, reflected in his language, on conceiving of Voldemort as more than an unknowable spectre, but a solid, specific entity that he could strive to understand, was ultimately key to Harry's ability to conquer his enemy. When we talk about cancer, it does bring close a number of things we might prefer not to face—the disease itself, our fears of suffering and death and the reality that we can't control the future. But it is by examining something up close—whether a disease, or just our fear of one—that we can gradually learn how it works. And by interacting with it we discover our own strengths and weaknesses as well. Perhaps someday, if we can learn enough, we too will be able to confront our Voldemort and win.

October 2003

When I arrived at school there was no one around. On a typical Monday several students should have been milling about, drinking morning cups of tea, and Suzy, our printmaking teacher, would have uncovered the presses. I wandered into the hallway and saw that Marlena, the art department secretary, was at her desk.

“Hi!” I said, “Where is everybody?”

“You haven’t heard about Suzy?” she asked.

Alice Springs, in addition to being well-stocked with expatriates who traveled home periodically, was home to many Australians who worked with surrounding aboriginal communities, dividing their time between living in town and working “out bush” where they might stay for weeks at a time. The result was an ever-rotating social circle. People seldom kept strict track of who was gone, and for how long; they were simply happy to see each other when they did.

“I’ve been away. What’s up?” I asked, expecting to hear Suzy had won an art prize, was out bush, or had gone to visit her relatives in New Zealand.

“She has breast cancer. She’s at the hospital in Victoria.”

I had not expected to hear that. I felt awful for Suzy. I asked for details, where she was staying, what the biopsies had shown, but at the same time my mind was reeling: Why had it happened to her? It felt callous to so quickly transition from my emotion of sympathy to logically calculating, but I think it is in our natures. In our physical world, there is no effect without cause: Person A wakes up late and decides to stop for coffee at McDonald’s instead of Starbucks. Because she slows down to turn into the drive-thru, Person B, driving behind her doesn’t make it through the next stoplight before it turns red. Person B tries to make up time at the next stoplight, hitting Person F who is stepping off the curb too early. Person F dies. You can argue for or against the existence of senseless events, you can argue for or against the existence of random events. But there is no such thing as a causeless event. What goes up comes down because of gravity. Night follows day because the earth spins as it rotates around the sun. The guy in the cubicle down the hall talks incessantly because of one or two or innumerable events that coalesced to shape his personality in that way.

So, standing in the hallway with Marlana, my mind was pre-programmed to ask the question: What could have caused my friend Suzy--a beautiful, artistic woman, who even in her late forties could easily pass for less than thirty--to contract cancer? It wasn't difficult to come up with an answer: She was a print-maker and a potter who worked around acid fumes and cleansers in the print room; dusts, resins, oven fumes from the kilns; powdered glazes that were also toxic.

And then the next question arose, like a ball tossed into play, Could this happen to me? A tennis match ensued in my brain:

Serve: I had been exposed to the same environment, engaged in the same activities in the print room.

Return: But I had only done so for a little longer than a year, and I had been fairly good about using my double-filtered mask around the more pungent solvents and cleansers.

Down the line: I had a secret love of the smell of citrus turps and the oil paints with which I had taken to inking my collograph plates.

Cross-court return: But I had barely entered my second semester of ceramics, rarely worked around the kiln, had only mixed a few glazes—quite different from twenty years of exposure.

Game point: Her cancer was obviously caused by exposure to environmental toxins that I had not been exposed to. No, it couldn't happen to me.

In little more than a month, I would find myself in this same hallway, with news of my own. When I told her, Marlana would be aghast.

“But you're so young!”

“It runs in the family,” I'd reply. And I'd see her grasp at this like a life preserver, quickly reviewing her own family history and thinking, “Thank goodness, it won't happen to me.”

SURE IT'S KILLING US...BUT IT'S GOOD!

To be able to sit down quietly at home and tempt fate by a debonair pull on the cancer stick is a way of asserting the individual's right to choose his own end. It is the Russian roulette of the sedentary citizen, an existential choice for a non-hero. Every time I pick up a cigarette, I think of death. But I still pick them up.

*Alan Brien, "Everyman's Russian Roulette"
New Statesmen, January 20, 1967*

Richard Doll was a British physiologist who has been called the foremost epidemiologist of the 20th century, who spent—wait, back up! You don't really know what an epidemiologist is, do you? Say, no, otherwise I'll feel dumb because I had to look it up: Epidemiology is “the study of factors affecting the health and illness of populations. Epidemiologists look at the frequency with which a disease appears in certain populations, noting demographics like ethnicity, race, age or occupation. They work in the field and in laboratories to identify causal relationships between exposure to things like alcohol, smoking, biological agents, stress and chemicals, and certain outcomes, like disease or death. When leaded fuel was deemed hazardous, it stemmed from an observation of more frequent illness among workers who had more exposure to lead. That's epidemiology. When you hear that cancers like breast and colon cancer have a lower incidence in most Asian countries, but that the rate increases for migrant populations in the U.S. within a couple of decades,¹ that's epidemiology, too.

Okay, back on track.

Richard Doll was an epidemiologist who spent decades investigating the physical causes for cancer, and was one of the first scientists to confirm a relationship between smoking and cancer. In 1981 he and his friend, Richard Peto, published a paper that listed the following causal estimates for all types of cancer (except for skin). This is what they came up with

35% dietary factors

30% smoking nicotine

10% infections

4% occupational hazards

- 3% alcohol
- 3% geophysical factors
- 2% pollution
- 1% medicines and medical procedures

This means that out of a hundred randomly chosen people with cancer, we can reasonably expect that thirty-five of their cancers are products of diet.² It also means that the risk of cancer could be reduced by 35% with a modified diet. Diet is complex, and that 35% is both a guess (although an informed one) and an average, arrived at by guessing that it might be possible to avoid 90% of deaths from stomach and large bowel cancers (like mine), 20% of cancers of the endometrium, gall bladder and other organs, and 10% of deaths from cancers at other sites.³ In a 2004 interview, Aaron Blair, chief of Occupational Epidemiology Branch at the National Cancer Institute, said that Doll and Peto's guesses are still reasonable in terms of diet and tobacco, however new information has emerged since the 1980s about the health effects of obesity and lack of physical activity, and more recent publications cite a obesity and sedentary lifestyle as causing of between 10%-20% of cancer deaths in developed countries.⁴

Another difference between Doll's report and the newer one is the addition of family history as a factor. This might be because Doll's report centered on *avoidable* risks only, and also due to recent strides in genetic testing.

When my genetic specialist, Dr. Alex Boussioutas, gave me my genetic test results a few months after my surgery for colon cancer, he seconded my friend Marlena's opinion that family history completely explained the cancer I had been diagnosed with. That same family history also put me at a drastically increased risk for having more cancer in the future. I asked him if there was anything I could do—outside of the prophylactic colectomy and hysterectomy he advocated--to change my cancer risk.

“Maybe change my diet?” I suggested.

His answer was off-hand and not encouraging “No, not really. You could try to eat more fiber—but I don't think it can really do much in cases like this.”

On one hand, the news that I couldn't help my odds was depressing. On the other hand, I was off the hook—at least according to this guy. I might be on the road to about six kinds of cancer, but at least I could stop at every McDonald's along the way, right?

Wrong(sigh).

At least according to Richard Doll. Doll points out that causes in different categories “interact with one another, increasing each other's effects, so that the combination of two or three may have a much greater impact than the sum of the effects of each cause acting alone. Any given cancer, may, therefore, owe its origin to several causes, and may, in consequence, have been avoidable in several different ways.”⁵ So if smoking cigarettes increases a person's cancer risk by 30%, and working with a dangerous pesticide increases it by, say, 5%, that person's overall increase in risk is actually much greater 35%. (It's synergy, but not the kind Tony Robbins advocates.) Conversely, there are several ways to decrease risk. One of these ways is diet and physical activity.

To understand why this is, it helps to understand how cancer develops—admittedly not the easiest information for those of us who aren't studying for the MCAT, but not impossible:

We start with a normal cell with intact DNA. Something comes along that damages the DNA, which *initiates* a mutation (this is called the initiation stage) and results in a defective, pre-neoplastic (loosely translate as pre-cancerous) cell. Examples of initiators are radiation, viruses, and chemical agents in the environment, including certain hydrocarbons that are in tobacco smoke or smoked meat. Normal metabolism in the body can also generate free radicals. At any given time, most of us might have a number of pre-neoplastic cells. Hopefully, the damaged DNA will send a signal to certain genes that in turn can repair the damaged DNA. If the repair does not work, the cell is asked to do the honorable thing and commit hari kari. Even if the cell doesn't listen to orders, the defender genes can often stop it from reproducing.

But not always. Sometimes a single mutated cell can hang out for years, or even decades, until some stimulus causes it to reproduce (called the promotion stage). There are a variety of promoters, like sex and growth hormones, irritants and carcinogens. Burnt and fatty foods can be promoters as well as initiators. Once the mutated cells start

to replicate, it takes an estimated 6-10 more mutations to transform—voila!—into a malignant cancer.

So by avoiding foods suspected of inducing free radicals—like red meat, refined sugar, fat—a person could decrease the chances of cell mutation to begin with; and by avoiding those same foods she could decrease the chances that the cell would divide and replicate. Additionally, according to James Barnard, a professor at UCLA, a diet high in antioxidants, whole grains, fruits and vegetables, can even reduce oxidative stress and the chances of free radical formation. Other foods, like soy and green tea, omega-3 fatty acids found in fish, and certain nuts and seeds are thought to be protective for other reasons. Diet and exercise can also work indirectly by altering hormones and growth factors, making cells less likely to be promoters.⁶

As a layperson, I'm reluctant to contradict Dr. Boussioutas, but I have found that people who are excellent in their specialties are not always highly informed in areas outside of them. I've met surgeons who know very little about genetics, and several doctors who didn't know a lot about nutrition. Maybe its because when all you have is a hammer, every problem looks like a nail. And when your hammer is very shiny and highly specialized, you assume it hammers nails better than everyone else's hammer, whether or not this is true.

In this case, there is a substantial amount of evidence that I could significantly lower my risk for future cancer by modifying my diet and increasing my physical activity.

So obviously, that's what I should do. It's what we should all do.

So why don't we?

One thing that holds us back is doubt. How does anyone know exactly what diet is best? Who can we trust? So many people of questionable qualifications have different opinions, and even the people who have good qualifications seem to keep changing their minds. Every time I log on to my MSN home page, there's a new study that contradicts older studies:

“Fish is good, eat it four times a week!”

“Fish is bad because it's full of mercury.”

“Chocolate is bad and it makes your skin break out!”

“Chocolate-induced break outs are a myth, and it has anti-oxidants...and by the way, so does coffee!”

Although these claims are likely in good faith, the net result is not dissimilar to the one that resulted from years of scientists and doctors under the influence of the tobacco industry recommending smoking for good health, and then later casting doubt on data that showed negative health effects: We don't change our habits.

A BBC News article published online in June of 2005 reported in its headline: “Red Meat ‘linked to cancer risk.’” They reported on a study showing that people who ate more than 80g of red or processed meat twice a week were a third more likely to be diagnosed with bowel cancer than those who did so less than once a week. The article was augmented by an open forum for readers’ comments. The first commenter, Steven from Scotland, wrote, “Red meat is a mainstay of my diet and this study won't change my eating habits. There are plenty of other cancers that people can develop and plenty of other ways to die that don't include red meat!” While the next, Ronnie from the UK, commented, “Confused more than worried. I eat red meat every day, approximately 70g a day, but I also eat fish several times a week and have a very high fibre diet. Where does that put me?”⁷

When I was diagnosed with colon cancer and decided to opt for a dietary treatment solution, I was overwhelmed by the seeming amount of contradictions, even among the piles of books written by nutritionists and holistic health advocates. Today I look at those same books, which in the beginning seemed contradictory, and I am now largely aware of their similarities...and the health articles on that pop up when I log into the Internet? I'm more likely to take them with a grain of sea salt, remembering that they tend to pull information from a single study and report it out of context, simplifying and exaggerating to make it seem like “news.”

Some real news that that just blipped on the radar in 2007 was the publication of a 500+ page tome called *Food, Nutrition, and the Prevention of Cancer: a global perspective 2007*. The World Cancer Research Fund International convened a large international panel of experts who systematically looked at all the research to date, argued over it then came to a consensus generating recommendations on food, nutrition and physical activity to reduce the risk for cancer. Understandably, five hundred page

books with lengthy titles makes for less snappy headline fodder than single studies with profound conclusions like, “Having more friends improves memory!” But for a cancer nerd like me, this book is a dream come true. Chapter seven lists almost every type of cancer, summarizes the results of all the published nutrition studies related to that cancer, notes how some results differed and offers theories on what might account for discrepancies before generating a conclusion.

Just as an example, let’s pick a cancer I can happily say I had never considered before—nose cancer. Just from reading a few pages, I learned that cancer of the nasopharynx is the 23rd most common type of cancer worldwide, with most cases occurring in southern China or immigrant communities from that area. The panel examined 74 publications and concluded that “Cantonese-style salted fish is probably a cause of nasopharyngeal cancer. This does not apply to fish salted or fermented by any other method. There is limited evidence suggesting that non-starchy vegetables, and also fruits, protect against this cancer.”⁸

Cool. Cantonese-style salted fish will be so much easier to avoid than high-fructose corn syrup. By the way, just in case I haven’t convinced you to download the entire 500 pages, I’ll tell you now that “non-starchy vegetables” are apparently protective against almost any kind of cancer. You should eat more vegetables. So should I.

So what about my vested interest, colon cancer? It is the third most common type of cancer worldwide, and increases with industrialization and urbanization. And the panel, after reviewing a whopping 752 publications, concludes:

The evidence that physical activity protects against colorectal cancer is convincing, although the evidence is stronger for colon than rectum.

The evidence that red meat, processed meat, substantial consumption (more than about 30g per day ethanol) of alcoholic drinks, body fatness and abdominal fatness, and the factors that lead to greater adult attained height, or its consequences are causes of colorectal cancer is convincing.

Foods containing dietary fiber, as well as garlic, milk and calcium probably protect against this cancer.

There is limited evidence suggesting that non-starchy vegetables, fruits, foods containing folate, as well as fish, foods containing vitamin D. and also selenium and foods containing it, protect against colorectal cancer, and that foods containing iron, and also cheese, foods containing animal fats and foods containing sugars are causes of this cancer.

There you go. It's like a battle plan in a bag.

So why am I still tempted to sit on the couch and eat cookie dough ice cream?

Why do I stay up too late and skip my morning workouts?

Why does anyone smoke, ever?

Why do good people do things that are bad for them?

I have some thoughts on the matter. They have to do with Plato, Barack Obama, advertisers, the FDA, and my friend Jenny's basement rec-room.

(end excerpt)

November, 2003

At the hospital I was gowned, laid on a table and given an intravenous sedative as they wheeled me into the examination room. The sedative was very nice. I woke only sporadically, and the times I was awake felt like a dream. There was a slight pressure inside me, there were two doctors talking, there was a TV screen up above showing something that looked like a cave. And then, in the cave, there was bubbly growth. It reminded me of a tree I used to climb with my brother and sister when we were kids. Inside a hole in the trunk, we had found a fungus, orange and bubbling, textured like this.

In my dream that wasn't a dream, one of the doctors said the words "definitely a carcinoma," and then I was gone. I came to on a big black reclining chair in the recovery room; a nurse came in. "Did you say I had cancer?" I asked him blearily. Later still—minutes or hours, I couldn't say—I saw Paul in a chair next to mine. I asked him, "Did they say I had cancer?" and, minutes later, I couldn't recall his answer. I was blissfully unaffected. Is it grim to say that, if the end of the world comes, I want Demerol? I think I could watch missiles rain down in slow motion with only awe and appreciation for how they glint in the sun.

Dr. Stephen arrived in the recovery room. Perhaps under sedation I had not been meant to hear the doctor's pronouncement of "definitely" in the examination room, or I hadn't been meant to understand the word "carcinoma," because he refused to confirm a diagnosis of cancer. Although he thought it was likely, he preferred to wait for the biopsy. He mentioned a few other things it might be and I went home and looked them up on the Internet, things like diverticulitis, colitis, and Crohn's disease. The doctor's voice in the examination room faded. I told myself I hadn't heard it, it had all been a dream.

CALL ME ~~ISHMAEL~~ A CANCER SURVIVOR

2004, the year of my recovery from stage III colon cancer, was marked midway by the debut of the “LiveStrong” yellow rubber bracelet. The bracelet was a signature fundraising item for the Lance Armstrong Foundation, a cancer support charity founded by the then five-time Tour de France winner. The first five million bracelets quickly sold out, as people bought them not just to support a cancer charity, but to show their support for friends and family afflicted by the disease, and not least to align themselves with Armstrong himself, on his way to his sixth consecutive Tour de France championship, post-cancer. Designed by Nike’s advertising Agency, Wieden+Kennedy, the bracelets, with their debossed, block letters exhorting us to “Live Strong” captured the imaginations and garnered the dollar bills of people ready to embrace an attitude, a worldview embodied in a cool, attractive, hard-bodied celebrity all could admire and only hope to emulate. We, too, wanted to conquer cancer and go on to win the race.

“LiveStrong” was not the only phrase Armstrong had helped popularize. In 1997, diagnosed with testicular cancer, he had declared himself “not a cancer victim but a cancer survivor, hell-bent on living strong.” Unlike LiveStrong, *Cancer survivor* was not trademarked, nor did it originate with Armstrong, but his choice of phrase highlighted an emerging sensibility, the seeds of which advocacy groups were already nurturing, about how people conceptualize their relationship to cancer. In marketing speak, Lance Armstrong was the perfect vehicle for a re-branding message to patients affected by cancer. We were no longer cancer victims, or even patients; now we were survivors.

However, Armstrong was not the first, even in recent history, to juxtapose the words *cancer* and *survivor*. The coining of the term *cancer survivor* is generally credited to Dr. Fitzhugh Mullan. A cancer survivor himself, Mullan published an article in the *New England Journal of Medicine* in 1985 in which he introduced the term “cancer survivors” to describe individuals who had passed the initial stages of treatment but were still experiencing physical and psychological fallout from the experience.

Beyond their initial diagnosis and treatment, survivors of cancer must grapple with a number of ongoing challenges related to employment, insurance and long-term secondary health effects—often called “late effects” of the disease and its treatments. I

recently heard a 2004 recording of National Public Radio's *Talk of the Nation* that featured Mullan as one of its guests. He talked about how it had not been his original intention to evince a fighting attitude, nor did he consider *cancer survivor* to be a perfectly accurate descriptor, but, he said, he'd felt the term was "serviceable" in describing the state of people living with or after cancer.

In 1986, Mullan helped found the National Coalition for Cancer Survivorship (NCCS). The NCCS used Mullan's word for its functionality, but also embraced it for its motivational properties. In the mid-eighties, cancer issues did not yet enjoy the advocacy and publicity we are accustomed to today. Ellen Stovall, current president of the NCCS, says that the phrase was intentionally used to "empower patients to make decisions about their care and to push for better research and treatment." The NCCS definition of a cancer survivor is stated in its charter: "From the moment of diagnosis and for the balance of life, an individual diagnosed with cancer is a survivor."

As the word has come in to more common usage, it has been, as Mullan observed, serviceable, but not without its difficulties. A number of listeners to *Talk of the Nation* called to comment. Two callers noted that the word *survivor* generally refers to someone who has lived through a finite experience—one that has an end—but that in many cases, individuals live and cope for years or decades with cancer and its effects. Though both callers were in remission, each mentioned that they expected their cancer to return, that they lived with the spectre of it each day, and thus were more comfortable with the alternately used phrase, *living with cancer*.

Listening to their comments, I considered my own case. Though medical tests indicate that I am cancer-free, as of this writing I have yet to reach what another caller termed the "bellwether mark" of five years beyond my diagnosis. Even then, my genetic profile indicates that I should never resume drinking Vodka gimlets, and should always feel deep remorse for moments of weakness involving cheese fries with bacon bits dipped in Ranch. I will always have to stay alert for symptoms. So perhaps I, too, am a *person living with cancer*.

Another caller, however, disliked this conceptualization. As someone who was now cancer-free and twelve years out from her first diagnosis, she felt she had left her cancer behind and no longer wanted to be identified as a *person living with cancer*. I

wondered if she might be called a *person no longer living with cancer*...but then decided there was a the problematic ambiguity in the phrase, *no longer living*. I thought of *Person living, but no longer with cancer* as an option, but was certainly starting to see the appeal of finding a noun to follow an adjectival “cancer.”

One caller expressed a conflict similar to my own when she questioned whether *survivor* might be too heroic a term for her cancer experience. Because she had not undergone radiation, chemotherapy or other grueling adjuvant treatments, she felt her cancer had been relatively “easy.” She found herself reticent to don the mantle of survivorship just because she’d had an operation. As the moderator joked, “Are there *appendicitis survivors*?”

Not everyone, of course, is so reluctant to display a badge of honor. When the National Cancer Institute (NCI) established the Office of Cancer Survivorship (OCS) in 1996, they wanted to acknowledge the burden of the disease on caregivers, so they adopted an expanded version of *cancer survivor*, stating: “Family members, friends and caregivers are also impacted by the survivorship experience and are therefore included in this definition.”

“That’s interesting, huh?” I said after reading it aloud to Paul.

“Uh...sure,” he said, not lifting his eyes from a game of “Who Has the Biggest Brain” on his laptop.

But I knew he’d heard me the next day when I mentioned chores and he fell dramatically to the couch, batted his eyes, and moaned, “Why are you so mean to me? Don’t you know I’m a cancer survivor!”

In addition to the NCI’s expanded use of the term (note: the NCI’s statistical reports do not include caretakers in their data), other organizations have adopted permutations versions as well. The President’s Cancer Panel in 2003 defined *survivor* as “anyone who has ever had a cancer diagnosis,” and in the same document stated it was “synonymous with ‘patient,’” a word that in other arenas refers to someone currently undergoing treatment. The survivorship program at Sloan-Kettering Cancer Center in New York defines *survivorship* as a “particular period in a cancer patient’s life, which is post treatment, separate from diagnosis and treatment and from end of life care.”

Further complicating matters, Ellen Stovall complains, is the fact that the term, which she notes was never intended to serve scientific purposes, is also co-opted and adapted by researchers to suit their own needs when they are establishing an area of study.

The mutability of the term also affects laypeople trying to navigate the cancer landscape in today's agenda-filled world. One attendee of NCI's 2004 Cancer Survivorship conference wrote: "One [statistic] ... was that there are 9.8 million cancer survivors in the United States. This was intended to be a positive number, showing that more ... people are surviving cancer....But because the NCI definition of a survivor is 'anyone who has been diagnosed with cancer from the time of diagnosis though the balance of his or her life,' I wasn't sure how to interpret the number. How many of the 9.8 million are sitting ... in the doctor's office being told, 'You have cancer'? How many are currently undergoing treatment? How many are in hospice? How many...are now living cancer free, and of that number, how many live with the late effects of their successful treatments?"

Though we still need an overarching term to describe anyone who has or has ever had cancer, for the same reasons that Fitzhugh Mullan originally coined *cancer survivor* we now need a fuller vocabulary, one that delineates the sub-categories of that population, in order to communicate clearly with insurance companies, medical establishments, and each other.

And in the context of such an expanded vocabulary, what should be the role of the term *cancer survivor*? It seems logical that its use should be limited to those who have lived through cancer, or at least who are still living with it—in other words, *survivor* should refer to people who have actually survived. If I die from the disease, then my friends might look back and say "She survived for X number of years with cancer," but to categorize anyone who dies of cancer as a "cancer survivor" stretches the definition to Orwellian proportions.

Unfortunately, I only listened to the recorded pod-cast of the radio program featuring Dr. Mullan, so I could not respond to his request for any alternatives to his phrase, but I do have a suggestion. It is slightly embarrassing for its new age-y overtones, but I believe its meaning is accurate: I would call myself a *cancer experiencer*. My

survival of cancer or anything else lasts only until it doesn't, but what I have experienced cannot be defined away.

This essay drew heavily from two sources: "Debating the Term: 'Cancer Survivor,'" a *Talk of the Nation* episode first broadcast on National Public Radio on June 9, 2004, and an article by Renee Twombly published in the *Journal of the National Cancer Institute*, titled "What's in a Name: Who Is a Cancer Survivor?" The conference attendee to whom I refer is Shirley Grandahl, and I am quoting her report from the NCI website, "Meeting the Needs of Post-Treatment Cancer Survivors, a personal reflection."

November, 2003

Despite the lack of official word, the medical machinery started to move.

Paul and I met Dr. Henderson in his small office with a desk that faced the wall away from the door. He swiveled his chair to turn to ours, and consulted his schedule.

“I can fit you in next Wednesday, you’d need to start a prep on Monday afternoon.”

“But what if it’s not cancer?” I asked, “Do you still need to remove it? I mean if it’s a polyp or...”

He chuckled spontaneously. I’m sure it wasn’t intentional. To someone who had seen the tissue, and could compare it to countless other instances of cancerous tissue, my question would have been like a child’s asking if maybe the sun wouldn’t set that night.

“I think we can safely assume it’s cancerous, but either way, the surgery will be the same, the mass has to be removed. Shall we schedule you in?”

Wait. Already I was a different person than the one who had shown up for a simple dye test just over a week before. I had questions. I wanted to know what the surgery would entail, even if this doctor mentally rolled his eyes at my insistence on knowing.

“Well, I’ll make an abdominal incision, take out the section of colon with the mass, and stitch the remaining intestine. It’s not a difficult procedure.”

We had other questions, pros and cons of perhaps going to a larger facility.

I asked him, “If this were your family member in the same situation, what would you recommend?”

“If this were my father, I would tell him that there is a system in place to handle situations like this, and to just lie back and trust the system—don’t try to outsmart it, okay? Now, do you have any other questions, anything else you’ve read on the Internet?”

*In his book, *At the Will of the Body*, Arthur Frank writes about a woman who meets with her doctor and asks more questions than he deems appropriate. He accuses her of “trying to control” her treatment, and asserts that he is “in control.” I did not read his book until years after this conversation, but when I did, it rose instantly in my mind.*

I felt shamed by Dr. Henderson's sarcasm, as if I had got caught trying too hard to be smart, but I really was dumb. I was supposed to be the good patient, but had succeeded only in annoying the doctor with my foolishness. We stood to go.

"Thanks very much," I reached out and shook his hand as we left. Not because he offered his, but maybe to make him reach out halfway. As we reached the hall I was trembling, anger beginning to wash over me, and, as usual, delayed so that I could not have the satisfaction of reacting in real time. Tears fell as soon as we reached our oven-hot car.

"I hated to even shake his hand, how can I let him take a knife and cut me open!"

"You don't have to," said Paul, "we can go somewhere else."

"It will cost more, you'll have to miss work."

"Your health is more important. Do what you need to do."

Later, more experienced people would lay it on the line for me. They would point out that this was my life, and I had a right—in fact an obligation—to fight for it. They would point out the ridiculousness of constantly worrying about inconveniencing others, of fearing that I would make a dent in someone's else's routine. Was that what I really wanted, to live without changing the shape of the world, afraid to destabilize any relationships? If I planned to spend my time on this earth trying not to impact anyone, then what was my purpose?

SO YOU THINK YOU CAN DANCE BE A CANCER SURVIVOR

I.

*I'm a survivor,
I'm not gonna give up,
I'm not gon' stop,
I'm gonna work harder,
I'm a survivor,
I'm gonna make it,
I will survive,
Keep on survivin'.*

Destiny's Child, "Survivor"

I'm intrigued by the word *survivor*.

On the reality TV show, *Survivor*, the person who survives the game—whether through determination, intelligence, or willingness to do aesthetically or ethically distasteful things—is the winner. When we see a friend in difficult circumstances, if he strikes us as resilient, we say, “He’ll get through it, he’s a survivor.” And when musical artists sing about being survivors, we know they aren’t just singing having lived through challenges in the past—they are singing about the ability to overcome them in the future, about the act of surviving. Yet strangely, when I look the word up in my old Webster’s, or scroll through half a dozen pages on Google, *survivor* is defined merely as a state: “one who continues to live after an affliction” or “one who survives or outlives another person, or any time, event or thing.”

There are no descriptions of a survivor as it is used in a contemporary context, no definitions that refer to the *nature* of a person who survives, even though most of us, if asked would have an opinion about what characteristics make a survivor. In her song “I’m a survivor,” Reba McEntire sings:

*I don't believe in self-pity
It only brings you down
May be the queen of broken hearts
But I don't hide behind the crown
When the deck is stacked against me
I just play a different game*

The word *survivor* has taken on an additional meaning that the dictionaries haven't caught up to yet: A *survivor* is a person who possesses certain determination and qualities of spirit that enable him or her to persevere in difficult circumstances.

Perhaps this secondary definition doesn't appear because it seems to have fully developed only in the last dozen years, although there were hints of the future in the decades before that. The late 70's gave us Gloria Gaynor's disco hit, "I Will Survive," which describes a woman who finds her personal strength after the adversity of a break-up. While the protagonist is simply vowing to live through her present circumstance, the anthemic music and powerful delivery imply a strength of character that we associate with her survival. In the 80's, advocates for sufferers of rape, incest, the Holocaust or cancer, sought to empower their constituents by reframing their experiences to de-emphasize the passive nature of victimization in favor of the active victory of survival. Survivors were encouraged to see themselves as strong, and the public was encouraged to see them so as well.

In 1994, psychologist John Leach's *Survival Psychology* arrived in bookstores, reporting patterns in human reactions to natural and man-made disasters, combat situations, and prisoner or hostage experiences. In the book, Leach notes that some exceptional persons "seemed equipped to survive even under the harshest circumstances," but he doesn't use the term *survivor* to imply that someone is thus equipped.

In 1996, psychologist Al Siebert's book, *The Survivor Personality*, hit the shelves. Siebert describes his time with combat veterans from World War II and the Korean War: "Being around them I saw that it wasn't just fate or luck that these were the few still alive. Something about them as people had made a difference." He specifically examines the traits and behaviors of the people he describes as "better survivors," or "the best survivors." In doing so, he essentially makes the transition to an active sense of the word, since to "be better" requires criteria for comparison. A better survivor then, is one who is better at the act of surviving.

As the book progresses, Siebert occasionally omits the modifiers and uses simply *survivor* to describe a "better survivor," thus establishing a shorthand for a set of characteristics still in the process of being defined. It might or might not be connected

that Lance Armstrong's 1997 declaration that he was "not a cancer victim, but a cancer survivor, hell-bent on living strong," took place the year following the debut of *The Survival Personality*, a title perfect-made to spread through the collective consciousness.

The year 2000 marked the debut of the *Survivor* television show, with albums *Survivor*, and *I'm a Survivor*, by Destiny's Child and Reba McEntire respectively, following in 2001.

As of this writing in 2008, the book, *Deep Survival*, by Laurence Gonzales can be still be found on the display table at our local Barnes and Noble. By the book's publication date in 2003, the transition was complete—Gonzales simply uses the term *survivor* (without any modifiers such as "best" or "exceptional") throughout the book to describe those who possess an uncanny knack for staying alive, and there is no question in the minds of readers as to what he is talking about.

Some people Gonzales highlights as *survivors* are Steve Callahan, a sailor who kept himself alive 76 days in a life raft, mending leaks and fighting off sharks; Juliane Koepcke, a seventeen year-old girl who after falling two miles from a disintegrating airliner, spent 11 days walking to safety through the Peruvian jungle with a broken collarbone and no shoes; and Joe Simpson, who, left for dead in a deep crevasse, climbed out with a broken leg and proceeded to crawl and climb for days across a snow-covered mountain in the Andes. After examining the narratives of such survivors, looking at psychology research and talking to neuroscientists, Gonzales compiled an extensive list of "what survivors do." Here are a few examples:

Survivors quickly regain their emotional balance, and are able to correctly perceive and adapt to a new and uncertain reality: Juliane Koepcke reported that even as the airplane broke apart and she was falling from the sky "I remember thinking that the jungle trees below looked just like cauliflowers."⁹

For most people, cortisol and other hormones released in response to stress interfere with the functioning of the pre-frontal cortex, where perceptions are processed. Under severe stress, the majority of us lose at least some sensory perception, memory functions, and ability to perform tasks. Gonzales reports, "You see less, hear less, miss more cues from the environment." He notes, "Only 10-20 percent of people can stay calm and think in the midst of a survival emergency." The fact that Koepcke was taking in her

environment, and even making imaginative comparisons as she fell from the sky, indicates that she was in the minority.

Those of us who aren't part of that 10-20 percent must work harder to regain emotional control. Leach notes that our reaction during the initial stages of a crisis often affects our chances during a later stage of a long-term ordeal. The longer people take to adjust, the less chance they have of ultimately surviving. A person who is in a state of panic, shock or bewilderment will make little effort to provide for his or her basic physical needs, and may miss information that could be helpful at a later point.

In Steve Callahan's account of his ordeal, *Adrift: Seventy-six Days Lost at Sea*, he describes his reactions right after diving off his sinking ship into his life raft. "I fight blind panic: I do not want the power from my pumping adrenalin to lead to confused and counter-productive activity. I fight the urge to fall into catatonic hysteria: I do not want to sit frozen in fear until the end comes." In the moments following these thoughts, Callahan forces himself to dive back into the frigid and tumultuous sea and swim into his sinking craft to retrieve the bag of supplies that will allow him to survive for the next two and a half months.

Survivors are open-minded about possibilities, willing to do what it takes: Soldiers, POWs and survivors of concentration camps all say that if there was food, even if it was rotten, or slimy and riddled with maggots, if you wanted to survive, you ate it. Beyond the aesthetically displeasing, survivors must sometimes choose to break social taboos. Siebert cites a group of coal miners who were trapped without water for a number of days. They eventually drank urine in order to survive until they could be rescued. Most people are familiar with the story, told in *Alive*, of the survivors of a plane crash in the Andes who had to resort to eating the flesh of human corpses.

Survivors organize, make small manageable tasks, establish discipline, rituals. John Leach describes how when a fishing vessel, the *West I*, sank, the 8-man crew split into two life rafts, tethered together about 30 feet apart. On one raft, third mate Doug Hamilton emerged as a leader. He established day and night watches, organized a system whereby food and water were inventoried, rationed and issued to each man publicly, and made sure that the raft was mopped regularly to prevent saltwater sores. On the sister raft, none of these chores were carried out, and the situation quickly disintegrated. When

the men were rescued by a Naval vessel two weeks later, the crew of Hamilton's raft were able to climb the boarding ladder, while the remaining crew on the other raft had to be carried on litters.¹⁰

The tasks that Hamilton set were not only necessary for physical survival, but they were psychologically important. Each ritual segmented the vast amount of time they had to pass, and various duties would have given the men a sense of purpose, which is often key to staving off panic or hopelessness.

Survivors think for themselves, are not rule followers. In the World Trade Center disaster, many people died because they did what they were told to do by authority figures. Gonzales cites one employee who began his escape from the 93rd floor of the South Tower, but went back his office when security guards announced that the building was safe and people should stay inside until they were told to leave. Before he died, he spoke to his father on the phone: "Why did I listen to them—I shouldn't have."¹¹

It is a general rule that if a plane crashes, staying with the wreckage gives one the best chance of being rescued. Out of the a dozen passengers on Juliane Koepcke's plane who survived the crash, she was the only one who looked to the jungle canopy and decided that if she couldn't see the search planes, they couldn't see her, and started walking. She was the only one who survived.

Survivors have a sense of humor, of wonder, and an ability to find the good in every event. Siebert calls this a "talent for serendipity," and it seems to encompass an outlook on life that allows for adaptation to one's circumstances. Early on in his ordeal, Steve Callahan noticed that the video camera on his sinking boat had been turned on. As he watched the blinking red light he had the whimsical thought, "Who is directing this scene?" On a neuro-chemical level, Gonzales says that there is evidence that laughter can dampen fear and help temper negative emotions by sending chemical signals that inhibit the firing of nerves in the amygdala. Likewise, he notes, when we appreciate beauty, it relieves stress, creates motivation, and allows us to take in new information more effectively.

As Joe Simpson prepared to crawl out of the deep crevasse into which he had fallen, despite the pain of his broken leg and the odds against his success, he said, "I kept telling myself that I was lucky to have found a slope at all." People who are in the habit

appreciating opportunities may be more likely to look for and to use them when they arise.

II

From the abundance of available observations and anecdotes, it seems evident that some people are *survivors* in the active sense of the word. That is to say that in a wide range of situations—from natural and man-made disasters to accidents in the wilderness; from artificially constructed reality television game-play to the everyday reality of the corporate workplace—there exists a spectrum of people, ranging from those who seem destined to perish to others who seem naturally suited to thrive under pressure.

But even accepting this as truth, can this perception of an active survivor be applied to cancer? Is there such a thing as a *cancer survivor*, who possesses a sheer force of personality, a “hell-bentness” perhaps, or some other qualities fundamentally different from others destined to succumb to the same disease? And if we choose to believe that the survivor spectrum exists in the realm of cancer, does that mean we have any control to change where we fit on that spectrum?

One less than politically correct result of accepting this alternate use of the word *survivor*, is that it paves an easy path to an alternate sense of the word *victim*, as someone who lacks the inner resources of a true survivor, who might, in fact, actively exhibit some quality that acts as a beacon to the universe, sending a message that says, *Choose me. I am willing to be fate’s sacrificial lamb.*

Fifty percent of all people diagnosed with cancer will die from it, many after enduring of the effects of both the disease and of extreme treatments that would prove to anyone their courage and commitment, as well as a mighty threshold for suffering. Many who witness the struggle take offense at such simplistic win or lose labels. A friend asked me, “My boyfriend’s mother died from lung cancer—does that make her some kind of loser?”

When I was diagnosed with cancer, the initial process of tests, results and decisions happened rapidly enough that we did not think to tell Valerie, the woman who cleaned our house every two weeks. She arrived at our door in the morning just as I was running about, preparing for our flight to a hospital in Melbourne. Standing in the

kitchen, Paul apprised her of the situation, and from where I was packing a bag in the back room I could hear her cry out, “Why does it always happen to the nicest people!”

This, I was soon told, is not an uncommon reaction. At first I assumed it was an odd form of politeness—I figured it made sense that people would start to say you were nice if you were dead or had cancer. But some researchers have noticed an actual trend whereby people known for being nice get cancer, and have theorized that niceness itself might be a factor.

The variously described stereotypical traits of a the somewhat controversial “Type C” or *cancer personality*, include suppression of emotions, particularly anger, and a “pathological niceness” consisting of “avoidance of conflicts, exaggerated social desirability, harmonizing behavior, overcompliance and overpatience.”¹² (Probably not too dissimilar to what Paul sometimes described as my “boundary issues” of saying yes when I wanted to say no, saying nothing when I had plenty to say.)

Just as the high level of expressed anger and hostility that typify the better known “Type A” personality have been associated with coronary disease, proponents of the cancer personality theorize that internalizing one’s emotions might contribute to cancer development “by amplifying the negative effects that stress produces on the immune system.”¹³ Thus possessing a cancer personality might not only decrease one’s chances of surviving cancer, but play a part in contracting it as well.

There are some who vehemently disagree with the very idea of a cancer personality. In his book *At the Will of the Body*, Arthur Frank, observes, “cancer represents how quickly lives can fall apart. We all fear that possibility; we want to be able to believe that we can avoid it, so we...blame it on the ill person.”¹⁴ Others point out the danger that relating recovery to personality traits, such as optimism, positive thinking and the “will to survive” simply invites additional stress into the lives of cancer patients.

Dr. Jimmie Holland, chief of the psychiatry service at Memorial Sloan-Kettering notes, “Patients often feel victimized to have gotten cancer in the first place. They are victimized a second time when they are told their personality led to their getting cancer. The guilt becomes overwhelming for some, especially those whose families insist that they must change since their personality may affect survival as well.”¹⁵ Dr. Paul Rosch, founder of the American Institute of Stress, agrees, “I can think of nothing crueller than to

add to the burden of cancer victims who are already guilt-ridden by suggesting...that their failure to improve is a result of some deficiency of character or inability to cope with stress.”¹⁶

Some recent studies have also discredited the “mind over cancer” line of thinking. A 2004 Australian study of patients with lung cancer reported that patients with positive attitudes didn’t experience any increased longevity compared to their less positive counterparts.¹⁷ And, a 2007 study out of the University of Pennsylvania that followed over a thousand patients with head and neck cancer concluded that emotions didn’t affect survival outcomes.¹⁸

The release of results from the latter study elicited a barrage of headlines. BBC News proclaimed, “Optimism ‘no bearing on cancer,’” CBS News reported “Attitude Can’t Overcome Cancer,” and Discover Magazine declared “Hope May Be Useless Against Cancer.” The BBC article called the study’s findings “reassuring” for people who might otherwise worry if they were feeling less than positive after a diagnosis,¹⁹ while CBS quoted Dr. James Coyne, the key researcher, as saying, “I wish it were true that cancer survival was influenced by the patient’s emotional state, but given that it is not, I think we should stop blaming the patient.”²⁰

If we are to credit such studies and reasoning, which certainly seem credible, one would have to conclude that there is no such thing as a *cancer survivor*. Perhaps because cancer is an internal battle fought on a microscopic scale on the terrain of a body, not on the side of a mountain. The same rules don’t apply.

But then there’s Ian Gawler.

If Steve Callahan and Joe Simpson are exemplars of survival in the wild, then Ian Gawler should be the poster boy for cancer survival. At the age of twenty-four, Gawler was diagnosed with osteo-sarcoma, a cancer of the bone, and had a leg amputated. When secondary cancers were discovered a year later, doctors predicted they would double in size each month, and estimated his lifespan to be only three to six months. Since radiation and chemotherapy were unlikely to extend this time by much, Gawler concentrated his efforts on meditation and diet, holding the cancer at bay for three months, during which it did not grow at all. Then, through what he feels was a combination of factors and new

stresses, his condition deteriorated rapidly. By March of 1976, his kidney was obstructed and his specialist predicted he had two weeks to live.

Despite the fact that he weighed just 84 pounds, was forced by pain to lie down except when it was absolutely necessary to move, and despite his skepticism in such matters, Gawler and his wife traveled to the Philippines to visit psychic healers. This led to a turning point. When he returned to Australia a month later, although the size of the cancer had not decreased, he was fourteen pounds heavier, mobile, and free of pain. For the next two years he continued to meditate—at times up to five hours a day—and to refine his diet, as well as pursuing any other avenues that seemed as if they might help.²¹

Thirty cancer-free years later, Gawler has written several books including his first, *You Can Conquer Cancer*, and heads a foundation that runs cancer support programs which advocate, in addition nutrition and exercise, meditation and positive thinking. Gawler is not alone in his recovery or his methodology. Petrea King and Louise Hay have also documented their recoveries from cancers and likewise credit and advocate mind-based practices and emotional work when it comes to healing.

So on one hand we have inspirational figures and self-help authors telling us that our emotional life can affect our lifespan, and on the other we have sound-bites and headlines that would lead us to conclude this is not the case. And if personality traits such as optimism have no bearing on survival, then it follows that personality has no bearing on survival, thus there is no such thing as a survivor personality—at least when it comes to cancer.

III.

The Roman emperor and stoic philosopher Marcus Aurelius, not such a bad survivor himself, recommended, “Of any particular thing, ask what is it in itself, in its own construction,” and this, before landing solidly on either side of the philosophical fence, seems appropriate advice.

Untangling the issues though, is like separating intertwined strands of Christmas lights, caught not only in the twisted wires, but also at the bulbs. The process takes some time and concentration, but it is necessary to see which strands light up. We can perhaps approach each strand with a question.

1. Why would we think personality could affect our health?

A number of books and magazine articles say that stress is bad for us. This is sometimes true. I recall my eighth-grade science teacher, Mr. Mooney, telling us that the body's reaction to stress is often referred to as the "fight or flight" response. When confronted with a physical threat—for example coming face to face with an angry bear—our bodies kick into high gear. In the brain, the hypothalamus sets off an alarm system—a combination of nerve and hormone signals—which prompts the adrenal glands to release a hormone cocktail with the primary ingredients of adrenaline and cortisol. Adrenaline boosts energy supplies, increases heart rate and elevates the blood pressure. Cortisol increases the sugars in the bloodstream, enhances the brain's use of these sugars (glucose). These reactions give the body extra energy, speed, concentration and agility to either fight the bear, or to run.

Simultaneously, cortisol also curbs functions such as the digestive system, reproductive system and growth processes that are nice to have in general, but are not needed for the immediate task of fighting or running from the bear. Cortisol additionally makes some alterations to immune system responses, increasing response to injuries, like creating inflammation around a bear scratch, but also suppressing other features that are needed for long-term maintenance. Afterwards, sitting safe in the cave, perhaps looking forward to roasting up some bear meat, all systems return to normal.

Today, although a disagreement with your boss in the boardroom may elicit the same stress reactions in your body as facing a bear, you are unlikely to attempt physically fighting or fleeing. Instead, you hold back, waiting to release that tension later, perhaps when you hit the racquetball court. In modern society, unreleased stress has become a more common problem, since chronic or unreleased stress can result in these immune responses remaining suppressed, which raises the risk of infections, auto-immune diseases and other conditions.²²

According to Suzanne Segestrom, a psychologist at the University of Kentucky, there are hundreds of studies that describe relationships between psychosocial stressors and the immune system, but, she reminds us, the relationship is not a direct one: system (CNS) can transduce psychosocial stressors into signals that can influence the immune

system.”²³ She’s saying that once our CNS (that’s the brain and the spinal cord) interprets events, the messages it sends to our bodily systems are what will influence how those systems react. We tend to think of events as possessing a certain amount of stressfulness, but in truth, it is an individual’s response to stimuli that dictates the level of stress. The notion of giving a speech in front of a room full of people might generate a stress response in one person, but not another. So the different ways people perceive and respond to things that happen to them—a function of personality—can change the effectiveness of their immune systems.

2. How is this related to the idea of a Cancer Personality?

If a “Type C” personality includes such traits as emotional suppression, stoicism, perfectionism and over-agreeableness (or “niceness”), it seems logical that the pressure to “keep a lid” on emotions boiling beneath the surface could create a fairly steady supply of stress. It also seems logical that the chronic stress could affect immune function, making a person more vulnerable to cancer initiation or progression.

The cancer personality theory is controversial however, as Segerstrom reports. Though some research has supported the existence of a relationship between personality and cancer, it has never been proven absolutely. Some positive studies have been called into doubt for using sample groups with different types or stages of cancer, which might be affected differently by immune factors; while other tests have been challenged for flaws in their design.

But constructing a test that would provide incontrovertible evidence is no easy task. For one thing, by the time a cancer is clinically detectable, it has probably already been growing for years or decades. For another, different immune parameters can react differently depending on whether they are reacting to transient emotions or stable personality factors. For example, some natural killer cells change rapidly in response to short-term influences, while other types of responses happen over hours or days, during which they might be exposed to any number of psychological influences.

If this weren’t enough, there are still a number of questions regarding the nature of a “personality” itself. What constitutes a personality? How much does it rely on a person’s inherent pre-dispositions, and how much is it affected by transient moods and

emotions? How much do moods vary due to physical conditions (am I hot or cold, hungry or full) and interactions with people and the environment (did I have a pleasant lunch with a friend or a fight with my husband)? Social psychologist Walter Mischel threw a wrench in the whole works in the 1960s by asking, does an innate personality even exist or is it just a construct?²⁴

And finally, what if personality exists and it affects immune function, but the effects aren't of the type or of enough magnitude to affect a specific cancer outcome? Mr. Mooney, my eighth grade science teacher once explained, "Work equals force multiplied by distance." He said that if you pushed an elephant with all your strength, but the elephant didn't move, then the net amount of work accomplished was zero. I always found this singularly unfair, that a person would get no credit even though they were pushing. So it is with the immune system. It might be working harder due to an emotional or dispositional factor, but it might not be strong enough to measurably influence and illness outcome. It doesn't mean no force was applied; only that it wasn't enough to move the elephant.

3. What about Optimism and Immunity?

Optimism is regarded as a single personality trait, and, as with personality and cancer, the results of studies focused on the relationship between optimism and immunity have been mixed. For example, in a 2003 study of head and neck cancer patients, optimism predicted a lower mortality risk, but as we've read, the 2004 study of lung cancer patients showed no effect. A 1996 study of mixed cancer types showed a positive response, but only for younger patients. Other studies have associated optimism with higher immune performance during straightforward or easy to resolve stressors, but found that with problems that were difficult or complex, it actually suppressed certain immune parameters.²⁵

Another mitigating factor in measuring single personality traits like optimism is that, like those strands of Christmas tree lights, different traits can overlap. In one experiment the optimistic participants were willing to work longer on a difficult arithmetic problem. But the participants with high optimism scores also tended to score high for conscientiousness, a separate trait. So maybe optimistic participants worked

harder (stayed engaged longer) because they were more optimistic about a successful outcome. Or maybe they stayed engaged longer (worked harder) simply because they were conscientious. And maybe they were more optimistic about achieving success in general because in general they were conscientious, which had led to past success.

A final note is that studies measuring optimism as expectations about specific items in the subjects' lives have shown a more straightforward relationship with immunity than studies that just measured positive expectations for the future in general. The majority of studies use the latter, more general approach, but the success of a specific and focused optimism is interesting because it seems almost to venture into the terrain of visualization techniques—another story altogether.

4. What about the recent studies that say there's a connection between optimism and cancer?

Now that I'm a perpetual student with access to a university database, when I'm curious about a health-related news story, I like to read original journal articles first-hand. (I know, should I just get a shirt that says, "Cancer-Nerd?") The big words can be daunting, but if I push through, I usually find that the facts that seemed so authoritative in the headlines look a little more human-scale in the original context.

Consider that 2007 study of head and neck cancer patients that concluded optimism had no bearing on cancer:

First, although the news stories used the words "optimism," "attitude" and "emotions," the study itself never claimed to evaluate these things. It merely stated that its objective was to examine the relationship between survival and *emotional well-being*.

Second, I was underwhelmed by how *emotional well-being* was determined. I'd somehow assumed that researchers must have used quite sophisticated methods of measurement—maybe brain scans or extensive interviews. Instead, I discovered the researchers gathered their information by giving participants a survey—not unlike ones I used for statistics class in eleventh grade. The study's assessment of emotional well-being was based on a single questionnaire given to patients with stage III and IV cancers as they were about to begin of a treatment regime consisting of four alternating types of radiotherapy. The questionnaire, which was only administered one time, consisted of five

statements such as “I am feeling sad,” “I am losing hope in my fight against my illness,” and three others about feeling nervous, worrying about dying, and worrying that the condition would get worse. The patients could rate each of these statements from zero to four. (At the end of the study, 650 of the 1100 participants had died and I wondered whether it was deemed more or less healthy under the circumstances to “worry about dying.”)

The 2003 study of lung cancer patients was slightly more thorough. The participants completed a twelve-item questionnaire on two separate occasions. Four of the items measured optimism and four measured pessimism, while the remaining four were filler items to disguise the purpose of the survey. Items included statements like, “In uncertain times, I usually expect the best,” and “If something can go wrong for me, it will.” The participants ranked their feelings on these statements on a five point scale ranging from ‘agree strongly’ to ‘strongly disagree.’

David Spiegel, associate chairman of psychiatry and behavioral sciences at Stanford University School of Medicine, has pointed out the obvious fact that such assessments don’t account for variance in mood, and he questions their ability to prove relationships with other variables.

Spiegel also criticized the 2007 study for choosing cancers (head and neck) with a relatively poor prognosis,²⁶ a criticism that could certainly be levied at the 2003 study as well, since lung carcinoma of the type studied has a five-year survival rate of less than 15%. This goes back to the elephant. The researchers were testing an emotionally motivated immune response, but they set up the test so that, in order to be recognized, the response would have to single-handedly increase survival rates in the face of very challenging conditions. That’s asking little immunocytes to push a very big elephant.

5. So...what?

Now that we’ve got our strands untangled, how are they relevant to our discussion of “Is there such a thing as a *cancer survivor*?” “Does it have to do with personality?” and “If so, do we have any control over our personalities?”

In criticizing the 2007 study, Spiegel noted that, “Positivity or negativity are not the issue...What matters is the way in which a cancer patient approaches the stresses in

his or her life.”²⁷ This comment is very relevant to our conversation, when we consider what we know:

Examining our first strand, it seems evident that how we process stress has an effect on our immune systems. Since we can define “how one processes stress” as a function of personality²⁸ then we can accept that personality can have some influence over our health.

Looking at our second strand we are faced with another essential problem of language. *Cancer personality* is one of those terms that is just too strong. It puts a lot of pressure on its proponents, and acts as an incendiary to its opponents. I’ve run across the phrase *cancer prone personality*, which is only slightly better. Certainly there are people who fit the Type C description—they bottle up their feelings, and have piss-poor stress management, and this, depending on their native robustness, might eventually have a depressive effect on the immune system. And certainly a depressed immune system will leave anyone more vulnerable to illnesses, including cancer. But cancer is incredibly *multi-factoral*. It is a disease that initiates and progresses through the interaction of a number of factors. One of those factors might be depressed immunity as a function of personality, so the idea of *cancer personality* is not as ridiculous as it sounds, unfortunately, it does sound ridiculous--and rather dangerous as well if you imagine the words coming from mouths of irresponsible gossips discussing their friends at Starbucks. The label, with its implication that a person could *cause* cancer with his or her personality, should be retired. The idea, however, that personality, defined as “how we process stress,” could be one contributing factor among many, is worthy of our consideration.

The “optimism” strands make it fairly apparent that science is still struggling in this arena. There is not a clear consensus on how to define optimism, nor is there any real articulation of by what mechanisms it is expected to perform. The studies which have observed a relationship between behavior associated with optimism and measurable immune function are the most interesting, but are still inconclusive. It seems likely that these observations will prove to be associated with stress processing. Positive outlook may well prove to be a cause or outcome of stress processing and thus associated with immune function, but until the scientific community can really define its terms, I think

we can safely set aside any specific conclusions about “optimism.” The bulbs just aren’t lighting up, and, as aspiring survivors, we have more important things to think about...Like figuring out how to change the way we handle stress.

IV

I never considered myself a “survivor.” I’ve no sense of direction. When I go to a white sand beach, my skin is the same shade as the sand, and will redden and peel off my bones inside half an hour without the protection of SPF 50 sun block for babies. All my life I have hung from monkey bars and doorway moldings, hoping to develop enough upper body strength to pull myself up from a hang. It has never happened. In my day-mares, I am Wiley E. Coyote tricked by the Road Runner over the cliff. Like Mr. Coyote, I catch the lone branch jutting out from the cliff-face, but the branch doesn’t break as it does in the cartoons; it holds firm. Instead, it is I, after straining red-faced for a number of minutes, who am unable to hold on any longer. My fingers slip ignominiously away from the branch and I plummet.

But one day, I heard the words “You have cancer,” and it turned out that surviving didn’t really involve upper body strength or skin tone. What it did involve, like those Christmas lights, is a little tougher to unravel. Lance Armstrong, in his book *It’s Not About the Bike*, says it in a nutshell “The question that lingers is, how much was I a factor in my own survival, and how much was science, and how much miracle?”²⁹ In truth, most of us will never know, we can only compare notes and speculate. John Leach says “In considering the factors which play a role in long term survival one must occasionally leave the science of psychology and enter more the realm of philosophy. This is necessary to understand the basic principles of survival which by their nature are rarely amenable to experimental investigation. People who have survived long periods of duress have a tale to tell, and from their knowledge and experience one attempts to distil and describe the basic principles.”³⁰

Leach is saying that we can’t always depend on the experiments to show us the whole picture. For real wisdom about the world we also have to look to empirical data—observations and experiences of people over time. And interestingly, it seems that

understanding strategies that work for other kinds of survivors might be beneficial for those who aspire to be survivors of cancer:

Survivors quickly regain their emotional balance, and are able to correctly perceive and adapt to a new and uncertain reality: Not long after my diagnosis and surgery, I attended a ten-day educational retreat that I fondly refer to as “Cancer Camp.” On the first day, I sat with 37 other anxious attendees and watched as Ian Gawler glided into the room on one leg and one crutch and took his seat at the head of our circle. During his opening comments, he hopped from his chair to a nearby white board, and pulled the top off a marker. “They say the first thing to do after you panic, is...” He wrote the words in capital letters as he spoke, “DON’T PANIC.”

Fortunately, a diagnosis of illness usually has a time frame that is more forgiving than being caught in an attack or a natural disaster, but it is still important to get your bearings. Until you can regain control of your perceptions and your rationality, you can’t make good, informed decisions...you can’t even effectively gather information to make those decisions later (this is a great reason to take a friend to the doctor’s office with you to listen and take notes; you can compensate for being part of the 80% who won’t remember things you are told under stress).

Striving for emotional balance remains an important goal throughout an illness experience. After his experiences, Gawler is of course a huge proponent of meditation, releasing pent up emotions and practicing relaxation to allow one’s bodily systems, including the immune system, to reset and recharge.

Survivors are open-minded about possibilities, willing to do what it takes: Bernie Seigel, a doctor and author of several books on healing, says that most patients who get better instead of dying react to their illness as a ‘wake-up call.’ Al Siebert adds that, “By that he means they make major changes in how they live, talk, think, feel, eat and spend their time.”³¹

Unlike wilderness survivors, cancer patients are often still surrounded by familiar people with familiar expectations. The threat is not as immediate and obvious as being trapped in a mine or on a freezing mountain, so it is in some ways harder to open one’s mind to change. For some, suddenly eating broccoli and exercising can seem as “out of

character” as drinking urine. Each requires a person’s commitment to change his or her mindset. Siebert notes that people who are “nice” may need to change to be *less* tolerant and forgiving, while others must become more so, and “learn how to give up the anger habit” in order to establish inner emotional balance. If every feeling has a corresponding neuro-chemical activity, then “lopsided habits in feelings and thoughts create matching imbalances in physical systems, which then make the body vulnerable to diseases and illnesses.”³²

Survivors organize, make small manageable tasks, establish discipline, rituals.

The small tasks Hamilton gave the crew on their life raft helped them survive physically and psychologically. During my cancer experience, I often felt overwhelmed and adrift in the ocean. The tasks I gave myself to recover physically were the same ones that kept me anchored. Even on the days I was distraught, I always had a few tasks to give me purpose. I walked to the end of our road and back. I chopped vegetables and made juice. I sat in a specific room and at least tried to meditate three times daily. If I accomplished nothing else in a day, I could comfort myself that I had done these things.

Reading Lance Armstrong’s book, I recognized that he went through the same processes: studying his disease, investigating and following a diet, exercising almost throughout his entire treatment process. Armstrong describes how at his worst, when his health prevented him from doing these things, his friend, Och, helped him:

“Chemo felt like a kind of living death. I would lie in bed half-asleep, and lose track of time, including whether it was day or night—and I didn’t like that. It was disorienting and made me feel as if things were slipping out of joint, getting away from me. Och created a routine so I could gauge the time. He brought my apple fritters for breakfast and chatted with me until I dozed off in the middle of a sentence. My chin would fall on my chest, and Och would tiptoe out of the room. A few hours later he would come back with a plate of vegetables for lunch, or a sandwich he had bought outside the hospital. After lunch, we would play cards until I passed out again, my head nodding and my eyelids fluttering. Och would take the cards out of my hand, put them back in the deck, and tiptoe softly out.”³³

Survivors think for themselves, are not rule followers. Gonzales says that

“Psychologists who study survival say that people who are rule followers don’t do as well

as those who are of independent mind and spirit. When a patient is told that he has six months to live, he has two choices: to accept the news and die, or to rebel and live. People who survive cancer in the face of such a diagnosis are notorious. The medical staff observes that they are “bad patients.” Unruly, troublesome. They don’t follow directions. They question everything. They’re annoying. They’re survivors.”

Norman Cousins, author of *Anatomy of an Illness*, and famous illness survivor, began taking control of his own treatment by moving out of the hospital—which he observed was not an environment conducive to healing—and into a hotel across the street. Lance Armstrong traveled to three hospitals before choosing his course of treatment. At the second hospital the doctor told him he had no chance of survival if he chose the third. He chose the third, survived, and won the Tour de France six times. And, I have no doubt that my own recovery and the health I enjoy today is the product of a number of decisions that ran counter to conventional wisdom.

An interesting note about the “optimism” studies: Each group of participants studied had already agreed to a course of treatment. Participants who discontinued their treatment were removed from the study. It is standard practice and good science to keep as many variables as possible constant, but it is also a reason that very few statistics exist for people who “break the rules.” Science is about trends in a group of people who are similar. Survival is about individuals who decide not to be part of the trend. This is why Ian Gawler says to the press, “I’d rather be a live anecdote than a dead statistic.”

Survivors have a sense of humor, of wonder, and an ability to find the good in every event: After Norman Cousins checked into his hotel, he borrowed videotapes of Candid Camera and old Charlie Chaplin films. His claim that laughter helped his pain and improved his health inspired a number of studies that have shown humor and laughter to be therapeutic and enhance immune functions.

Feelings of gratitude stimulate neurotransmitters to increase chemicals like serotonin, producing feelings of peace and calmness, which lowers cortisol levels and strain on the immune functions. At cancer camp we were given techniques for developing an “attitude of gratitude” and it involved nurturing our awareness of what was beautiful around us, and what was good.

The practice of seeing the good goes far beyond any of the Pollyanna-ish stereotypes I might have harbored, and far beyond the rather superficial advice one receives to “think positive.” Instead, I found this practice gradually nurtured in me both appreciation and gratitude, and more—a sense of wonder. I became curious about the things that I appreciated, from a cup of juice to a tree to books and writing. I wanted to learn more about them, why and how they worked.

Ian Gawler’s curiosity and will led him to experiment with 27 different treatments to discover what would keep him alive. Lance Armstrong made his nurses explain every x-ray and procedure. Our sense of wonder propels us forward, if just to see what happens next. And if we can find the good in what happens next, or something that entertains us and makes us laugh, or makes us wonder again, then it seems like we might have an edge, survival-wise.

For me, curiosity and wonder deepened into interest, a genuine interest—not for the sake of passing a test or pleasing someone or trying not to die—but one that made me want to stay alive to learn things. And suddenly everything I was learning was helping me survive.

V

I’ve never seen any studies that try to measure whether grateful personalities really help people survive, but it has been observed that survivors of all types, when they look back, tend to see their entire difficult experience as fortuitous. Although they would seldom choose to repeat their experiences, they are grateful for them. In *Touching the Void*, Joe Simpson writes: “I often wonder what would have happened to my life if we had not had the accident on Siula Grande...I’m not confident that I would be alive today. In those days I was a penniless, narrow-minded anarchic, abrasive and ambitious mountaineer. The accident opened up a whole new world for me.”

Many cancer survivors, including Lance Armstrong and Ian Gawler, say they are thankful for their cancer. It is not uncommon for people to say that cancer is the best thing that ever happened to them, that it revealed inner resources they hadn’t known they had, and produced a deeper love for life and a great acceptance of events in life.

Psychologist Julius Segal has noted that “In a remarkable number of cases, those who have suffered and prevailed find that after their ordeal they begin to operate at a

higher level than ever before....The terrible experiences of our lives, despite the pain they bring, may become our redemption."

Of course, not everyone prevails. Life ends. And though our mental or emotional states may play a role in making that later rather than sooner, there are no guarantees. If you want to be a *survivor*, you simply do what a survivor does: evaluate, adapt, move forward regardless of prevailing opinions or statistical probabilities. A survivor must accept that whether it's in the wilderness or a burning building or a hospital room, there will be people who seem to do everything "right" and die, while others may do things wrong and live.

But even if our personalities can't save us from death, they will certainly affect how we experience it. So it seems worth it, even though there are no guaranteed outcomes, to cultivate survivor personalities if we can—to take a real look at the world, accomplish our small tasks while we can, find things to laugh about and think about, and when death comes to greet it with a sense of wonder, and gratitude.

December, 2003

As Paul helped unpack the groceries—finding the orange juice in one of the bags, opening it and drinking from the carton—he said, “Do you want to go to Perth in April?”

“I don’t know, it depends on the chemo schedule.”

“Did you decide to do the chemo?”

“Just for today.”

“??”

I moved around him to put the vegetables into the fridge. “My book says that you should weigh all the facts of a matter, but if you don’t see a clear choice, you should consult your intuition—like what does your gut say when you think about making a certain decision.”

“Uh-huh...” He was giving me a look that said he thought I was being a little crazy, but he was just going to roll with it, ‘So what does your gut say?’

“That’s the problem, I can’t really tell. So I have this plan. For the whole day today I’m going to be totally committed to doing the chemo. I’m going to make all my plans incorporating that into six months, and do my research and talk to people as if I’m doing it.”

“And then?”

“Then tomorrow I’m going to spend the whole day as if I’m not going to do it, and see if I feel different... I might have to do it a couple times...I’m waiting to feel a ‘sense of knowing’.”

“Okay,” he put the cap back on the juice and set it down on the counter, “If this works for you, that’s fine. I want you to feel good about your decision. But you need to know that I can’t do this. I can’t take the going back and forth. So I can’t talk about this anymore, but when you’ve figured it out, let me know.”

MY STRATEGY ON THE GROUND

Most people have at least unconsciously observed the infiltration of military terminology into the vocabulary of the cancer experience. Upon signing the National Cancer Act in 1971, Richard Nixon declared “a national commitment for the conquest of cancer, to attempt to find a cure.” This was quickly defined, and is now ubiquitously referred to, as the “War on Cancer.”

“Fighting cancer,” “battling cancer” and the obituary favorite “after a courageous battle with cancer,” have been used to the point where the satirical publication, *The Onion*, titled a news story, “Loved Ones Recall Local Man’s Cowardly Battle With Cancer.”

As Susan Sontag and others have pointed out, there is an “arsenal” of drugs and treatments available for each type of cancer. Since most of these cannot help but kill some healthy cells in the attempt to eradicate cancerous ones, the more recent extension of referring to these casualties as, “collateral damage” has not seemed unnatural.

It's the eye of the tiger; it's the thrill of the fight

Rising up to the challenge of a rival

(American Rock Group, *Survivor*)

“Beating cancer,” sometimes evokes for me a surreal scene from a football movie. It’s the last big game, the one that really counts for our hero. The Cancer team is clothed in red and black, while the Killer T-Cells are clad in glowing white. The cheerleaders in their white skirts, each with one hand on hip, the other arm circling in the air, extending on cue to accent their urgent message to the roaring crowds:

What do we do? We fight!

What do we fight? The rival!

I do not expect that language affects us all equally, but for me the best argument for military metaphor is its ability to galvanize, energize, bring to bear every rock anthem, movie, comic book, and TV show where the hero fights and overcomes. That’s

big-time belief that can support morale through treatments that are often tests of endurance—“a long and drawn out battle,” if you will.

And for me, the best argument against military metaphor is its inherent need for an enemy. The rival is that thing which is outside of us, threatening our survival. That’s why it’s so easy to get pumped up about hating it.

The problem, of course, is it’s not outside of us. Unlike viruses or bacteria, cancer cells are not invaders; they are us, our own cells with confused programming, our own genetic material gone wrong.

It seems like it would be tricky to declare war on ourselves, but we do it all the time. It’s just a matter of subdividing and naming, of separating single entities into parts, and conceiving of those parts as wholes unto themselves. Thus mind separates from body, head from heart, breast from bone from blood, just as peoples find their identities in their ethnicity, religion and political affiliation, and the globe becomes secondary to its countries. Having separated these things in our language, we start to believe that the parts are actually whole in themselves, that what we do with one part will not affect another.

In the realm of current events as I write this, we are engaged in what could also be described as “a long and drawn-out battle.” The war with Iraq was touted as essentially at an end after the 2003 “surgical-strike” in Baghdad eradicated the tumor of Saddam Hussein’s regime. But even around a surgical wound the tissue can become inflamed and infected if it is not tended to carefully, just as cancerous cells that are not eliminated, are likely to mutate and gain resistance, even break away and metastasize.

It’s tempting, especially when motivated by fear of disease in the body or disease in the body politic, to focus on what we want to cut out, to tell ourselves that doing so will not affect what remains—at least too much—and that what remains will not affect us. What is interesting is that when this proves not to be true, our thinking rarely changes; instead we are likely to expand the area of attack, still hoping that a stone thrown in the water might ripple in only one direction.

A holistic view, on the other hand, sees all our parts as interrelated, intertwined, forming a whole. Poison in the water upstream affects the fish and the people downstream. It affects the crops those people grow and sell to more people who might

not live near the stream at all. The world is composed of infinite elements striving to achieve some balance, and every action has a reaction. In this conceptualization, the idea of a surgical strike is hard to envision.

Why does metaphorical terminology matter to the person with cancer? Because to accept a vocabulary can be to—consciously or unconsciously—accept a worldview. And if we lack awareness of our own worldview there is the danger of making decisions that don't really investigate our deepest philosophies about what comprises a good, worthwhile life.

For instance, it seems logical that the removal an imminent threat to one's life is worth some long-term consequences. When I discovered there was tumor in my large intestine, I couldn't get it out fast enough. This was a reaction born of panicked terror, but fortunately, I believe it was also the right one. My surgeon was excellent, the strike about as surgical as you could get. The consequences are certainly manageable. I will probably need to support my system with diet and acupuncture for the rest of my life, but considering the alternatives, I am happy with the decision I made.

On the other hand, in 1980, my father found a small bump near his right ear. Fearful that the growth could extend into his ear canal, even invade his brain, he allowed the surgeons to take the largest portion of the ear, including the cochlea, the ear canal and eardrum, leaving only the pinna, or the outside rim of the ear behind. Pathology reports revealed that the bump, though cancerous, had not extended to the majority of removed tissue. In fact, a dermatologist later told him that using a laser, the cancer could probably have been removed with minimal damage. Instead my father endured pain, disfigurement, and severe hearing loss accompanied by a constant tinnitus. More than a year later he was experiencing anger, guilt, intense anxiety, and seemed unable to stop re-visiting the experience...symptoms of post-traumatic stress not dissimilar to those first observed in soldiers coming home from battle.

In 2003, months before my diagnosis, Paul and I watched on CNN as the United Nations debated the issue of an invasion of Iraq, and argued over the reliability of information from the Intelligence community regarding the existence and threat of weapons of mass destruction (WMDs) within the borders of that country. Paul and I asked each other, if there were evidence of weapons of mass destruction, was an attack

warranted? What if there was no evidence, simply the *fear* that there were weapons of mass destruction? What if the odds were 50% that there were, 50% that there weren't? What should such a decision be based on—practicality, logic, or morality? Should notions of morality change if a large number of lives lay in the balance? Did obligations to our millions of citizens change the moral nature of attacking citizens of another nation based on fear?

When the pathology reports from my surgery came back, they indicated that my cancer had been stage 3—it had broken through the intestinal wall and affected the lymph nodes along the tubes of the artery. The surgeon came to my hospital room to speak to us and said he had taken everything he could see, but he couldn't guarantee he'd gotten everything.

I looked at him. “Do you *feel* like you got it all?”

He met my eyes. “I feel like I did.” He was the kind of man you trust.

So it was possible that as I sat there I was already cured. There had only been one weapon of mass destruction and it had been removed.

The fear was that I was not cured, that clumps of mutated cells, called micrometastases had already spread away from the colon. When the oncologist came to visit the next day, she gave me the latest intelligence reports: In slightly more than 60% of cases like mine, colonies of cancer would appear elsewhere in my body within five years—the majority within the first year or two. If that happened, it was only a matter of time. The best outcome in a battle like this would be that it was long and drawn out. In slightly less than 40% of cases like mine life continued. The option the oncologist recommended was decreasing these fearful odds by 15% to 20% by means of a wide sweeping attack.

Chemotherapy in general is based on the principle that cancer cells are fast growing—they divide more rapidly than normal cells. If you subject a body to a cocktail of chemicals that are deadly to cells when they divide, it will kill many of the cancer cells, and not as many normal cells. Many of the side effects of chemotherapy, such as hair-loss, digestive problems, and mouth-sores, happen because cells found in hair, stomach-lining, and mouth tissue are fast growing. Chemotherapy can be curative—i.e. rid the body of cancer—only if the cancerous cells are still free-floating in the system.

Once they take root in another organ, any treatment is seldom more than palliative—it can temporarily shrink a tumor, it can extend, but can not save your life.

So for me, the object of six months of chemotherapy would be to eradicate the microscopic mutated cells before they could set up lodging, find sustenance and grow in other parts of my body. The object was to eradicate these cells, *if they existed*. We had no *evidence* that they existed, only history to indicate that in some past cases they had existed—and in some past cases they had not. The nature of the decision was strangely familiar: Is it ever morally correct to inflict damage out of fear? At what point does *likelihood* become grounds for self-defense?

Most people intuitively have an answer for this--our legal system is based upon it: Even a fearful criminal is innocent until proven guilty. In an ethical world—one that our government admittedly has strayed from—even accusations of conspiracy must be accompanied by proof. At the time, the U.S. government argued strenuously that there was evidence of weapons of mass destruction. The division of public opinion over our right to attack was based on differing beliefs about the existence of the weapons, and even those who held the most aggressive stance would not openly admit that they were willing to act based on fear rather than evidence.

In my case, there was no evidence. There was only fear. There was the knowledge that over half the time miniature weapons of mass destruction would hide in a person's system.

If I chose to attack with chemo, and no cancer revealed itself in five years, there could be no search to verify it had ever existed, but we would assume it had. I would be counted as part of the 55% for whom the chemo had worked, although there would be no way to tell if it had. The oncologist who came to visit acknowledged that my immune system would be compromised, and my long-term risk of developing other forms of cancer would be increased. If I chose to deploy their “top-of-the-line” recommendation, a cocktail formulated with platin drugs, I would likely have nerve damage in my extremities, and platins had not been in use long enough to say if that damage would be permanent.

“Wow,” said Paul after she explained the battle plan, “That’s certainly...*inelegant*.”

The collateral damage was certain, even though existence of the enemy was unsure. The oncologist argued urgently for the chemo, but ultimately, the choice was mine. It was up to me to decide: If my body was made up of civilians—healthy normal cells unaware the conflict, who had done nothing but provide service over the years-- could their destruction be warranted by my fear?

Embodied in this question was another: How did I intend to conceive of myself? Was my body a landscape to be co-opted as a battlefield while my mind bore witness? Or was it an integrated system, a whole entity that could be affected by any number of causes?

In the end, I answered these questions for myself and chose to set aside my conventional weapons. It was a decision that my husband and family supported; that some friends feared indicated I wasn't "facing reality."

I can't pretend my decision was all about an enlightened pacifist mindset. Like anyone, if I had been able to see my enemy, and had the means to make it disappear with no price to be paid, no vigilance required in the aftermath, it's likely I would have done so. But in cancer, as in modern warfare, facing reality means facing the fact that even seeming victories cannot entirely erase the fear of retaliation from unseen quarters. Nor does my choice to gamble on long-term health at the expense of a short-term solution eliminate the fear that I may have trusted too much.

Every decision exacts a cost. In my case, military/medical language might have called the price exacted for chemotherapy, "collateral damage." I called it "me," and decided the price was too high.

DETOUR, CANCERLAND

If Tom Cochrane is right, and life is a highway, then getting cancer is an unforeseen fork in the road. Maybe you've not been paying attention, or perhaps the large semi-truck in front of you that has obstructed your view, so that by the time the green and white signs overhead become visible, the road is already dividing, and you're a lane headed to Not-Where-You'd-Planned-To-Go at eighty miles an hour. You begin searching for an exit ramp but there are none in sight. Carried with the speeding traffic ever farther from your original destination, you start to fantasize about illegal U-turns, but on cue, the median strip sprouts a metal fence, then a concrete divider. As the scenery becomes unfamiliar, your cell phone drops out of network; it's time to reconcile yourself to the fact that your trip will involve a detour. Down the road, when you finally spot an exit and pull off, you'll find yourself in a place you've never seen, with no clue how to get back to where you were.

When I was diagnosed with cancer at the age of 33, I was surprised, as anyone probably would be. And yet, looking back, I think there was a part of me, underneath, that wasn't so surprised, a tiny part of me that had expected to be pushed off course. After all, I'd been getting lost my entire life.

When I was four, I had a small red plastic pedal car. In the evenings, my father walked along with me as I toured the sidewalks of our neighborhood. He carried a hooked cane with which he could snag my bumper and pull me back if I started to drive into harm's way. The floor of the car was only inches from the ground and as I pedaled, I felt the vibration of the bumpy cement sidewalk through my plastic wheels; I listened to my father's voice; I watched the multi-colored pebbles embedded in the concrete roll past; I studied the sandy brown ant hills in the cracks. What I did not notice was where I was going. I remember these drives as pleasant, but on at least one occasion the evening turned sour. As we paused at a corner on the way home, I waited for my father to nudge or tap the car with his cane, indicating a direction. Instead he asked,

“Which way?”

I froze. Suddenly asked to contemplate the big picture, to look up from my vantage a foot off the ground and comprehend the houses and streets and where our house sat in context, I was stumped. Not wanting to disappoint, I tried to fake it, and

turned my black plastic steering wheel the wrong way. He corrected our course, but at the next corner I found myself at the same impasse.

“Do you really not know where we are?” My father asked. “Go right.”

Flustered, I got confused and turned the wheel left, unleashing a harangue of back seat driving that lasted the rest of our journey.

“Stop up here...Goddamn it Susie, I said stop! Were you planning to stop? Now inch up to the curb and take a look. Now do you know which way to go? Jesus Christ! Go left!”

My father was forty-four, a college professor. I was the first product of his second marriage. Calculating the dates, I know now that as we traversed the neighborhood, he must have carried in his body his first of several cancers—its discovery just around the corner.

When we arrived at the house, he recounted our travails to my mother. “I don’t know what to do if she can’t tell her goddamn right from her left!”

“Gene, calm down. She’s only four.”

“Well, I don’t know what she’s going to do out there!” *Out there* apparently referred to the vastness of the world I would someday be asked to navigate. He shook his head, the red slowly subsiding from his face as he stalked away, leaving me, with my own red face and my tears, to the care of my mother. She sighed, gave me a Popsicle and permission to go out in the yard and play with the neighborhood kids while she finished the dinner dishes. At thirty, she was younger than I would be at the time of my diagnosis. She had already borne three children and begun to manage a few rental properties. She had recently moved her dying mother from California to a small house a few blocks away from ours in Indiana. She was smart and industrious, still new enough to marriage to think that she might, through some effort, find and repair the hidden switch that seemed to turn on her husband’s sudden bouts of angry despair.

My father’s bouts of anger were, to a child, terrifying—made more so by their seeming randomness. Only later have I come to understand that his outbursts were always provoked by anxiety or fear when encountering circumstances that were beyond his control. And our ill-fated trips in the little red car must have highlighted, for him, more than my inability to navigate. He must have seen, if only subconsciously, certain

uncontrollable aspects of himself becoming manifest in me. He must have noticed in me the same dreamy quality, the same tendency to be snared by the odd details on the fringes of existence that compelled him to do things like rescue plastic cottage cheese lids from the kitchen trash and transform them into model airplane propellers. At a subconscious level he must have been aware of the fact that he, himself, had little sense of direction.

My younger brother and I resemble my father most in terms of appearance, temperament and talents. In the mid-nineties I moved to Los Angeles, with the idea of directing films; my brother followed a half-decade later to pursue a career as a composer. We can share almost identical stories of setting out for Pasadena and ending up in Pomona. A conversation once revealed that we both considered Dominoes pizza delivery to be the most stressful career we could think of.

My father, whose misgivings regarding my navigational abilities were indeed prophetic, lives in some denial regarding his own sense of direction. Visiting our adopted hometown of Los Angeles he rides shotgun as my brother drives us to Santa Monica.

“And up here is where we’ll turn onto Sepulveda!”

My mother, next to me in the back seat, says nothing, but I see a suppressed smirk, hear the slightest exhale of air. My brother and I suspect her of somehow withholding that genetic material which contained aptitudes for numbers, finding things, completing tasks on lists.

“Pretty good,” I reply, diplomatically, not wanting to treat my father like a four-year-old in a pedal car. “Actually we’ll turn onto Wilshire. It goes east-west, but it does meet up with Sepulveda...a few miles from here.”

In my temporary home of Tallahassee, Florida, I let my husband, Paul, do any driving that extends beyond the most commonly traveled territory. Occasionally, however, I feel momentary twinges of obligation to note my location in the world and so rouse from a reverie of shiny streetlights and store windows to ask, “Is this Adams?”

Lacking my own diplomatic nature, he simply looks at me to make sure I’m not kidding, then shakes his head in amazement, saying, “I can’t even imagine what it’s like to be you. If I was really that lost all the time, I think I would freak out, and possibly try to kill myself.”

I can conjure only the faintest sense of what it would be like to have a sense of direction. What if driving across town felt like walking to the neighbor's house across the street? What if the route seemed that clear? What if I felt that much control over my destiny?

Upon a diagnosis of cancer, how you feel – how I felt—before you feel anger or despair or panic, is lost. A big bowling-ball-in-the-gut lost. A sucked-into-the black-hole or pulled-through-the-stargate, or beamed-into-a-million-separate-particles-in-the-deep-void-of space lost. One day I was in Alice Springs, preparing for an art show, taking my fertility tests, picking out baby names, and the next I was nowhere, my plans left scattered on the side of the road as if abandoned by a hitchhiker who got abducted by aliens. But despite this, I wonder (as I drive around, not thinking about where I'm going) if that moment of lostness was easier—or at least more familiar—for me than it would have been for Paul, or one of those other people who, from the outskirts of an unfamiliar town, can dead-reckon their way to the center and find the exact Mexican restaurant vaguely described by some guy at a road-stop two states away. If I had been someone who could find my car parked at the shopping mall, who was accustomed to the experience of leaving my house with a destination in mind, and actually ending up there, who had had a plan, what would that moment of being blown off the road have been like?

I can't imagine.

My father wanted to be a comic strip artist. From a young age he drew, in the muscled, clean-cut 40's newspaper strip style of *Steve Canyon* and *The Phantom*. When I was young, my sister, brother and I were the stars of our own series, about children who are whisked away from their home on a Viking ship. I sat squeezed next to him in his black leather recliner while he showed me our ongoing adventures, too young to read into these escapist fantasies his dissatisfaction with his life as a sociology professor. Only later do I recall him telling how, as a teen right after the Second World War, he had traveled to New York City with his father, and visited "the syndicate." The editor there had looked at his work and said he had talent, that when he finished school my father could come and see him about a job.

My father never went. Instead he finished college, joined the Air Force, worked for an oil company, went back to school, married and began his first family, divorced, remarried and had us. Then—was it before or after his surgery for cancer of the colon, or cancer of the pancreas, or of the eardrum?—he began to say, and continues to say, thirty years later, “I probably should have gone to New York.”

I graduated from college with a degree in theatre, and decided to become a film director. In school my most successful efforts arose from directing scenes I had written. I dreamed of telling cinematic, otherworldly stories in the style of Lynch or Jarmusch. And yet, when I arrived in Chicago, and later L.A., I continually took jobs where I organized, managed, and facilitated other people’s ideas for selling cereal or cars or Shimmer-and-Shake Barbie dolls.

I could look back on those years and say, “I probably should have taken a screenwriting class, or applied to film schools, or tried to find a mentor in the business.” Why didn’t I? My answer is eerily identical to the one my father gives when asked why he didn’t go to New York: It didn’t occur to me. Only in hindsight do I see any of the practical steps that might have led to my stated goal. It was as if I could only think about my deepest desires in the abstract. In the concrete, I moved as if magnetically pulled toward positions that utilized, not the creativity bequeathed by my father, but the strengths inherited from my mother: my resourcefulness, my reliability, my overwrought sense of responsibility and accountability that made me ideal for making lists, making phone calls, “making things happen” for whomever hired me. As a chauffeur for other people’s details, I did not falter. I ensured the T-shirts were printed with the correct logos, the blue-screen paint arrived on time, the fake walls were cut to fit through the loading dock doors.

But in terms of making things happen in my own life, I was like a novice at the pool table—I made my shots without calling them, and soaked up the praise for any ball that went in a pocket, half believing that was where I had intended it to go all along. This is what I imagine happened to my father. He simply took whatever road presented itself—a job with an oil company, a degree in sociology—without wondering if perhaps he should wait for the one he was looking for that might be a little further on.

As the jobs I received became more lucrative, I no longer talked about wanting to tell stories. The people I worked with saw me as someone who had a direction and I told myself they were right, that the path I was on was somehow a path I had chosen, or at least one that had chosen me. Perhaps my fatalism was connected to my lack of navigational skill. Despite maps and strong intentions, in my experience, the endpoint of any journey was a matter of luck. I believed in the concept of a life's calling—but didn't see how, even starting with a sense of what that was, to find my way to it. In need of some overarching principle to explain this seeming paradox, I concluded that wherever I ended up must be where I was meant to be. When opportunities appeared, in the form of jobs, roommates or boyfriends, they were the ones I was meant to find. It is possible, of course, to extend that logic even further: If I ended up in Cancerland, then that must have been where I was headed.

A common response to cancer—both for the patient, and for friends, family and co-workers of the patient—is to express a desire to “get through” the treatments, so that one can get “back to normal.” From this view, the cancer is merely an unfortunate detour, and one's main aim should be, as quickly as possible, to regain the road from which one has been removed by disease. A less common view, but one which has its proponents, is that disease is a message, from your body or the universe, suggesting that the road you are on, or the speed at which you are traveling, is not quite right. An acute disease pulls you off your path, out of your life's traffic, and ensures you have the time to contemplate a change in course. Such a perspective naturally, once one becomes conscious of having gone astray, leads to a desire to mentally retrace one's steps, to figure out what might have been the impetus for the detour.

In the earliest days of my illness, I joined the former group. I wanted the quickest route back to the main road, and for a while I was so scared of making a wrong turn, I couldn't move. For several weeks I was stalled out, unable to decide on a course of treatment. Friends in California convinced me to talk to a woman named Parmelia. She was an amazing psychic, they told me, and a dear friend. She was really looking forward to talking with me. I called her, long distance from Australia.

“The cost is \$250 an hour,” Parmelia announced.

I didn't ask if this was the discounted price for dear friends. She slowly and clearly recited her address in the Pacific Palisades where I should send a check. She advised me to wear greens and blues and not red while I was healing, to get massages, prodded at me with questions like, "Can you accept that you are the most important person in your life and that your needs have to be met? Can you ask for help? Are you comfortable asking for help?"

I listened to the tape of our conversation recently, and was surprised to find her tone not quite as overbearing as I remembered. Although I can only hear her side of the conversation, it's evident that much of what I'd perceived as prodding was in response to my own rigidity—I was *not* willing to say I was the most important person in my life. Long pauses follow her questions as she waits for me to finish tap-dancing around what seem now to be yes or no questions. They didn't seem so then. It felt bald, even crass, to say plainly that I was the most important person in my life. Not only was I uncomfortable asking for help, but I was embarrassed even with the implication that I needed help.

What I received in that hour was less a psychic reading than a crash course in common holistic perspectives on illness. My first instinct was to reject advice that was so obvious, cliché and overpriced. On any other day—that being a day I wasn't terrified about dying—I would have rolled my eyes at being told that the path to healing was to love myself, do things that made me happy, pay attention to my spiritual well-being as well as my physical health, express myself more readily. As it was, I hung up the phone disappointed there had been no epiphany, no sign indicating without question which direction I should go.

There is a story about a man who finds a large rock with the inscription "Beneath this stone lies a new truth." The man sweats and strains to move the rock, and finally uncovers a small box with a scrolled parchment. The man unrolls the parchment to find written, "Why do you seek new truths when you do not use the truth you know?" As time went by, Parmelia's life hints would keep appearing, in other forms, from other sources. Little by little I would come to realize that what I had defined as simplistic advice was not so simple. Understanding the words "love yourself" was not the same as doing it. But in the weeks after my diagnosis I did not want advice I could hear in a Whitney Houston song. I wanted to find some new, powerful knowledge that would change everything, a

magic portal that would lead me back to what I deemed “my life” directly, with no twists or turns.

In her book *Heal Your Body*, Louise Hay, a cancer survivor and popular self-help book author, lists various ailments and areas of the body and the kind of emotions they relate to. Bowels, of course, represent the release of waste, and problems with them indicate a fear of letting go of what is old and no longer needed. Cancer indicates a harboring of long-standing resentments. Susan Sontag railed against the idea that our diseases result from our natures, exhorting us “To regard cancer as if it were just a disease.” Her reasons for this I recognize as valid, but I still pick up Hay’s rainbow-colored books from the bookstore shelves and look at the checklists for familiar characteristics:

On my father’s side of the family, I am the descendent of holders—people who cannot let go of old baggage or old luggage, or papers or textbooks or half-broken musical instruments. And resentments? My father’s mantra regarding his missed opportunity in New York is interspersed, even in retirement, with sporadic diatribes about shortsighted department chairs and decisions they made years ago. My brother, whose first colonoscopy at the age of 31 revealed a pre-cancerous polyp, can take a single example of injustice and wield it like a knife, whittling away at his abuser’s character until there is nothing left but a pile of curled wood shavings on the floor. And I, in the days before my diagnosis, spent entire days filled with a rage I was unable to understand. It arrived randomly, and though it associated itself with whatever situation was close at hand, I could intuit that the people and things around me were simply landing pads for the anger alight upon, not its source. Since I didn’t know where it came from and my environment didn’t contain a legitimate receptacle for my anger, I held on to it, along with my fifteen-year old piccolo from junior high and my super-eight camera.

In the realm of conventional medicine, cancer is a physical condition, to be treated physically. One does not need to know the birth of the disease to begin striving for its death. In holistic thinking, the cancer is regarded as the symptom of a deeper imbalance, that might be emotional or spiritual as well as physical, and to understand the source is a step in regaining the balance needed for sustained health. From the beginning I resisted, and still do, the idea of one-size-fits-all causes—or cures—for cancer. At the

same time, I think there are very few people who upon deeply contemplating their lives can come away without seeing any areas that might be re-interpreted, and perhaps re-envisioned in the future.

In screenwriting, as in acting, there are a number of questions you ask of your characters in order to develop them into Oscar-worthy three-dimensional personalities. The exact type and number of questions differ according to the method of guru you subscribe to: What does your character want? Is your character a do-er or a be-er? What would your character wear to a party? My favorite screenwriting teacher once pointed out that each template list of queries is just a different way of “plowing the field,” an imperfect exercise in churning up information and softening the ground of a story. The exact list of questions you ask or number of blanks you fill in is unimportant; what is important is that these tools help you do the work of deepening your understanding of the world of the character.

Psychics and self-help books naturally fall into the category of imperfect tools. Neither provided me with any custom-fit answers or formulas for fixing my life, but as I careened about in the weeks after my surgery, they were the random obstacles into which I crashed. And their impact was that I became aware that there was a field to be plowed. For the first time, I paused and began to question the implications of my illness. I wondered if there might be some meaning in what I was going through, and by extension, if there were some relationship between my emotional life and my father’s. Had similarities in the way we traveled through life brought us to the same place?

Throughout my childhood, each time my father was confronted by cancer, he’d appeared to galvanize. He’d gritted his teeth through the pain caused by surgeries, and after, with daunting emotional or mental energies, somehow rebuffed the recurrences typically experienced by others. And for short periods afterwards, as physical relief replaced pain, he’d expressed joy and gratitude. Over time, however, his repeated illnesses had not inspired him to let go of his fears, but given him reason to cling to them more dearly. Could the way I grappled with these same tendencies make a difference? Was there a lesson I could learn to avoid sharing his fate?

I should disclose at this point that the answer to these questions, at least according to my genetics specialist, is no. My family’s cancer is not an outcome of any paths we

have chosen, but merely symptomatic of our internal maps of spiraling DNA. Someone adept at reading such maps could perhaps even point to the culprit, a gene located on chromosome two between base pairs 47,483,766 to 47,563,863. Someone with a supernaturally keen eye could see where, in the microscopic twists and turns, something has veered off course, snarling traffic, causing a chain collision of sorts: The protein emitted by the confused gene doesn't perform its normal function of repairing mismatched DNA pairs, allowing for mutations that result in cancerous cell growth.

If there were not the easy explanation of genetic legacy, there would be other causes to consider: Pollution, pesticides, trans fats, processed foods, the nutritional depletion of our soil and a proliferation of hormones and antibiotics in our livestock. Since 1950, the overall cancer incidence has risen by 44%, breast cancer by 60%, prostate cancer by 100%. It would not be a stretch to see anyone's cancer as a message, not just to that individual, but to an entire culture that is careening off course.

Medical science has direction: Its purpose is to try to kill cancer while preserving human life. Its purpose is not to have warm and fuzzy discussions about what any given cancer might say about changing one's life.

People who know where they are going, who have a mechanical sense of how things work, have less need to create myths and other constructs. If you can chart the weather patterns, if you can see a hurricane as a simple convergence of low air pressure and warm temperatures over moist ocean air, you are less likely to conclude that it is the work of angry gods.

But what if a hurricane is just a combination of those components AND the gods are trying to tell you they're angry?

At its core, this question only echoes the neglected viewpoint of those overlooked vehicles of reason in one of the largest roadway debates of our time: Jesus-fish versus Darwin-fish car decals. Everyone is having so much fun battling each other with their fish that there's little room for those in the middle of the road who point out that scientific observation of events does not negate the possible existence of higher powers.

Thus scientific medicine must align itself against alternative medicine by insisting that a disease that manifests itself physically can only be the result of a physical cause

only treatable by a physical cure while at the other extreme, there are alternative practitioners who don't admit that any disease could be rooted solely in the body. It is left to those of us living with illness to wonder: Is it impossible that we can now look inside our bodies, map the spirals of our DNA, see the patterns...*and* that the gods are still trying to speak to us?

Two years ago, over twenty years after his first diagnosis, my father was diagnosed with primary stage colon cancer for the second time in his life. His battle with prostate cancer has been ongoing for several years, his PSA count—those numbers with which one's time left is estimated--have risen, then fallen with the addition of new treatments. He still jogs a slow three miles every other day, but when I visit, he speaks of waking in the mornings with feelings of anxiety. He worries he might outlive the relative physical ease and comfort he now enjoys, he worries that he might live beyond my mother's ability to care for him in the manner to which he is accustomed--but he does not want to die. He still draws his comics, weirdly anachronistic military sagas that place World War II style and sensibility into early twenty-first century political landscapes and deliver Fox News-inspired messages. He still hints that he would like fate, in the guise of friend or family member, to miraculously transform his piles of drawings into a media empire. But when it comes to taking the next step himself, he has a litany of reasons why he can't, he couldn't, how it's too late. In his heart, he long ago decided that the road not taken was somehow the only route to his dream destination.

Some of my friends with cancer have always known what they wanted; be it houses and babies or specific careers, they could see their futures in their minds' eyes. They were on the right road, until cancer came and pushed them off it, like a careening semi or hundreds of incontrovertible orange cones. They firmly feel the wrongness and injustice of this and do not ruminate on the idea that what we see as disease might only be the symptom of something larger. In the face of their pain and suffering which has been inarguably worse than my own—it feels almost disrespectful to say that I am thankful for my cancer. For a—so far—relatively low price, I have been given access to tools I did not have before, somehow I am less afraid of failure, more willing to set course for a destination, better able to discern if I am heading in the right direction. If, as Tom

Cochrane says, life is a highway, then cancer has provided me with, if not a map, then perhaps a compass.

By stating the matter thus, I forfeit my right to jump confidently into activism, to walk and run and march for a cure. Nor can I be one of those who, upon seeing the entrance ramp, jumps back on the road, maneuvering into the passing lane in order to get back to “normal” as quickly as possible. I am healthy now. I have left the heart of Cancerland, and gratefully so, yet I find myself reluctant to merge with traffic too quickly. Instead I take the service roads, going in roughly the same direction as the others, but more slowly, still looking back in the direction from which I’ve come. This time I’m trying not to let the trees and fields fly by unnoticed. I think I am more able now to see the bigger picture, and that can even begin to visualize where I am in it. The road under my wheels feels familiar, like I might have been here once before, long ago, and I have somehow found it again.

I *feel* inside myself, that I am already doing what my father could not, that by accepting my detour, by taking the time to more fully explore the places it has taken me, I have somehow changed my ultimate destination.

This could be wishful thinking of course. It could be that none of us has a destination at all; those green and white signs are merely illusions, placed overhead to give us a sense of purpose, to keep us moving. According to the *Newsweek* and *Wired* magazines that appear in my mailbox, it is only a matter of time before science will be able to link our every emotional response and inner conviction to certain neurotransmitters and chemical balances in the brain. But that doesn’t mean the gods aren’t communicating with us. It doesn’t mean they aren’t standing in the roadway, wearing jumpsuits and holding orange flags, trying to wave each of us onward, in the right direction.

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²⁵ Segerstrom (2003) One hypothesis to explain this is that optimists might be more disappointed by failure, with the emotion of disappointment affecting the immune function. Tennen and Affleck put it, “The best doesn’t always occur. When things go wrong in a big way, the optimist may be particularly vulnerable.” Segerstrom, offers an alternate hypothesis, proposing that optimistic people are likely to keep trying to resolve a difficult situation after more pessimistic people would have disengaged. In laboratory experiments, optimists were shown to spend more time on difficult arithmetic problems or anagrams than those who were less optimistic. Segerstrom notes that, at least in the short term, continuing to engage with the situation might be physiologically more stressful than giving up. If this is the case, however, the long term effects of optimism in difficult situations remains to be tested. In some instances it seems likely that prolonged engagement might actually lead to success, or at least the knowledge that whatever solutions were available have been tried. This, in the long run, might alleviate stress and thus raise immune function.

²⁶ HealthDay News Oct. 22 2007 <http://www.healthfinder.gov/news>

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²⁸ Here it’s helpful to go back to basic definitions. One aspect of *personality* includes *the behaviors and techniques for solving problems that are used by an individual. Behavior* can be defined as our *actions or reaction in response to external or internal stimuli*. Finally, *a stimulus that causes a physiological reaction is a stressor*. So we know that the way we react to stress, as well as to non-stressful events, is a large component of our personalities,

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BIOGRAPHICAL SKETCH

BARRINGTON SMITH-SEETACHITT

Education

M.F.A. Creative Writing Florida State University, expected June 2008
B.A. Theatre and Drama. Indiana University. May 1992

Other Training

Certificate III. Creative/Applied Arts, Charles Darwin University (AU). December 2003
Spanish Language. University of California, Los Angeles Extension, 1995-1999; Instituto IDEAL Cuernavaca, Mexico 1998; Forrester Institute, San Jose, Costa Rica. 1999

Publications / Awards

Publications:

Paul Eats: Perth, the Diner's Best Friend in Perth Woodslane Books, 2005
"Drawing from Life" *Bushmag Journal of the Outback*, 2002
"One More Reason to Stop Drinking Sodas" *Moxie*, 2002
"My Panda," *Sycamore Review*, Winter 2007

Awards:

Scholarship, Key West Writing Seminar, 2008
Teaching Assistantship, Florida State University, 2005
Nominee, Excellence in Teaching First Year Writing Award, 2007
Honorable Mention, Best New Artist, Central Australian Art Society 2002
Best Work in Media Prize, Centralian College / Charles Darwin U. 2002

Readings / Conferences

Readings

Ali Baba's Restaurant 2006, Featured Reader
Northern Territory Writers "Hot Words, Cold Nights" 2003, Featured Reader
FSU Writers Series at the Warehouse, Fall 2007, Featured Reader
V89 Radio, Tallahassee "Voice Box" Winter 2007, Featured Reader
V89 Radio, Tallahassee "Voice Box" Spring 2008, Featured Reader

Conferences

Association of Writers and Writing Programs (AWP) 2008, New York –Panelist
Association of Writers and Writing Programs (AWP) 2007, Atlanta –Attendee

Work Experience

Florida State University Web Content Provider 2006-Present. Writing news items, alumni profiles and public interest pieces for the English Department website.

Florida Department of Education, Assistant Editor, 2007. Reviewed and edited test administration manuals, letters, memos and reports.

Florida State University, English Composition Instructor 2005-2007. Duties included planning syllabus and reading materials, delivering lectures, evaluating student work and one-to-on conferencing. Courses taught included

Composition and Rhetoric ENC 1101

Writing the Research Essay ENC 1102 and 1122 (Honors students)

Improving Reading and Writing Skills ENC 1905 (Individual Tutoring)

Florida State University, Reading and Writing Center Tutor 2005-2008. Provided individual English skills assistance to a variety of students, including ESL and remedial.

Red Dust Theatre, 2002-2004. Provided production assistance and organization for administration and theatrical productions. Facilitated creative workshops.

Freelance Event/Video Producer and Coordinator, 1999-2001. Produced and/or coordinated large events for companies in the Los Angeles, CA and Costa Rica.

Mattel, INC Production Coordinator 1996-99. Liased between marketers, creative and production personnel to produce and cast in-house and public events including the annual New York Toy Fairs.

Universal Studios Hollywood, 1996. Stage Manager for a live show featuring musical numbers, mechanical lifts and pyrotechnics.

Freelance Film Production, Los Angeles 1995-96. Served in a variety of production capacities for films, commercials, interactive games and music videos.

Freelance Media Production, Chicago 1993-95. Served in various capacities for commercials, industrials and short films. Roles included: Production Coordinator, Grip, Production Assistant, Stylist's Assistant, Office Assistant, Props Assistant.

Community / Arts / Volunteer Work

Co-Host Creative Writing Program Visiting Writers Reading Series, Spring 2007. Organized publicity for weekly guest readers. Coordinated with venue and audio-visual technician. Served as M.C. at each event.

Actor, 1989-2007. Supporting roles in academic and community theatre and film.

Director, Red Dust Theatre, 2005. Directed three short plays staged at the 2005 Alice Springs Festival, one of which continued to the Fringe Festival in Darwin in 2006.

Central Australian Art Society, 2001-2004. Committee member 2003. Helped produce and promote the society's Annual Art Prize 2002 and 2003.

Dance Instructor, Mapping New Territory, Sept-Oct 2003. Taught weekly creative dance classes for students of mixed abilities for a disability/arts initiative.

Dance Instructor, Community, 2002- 2003. Co-taught four 6-8 week sessions introducing Latin and Swing dances at a high school and community center.

Documentary Filmmaker, Red Shoes Theatre Company, Sept-Nov 2002. Recorded pre-production process, and coordinated multi-camera shoot of an all-woman outdoor show, *UnSpun*. Edited sequences used for documentation and funding applications.

Event Volunteer, Dream Halloween 1996-1998. Assisted on-site for this annual Los Angeles V.I.P. fundraiser benefiting the Children Affected by Aids Foundation.

Member / Director, Subterranean Theatre Company 1996-1997. Founding member Los Angeles based theatre. Directed two short plays for premier showcase.