WHAT ELSE BUT GRACE

not well, but better

BY

JANET KENNEY

(c) Janet Kenney
52 Strathmore Road #44
Boston, MA 02135
617.543.1403
missjanetkenney@gmail.com

> Any fool can handle a crisis; it's the day to day that wears you down.
>
> Anton Chekhov, Russian playwright and country doctor

For my Mother and Father,
Helen and Bud

But he said to me, “My grace is sufficient for you, for my power is made perfect in weakness.”
2 Corinthians 12:9 NIV

Courage is grace under pressure.
Ernest Hemingway

Grace is not part of consciousness; it is the amount of light in our souls, not knowledge or reason.
Pope Francis

Everyone is flailing through this life without an owner’s manual, with whatever modicum of grace and good humor we can manage.
Anne Lamott

March 2007

Memoir Now

I am writing a memoir because I think I'm losing my mind. When I was teaching as an adjunct professor, my students' names would morph and I would be forced to call them by one another's names, which they minded. This happens to the children I nanny for now; they get mad when I call them by the dogs' names. It's the frustration I feel when my dog forgets where her leash is. She has two, so there's really no excuse for that kind of carelessness. It may just be the kind of loss that comes from city life and country life and suburban life. There's just this loss that happens to middle-aged people, people with children and/or pets, people who live on earth and people with more than thirty years of debilitating, progressive chronic illness behind them.

I didn't plan to write a memoir until I was at least seventy. This would be after the Pulitzer Prize for drama. I've written a dozen plays or so by then, but they can't all be Pulitzer prize winners. I'm happiest about the Obie, the Off-Broadway awards. I live on the income from a few movies that have been made. Or one, even. There is some teaching - special seminars with people who really want to study writing, and who, maybe, want to study with me.

My husband (or perhaps he's just a gentleman friend) and I live in a small house on Cape Cod and tend an English cottage-style garden. In the evenings, we walk our plot of land, listen for the crunches and squeaks the night creatures make as they take over the property. The dogs walk near us, but not too near, exploring, and letting these night creatures know they'll be around. This man and I hold hands. We talk ourselves to sleep, still full of secrets and ideas.

Our home has original pumpkin pine on the floor, hand-made quilts piled and hung everywhere. The windows are sparsely decorated to let in the light, and to keep the land in view. If I go to town during the day, I come back with a bit of gossip; he does the same when he goes. It's just storytelling; there's no viciousness in it. After a morning run in the nearby woods, the dog snoozes nearby while I work, and I've long given up on keeping her off the quilts. There's one on the bottom of the bed that has some tears in it; that's hers. We've been through some scares; the man has had prostate cancer, but it was caught early and cured. He has a stent in his heart. As for me, I am always, always, always sick. We're used to it. We made it through the bulk of our lives together intact, not bitter, and we have love. So it's time to write the memoir.

Except it's not, because I'm not 70, or near it. I'm 48, and if I make it to 50, it'll be a miracle.

Recently, I almost killed my dog. Grace is a beautiful Maltese poodle mix, though there's something else in there, I think. Bichon? She is probably an African white dwarf giraffe. I have her hair cut short by our groomer, so she looks like a lamb. People stop us all the time to ask what she is. I tell them, yes, she's part sheep. At two, she's about 18 pounds with floppy, fluffy ears and brown vampire eyes.

For a dog purchase, white was a dumb choice. She's at the park or in the garden or at some other dirty spot every day, so she's always filthy. She likes to dig holes. She digs until she can fit her whole body in the hole. I read or write or garden, look up to check on her, or just sit and watch her do this thing she excels at. She glances around from time to time, suddenly territorial, because, really, it's a great hole and it's *her* hole. Fun for her, fun for me, till this filthy creature wants to come into my home.

Before I got her, my apartment was ready for its *Country Living* close-up. I pour over magazines like that. I cut out pictures of rooms I like and keep them in a photo album. In my home, which is decorated seasonally, there are fresh flowers in vintage McCoy vases, white bureaus (butter cream white, painted the same color as the walls), a white office armoire that was built to fit that space, and a matching wooden file cabinet with multiple drawers to keep the clutter down. There is a hand-made white and periwinkle blue bookcase from, probably, the '30s, white beaded or embroidered or quilted pillows...white as far as the eye can see, which is not very far. It's a 427 square feet studio in the Brighton area of Boston.

In the 16-foot kitchen, a red and white plaid tablecloth that belonged to my friend Suzanne's grandmother is neatly hemmed and tacked with red buttons for a valance. There's a bright red hand-made shelf whose legs are made of empty spools of thread held together on a dowel. 1940's-era white and red aluminum-ware sits near the stove and on top of the refrigerator. The bathroom, working off of the white and black log cabin pattern floor tile, is done in white, with a jacquard pattern lace shower curtain and a sequined white window curtain and vintage crystals hanging from a plant hanger. I keep the blinds half-open to let the soft north east light in.

Into the middle of this comes Grace. Grace has usually found something disgusting to roll in. Dog pee is easiest to get at, goose poop sticks best, and spreads nicely on her coat and leaves a deep green stain even after it's wiped. She's so curly it's impossible to really brush it out, but I wipe her down as best I can and think of myself as a lesser person because I don't want my dog to be dirty, even though it’s her birthright. We negotiate this all the time, and I’m trying really hard. My first priority is her health, but my second priority is my sanity and, then, third, my décor.

We live near the Cleveland Circle Reservoir, which is a state park. There, I let her off her leash because, after lots and lots of training, she comes right back when I call her. I like to give her as much “dog” time as possible, and I’m most content when watching her enjoy herself, but when I see her dive towards the ground, long graceful neck first, I know she’s got something dead.

“Leave it!” I call, but she’s too far gone. Somewhere inside that goofy little house pet, there’s a wolf that needs to cover its tracks so its enemies cannot track it. The best I can do is to get it away from her. I hobble over. I wear a cast on my right leg. There’s no point in it, meaning that nothing is healing in there, but it’s too awful to walk without it. She’s rolling in a mouse’s little corpse, transported. Using a stick, I pop it away from her, knock it as close to the water as possible. She gets a good scolding for not listening, but I can see in her eyes that she can’t help herself. And I think, Fair enough. That was a really good corpse.

- Would you like to go to a shelter? I ask her, but she doesn’t get the joke. Or maybe she does, and she knows I’m too far gone; nothing could make me lose her now, except for my own carelessness and extraordinary level of distraction brought on by intractable fatigue, terrible pain, the 12 or so diseases I have acquired and the 27 medications I take.

On the afternoon that she was almost killed, we headed out in our usual discombobulated state. Our friend Moxie, a shih tsu/bichon mix, was with us. First, I went back for my scarf. Then, for my crochet, in case I had time to work on it later. Then for my

Transportation Access Pass - a discounted pass for the disabled passengers on the Boston transport line. I locked the door, then the two dogs waited patiently in the hallway while I unlocked the door another time and go back in for some water. After going back one more time for dog treats, we headed out. I asked the trainer if that would make the dog crazy – this “six trips back in” all the time, but she told me that dogs get used to what they are used to. Grace doesn’t know some people make it out the door on one try (show-offs).

Right before we left, I had checked my temperature. Slightly elevated. My right ankle and foot were throbbing, though I’d taken one and a half Percocet half an hour earlier. Sometimes, it takes at least an hour to help. Some days, it just doesn’t get through. My glasses felt as if they were crooked. Some days they are, and other days it’s my eyes that are off. Fairly often, the left eye blanks out completely for ten minutes, and I have to walk around winking till I’m back to two eyes.

Grace and I live on the fourth floor of a twenty-eight-unit apartment building which, thanks to me, I must admit, has a lovely garden in the courtyard where there used to be a trash heap. The only problem with the area is that it is perilously close to the colleges. It makes for a lot of drunken late-night parties. Grace only barks at shopping carts, garbage bags and drunken college boys. She loves drunk college girls; they’re sloppy and emotional with her: she’s the most *gorgeous* dog in the world; she looks like a *muppet*; they miss their own dogs *so much,* ohmygod, etc. She spots them a mile away and topples onto the sidewalk for a belly rub. It’s not a bad neighborhood, though, and it’s good for me, as it’s close to transportation of every kind, which is nice when each step hurts. I hit our cranky old elevator button and we get in.

As the elevator groans to a start, I lean against the wall and close my eyes for a moment. I'm already tired, wondering what the fever is about, wondering when, if, I'll get the cast off, because snow is coming, and it only has a bit of foam at the toe. I'm worn out already, though I haven't done much, so there's no particular reason for my terrible fatigue, except that I'm always terribly fatigued, and I have several hours of baby-sitting ahead. All I've done so far today is call doctors and medical personnel.

Can I get the TENS unit (a small neuroblocker that can distract the brain from a pain source) from the dealer now that the insurance company has finally approved it? Can the folks at Faulkner pain clinic send a fax to my primary care physician with the notes from the last visit, at which time we discussed a narcotic patch that would deliver more consistent pain relief than the up and down all day of Percocet and Tylenol? Does anyone have any free samples of Lamictal, because, somehow, I lost them (not the bottle, just the pills) and my insurance doesn't have a replacement policy.

Like that. That's normal for a Monday.

Perhaps it was the two red leashes that caused the problem. I'm not sure, but, I didn't see that Grace's leash was not completely inside the elevator until it was too late. Awkwardly, I swooped down to grab it, but the elevator was already moving. Her leash was dragged by the elevator's motion to the side of its door. She was swept up and dragged all the way up to the top of the door. She was dangling by her neck, her head smashed against the corner of the elevator. I screamed and reached for her. She was too high for me to get at her collar. I tried to loosen the hook but couldn't. I'm only five foot zero, and I'm not a good jumper. I jammed her up, trying to ease the pressure on her neck so she wouldn't be strangled. She yelped. She was dying. Her neck was broken.

I had time to picture us in the elevator, me holding her lifeless body, keening. Two years of my life, and a love that surprises me every day. More work than I could have guessed at. In some ways, the most extraordinary gamble I've ever taken, and had won beyond deserving, and I could not reach her. I didn't have the time or the presence of mind to hit the emergency stop button, or I thought it would just make it worse. I can't claim either one for sure. I did nothing useful while my little love, *ma bahby geeerl*, died just above me.

When I was sure I had lost her, the elevator hit bottom, the door opened and the two of us tumbled out. We hit the floor of the lobby somehow touching each other. I landed hard, she landed beside me, nearly beneath me, then she popped up and ran to me. We rolled on each other, all paws and hands. I grabbed her. She had a bit of blood on her neck where the clasp from the collar had dug in. She jumped away from me and ran all over the lobby. When she noticed that I was crying, she came over and licked at my face, which is what she usually does if I'm crying, even if she's the one who made me cry by being annoying or not peeing within a reasonable time frame at 11:00 pm on a freezing cold night.

After a moment, I ran her outside, thinking she needed fresh air. My neighbor was on the garden wall. I tried to tell my neighbor what happened while Gracie crawled up on my shoulder, her parrot spot, her safe zone. She's entirely too tall to fit up there, so it looks ridiculous. I could feel Grace's heart racing against my neck as I rocked and kissed her through her little sweater (she hates sweaters).

I tried to move her to my lap so I could get a look at her, but she refused to come down off my shoulder, wriggling up higher whenever I tried to lower her. My neighbor was petting her, checking her legs and body for lumps and breaks.

- Gracie’s fine. She’s not hurt.

It began to seem that my neighbor might be right. I couldn’t see Grace’s face, but I could feel her, and she was alive. She was clinging to me for comfort, not knowing I’d been the problem. The leash was too high, too thick; I was too short, too weak. I was sore the next day, but she probably was, too. She was not still crying the next day, but I was.

Over thirty years ago, I came down with, or came up with, systemic lupus erythmotosis, (SLE), or lupus. It’s a still little-understood autoimmune disease: my immune system attacks any healthy tissue it suspects is a problem, even though there’s no problem and it’s my own tissue. It’s a chronic inflammatory disease with no cure, and little effective treatment. The treatment for it now - steroids, mainly - is about what it was when I got sick. It’s about what it was when Flannery O’Connor, one of my favorite writers and a personal hero, died of lupus in 1964.

Some things are better. They’ve been using low doses of chemotherapy for the last ten years; having noticed that cancer patients’ immune systems are weakened by the chemo, someone thought, ah, let’s give it a try. Every week I inject a bit of methotrexate into my leg. It’s supposed to maybe help, or not. We’ll have to keep an eye on things to see if my liver and kidneys can tolerate it. The small truck load of pills I take helps to keep one thing and another under semi-control; one for seizures, one for fevers, one for depression, one for high blood pressure, one for asthma, one for allergies, one for high cholesterol, one for dry eyes, two for sleep, one for pain, another for pain. The dreaded steroids. A pill, a lotion, a pad, another pill, a gadget.

I’ve experienced truly astounding levels of pain. When I first became ill and manifested arthritis, I thought I’d borne the worst pain that could be borne. But when I had a biopsy on my knee, and they hit a nerve on the way in, that was new. I developed an ulcer and discovered another level, and a new quality. There’s an endless variety of pain. I have to assume it’s endless, since I’m still often surprised, even after all this time. Sometimes a thing burns, sometimes it throbs, sometimes it rubs and cracks. Sometimes it’s heavy, sometimes it’s oddly numb. Sometimes it’s sharp, often it’s dull. But here’s the thing: it never, ever goes away. Not entirely. At any point in the day, or - one of the reasons I’m bad at sleeping - the middle of the night - something, often many things, hurt. It hurts awfully when I walk, especially my right leg, which is very heavily damaged.

The right foot was so bad I thought it was coming off. I’ve had this thought about various parts of my body before: nothing can hurt this much and stay attached. I tried to help my long-suffering rheumatologist, Dr. Robert Sands, break it to me.

- Is this it? Is it, you know, is it going?

- Going where? he asked, distracted, puttering, checking for swelling in my hands.

- Going, you know, is it, you know, gone?

- Gone where?

He pokes at the redness that’s always present. Checks the quality of ligament.

- Am I going to lose it?

- Lose it?

I’m thinking: *Buck up, man! Break it to me!*

He stops examining my hand and looks up at me.

- Losing it? Like, coming off? he asks.

- Yeah.

- Off? As in, off? Is that what you’re thinking? Your foot? Off?

- Of course. At some point, it’s just going to have to go.

He pauses, collects his thoughts, probably wishes he’d chosen another specialty. Surgery, maybe: in, out, good-bye, and your patients are asleep.

- Losing it? No, no, no, of course not. Losing the foot? Of course you’re not losing your foot.

- Really? What do you mean, like, not losing the foot? It’s not coming off?

- Of course it’s not coming off. We don’t just lop off feet. What are you thinking?

- Oh. I thought it was coming off.

He leans against the counter and folds his arms across his waist the way he does whenever I’ve worn him out. He looks at me with over twenty years of history between us. He shakes his head.

- Will you please tell me when you’re thinking these kinds of things?

I promise. The foot’s still on, but it hurts like hell. On a good day, it hurts a lot, on a bad day, it’s unbearable. “Unbearable” to me, means, not that I can’t bear it, because, obviously, I have, and have to, and do. It means I can’t focus on much else. It means that anything that manages to slip through to my consciousness is going to hit a wall, and will do well to filter through in some smoky, half-visible way. On most days, my whole body has a pin ball game going on: ping, pam, whack, bing, whack, whack, bing, everything bouncing and reacting, over-reacting all the time, lights flashing, wires twisted and hot.

So I'm writing a memoir now because I'm not sure I'll get any clearer, and I'm justifiably worried that I will get worse. I have not been able to wait for the husband. At my age, I wonder if I'm past the point of that much compromise. I never did have kids, although I do have eight endlessly interesting nieces and nephews and the several other children in my life who are achingly precious to me. I've had several productions of my plays, and some modest success with them, but have not won a Pulitzer yet. Though I've written some movies scripts that I think are quite good, none has been produced yet, thus, there has been no astounding monthly royalty payment. I live on a disability payment, which is not enough to cover the bills, so I put groceries and sometimes a new shirt on credit cards, which increases my monthly minimum and contributes to the monthly bills, which leaves me with no money for food, so that goes on a credit card, and on and on. If I need dental work, that goes on a credit card, too.

I worry that I'll end up living with one of my brothers, a burden. They wouldn't be able to manage that, and, after several excruciating family meetings, they'd have to put me in a state-run institution. I'd spend long, lonely days with someone's dirty hand-made afghan draped over my shoulders, though I'm not cold. I'm too warm, but I don't know how to take the afghan off my shoulders, and no one has noticed that I'm uncomfortable. If anything like this happens, I won't be able to write a memoir, though I won't be, probably, able to worry about that. The worst would be, of course, to still want to write a memoir and not be able to. So I'm not waiting till I'm 70 in case that's not a good idea. Because I'm heading into my fifties, and I don’t know what they’ll be like. I’m writing it now in case, in five years, or in eight months, or in two days, I can’t.

1959 - 1980

Home

We had the biggest, flattest yard in the neighborhood so everyone came to our house to play Duck, Duck, Goose, Red Rover, 1-2-3 Red Light, Hide and Seek and just general pig pile stuff. There were kickball games and whiffle ball games and football games and anything that could be done with a ball was done. I spent half of my summers swimming back and forth in our four-foot pool. Or maybe I was at Island Grove, the town pond where we were given bracelets saying how far we could go in. I was a deep-water girl. On summer weekends in the pool, we'd all climb aboard my Dad's enormous back and go flying off when he submerged. We were woken up to watch a really good thunderstorm come in; we were awoken for Apollo 13, and, once in a while, to go to see the sun come up over the beach. We climbed the neighbor's pear trees, roamed the woods or lay on the flat stone in the middle of the field next to our house where wild daisies grew.

Every weekday morning, I sat at the end of my parent's mahogany sleigh bed watching Dad ("Bud," a nickname he acquired nearly at birth), a salesman for a wholesale upholstery company, dress for work, marveling at that complicated knot at his neck, always having it turn out right. Often, he let me pick his tie. He combed his hair exactly the same way every day and it always it turned out right. A few times a year, he'd go to Camp Drum in New York to fulfill his National Guard Duty; watching him dress for that was heaven. The heavy canvas pants crackled, there was wonderful pop as he snapped the elastic laces into perfect place on the shining boots. Of course, he was the most handsome man I'd ever seen, and he stayed that, bringing a little flutter to my heart whenever I saw him, even in the years when we didn't like each other very much.

In my early memories, my mother is applying a precise layer of red lipstick getting ready to greet my father when he got home from work; she's crushing out a Winston's cigarette, bright red butt in an ashtray; she's carefully draping tinsel on the Christmas tree, as the tinsel strands could not touch one another. She is warm soapy water in the bathtub. Tea and toast when we were sick. Shalimar perfume. Each night, she tucked us in. My brothers were in the next room, yelling and bouncing on the beds and squeezing in one more fight before sleep. She'd dash back and forth between our rooms, trying to corral the boys then dashing back to me to brush my long, thick hair. Her gift was nurturing children.

Mom - Helen - worked like a horse. There is Helen standing at the ironing board, the smell of spray starch, the spritz of it, and the steam that rose from the hot iron and the sticky starch. My father's shirts had to be laundered and starched and pressed. Five shirts a week. Every night there was a simple, bountiful dinner waiting. Dad liked routine, so Mondays we had beef stew and Tuesdays we had chicken with rice and corn. Saturdays we had franks and beans - an easy meal so she could pause before she built the Sunday dinner, a pot roast or a roast beef.

On Sundays, we'd go to Mass at Saint Bridget's in Abington, MA, about thirty miles south of Boston, where, during the week, we were taught by nuns. For church, Mom dressed like Jackie Kennedy in tidy suits that fit her Jackie-slim figure. She wore white gloves and covered her head for Mass with a pretty matching hat. Clear image: a beige suit with a perfect-match pillbox hat sitting atop her tight black curls; one hand gloved, holding the glove she had removed, a small clutch purse in beige. She wore a silk scarf tucked into the suit's collar. We didn't have much money, I'm told, so I don't know how she managed to dress like the First Lady, except that she was so thin and pretty anything would look nice on her, even her one good suit. I loved Mass: the smells, the sounds, the colors. The aesthetics would linger and please me long after I'd given up on the politics and policies of the Catholic Church.

After church, we'd stop at the little store in the center of town to get the Sunday paper, a bottle of root beer and a bottle of orange soda for Sunday dinner, a quart of vanilla ice cream, and a quart of chocolate ice cream, hand-packed tightly by Mr. McP. as he pushed and grunted, cramming as much ice cream as possible into the paper quart, because we were good customers, and well-behaved children. Then we'd head home to spend the day playing in our yard or, if we were lucky, take a trip to the town dump with my father. The man who worked there, Joe the Dump Guy, frightened me because he wore the marks of his profession on his clothes and skin, but my Father could chat with anyone.

When my Nana Kenney came to visit I'd sleep on the couch in the living room so she could have a proper bedroom. I'd observed my mother's unsteady steps at night at times and I worried myself sick that she had a brain tumor. I begged her to see a doctor. Then when I was about 12 or 13, I caught her drinking and begged her to stop. That didn't work. Lord, she suffered. Unable to work out her own wishes with her sickening need, she drowned in shame. This went on for some years. When she joined AA, she started knitting. She had a mathematical precision and was an expert on her first try. Although I've always been obsessed with fabric, I cannot follow directions or think in straight lines. When she slipped and had a bad night, I was furious, but there was the Chevron afghan, brown and gold, patient as a dog.

In 1980, doctors were beginning to tie high cholesterol to heart disease, so when my mother had a heart attack and her cholesterol was a combined 800 plus, they asked themselves: *Is that high*? Her sisters, it turned out, had high cholesterol, and they would all have heart attacks and open-heart surgery at around that same time. They were written about in the *New England Journal of Medicine*. Two of my brothers showed high cholesterol when we were all tested, because they were starting to wonder if high cholesterol could be inherited. One of my nephews and one niece have had it since birth. But “800” seems high to us now because it *is* high, and because there’s been so much research in this area we know how dangerous it is. When my mother had a full quadruple bypass they were new and even more terrifying then they are now.

Right before she died, my Dad took me to the hospital to see her. The doctors had made it clear to him that her odds were not good. They couldn’t get her heart to regulate itself.

I was twenty when all this was happening. I was happier than I’d ever been in my life. After aching to get out of Abington and leave the suburbs behind, I was in the city - not living in the city proper, but commuting and spending my days in the outskirts, in Dorchester, on the U Mass Boston campus, hanging lights and making costumes and stage managing and writing and acting. There were teachers who saw terrific potential in me, and I knew it, and was deeply relieved: I can’t remember not wanting to be an actress. At 6 or so, I went to my first real movie theater to see *Mary Poppins* and Julie Andrews left me dazzled. I understood what she was doing and that was what I wanted to do. And here I was, doing that. I don’t know how, at 6, I knew what she was doing. And it was too precious a secret even to be exposed to light. I couldn’t tell anyone for fear that exposure to the wrong kind of light would kill it entirely. In high school, I couldn’t even try out for the yearly musicals. For one thing, they were musicals. I wanted to do serious, dramatic acting. Again, I don’t know how I knew that, having grown up on *Cinderella* and *The Wizard of Oz*. I just knew it. I spent my first year in college taking my core requirement courses, math and biology, afraid to even walk into the theater. In my second year, now or never, I started with shmarmy music scenes, all of us wearing black leotards and skirts and hamming it up. Finally, I got the nerve to take a class with the reigning king of the theater department, Tim McDonough, and I was saved. I walked across the carpeted lobby of the theater in the most artful and gorgeous manner and Tim, after a long pause, said,

- What the fuck was that?

Finally, the one I had waited too long for. I hardly left his side for the next three years. Tim took a bunch of screwball ego-maniacs and instilled in us a sense of art and dignity and a social conscience. I found my teacher, my calling, my delight.

My mother was tiny in her small hospital bed. Even as we walked in, my Dad warned me about not keeping her talking long.

- She’s really tired, so make it quick, OK?

I stood for a moment watching the machines do her breathing. I could see she was gone already. I felt that if I pushed a finger into her chest, it would collapse like *papier-mâché*.

- Get better, Ma, OK? You can do it.

I smoothed her arm gently.

- OK, that’s enough.

Dad eased me away. I knew that if I could talk to her, explain how easy it would be to get better if she just put her mind to it, then she'd manage somehow. What he knew was that her heart would not beat.

In the years after she died, we left notes on the kitchen table for each other: "Call Dad;" "At Eddie's. Be back at 6;" "Call McCabe's if you want me." It softened the empty kitchen only a little bit. I stayed at home for another year, but, finally with multiple productions and a job in the city, I had to leave.

1982-84

Boston Theater

In 1981, I graduated *magna cum laude* with a degree in Theatre Arts. The diploma didn't matter much. I just wanted to work. I was, and, much to my frustration, still am, ferociously ambitious. I had a very solid plan: work till I had "my chops" in Boston then go to New York and get more chops then get an Obie then do movies and get some Oscars. I was still living in the vermin-infested apartment in Dorchester I'd rented in college. It was gross, and in a dangerous neighborhood, but I didn't care. I spent very little time at home. I had a job at The Ritz Carlton that had me up at 4 in the morning. I took the orders for Room Service and checked the orders before they went up. The staff were lunatic and raunchy, largely escaped from the Duvalier regime in Haiti. Between the Ritz and school and theater, I was working all the time.

I slowly wound down an internship with Theater Works that put me to work for two years as one of the assistant stage managers for a brilliant one-man adaptation of *Hamlet*. That one man was Tim McDonough, and Vinnie Murphy, my other mentor, had directed. Playwright Jon Lipsky and Tim and Vinnie managed to weave together the most famous Hamlets of all time and Tim's personal life story and a thousand brilliant, pertinent details. I learned so much from watching and working on the show night after night. My high-stress job was to get three ill-tempered slide machines - that was very cool on stage in the 'eighties - to change simultaneously and get three new images to appear at precisely the right moment, in one of three different framed fields. The horror when a lightbulb that lit the image failed cannot be described. I stayed with Theater Works for another year or so, until I was finally getting roles in their constructed plays. I was called in to replace one of my favorite actresses in a show that Theater Works was extending. It was an amazing rush for me. Theater Works was the hottest company in town, and now I was part of their troupe of actors. But, having never really caught my breath since the loss of my mother, I was also restless and angry. I needed some way to clear my head. New places. New people. New anything that did not remind me of all that had happened. My poor mother dead, just as we were getting her back from that dreaded poisonous alcohol - just as she was trying, just as she was starting to live. I told Dad:

- I'm going cross country by bus. I'll be back in about six months.

If one of my nieces pulls a stunt like that, I'll chain her to a chair. I had a bit of money I'd saved since I was a kid. I couldn't afford, and did not plan to take, the high road. I had managed to squeeze in the requisite production of *Godspell* somewhere between my junior and senior years, and had a friend from that show who had moved to Arizona. I would stay with her, and with friends and people who had friends who knew someone who lived in Philadelphia or wherever. More than once, I showed up on someone's doorstep and said,

- I'm a friend of so and so's - she thought I might be able to stay with you a few days.

That always worked, and I have a few life-long friends because of it.

I spent a hot May and June in Arizona. I needed money, so I stood on a corner selling flowers on Mother's Day. I wanted to see how much torture I could take. After working briefly in a pizza parlor to save enough money for the next leg of the trip, I moved on and showed up on Marie and Steve's doorstep in Alameda, a small suburb of San Francisco. She was a friend of Mary's, and I had so much fun I stayed all summer and took a job waitressing in a very busy lunch place on Market Street. It was owned by a Korean family, and I learned just enough Korean to get food out of the kitchen in a hurry politely, because you can't speak disrespectfully to a Korean grandparent even if he is taking too long with your order. By mid-summer, I started to feel awfully tired. Surely, home was calling, and I was saving money for an airplane trip back.

One Sunday, Steve and Marie and I spent the day on some hill overlooking the Bay. It had a stunning view of the Golden Gate Bridge, long green hills rolling all the way to the water. It was a bright, sunny day, and I'm sure I wore no sunblock. Instead, I wore an ice-blue chenille bikini with chenille dots. It was Marie's. It's a good friend who will loan you her bikini. I got one of the worst sunburns in my life in it. By the next morning, I could not get out of bed. The skin on my belly was so full of fluid I looked like I was ready to deliver twins. I went to the nearest Emergency Room and they told me,

- Nice job. That's a second-degree burn. Here's some cortisone cream. Don't be such an idiot.

They sent me home to cool and blister and peel.

The first burn is just a family story. I was three months old when my parents took me to the beach, put me under an umbrella, put a hat on my head and took what precautions were considered normal for 1959. I had second-degree burns over most of my body. My mother could be brought to tears if anyone even brought it up. Growing up pink and Irish, I had a very serious burn at least twice a summer. I don't mean red and peeling: I mean blistering and bleeding. I recall being about or six seven and my mother having to sit me in the tub and rinse my back with warm water over and over to get my pus-caked pajamas off in the morning, my favorite light blue seersucker lamb ones. I sat weeping and screaming in the tub while my mother wept and rinsed and eventually got the shirt off.

In high school, of course, I had to “get some color.” The tan I longed for never materialized. I’d burn, peel, then be white/pink again. I’d lie in the sun, tortured and bored, waiting to roast, and I’d put baby oil on to speed the tanning (basting) process, and the next morning I’d be full of fluid and bloody red and raw. Very pretty. This was long before we understood how dangerous it is to be in the sun for extended periods and long before Climate Change made the sun quite as hot as it is now. I’ve thought that these early burns were some part of what damaged my immune system so badly. There’s no way to prove it, but I’m sure I’m right.

When I was in San Francisco, at the end of the summer in 1982, I got a call from Vinnie saying they wanted me in another show. Big shot, I took a plane with all that waitressing money back home. When Dad met me at the airport, he said,

- What’s the matter with you?

I guess I didn’t look so good. We went into rehearsal. Like all theater groups, we had lots of little intrigues and crushes and issues, so there was as much drama off stage as on - very fun. The material, an adaptation of Jules Henry’s *Pathways to Madness*, was beautiful. Dr. Henry was prescient in his interest in the entire family of troubled children, so he managed to get himself invited to live with families from which these children had come. Theater Works dramatized one of those stories. Like most of what they did, it was greeted by enthusiastic praise from audience and critics, teaching me early on that people respond to really good work at the most profound level, giving me that standard to try to hit for the rest of my life.

All through the rehearsal, though, I was exhausted. In the Boston Irish Catholic work ethic, ‘exhausted’ is the same as ‘lazy.’ I had no way to separate the two, and I struggle with it to this day, when I really ought to know better. This moment, as I write this paragraph, my eyes are physically trying to close. They are weighted with tiny lead weights. But I have to work, and they don’t have my permission to close, so I keep blinking fiercely and changing positions. Should I go home and take a nap? How will the work get done? Am I ignoring my body’s needs? Yes. But it needs too much.

In the middle of the run of “Pathways,” after a few months of journal entries that started “lousy again today;” “another cold;” “sick again. I don’t know what the hell is wrong with me,” I finally went to the hospital to see if they could make me less tired. I had the worst case of mononucleosis they’d ever seen. My liver was so swollen and damaged that they first thought it was hepatitis, and my spleen was so enlarged that there was real danger of its bursting. More worried about the play than anything, I asked the nurse about the especially physical scenes: the dance scene? What about the scene where I got dropped on my butt?

- If you do either of those things, or anything like that, she said, you will definitely rupture your spleen; your stomach will fill with blood, you will immediately go into shock, be rushed to the hospital and be operated on, if you’re lucky, in time to save your life.

Jeez, I thought. We’ll have to change the blocking. I prayed they wouldn’t fire me. Of course, they were wonderful. One of the girls in the company, who had been assistant stage managing this show (we all did everything) took over the part for two weeks while I was recuperating and waiting for permission to work again, then we re-did the blocking so I wouldn’t die.

Even though the initial ‘spleen explosion’ nightmares had subsided somewhat, the first night back on the show I was terrified. I could see my spleen bursting right through my skin, splattering blood and tissue all over the other actors and the first few rows of the audience. Beside the normal pre-show nerves, I had this to worry about. I was trembling when the show started. But we made it. One of my fellow actors, every night of the show for the rest of the run, when we tore, giggling and adolescent, “upstairs,” and dove onto the bed to fade out of the audience’s focus, would whisper,

- Are you OK?

- Yeah, I’d whisper.

Out of focus of the audience, she’d pat my hand. In the ensuing months, I was terribly frustrated by how long it was taking to get well. Finally, I began to feel like myself, but I was never really healthy again.

By the end of 1982, I decided that it was time to leave the womb of Theater Works and try my work at the other small theaters in Boston. There were lots of them, and since I was only interested in learning and getting better, was working for free or small fees. This, of course, drove my poor father crazy; this nut kid with a college degree was working for nothing. I did a few shows that were so bad I cringe even glancing at the notes in my journals twenty-something years later. Really icky stuff. Good practice.

But working for nothing meant that I had to stay at the Ritz Carlton, so I had to get up at 4 am for work. I’d get back home by 3 or four in the afternoon, fall into a dead sleep for an hour, then drag my aching body into rehearsal. The adrenalin and my excitement about the work would kick in and I'd be fine till about midnight, when I got home and fell asleep for about three hours. Whenever I got over-tired, my spleen would ache and I'd start to worry about it bursting again. My feet and ankles were always sore. I wondered in my journal if there might be some kind of explanation for the pain - bursitis or arthritis or something because I would love it if there was a cause for all this inexplicable pain so it could be fixed.

Because of the prohibition against exercise for about a year after the spleen alarm, I had gained a bit of weight and I was working really hard at losing it. I'd been a little chunky as a child. I've always complained that I inherited my Mom's funny chin and my Dad's boobs (he wanted a "manzeere when Seinfeld invented them). When I was about 13 and my breasts were beginning to develop, my dear, gentle Nana screamed from across the porch,

- Jesus, Janet! You look like a nursing mother!

My mother tried to call her off, but the damage was done.

Every day I struggle with my weight, mourn the loss of thinness, but, at this time, in the early 'eighties, in my early twenties, I was pretty hot. This was the time of Jane Fonda's series of workouts. I don't know if she'll be remembered for her Hanoi Jane stunt, or some of the movies she made, but who can forget that striped body suit and the leg warmers? The music was great - mostly from the "Thriller" album, and, yes, it was a good work out.

I belonged to a little gym down near Government Center and I went so often to the "Jane Fonda Workout" that one of the girls, who was dying from boredom with it, eventually let me "teach" it. That meant, I'd get up in the front of the room (a favorite spot of mine) and lead the ladies as Jane did all the talking. I'd wear a black body suit, black tights and a red bandana - around my waist. I'm trying to make it clear that a standard-size bandana fit around my waist at that time. What size waist is that? Small. I don't say that there was a *lot* of left-over fabric, but it fit and I led the workout a few times a week.

I did a nice little lesbian feminist drama. I had worked hard to become a feminist in college, which, in the 'eighties, meant we had lots of work to do. My nieces, who mostly excel at sports and complain if someone "plays like a girl," don't know how hard we worked to make sure they *had* sports. The play was set in the Medieval period and told of a woman who had disguised herself as a man so she could be a knight. I was her friend, a nun who was the only one who knew her dangerous secret. It was just a quick little thing, but it was fun.

I went back to Theater Works and did a punk-rock apocalyptic nightmare called *Out! Out!* though I never cared for punk rock (too noisy; too angry), I took it because they asked me to. I tried to take a break after that, but slipped in a quick new show in which I got to wear army fatigues and play a mechanic and trace a real knife down another actor's chest (the director should not have let us do that). In March of '83, I wrote in my journal, "I've had enough of this illness stuff. I want my body back," and, for a while, I had it, or I thought I did.

I think I finally really hit my stride - meaning a place from a which a stride might start - doing *Fifth of July* by Lanford Wilson with a brilliant director who would become a very important teacher and long-time friend. I had a wonderful part: 13 year-old Shirley (I was in braces) and it was very well-received. "Very well-received" means that we had excellent reviews that led to full houses. We had the requisite backstage dramas, but it was the first time I felt I had really graduated from my Theater Works home. Even my teachers were impressed. "You're a helluvan actress," said Tim. I still do admire him, and he's still turning young goofballs into fine actors as Theater Studies Chair & Professor at Emory University in Atlanta.

The braces were excruciating, and, with my immune system quietly rumbling and attacking without my knowing it, I had constant infections in and around the teeth - but the braces were getting me work. *Miller's Court* was an early local version of all the Judge Judy types of shows. I played a girl who sued the doctor who told her parents she'd gone in for birth control. They worried about whether I could pass for 15 till I told them I'd be playing a 13-year old that night. I joined the TV Union, AFTRA, my first official actors' union, and got paid for that.

I quit the Ritz so I could get off the ridiculous sleep schedule and started cleaning houses and condos on a schedule that would easily accommodate rehearsals. It was good, quick cash and hard work. It was hell on my hands; I don't mean dishpan hands - I mean arthritis, though I didn't know it was that. My spleen had become an old football injury; whenever I was over-tired, it would ache and swell. I started to think of myself as a hypochondriac.

The next production was a hysterically funny satire of B-movie women's prison films from the fifties by Tom Eyen called *Women Behind Bars*. Every bad stereotype was included. It was a triumph for me, artistically and career-wise. Playing Mary, I was the innocent ingenue who had been wronged by a man and ended up in jail with all these strange women. No nine women in a mouse-infested often-flooded basement dressing room ever had more fun. We all had crushes on each other. That happens a lot in theatre; you fall in love with the play, the theatre, the characters, your fellow actors. It's such an intense little period of time. You prepare for the show from the minute you wake up in the morning, and you go out for beers afterwards. You know it will be over soon, so you do and say things you normally wouldn't: have flings, have fights, kiss girls on the lips, because you're high on adrenaline and art. One of the girls in the show had been in *Roses for a Knight,* and I had a terrible crush on her. This was my lesbian period. It was a really great month.

Every night on stage – my idea, so I can't blame anyone else for it – leaning against the wall in my pillow-stuffed virgin birth maternity prison gown in white lacy socks and black Mary Janes, I used a dill pickle to scoop out vanilla ice cream from a cup, while talking about how strange those other girls were. It took the audience a moment to get that I was actually eating pickles and ice cream, milking another bad cliché, and there was always an appreciative groan from them. There's a communication between an actor and an audience, when things are going well, that is often silent, but is wildly intimate, and always a worthy goal.

The only problem with this otherwise dreamy experience was that the pain was building, sometimes culminating in incapacitating attacks. I went to see the doctor in Boston who had been my grandfather's doctor; my Grandfather had died early, partly because of the gold injections they used in the ‘forties for his arthritis. Hard on my Dad, I'm sure, but the doctor said I was fine, I did not have arthritis. The next night we had to cancel rehearsal because I was unable to walk and was screaming in pain. One of the girls from the show took me to the Emergency Room and we spent the evening at Mass General. There they said it “looks like arthritis” so I skipped my house-cleaning jobs the next day. The blood tests all came back negative, and mostly, they still do. It's taken me years to learn that they just have not developed the tests that catch my disease. But at the time, I just chocked it up to my extremely physical life.

1984-1985

New York City

It was lucky that I didn't have arthritis because it was high time I moved to New York. If I had made it in Boston - and, in terms of where I wanted to be in Boston, I had - then it was time to move to the Actor's Official Pass or Fail Zone. My health was not improving, despite negative tests. My journals are full of "I'm sick again (yes, again)"; "I've had the world's worst headache since Saturday," and I'm sure it was only my professionalism that kept me from throwing up during some shows; indeed, there was "always something wrong with me." Attributing it to the last of the mono and nerves about going to New York, I moved in the fall of 1984.

Through a friend from *Fifth of July* who had also recently moved to New York, I ended up with two swell roommates who were boys and lovers. This was another way to horrify my family, which delighted me. The boys were good to me, and they were going to end up being better than they could have imagined on some long and awful nights, calling ambulances against my protests, and tending me gently when I came home. Brian smoked, and I can't believe, now, that I ever lived with a smoker, but that was long before smoking got you into second-class citizen status. I wished he didn't, but it wasn't a deal-breaker. Together, he and Bitzi and a big, beautiful room with enormous windows were enough to make me feel at home.

We lived in Long Island City, a working-class neighborhood in Queens. It's right near the Hudson River, so if you walk or, as I did, run, to the river you can see Manhattan. Many of the buildings are old factories, many shut down at the time, and they all had copper pipes and roofs, so the whole place had an Edward Hopper-green tint to it.

The mid-eighties in New York was the time of “New Age.” Several years into it, we were beginning to understand the size and scope of the AIDS nightmare, and there was nothing for it so everyone was looking for old ways to heal a new problem. I took a crash course in how to get work in commercials that was based on the old/new age principle that the Universe cannot resist your impulses because you are part of it; your commercial success depends entirely on your positive state of mind - like that.

The company was a two-person show run by a scary Tammy Faye/Jim Baker duo, who were hauling in cash by the bucket. They said exactly what we all wanted to hear: it’s not up to the casting agents and the commercial directors and the whomevers: it’s all in your head, thus, your power. Think positive: you cannot afford a negative thought. I’ve come to be suspicious of all that, and no longer think of anything as simply negative or positive (that works for batteries, I guess) but at the time it was just what I wanted to hear, and how I intended to do things.

I never did get a commercial, but the course did one good thing for me: it opened up a conversation with God that I had neglected. In theater, so many of your friends are gay, and here is the Catholic Church I grew up in telling me they were condemned. I could not reconcile what I saw with what I was told, that they were all going to hell. I had long abandoned the fire and horns version of hell, but experiencing kindness and love from people who were not welcome there made me not welcome there, either. There is still so much about the Catholic Mass that I miss, but the Church’s stance on important issues and, as would be uncovered eventually, dreadful misbehavior, had left me without a church. But it had not left me without faith, and a wish to understand and love God. It continues to be the primary work of life, despite frequent of fits on my side.

Every day when I wasn’t waitressing, I made “rounds.” Usually, I’d been waitressing the night before, and attributed my soreness to that. The solution, of course, was to go jogging before rounds to loosen up the limbs. Rounds consist of going from door to door of all the agents listed in the various periodicals for actors, dropping off headshots and/or show postcards and hoping someone sees you. The good agents are behind seventeen layers of secretaries, so they never see you. You’re left with the ones whose secretaries left in the ‘fifties: old men behind gray school teacher desks who call you “Irish” and tell you about the time they met Talulah Bankhead, and you nod and wait, standing, and your feet are throbbing and you want to hit ten more places before you have to go work and you realize he needs you more than you need him in, but it’s too late. He knows your number.

Such a gentleman took a kindly interest in me and got me some of the stupidest jobs that could be got: modeling in a hair style show by letting some guy cut my hair and then walking down a runway, the petite model for some California dress company, and a Christmas card elf. I was still getting sick a lot, but, according to New Age principles, as I often wrote in my journal after listing symptoms or a new infection, “but, no matter: I am in perfect health.” And it didn’t matter because I was working in New York, and the Universe would bend to my intractable will. The inexplicably swollen half of my face could be shaped with blush.

The second-to-last waitressing job I had (and, barring both a miracle and a disaster, will ever have) was at a seafood place on the upper East side. It’s easy to get waitressing jobs in Manhattan if you’re an actress: one of your friends from a class or an audition or a show recommends you when someone else gets a gig or heads back to Nebraska. You work there till the boss drinks himself out of business, then you break into a few herds and move on to different restaurants. My pal from Boston, who had moved to New York at about the same time, got me in there and we mostly had a good time.

It was important to me to have landed a role in a play before I went home for the Christmas holidays, and I did. It would assure my friends and family that I was doing well in New York, and it would give me something to come back to. By early 1985, when I was not making rounds or waitressing or waiting for the phone to ring, I was playing the princess in a production of a fractured Humpty Dumpty story in a tiny, grungy theatre in Greenwich Village. The little theatre ran shows for children and their savvy parents, so the shows were filled with double *entendres* and pop culture references so the adults wouldn't be bored. There was lots of audience interaction, so you got to improvise quite a bit. In a wildly tacky turquoise blue gown, carrying a four-foot hot pink hankie, I'd run downstage and scream out to the kids:

- What should I do? Should I marry the King?

- No! No! they'd all yell. The prince is an egg!

Now, I'm not supposed to know that the prince has been turned into an egg by the evil King, so I have get that under control.

- Oh, no! Don't say "egg!" I'm (Hack! Sneeze! Cough!" allergic to eggs! If I even hear that word (hock a huge ` loogie into my hankie) I get allergic!

- But he's an egg!

- What did I just say? I can turn you all into frogs. Don't think I can't do it!

We did two shows on Saturday mornings. One day, I had waitressed and gotten home at two or three the night before. When I arose, I had my familiar morning horror, throbbing and aching joints, but took some Advil and headed into the Village to work by 8:30 am. I got through the first show with only a dull throbbing trying to warn me. We cleaned up a bit, but didn't take off all the make-up, so that people in the diner where we went to have a breakfast would know we were actors, then did the second show. I was getting a thick, sodden feeling in my limbs, but finished my coffee and went to do the second show.

Part of the gig was to greet the children after the show. We lined up in the lobby like a wedding receiving line, and we shook hands, signed autographs, and teased and joked with them.

- Yes, I am a real princess. Check out the tiara, honey.

- It's just made of shiny stuff.

- That's how it sparkles, honey.

- It's not diamonds.

- Diamonds cost a fortune, honey. Ask Daddy for a diamond and see what happens.

Daddy would snicker and tell the child they would talk about it when she graduated college. I had knelt down to talk to the kids, but my legs weighed over two hundred pounds each and they were filled with sand. I couldn't possibly get up. I stayed on my knees to greet the rest of the children. When the kids were thinning out, I said to the prince, who was standing beside me,

- Honey. Sweetheart. Love. Could you please help me up?

- Of course, my darling. Anything you say.

- See how he does what I tell him girls? Oh, thank you, sweetheart, you're the angel of my dreams.

After we waved the kids off, using super-human strength, I managed to get dressed. There is a particular ache that is the mark of a flare coming. My limbs feel slightly detached, very heavy, and they stop working. I couldn't lift my right arm. Actors are notoriously observant and one of the girls said,

- You're not left-handed.

- I have a cut on my right. I don't want to get goop in it.

Luckily, rather than asking to see the cut, she led off a discussion of cuts and infections and hideous injuries people had had (actors are disgusting). I begged off an afternoon beer. I would miss an afternoon audition, but already I was expert enough to know that this was going to be bad, and I had to get home as soon as possible. It took almost an hour to walk the several blocks to Union Square. Then I had to get from Greenwich Village to Long Island City. No elevators or escalators. Just steps. Hundreds of them.

It was worse, as it has continued to be, on my right side, so, though both sides were ready to blow, I favored the right. I kept looking down at my sneaker, focusing all my energy on that foot, getting that foot to move NOW. I could see how swollen my feet were right through the sneakers. At the subway gate, I couldn't use my fingers, but pawed a token out of my jeans pocket and worked it into the slot, holding it with my palm and trying not to drop it.

We arrived at 23rd/Ely in Queens. The closest exit gate was locked. Everyone swore and grumbled and headed for the open gate 100 yards away. An older woman asked if I needed any help. She was right from an advertisement for Swiss Cocoa. She wore a blue raincoat and a flowered handkerchief over her gray hair. She was carrying a bag of groceries and a little black purse. She had sparkly blue eyes and bright red spots on her cheeks. I wondered if her perfect teeth were her own.

- No, thanks. I'm fine. Hurt my foot. Going home to take a bath.

- Oh, that's the best thing.

As I progressed towards the exit, which was now 600 yards away, I could only move by gathering the fabric of my jeans at the knee, using that fabric to pick up the leg, and letting the leg down gently for another five or six inches of progress. Each step left me breathless and shaking. My shirt was tear-soaked. I was panting. In between steps, I stopped, holding onto the subway wall to keep from collapsing, and got my breathing under control.

Finally (was it an hour? At least.) I got to the exit gate. I looked up. Steps. Eight of them. Never happen. The stairs leading outside, leading to my home, my Advil, my tiger balm, my roommates, my bed, were right there in front of me, but I just couldn't do it. I held onto a wall. I waited. Another train pulled in, and another man offered help. I didn't even look at him. Just shook my head. He reluctantly walked away. My legs trembled uncontrollably. I could normally stare them into submission when they did that, but they ignored me. My feet were cemented to the floor. There was really no way to move.

A policeman appeared on the other side of the tracks. I waved him over. He disappeared for a moment and when he came down the stairs he looked angelic with the light behind him. He was beautiful. He had impossibly dark black skin, and the slightly yellow eyes some Africans have.

When the policeman was at my side, I said,

- Arrch. Uch.

He checked carefully with his street-smart eyes to see if I was on drugs. I wasn't.

- Easy, honey, he said, easy. What is it, dear?

- I have to get to that step. I can't walk. I need you to help me.

- OK. How come you can't walk?

- Arthritis, I said.

- I'll call an ambulance.

- No, no, don't. My house is down the street. I just want to go home.

- Seems like you should go to the hospital.

- No, no, please.

He didn't love the idea, but he was game. He tried taking my arm as if he were escorting me across a busy intersection, but that didn't work. I couldn't budge, but I could make awful noises. Next, the officer told me to lock my arms together, take a deep breath, and he got his strong arms under my trembling ones and when he lifted me up, with such a dramatic change in pressure, I screeched. A banshee wailing. An enraged bear. A *Friday the 13th* victim.

The officer hoisted me up like, er, like a princess, and he hauled my body over to the stairs. I screeched. He put me down and got his radio and called for an ambulance.

- You're going to the hospital.

- No, no. I'm an actress.

- What's that got to do with it?

- I don't have any insurance.

- So don't pay the bill. You can't walk and I can't carry you.

It takes a lot for me not be able to argue anymore, but I just sat on the step trying to calm myself, and the officer kindly talked only enough to get some needed information, and the ambulance came and took me, and I was sad to leave my hero.

The blood tests were suspicious, but not conclusive, and for the first time one of the doctors wondered if I might have lupus, whatever that was.

I told the young doctor at the city hospital that he was lazy and he would not find out what was wrong with me. He would give me an aspirin and send me home just like all the other doctors for the last few years.

- No, I won't.

- Yes, you will.

- Well, it looks like rheumatoid arthritis, but it's hard to tell.

- Yes, that's what they all say. And then they take off.

- I will stay up with you all night if it takes that, OK?

I gave him half a chance. He brought in an older doctor. I wondered what he had done wrong to be in a city hospital at his age. Probably he accidentally killed someone and could only get a job here. He said it looked like rheumatoid arthritis, but it was hard to tell. The young doctor and I shared a small laugh.

After four hours, and some Motrin (this is like patching a head gash with one band-aid), the young doctor made me promise to return the next day and go to the Arthritis Clinic. He had finally won me over, and finally I was desperate enough to cooperate. And, finally, the anti-nucleus antibody (ANA) was positive. The ANA indicates that the immune system is in hyper-drive. After five years of excruciating pain in almost all of my joints, though the ones below the waist were, and remain, the worst, we almost had a diagnosis. One of the doctors said it didn't look like lupus.

- What's lupus?

- Believe me, you'd rather have rheumatoid arthritis.

I didn't want either, so it didn't matter.

Things quieted down for a while. I turned 26 in the spring of '85 and I was so in love with my life that I was either in remission or in denial. I did a gay re-telling of Romeo and Juliet, fell in love with the gay "Romeo" actor and got good New York reviews. I was so happy with my revolving show schedule and agents (albeit, easy agents) helping me get little jobs, I felt better than I had in three years, since I'd first been sick.

My next show was very like the one I'd done in Boston. It was called *WACs in Khaki*. A four-women show, it was a send-up of WWII movie posters and films: very silly, very funny, very physical. I was getting sore again. Flares came and went, blew up then cooled. My Dad wondered if I might be just as happy being a writer, as I'd always loved it and it wasn't so physical, but he was scolded soundly for that one. One long night a friend from Boston came down to see how I was and ended up tending me through a flare, unable to do anything but offer me a grapefruit juice and vodka at three in the morning.

Walking down a street on a fall afternoon, I heard some nice music coming out of a store; I pictured myself in a long flowing skirt, dancing, strong and lithe, and I started to cry. My one resolution for 1986 was, "to get well, permanently."

1986-1988

Healing Arts

One of the girls from *WACs in Khaki* had an actor friend who did a kind of healing work called *Reiki*, the Japanese word for energy, or life force. I thought of Yoda, *Star Wars* and The Force, which always made perfect sense to me. My friend said Reiki could move energy and release blocks in the body, and that her friend, Mac, was brilliant at it. Since she was pretty and thin and had long, curly hair, I thought she must be right. I was sure it was just a phase my body was going through, but I was also sure that I was in way over my head and would need help.

Mac's apartment was done in New York New Age. Just about everything in his tiny living room was purple: purple curtains, two way over-stuffed grape-colored chairs, a red and purple oriental carpet underfoot (it had seen better days). The smell of incense, something dark and smoky, filled the place. There were two large windows with prisms hanging; they were sort of wasted because there was almost no sun. There was a bookshelf in the corner filled with all kinds of "heal yourself" books, which, at the time, were being published every seven minutes.

Mac greeted me at the kitchen door wearing a lavender T shirt with a black geometrical design. He was a large, dark-skinned black man with short nappy hair and surprised eyes. When he shook my hand, I noticed that it was soft as a child's.

He had me settle on the purple table, placed a tissue over my eyes and then placed his hands there.

- So, what do you do? he asked.

- Wait tables.

He laughed, a laugh I decided was ancient and mysterious.

- Of course. Tell me when you feel stuff, OK?

- OK.

I had no idea what he meant, but, when in Rome...

- Where are you from?

- Boston.

- You don’t have a Boston accent.

- Thanks.

I hadn’t wanted one. I was in third grade when I noticed that Mrs. Avery did not make the sounds I saw written on the page. I could perfectly well see an “R” at the end of the word “car,” but she said, “cah.” My Dad and his immediate family all have the real deal - the thick West End accent that the best actors in the world can’t get right, my Mom’s was an odd Cambridge and Boston mix. I determined to say words based on the way they were spelled. I’m also half-parrot, and pick up sounds and phrases and accents from anyone I spend more than ten minutes with. This would come in handy when I was acting and was starting without a Boston accent, from a more neutral place. I slip in and out of it at will now, just for fun.

Mac moved his hands around to the back of my neck. My feet were aching, but I was still waitressing, and had performed the night before, so I expected it.

- Have you been running fevers?

- Yeah.

- Your head’s hot.

- Oh. I didn’t think I had one now.

- You don't.

I lay still (that in itself a rare thing) but his hands were firm and quieting and knowledgeable. He hummed along with the flute music on the stereo. I felt physically sleepy, but my thoughts were racing: Who is this guy? What is he doing? My feet hurt, shit, did I leave my answering machine on? Oh, I have to call Dad, should I tell people I'm sick, or just wait till I get better and say that I was, or am I even sick or having a breakdown ofsomekind what ifit's avirus and it just needstorun its courseoh ... I wonder if I'll gettowork withPaul Newman...

My left foot twitched, and Mac laughed.

I took a deep breath. Hadn't done that in a while.

- Do that again, he said.

I did. He moved his hands to the front of my throat, with his fingers pointing towards my collarbones. It made me feel vulnerable.

- Keep breathing.

Bossy, I thought, but I did it.

He moved his hands to my chest. I started coughing.

- Good, he said.

My legs started to ache. My knees swelled up. I could feel it happening, as if someone had turned on a spigot and filled them with water. They were inflating, pounding. I bent them up and let them down again.

- Are you OK? He asked.

- My knees hurt.

- It's not your knees. Here's the trouble here.

- What?

- It’s in here.

- What’s in where?

- What’s your favorite color?

- Um, pink, I guess.

- Yeah, pink, he said, half to himself.

I wanted him to rub my knees, to pull that furious heat out, but he stayed where he was, hands on my chest.

- Who’s in here, he asked. You’ve got someone in here. Who stabbed you in the back? Who hurt you?

I didn’t want to talk to him. I pretended I was sleepy, but there was too much going on in my body to even get comfortable, let alone rest.

A little chest-sized bomb exploded and I had a long, nasty coughing fit.

- Atta girl, he said. Cough it up. I think you got to cop a confession here. Who hurt you so bad?

- No one.

He was pulling his hands away, shaking them out. His fingers snapped when he did that.

- Who is this? he insisted.

Since he put his hands on my chest, I’d been thinking of my Mom; when I last saw her, her tiny empty shell at the hospital, her wake, the gray and white dress; those stupid white satin pillows underneath her head, as if she were having a nice nap. I wondered if that was what he was talking about. I said,

- Um. There's my mother's death –

Well, that was what I meant to say. I got about as far as, "There's my moth -" and it felt like something blasted through a foot or two of wet sand, some bird-like creature escaped, wretched. Behind my eyes, things went dark, but I didn't dare open them. I was sobbing and making some scary diving-for-prey sound on behalf of this creature.

- There it is, there it is, there you go, whispered Mac.

He was rubbing his hands in small circles over my chest, clearing and clearing, crooning to me, sighing. Pulling this stuff away, shaking, snap, snap, snap. I caught my breath between screams.

- Oh, Jesus. Oh, my God.

- There you go. There we go. So much pain in this body, he murmured, and whisked and shook his hands out to cool and calm them, to release my stuff, and free himself of it.

- Oh, so much pain, he murmured. Poor body.

I cried till exhaustion finally stopped me.

We sat in his little kitchen drinking strawberry herbal tea. I'm not a "grass tea" drinker, despite all the attempts of the many alternative healing people I've seen. Give me an espresso, or at least a nice strong Irish Breakfast tea, but caffeine seemed sacrilegious at such a time. The traffic on West 17th crawled and smoked, but it sounded like the ocean to me. I was blinded by the sun on its way down, so I stared into my tea. Mac puttered at the sink, putting away the morning dishes.

- What the hell was that? I finally asked.

He chuckled. I leaned my head against the wall. The kitchen was probably a grand total of 6 feet by 6 feet. It had yellow curtains with a silly chicken print. Tired old dish towels hung on nails on the cabinets. The table was a little sticky so I moved my arm. Mac came to sit across from me, blowing on his tea, then taking loud, grateful sips. I watched him for a minute.

- What was that?

- Reiki. Energy. Life Energy. When it's blocked or jammed, as yours is, the result is illness. Your major blockage is in your heart center, or chakra. Also your root is blocked, your lowest chakra.

- Oh, my legs. That's why they hurt.

- No, it's your sexual organs. It's also your connection to the earth, your grounding. Your legs hurt because your energy is in disarray. Basically, cookie, you're all out of whack.

Even I couldn't argue with that.

- So, it's my Mom, then? I have to get over her death?

- It's more complicated than that.

- What else? You mean there's more? How is that possible?

- We'll see.

Oh, Lord, I thought. Getting well will kill me for sure.

But I was open to anything. One of the girls I'd done a show with was channeling. That means you go into a deep and meditative trance, and you listen for what you can hear. You channel spirits, ghosts, angels, the dead, the living but away, some part of the Universe: whatever. It varies by person and I'm very comfortable with that sort of thing, always have been. Perhaps because I'm an actress, and now a writer, the barrier between the tangible and the intangible has always been porous for me.

We met in her small apartment, which was rich with eastern and Christian religious icons and bright sunlight and soft pillows. We set up the tape recorder. We said some prayers, asked for openness and love, and the presence of God. Jane said,

- I am an open channel of light and love and truth and wisdom.

We waited, and as Jane settled into a trance state, I felt a little shift in the room.

- I am Mary, Jane's new voice said. I am a special guide to Jane, and I welcome you, Janet. We are very pleased to see you here and hope that we can speak to you of things that will give you comfort and more hope. I will be back at the end of the session to close out, but now there are others who would like to speak to you. Bless You.

I thanked her, as I felt another little shift in the room. There was a pause.

- I am with you, my child, the next voice said. It still sounded like Jane, but the feel was different.

- I am called The Mother. I'm part of the Mother Energy, of which Jane is a part and of which you, too, are a part. Right now you feel more like the child than the mother. But now is an important time for you to be mother to your own child. To nurture and love the parts of you that are frightened and that worry and have fear and frustration and sorrow. It is hard for you to know how, but it is true, and I say to you that it is the truth, and that you can comfort these parts of yourself and you can love them as a mother loves her children, to nurture them in their suffering and fear and give them what they need. Because whatever image we use, perhaps the one thing we learn in this life is to love ourselves.

The session went on for a while, but this was the major lesson. I saw Jane for channeling several times, and each time she and her visitors reminded me to be gentle and loving with myself, that I had a special gift for healing, but little patience. Indeed, there were times I felt I could heal all of Manhattan, but they kept saying I should take it easy.

I worked with a neuro-linguist programmer, or NLP therapist. The theory here is that anything *in* you is in service to you, and it may need to be re-directed. She gets you into a very relaxed state then talks to the unconscious. She asked my unconscious mind what this episode in my life was trying to teach me. Quietly I replied,

- To teach me to love myself.

I started therapy. In my opening monologue, which took up almost the entire session, I told Barbara that I was temporarily ill, I had this background and that ambition and this problem and that solution. I told her,

- If I can’t act, there’s no reason for me to be here.

- You know God’s will for you?

- Yes.

- How do you know that?

- Because if He didn’t want me to act, He wouldn’t have made me so good at it. And I really am good at it. I see it as a sacred duty. It’s my calling.

- I believe you. Still. You don’t know God’s will. It’s our life’s work to find out what that is.

- I know it. I know me, I said.

- No, you don’t, she said and I thought about leaving, but I stayed with her for the rest of my time in New York.

She kept the lights in her office down low and wore crystals around her neck. We brought up loads of anger; I threw a lot of shoes against walls, and in one session, she had me hit a pillow with a tennis racket till I nearly fainted with the exertion. Finally, she asked,

- Who are you hitting?

- I think it’s me.

- Why?

Oh, God. Perish the thought. It couldn’t be true.

- Because I’m sick. Because I’m sick.

I was missing my Mother dreadfully. She had died so young that it was as if she hadn’t even been here; she was a phantom. It’s not possible to fully mourn the death of a parent. There’s always a longing, a gap. I asked Barbara how I could even begin to get over such a loss, and she comforted me by telling me I could not.

1986 - 1987

Lupus

One Saturday afternoon, I was out puttering around 14th Street doing some pointless shopping. That heaviness in the limbs; the weakness: I felt a flare coming on, and dashed back home. By evening, I couldn't walk, and called in sick to the restaurant and was told by the drunken owner that I was fired if I didn't come in. I said some bad words to him and slammed the phone down. I miss that with cell phones; you can only press the red button really, really hard. I was sad to lose the job, even though, of course, someone with agonizing arthritis and who might even have lupus shouldn't really be waitressing.

All the girls called on the sly that night to see if I was all right. Two of them were leaving because he was such a pain anyway, and did I want them to put in a word at the next restaurant, and, yes, I did. Some days I could walk all right, and all I had to do was find the source of my illness and I could cure it, so it was a matter of time and hard work, and hard work did not phase me. Waitressing remained the best way to work around auditions and plays and, at this point, medical clinics. So my next waitressing job was in a Mexican restaurant.

Mexican restaurants double plate because they put the cheese on at the last minute to melt it and need the second plate to keep clients from burning themselves. But that's food, plate, and other plate. You load them up beside each other, setting a few on each forearm. I dropped a few plates, woke up unable to move my arms a few days, and that was, finally, it for my waitressing days. Well, I thought, that'll allow me to focus full time on curing myself.

If I'd had credit cards, I'd have piled an enormous amount of debt. Instead, I scrambled for every month's rent, each bag of groceries, every session with an alternative healer or therapist. I signed up with a temp agency and got a job at a major magazine publishing company, CBS Magazines. I couldn't type, but I knew the alphabet pretty well, so they hired me to clean out what they called "the dead files." It was an entire room's worth of files from old clients that couldn't be thrown out because they might contain one bit of needed information. I love work like that: give me a truckload of garbage, and I'll alphabetize it. Soon enough, they called me "The Detective" because I could find anything. In only a month or two, I had managed to make myself useful.

The head of the department, Bette, a dynamo in perfect size 6 Armani said,

- We love you. You have to stay.

- I'm an actress. I just have to get well, then I'll go back to work.

- OK, but you should stay.

The people were lovely and supportive and rode out all of my doctors' appointments and sick days with loving patience and good wishes. They asked me to work as an assistant to one of the Sales Managers, Dave Wolf, a temporarily displaced poet. It was sort of a promotion, but I said OK anyway.

In high school, I resented that all the girls had to take typing while all the boys had to take wood shop. Though I usually was an "A/B" student, I warned my mother I'd get a "C" at typing and she thought that was a good idea. So, in the days before word processors, when you had to actually hit the right keys to get the right letters to appear, when I typed something for Dave, he'd bring it back and say,

- This is great. It's only about 16 errors. Can you try it again?

- Oh, sure, Dave. Sorry, Dave.

And he'd settle for three or four errors. If I was having a bad day, he did my filing for me. My favorite part of the job was giving out monthly commission checks to the salespeople. If I wasn't walking well, I'd whip around on a wheeled office chair using with whatever leg was best that day to paddle with.

- Here you go, doll.

- Oh, goodie.

- Spend it on me.

- OK. How's the leg?

- Fine.

I'm almost embarrassed to write this, but I also had a night job. Temp jobs don't pay very well, and Mac was not cheap, so I took a job as a coat check girl at a nice restaurant in mid-town Manhattan. The *maitre'd* was the father of the bartender and they spent their evenings competing for my attention. I did look awfully cute in the French maid costume I was forced to wear. There were a few problems with this job. I was on my feet most of the night, and no sneakers here - little black pumps. I sat down whenever I could, but that didn't look good when clients came in and was discouraged. The coat check cubby was right near the front door, and this was the middle of winter, so every time someone came or went, an arctic blast whipped through my body.

One night I got home from coat checking at about two in the morning. During the evening, I'd been OK, but by the time my shift ended, and the last coat was gone (that last coat was always a long wait) I could tell there was another flare coming, a bad one. When I got home, I panicked to see that the Motrin they'd given me a few weeks earlier at the hospital was gone. I'd stopped taking it the minute the pain settled down and hadn't given it another thought.

Both Bitzi and Brian sat with me in the kitchen while I screamed. I asked for my crutches so I could get to bed. My bedroom was the nearest to the kitchen so after about half an hour I made it to the bed. I called for my Tiger's Balm, which is basically Chinese Ben-Gay, and smeared it on my right hip. I might as well have put toothpaste on it. Meanwhile, my sneaky roommates had called an ambulance. I protested and scolded them, but they had become experts and I knew they were right. When the EMT's arrived, they couldn't get me onto the stretcher because my legs were trembling so violently.

- Wait, I said.

I stared at my legs. I willed them to stillness. They stopped.

- Go. I can't hold them for long.

In the ambulance, every bump in the road elicited a roar. The EMT chatted:

- So tell me about yourself.

- I'm an actressachh ach. Ach. Godalmighty.

- No kidding? An actress. She's an actress, he told Ted, who was driving.

- That's great, Ted called back.

- Can you sing?

- Yeah, I can aacch oohh, oh, god, ah shit oh fucking god.

- Yeah? Can you sing something for me?

- No.

- Yeah, sing something. Ted, you want her to sing something?

Ted did.

As a kid, I had sort of taught myself to sing by imitating - trying to imitate - Linda Ronstadt and Barbara Streisand and Olivia Newton John, *et al*. I'd close my bedroom door and use a comb as a microphone, and I'm sure my mother heard every note, but was sweet enough to not violate my delusion of privacy. Bumping towards Elmhurst City Hospital, the song that came to mind was Karla Bonoff's beautiful, "Save Me."

- Nothing can save me/ from this ball and chain/I made up my mind/I would aaaaaacccch oh oh ach, oh Jesus oh, shit/I would leave today/ but you're keeping me going – oh, god, oh god, oh aach, jesus god –

- Geez, nice voice. Doesn't she have a nice voice, Ted?

Ted thought that I did.

At the hospital, they gave me something for pain. Once the pain lessens in a case like this, the fatigue is overwhelming, but I did my best to stay awake when a young Indian doctor came in with a million questions. I told him I was not leaving until I had a diagnosis.

- Oh, honey, you don't want to be admitted here. It's gross.

- I don't care. I'm not leaving without a diagnosis.

After murder by X-ray, this same doctor came by, dramatically took my hand and said they were going to admit me. I whined:

- You said I didn't want to be admitted.

- Yeah, that was stupid. I shouldn't have said that.

- You were right. I want to go home.

- The X-rays look a little funny. We want some other people to see them. They’ll be here in the morning.

And then I stopped fighting him. It was time. Five years from what looked like mono. He was right. He was also right about the hospital. A New York city hospital is very gross. There are people there who are, technically speaking, in prison. One man was handcuffed to his gurney. He winked at me as our gurneys crossed paths. If I could have mustered any compassion, I might have winked back, but I was just so tired. There are lots of drug addicts in various states of high or crash. There are people dying with no one to send them off, so they’re in the hallway.

I was put into a room with three other women. They were all elderly. All of them were incontinent and due for changing, and one spoke only a few words of English: “nurse” and “ca ca.” But as I lay there whimpering, it was she who got the nurse into the room with her persistent calls. When the nurse came in to see what she wanted, she pointed at me. I was too tired to ask for help, in too much pain to sleep.

- What’s up, honey?

- Hip. My hip.

She put a pillow between my legs, which immediately took half a ton of pressure off, got me some Tylenol with codeine in it, and I fell asleep.

I stayed there for four days. After a few weeks of clinic visits and tests, I finally had a diagnosis. Finally, they settled on Lupus. Systemic Lupus Erythmotosis, or SLE. No one I knew had ever heard of it. There was talk of me coming home to the suburbs for a while to pull myself together. But I was angry and sick and raging and my Dad was angry and sad and drinking. As much as we loved, adored one another, it did not seem like a good fit. He would go to the library this very week and get books (there were none). I discouraged that.

- It’s no big deal. Now I know what I have to get rid of.

- The body is quite literal, Mac explained. Its most primal instincts have to be expressed, the way children express things: instantly and physically. Any kind of back log will create what we know of as illness - “dis-ease.” Illness is just despair gone inward. That’s a little over-simplified, but you get the idea.

- Yeah, I said sleepily from somewhere under his hands. I had expected, after that first session, that our sessions would be quiet, just finishing up and healing and soothing the body after its terrible ordeal of the last few years. But they were all like the first: raucous. I was amazed at the amount of junk in there.

- Touch is a most powerful tool, he continued. That’s why there are more than two humans: so we can heal each other, help each other in a physical way. Lupus. Let’s see.

He went to his bookcase and pulled out a little book that looked like a Cliff Notes. It was, *Heal Your Body* by Louise Hay and it contained a chart with diseases/challenges.

-‘Lupus’

- It’s not Lupus. That’s just a name.

- OK. It’s something like that. Some kind of immune system thing. This’ll give us something to work with. Let’s see: “Anger. The inability to stand up for oneself. I’d rather die than stand up for myself.” Does that sound familiar?

- No.

But just to be safe, I started shooting my mouth off. There was not a cab driver in New York who was not terrorized. I sent lots of awful notes to my family and friends, telling them what was so dreadful about our relationship and how it needed to change if I were ever to get well, or just telling about something they had done that needed to be acknowledged or I'd not be standing up for myself. No one was safe from my desperate need to get well.

At CBS, Bette put her tiny, high-heeled foot down and insisted I come on board. While I'd been in the hospital, they'd sent flowers and, knowing I was paid only when I came in, they'd taken up a collection. I was in good hands. At that time, you didn't tell employers and co-workers you had a major illness. It was not illegal to reject someone on those grounds, and here's Bette insisting I stop temping and become a real employee because I had a major illness and needed insurance.

- You can't go running around without health insurance. That's crazy.

- But that's not fair to you guys. As soon as I get well, I'm going back to –

- We love you. You need insurance. You'll stay till you get well. DIANA!

Her assistant Diana (now my friend of thirty-five years) did some fancy footwork with Human Resources, and though it was almost impossible to get pre-existing conditions covered, she did it. So, I did it. Having come to New York to pursue my dream of acting, being sure that nothing could get in the way, being sure this minor bump would be straightened out in a month or two, I took the job at CBS Magazines. I did it because I did not want to spend another night in a New York city hospital. And because even I was beginning to think it would be a while before I could act again.

One day I was in the Lady’s Room looking for signs of illness on my face and a woman who worked in another area came in. She said,

- Now what’s going on with you with all these tests you’re doing all the time?

It was hard for me to answer the question, but, as an experiment, I said,

- Oh, ah, it begins to look like I might have a thing that’s called, uh, lupus.

- Ah, she sighed. My sister died of that.

She wished me luck, then left. I crawled back to my little office area, which I shared with Judy and Blanca, the two other Administrators. I walked in and they both said something like,

- What happened to *you*?

I wasn’t crying, but I guess I was a funny color, and every emotion shows on my face.

- Karen’s sister died of lupus.

- What? She *told* you that? asked Blanca. Ah, *dios mio*.

- Bitch, said Judy.

One of the salespeople was standing right there and she grabbed my arm and dragged me back to the bathroom. She stayed with me for a bit, rubbing my back, waiting for me to settle down. Then she took my arm and turned me directly towards her.

- I’m going to tell you something and you are never to tell anyone else.

- Um. OK.

- I have lupus.

- You? You have –

- I have lupus. I’ve had it for years. I’m not dead. You’re not going to die. You’re going to have some problems, but you’re not going to die.

I had two possible outcomes. Some people live and function, and some people die. And I didn't want to be either of them. Unlike Karen's sister, I would not die. Unlike this nice lady who'd had lupus all these years, I was going to get well. I couldn't tell her that, because it might make her feel badly that she hadn't been able to do it. She gave me the name of her doctor, and, since I had insurance, I met my first real rheumatologist.

A gentle woman with a child's voice, Dr. Bauer told me she didn't think it was a killer case of lupus, and she put me on Plaquenol, an anti-malarial that seems to help with fevers and some of the milder symptoms, and Clinoral, an anti-inflammatory. And I, who had disdained even aspirin, couldn't get to the pharmacy fast enough.

- Rule number one, she said: Stay out of the sun. For reasons we don't understand, the sun aggravates lupus (I hated it when she used that "l" word when referring to *me*). Always, always wear a hat in the summer. Wear sunblock every day. The sun can trigger a flare almost immediately, so that's the first thing to do, OK?

- I said, OK, but I was thinking: I am not one of those people who can wear a hat. My hair is wavy; it gets flattened out. Even if I have one I like, it seems to blow right off. And sunblock? Yick. How can I stay out of the sun? It covers the world.

I flashed on all those early sunburns.

The worst threat, to my mind, was steroids. Steroids are the mainstay for treating lupus and there'd been some talk of it at the hospital. They cause weight gain and bloating and ulcers and damage to veins and thin skin and osteoporosis and compression fractures and on and on. And weight gain. I told her,

- I'll never do steroids. Ever. I don't care if I die, but I'm not gaining weight.

- We'll cross that bridge when we come to it.

I took that as "OK."

Against my better judgement, I took another promotion at CBS Magazines and was Assistant to the Sales Manager. I never saw Nancy wear the same thing twice - probably because she gave it to me right after. She got her nails down twice a week and she drove a BMW. This would cure me forever of wanting to be someone's assistant, because the line between correspondence and dry-cleaning blurs quickly. And although I did not share Nancy's enthusiasm for the industry, I did share Nancy's enthusiasm for Nancy, so we got on fine. We practiced having me run into her office in three seconds or less, and I felt naughty, knowing I might not stay, but I needed the money for the special tea, the supplements, acupuncture, therapy, Reiki, channeling and voice lessons.

But those new long days at the office took a toll. I'd left the boys in Long Island City because they were breaking up, but I was lonely for them and for my body, my career, my hopes, my family. It was the darkest time for me so far. I'd been ill for years, and, despite having worked so very hard, was not much better. I had lost contact with most of the people I'd met in theater, because if you're in New York to do theatre, that's pretty much all you do, and a sick ex-actress makes you nervous. I was making myself nervous - not for the last time - and wondered, if I'd ever be happy again.

I decided in June of 1987 that I'd move back up to Boston in the fall. I had studied with Mac's teacher and was practicing Reiki on friends and felt God's wisdom in my hands, which, I think, coaxed me to apply that wisdom to my own life. I'd been learning with all these good teachers that everything that was not God was illusion, then "failing" at acting, even acting, even a career, even anything, was illusion. Only what felt true was true. So I would go home. For the first time in a long time, I was content.

Summer 1987

The Cure

Shortly after that, I finally got the news I wanted: I didn’t have lupus at all, that there was no such thing and that all I had was food allergies. The fellow who told me that was a strapping young man in his late twenties with a thriving chiropractic and Christ-substitute business. He specialized in cranial-sacral work and was fanatical about food allergies. He was handsome in a young Beach Boys kind of way, with intense blue eyes that never gave mine a break. He had nothing good to say about current Western medicine, which was fine with me, since that was a lifetime of illness and steroids. He bragged ferociously about how good he was, how important the work would be to me, and, after about ten minutes, he told me that he had already spent way more time with me than most Western doctors would. I thought kindly of Dr. Bauer and our long chats and her eternal patience with me, but let it go. I couldn’t get a word in edgewise anyway.

He believed that all disease was a result of no energy, via cranial-sacral fluid, moving up and down the spine, and food allergies.

- I can tell by looking at you that you have food allergies, he said.

Not to be outdone, I said:

- I can tell you what I’m allergic to.

- What?

- Sugar and pasta. Wheat, I guess.

- How do you know that?

- Because when I’m sick, that’s all I eat. I use them like drugs.

He continued talking at machine-gun clip, telling me I'd need an $825 food allergy test, and I'd need to see him three times a week and I could be better in a few weeks ---

- Wait a second, wait a second, I stopped him.

I looked away, gathered a bit of strength, looked back.

- Listen. I've been working through this for a few years and I've made a lot of progress. It is not *your* job to make me well; it's mine, too. You're making me nervous.

I really didn't want anyone else in charge of my case. Weeks? I told him I'd been doing this for so long, I didn't even think I'd be ready to be "better" in a few weeks. Also, I told him, I'm going back to Boston in a few months, so we didn't have that much time.

- What if you were 50% better. Would you stay?

I said "no," but I thought, "yes," "maybe," "I don't know."

I cried in the cab on the way home. Cured in a few weeks? Food allergies? If it's all food allergies, then I didn't need to go through any of this? I could stop eating what I'm allergic to and just be well? What about the memories and the immune system's powerful messages and the chakras and the channeling and the unravelling? And, also, did I really want to live without bread?

I called my Dad and told him I might not move back after all. He was very disappointed and urged caution. I took his, "Who is this guy?" as a condemnation of all that was possible, all I hoped for, as confirmation of his eternal negativity.

Dr. Bauer urged caution, as well, noting that nothing he was saying had been confirmed.

- Has not been confirmed by the people who are OK with my being sick for the rest of my life, I said.

- No one’s Ok with that. There’s just no data, medically speaking.

- “Medically speaking” I have no options but drugs that are very dangerous, especially long-term. “Medically speaking” I have nothing but trouble – no cure, no hope.

- There’s always hope, she said.

But, what could anyone do, but let me do what I had to do?

Dr. Maniac, the chiropractor, had started working on the cranial-sacral problems the first night, the idea being to get the spinal fluid, the body’s own healing tool, moving. He twisted my neck and it popped it in six different places. He worked my back with his hands and a little gadget that looked like a hammer, but it had a spring in the front of it, and my spine popped and cracked and released. He put one finger on the roof of my mouth and one on my forehead and my legs jumped.

The treatments felt absolutely wonderful. I came floating off the table after them feeling liberated and light. A few days after the first treatment, I was walking down the street and found myself suddenly suddenly jogging – something I hadn’t done in months. I started writing again.

I went home in July and spent time with friends and family and I really did seem better. One of my friends and I met a woman who knew a woman who knew a woman who had had lupus but it turned out to be food allergies. I danced to “Good Love.” I hadn’t danced in a couple of years. Another friend noted that I was starting to believe what I’d been saying through clenched teeth for a few years: I would get well. That weekend, still waiting for the food allergies test to come back, I ate anything that didn't crawl away: bring on the sugar and the wheat and anything and everything that came off my Dad's grill.

Dr. Maniac was popping and jabbing when he explained,

- You're loaded with toxins.

- Mm. The medicine I'm taking -

- That's only part of it. It's environmental, food, stress, structural - everything that's foreign to the body creates a toxic build up.

He somehow convinced me to do enemas. When you were raised Boston Irish Catholic, you don't touch your body, especially below the waist, and you especially don't touch your body fluids, and you then, extra-especially don't do this particular sort of act unless you get a letter from a priest. It's also a hard thing to do when you have roommates. You need the bathroom for about two hours, so I had to be sure it was a time the roommates were gone for a while. But I managed. It had to be done.

On July 20, 1987, I wrote in my journal, *"I am cured! I am cured!"* What I meant, of course, was that the food allergy tests were back. The food allergy test came back showing allergies to sugar, wheat, oranges, blueberries, olives, some nuts. They also indicated an overgrowth of *candida albicans*, a common yeast bacteria. It's easy for that to happen when you take a lot of antibiotics, since they wipe out acidophilous, which balances the bad bacteria. In the end, my diet came down to nothing. White sugar and white flour were gone. I gave up sugar to the extent of not eating fruit. He put me on very expensive supplements and this special tea that was for de-toxing and...stuff. I could buy it from him or send to the company. Of course, I bought it from him. The tea was about a hundred dollars a box, and he took just the smallest percentage as a handling fee for any inconvenience it caused him. I spent weekends cooking so I could bring my meals with me everywhere.

I gave up coffee. I adore coffee. I gave up everything but vegetables, whole grains, legumes and meat. I went macrobiotic. I read all the "how to cure yourself with food" books; all the books that would give me any shot at getting well enough to leave my publishing job and get back to the business of acting. To this day, I can't help wondering, despite her luminous perfection, if I might have just been slightly better than Julia Louis Dreyfuss in *Seinfeld*.

I was playing for time and to see how things turned out: If I get well, I'll stay. If I don't, I'll go. If I find a nice place in the fall, I'll stay. If I don't, I'll go. If this and if that. But no matter how all the food allergy and wellness things turned out, it wouldn't have been fair to leave my job before the big sales conference that was planned for the fall out at Montauk. As Nancy's assistant, I would be one of the people primarily responsible for it, so I bought myself another few months before I had to make a decision: I can't leave now; Nancy needs me.

I spent that tortured but hopeful summer in a sublet in Woodside, Queens. I was living alone, which was crucial for a person doing weekly enemas. I just needed quiet. Unfortunately, I didn't get it. I was in an Hispanic neighborhood. I woke up to salsa and I fell asleep to salsa and was frequently woken up by salsa in the wee hours. I still don't like salsa. I happily lost a ton of weight. I was down to about a size six. My normal, healthy size was, at that time, more like a 10, or an 8. When I look at photos of me at my brother's wedding in

1986, I’m horrified. I look glassy-eyed and pale. I’m so thin I can see the bones in my fingers as I stand next to my very handsome and corpulent Dad.

When I announced that I’d need a new place for the fall because I’d be cured, Diana told me about a guy who wanted to sublet his little studio in Manhattan. I grabbed it. It was cheap, dark, dank. Everything in it was brown. I loved it. I called home to say I had the most adorable apartment and I was staying in New York. My poor father. My poor family. My poor friends. They were all sad, and encouraged me to re-think. I re-thunk about 67 times a day.

The night before I moved, the fellow who owned the apartment called to say he had to take it back.

- What? You can’t do that!

His lover had full-blown AIDS. They had moved out of the city to their beach house so his lover could rest and recover, which is how I got the apartment, but he’d become much sicker and they decided they’d better get back into the city. I begged and pleaded. I was so sorry, but, really, where was I supposed to live?

- Do you want to trade places? he asked.

I refused to nip at that bait and stayed calm as long as I could.

- I’m really so sorry – but what can I do? I’m moving tomorrow – I mean tomorrow morning! I have nowhere to go.

- My lover is dying, you fucking cunt!

And he hung up. Of course, we say things we don’t mean when we’re upset. I assume his lover died shortly after that.

This seemed the last straw, a screech from God: GO HOME. But there was the Sales Meeting, so I moved into Diana's one-bedroom apartment in the Village. She had a pretty little place on 19th Street at 6th Avenue. In typical Diana fashion, I got the bedroom. For herself, she had one of those swell Murphy bed things that went into the wall, so she slept in the living room. We spent long hours talking and laughing and living happily together. One night we watched the 25th Anniversary of *Johnny Carson's Tonight Show* and we laughed till we wept. We took to calling each other "roommate" (we still do) and she got used to large vats of black beans and sloppy globs of quinoa all over her three-foot kitchen.

The Sales Meeting went beautifully. Along with the obligatory meetings about sales techniques and awards for the top salespeople, much of the purpose of the meeting was bonding and team building. We planned lots of silly competitive games to play, and nights full of rich dinners and open bars. I almost starved to death. I brought a bag of carrots that I ate the first day, and I hadn't thought to bring my black beans and quinoa, and everything served was covered with sugary sauces. We must have hired a caterer and left it to the them to choose meals, or I'd have caught that. Luckily, I'd brought the hundred dollar-a-box tea, and there were always trays of fresh vegetables.

I sang a few songs at the Sales Meeting's No-Talent-Needed show. Though I was excited about singing, a torch song was probably not the right choice for a bunch of drunken salesmen. There's a photo of me, 16 pounds and with huge hair, singing "Stormy Weather," and it looks, from a certain angle, like I'm sticking the microphone in my eye. That about says it all. Diana likes to sing: "Don't know why/there's a microphone in my eye/stormy weather..."

I probably should have skipped the “Color Wars.” I should definitely have taken a pass on the Tug-of-War. The rope caught around my arm and smashed my ribs. That night, I had to ice my ribs to get a breath, my legs were dreadfully swollen and I was getting the clear message from my body that I was perhaps over-doing it. By the second day, I was gobbling aspirin and ibuprofen so Nancy wouldn’t notice my limp and become hysterical before her big speech.

That fall, the movie *The Princess Bride* came out. It is based on William Goldman’s novel of the same name, and it’s been one of my favorite books since college, a book I’d read about a dozen times. Though the movie version is much lighter and lost the dark edge of the novel’s “life is not fair,” central theme, I was pleased enough with the results to see it three times opening weekend. I cried all three times. I wanted so much to be well enough to make movies like that. If it meant leaving New York for a while to finish getting well, I remembered the message from the book: who said life is fair? I took that to mean, not that I couldn’t act again, but that life does not make sense. It goes off track, follows a different trajectory than the one we had planned, but ends up in the right place. Maybe.

Dr. Maniac said I was de-toxing. This meant that all the stuff I was allergic to and had been eating all my life was slowly working its way out of my body. That meant mood swings like crazy: either, “I’ll be acting soon! I’m getting well! Black beans are good!” Or, “I hate this guy! He’s an asshole! This food tastes like garbage!” He said that the *candida* was leaving the system and that created what’s called “die off,” that can present as nausea, sugar cravings, etc. My joints kept swelling, and I was generally feeling more ill than usual. Worse, I was covered with deep, dark bruises that I couldn’t explain. I showed this to the chiropractor and he said he had never seen anything like it, but it was surely the toxins leaving my body, and it was a good thing and not to worry. I told him,

- It’s like my blood is not...holding...not holding itself together.

He sent me to an acupuncturist friend of his (thank God for the promotion and the extra cash) and he said it was the toxins leaving my body, and the bruises were just an indication, a good thing.

Though I had given up on Western medicine, Dr. Bauer managed to get me to come back to see her before I left. The arthritis was getting worse. There were many days I just could not move a body part. She had never seen anything like the bruises, either, and wanted to do some blood tests, but I said,

- No, it’s OK, it’s just from the chiropractic work. It’s really aggressive stuff.

- No, I don’t like the looks of that. Let me run the blood tests.

- No, it’s fine.

- Please.

I indulged her.

And despite my assurances to Dr. Bauer, the bruises were terrifying. I could press down on a soft part of my arm and immediately leave a little trail of blood-freckles. Not wet, but not *not* blood. I was beginning to think I might die. After a few years of truly trying to surrender to God’s will, I had to think that maybe God’s will would remain entirely separate from mine. Maybe there was no will to decipher. And that maybe what I didn’t want, but what was going to happen anyway, was that I was going to die at 27. And, for that, I wanted to be at home with my Dad.

Update

Winter 2007

The dog is visiting friends so I don’t have to walk her, since I can’t walk very well, and we’re in the middle of the first true storm of the winter and my open-toe walking boot provides no traction. Also, I just got out of the hospital. I went to the hospital a few mornings ago and stayed overnight. It was a pretty bad flare, and it was badly timed, coming 7 days before Christmas, though it was not the worst flare I ever had. It was a bad night – one of many, since pain and fever tend to get worse at night -- but not the worst.

On a bad night, I lie *on* the bed, not *in* it, because the sheets hurt. I can’t use my regular blanket or wear my pajamas because they’ll tear my skin off and I’ll die. Skin swells like any other organ, and it presses against the nerves on one side and against clothes or bedclothes or air on the other. On a bad night, I wish I could shed my skin the way a snake does. I could wriggle out of it and leave it somewhere in the desert between a rock and a cactus.

At two in the morning, I want to talk to someone. The nice nurse on the all-night line tells me to go the Emergency Room, but I’m not ready yet. When we hang up, I take prednisone, pack ice on my head and neck. Put a hot water bottle on my pelvic area. My temperature is slowly creeping up. At full-flare level, it hits 105° and the kidneys may be affected.

I say, “the” kidneys, I know, as if they are not mine. Surely, the whole body was meant for someone else, or at least not me.

The whole week, I'd been calling doctors and going into the clinic. I was sure I had a urinary tract infection, which happens a lot. The blood and urine tests were fine, but they put me on antibiotics anyway, since I'm just as likely to have an infection as not, and I was describing a urinary tract infection. I went in two days later when it was worse, and they tried another antibiotic. I got an immediate girl-crush on my doctor, a tall, beautiful African woman in traditional African dress who curled her whole body up to listen to my tale. She moaned and whimpered with each development in my history and, when we finished, she'd given herself a cramp in her leg, which she says she does often and I said it's because she curls in for a fireside chat. She laughed and said she did.

It took two hours to leave a urine sample. The cramping was so bad I was sure I was bleeding to death and I couldn't even sit still long enough to do my task; I had to keep walking. When they finally got the results back later, my beautiful doctor said it was now a "frank" infection, meaning it had blossomed despite antibiotics. This means either it was the wrong drug or, just as likely, I'd become resistant to that particular antibiotic. I'm one of the people who has to pray that they keep coming up with new ones, because I'm wearing out the old ones, and one of these days I'll get an infection that resists treatment, and I'll end up dying from the bacteria on a piece of lettuce.

If I could think clearly before a flare sets in, I would. But part of the wonder of a flare is its ability to camouflage itself, and then to wipe out what little brain I have left. I believe, though there's no evidence to support it (but that only means there's no evidence, not that I'm not right), that there's some kind of endorphin surge before the full flare hits. I'm usually high as a kite. One night, I lay in bed feeling the bumps on my mattress with my heel. Wow, I thought: these are really big bumps. These are fabulous bumps. I'm awake and asleep, feverish, dreaming and attentive.

Going to the Emergency Room in the middle of the night is the ultimate long night. If you get there too close to the middle of the night, you get all the heroin addicts. We have quite a problem with it in Brighton, and the ward is full of them at night. I hear the nurses, angelic,

- When was the last time you shot up, love?
- Uh. What day is it?
- It's Tuesday, dear. When did you shoot up last?
- Monday. Monday, I think.

They have to get the slick IV nurse in there to do the saline lines, because the veins are shot. The patients tell her,

- I have bad veins.

I had called my sister-in-law in the evening to, ostensibly, check on the Christmas plans. I could hear myself talking, manic, non-stop scary talking, panting. I was actually out of breath when I got off the phone, having clarified every single plan all four of her children had for their week of vacation. I had hopes of having them in for sleepovers, but that, of course, didn't work. When I hung up, I lay on the bed for a moment to catch my breath. My eyes were watering. The dog was suspicious. She was watching me from her windowsill. I must teach her to talk. She could say:

- Jan. Calm down. Or, Whoa, mum. Flare coming?

Like that. But she just watched.

There’s that little thump of hers as she jumps down and goes under the bed. Honestly, I don’t know where she sleeps. I thrash around too much to be a good sleeping companion, so I won my bed back by being annoying, and by the time I wake up, she’s back in the bed, visiting. The apartment is so tiny that, when I’m awake, she’s awake. At 3 am, I’m up with my skin on fire. My pelvic area is heavy like cow’s udders, aching to be emptied. I can see myself taking a large pin and puncturing just below my belly button to let some of the volcanic fluid out. That would probably be grounds for admission to some kind of hospital. And in the part of my brain that’s still working, I know it’s not really a volcano ready to rupture, so that wouldn’t work anyway.

- Come on, buddy.

Even at 3 am, God bless her, she’s ready for a walk. Her life’s motto is,

- Where are we going?

The air has that nice pre-storm stillness to it. The snow’s late for the season, but winters are different from what they were when I was a kid. Even with lots of college kids in the area, at this hour we have the place to ourselves. She does her business, which she would not have to do till morning if she were asleep. Dogs don’t wish, though. If she’s out walking with me, that’s all she’s doing. There is no “rather.” We walk for blocks, and, at this point, I know I’ll have to go to the hospital, so I enjoy my time with her, knowing I’ll lose her for a few days.

When we get back home, I wash my face again. My skin hurts too much to take a shower, so I just fix my hair a bit. I put in some curlers so my hair will be fluffy in the morning when I go to the hospital. I think of my Nana, my Dad's mom. She was a very pretty woman, and she was vain. When I was little, I'd watch her "put her face on" and she really did put another face on top of the one she had. Even at the end of her life, she was careful of her looks, so we'd go to see her in the hospital and she'd have her face on, her pretty quilted bed jacket tied up at her neck, all her jewelry on, bright red lips. She'd have had the hairdressers at the hospital in, her cheeks were painted firmly in place. You could scrape the foundation off with your fingernail.

Walking down the cold, quiet street, I can feel the heat coming off my joints. I picture a skeleton; the bones are white and glow slightly as the thing lanks along, walking down the street with a small white dog, and the joints are all red and there are small flames licking off of them. The flames jump and pop, the way a fire does when it gets a bit of paper thrown into it. But it limits its burn, and doesn't catch at the trees or shrubs.

When we get home I go back to bed, wishing I had saline. I could run a saline line myself. I do injections every Wednesday. What's the big deal? Why can't I keep a saline kit at home? My jaw is starting to tighten up. That's one of the last things to go, and it's often the final clue as I try to determine if I'm lazy or having a flare. I want a chicken salad sandwich. I fall asleep for a few hours, dream of saline and chicken salad. When I awake at 7, my temperature is 102.5, which is one of my signals for time to go to the ER. The sun is up, so I can go now.

I pack a bag. I'll need a few things. Fresh underwear and socks. At the hospital, if you stay overnight, they give you these scary net mesh things that are the underwear equivalent of a johnnie. Crochet project, including the pattern book. Notebook. Book. Over-the-counter medicines: saline nasal spray, Aphrin (to which I'm completely addicted), cortisone cream, eye drops. Toothpaste and toothbrush. Floss. Deodorant. I take the "travel size" stuff out of my swimming bag. Huge bottle of water with a bit of tonic water added to it to help with nausea. Yogurt. Crackers. Bread with margarine spread. Celery. You can never get food when you want it.

I bring the tray of pills, the one that has S M T W Th F S on it, so you can remember to take your pills every day. I only use one of these and I refuse to go to two, so each "day" has more than one pill type in it. I sort them by function and color, so I can whip through the pills at night, piling them on till I have a small handful. Sometimes you can get your drugs in the hospital, sometimes you have to wait, or sometimes you just fish them out of your bag when no one's looking.

I bring Percocet in case I can't get it when I want it. I pack Ambien, my scary awful sleeping medicine, because I can never get it in hospitals. I can barely get it at the pharmacy. Because I've been on it so long, I take more than I should, so I have to pay cash for it at least once a month to patch the prescription. The insurance company doesn't want to pay for it at all, so I have to have doctors write letters and get things approved every few months. If I don't have it, I just don't sleep.

It’s hard enough to sleep in a hospital. It’s noisy, of course. You’re never far enough from the nurse’s station, and you don’t want to be too far. The bed is unfamiliar and uncomfortable. There’s a bed-wetting emergency chuck under you. It’s plastic on one side. Even if the soft side is toward you, you know you’re lying on plastic. They remind me of the puppy pads I house trained Grace on. We don’t use them anymore, because I don’t want her peeing in the house, ever, even where she’s supposed to, and, anyway, she eats them.

The worst of it is the stranger 5 feet from your head. It took me a year to get used to having a dog in the house, and she doesn’t say much. She doesn’t have this whole complicated history, and she’s not in pain. She doesn’t talk to herself all night. She doesn’t snore, though I do. The roommates always talk to themselves. Last time, my roommate called all the time,

- Mama? Mama, where are you? Mama, Oh, Mama, it hurts, it hurts. Mama? Come get me.

She was in her eighties. In the two days I was there, no one came to see her. After listening to her for an hour or two, I moved into her part of the room. I said,

- Ms. Jones? I’m your roommate. My name is Janet. Can I get you anything?

- Mama.

- She’s not here. Can I get you something?

- Mama?

- Was your mother pretty?

- Mama.

- Are you sad? I’m sorry.

- Ow.

But now, I just need her to shut up. At two in the morning I ask the nurse if I can change rooms. She, as if she had nothing better to do, calls for Housekeeping and helps me move my few things over to a new room, to another cold, strange bed. The lady in this room has the TV blaring. She is, also, wide awake. She is watching those horrid “blacksploitation” comedy shows that some of the tacky networks run. Just the way we do when someone has a newspaper near us, I can’t help looking over, and I see them all acting like little circus dogs, and I’m sad.

At three in the morning, I tell the nurse this was worse than my original room, and I am moving again. She calls Housekeeping again. I take my stuff and my blankets and some pillows and sneak down to the Visitor’s Lounge. There is a grimy fake leather couch there. Naugahyde, I think. Because of my Dad’s job, we know fabrics in our family. In the 60’s, Naugahyde, which is an industrial-strength leather substitute, had an odd promotion: a hideous doll made of Naugahyde. It had pointy ears and little bits of limbs and jagged teeth. It was a Naugadoll. We had several of them. The Naugodoll looked like a kimono dragon. I don’t know what was supposed to be cuddly about that, but we liked them, and they packed a good wallop when smashed against a sibling’s head. This couch in the lounge is cold and not quite long enough for me to lie stretched out, so I curl my legs up. There are two Coke machines humming and lighting the lounge. It isn’t nice in there, but there is a door I can close. I pile the blankets and pillows all over to disguise myself as a pile of laundry and a catch a few hours of sleep.

October 1987

I T P

The foliage was spectacular from Interstate 95. The view was endless orange and red and yellow and the thousand shades of October. I'd assured Dr. Maniac that I'd be back every few months to see him, but I never saw him again. He gave me the numbers for several chiropractors who were doing similar work in the Boston area. Dr. Bauer gave me the name of a colleague in Boston. I didn't plan to call.

My brother came to get me. We drove home mostly in silence. He's not much of a talker, and I was heavy with thoughts. I had failed. I had gone to New York to take it by storm, and there were a lot of people who agreed with me that I was just the girl to do that. Instead, I was crawling home with a few minor acting credits behind me, lots of waitressing experience, a bit of magazine advertising knowledge, and not much else. On the five-hour drive, mostly, I looked out the window and cried. Occasionally, my brother reached over with his very small, very fine hand and squeezed mine. He could not begin to understand my heartbreak, but he reached over anyway.

For then, for just that period of time, all I wanted to do was rest. I was finally letting myself be as tired as I had felt the last few years. I'd fallen into the soft, cushy couch that was my childhood home. But I had an appointment with a chiropractor the day after I arrived home. I drove into Boston with my Dad then headed off to see him. I brought my food journals, and they were impressed and probably amazed. They emphasized rest, diet and a supportive environment. Not one to be told how to heal, I told them I'd come back to Boston for just that reason. I spent most of the day at the office, then waded back to my brother's place, which was in the city near my Dad’s office, fell asleep, then drove home with my Dad. He took me out to eat, and I devoured a lobster, which delighted him.

The next day, we had an appointment with Doctor Jonathan Coblyn in Brookline. We’d met briefly a few years earlier when the diagnosis finally came in. My Dad wanted to go to a doctor with me and try to get an understanding of what I was up against. I indulged him by sitting through a visit. I spent most of the it trying to convince the doctor and my Dad that I was already well on the way to healing, and I had just come up to Boston to finish the job. Dr. Coblyn didn’t like the looks of the bruises, either but I was determined to get them under control on my own.

Everything about the house was unchanged since I’d left. Because of Dad’s work in the upholstery field, we always had lovely upholstery and changed all of it every eight years or so, but that was it. Other than that, everything stayed the same forever. The couch, the coffee table, Ma’s chair, Dad’s chair, the TV, the side lamps, had all been in the same place my entire life. I sat in “Ma’s chair,” the flowered chair, in the evenings, and quilted. Dad watched ball games of any kind. He often politely inquired if there was a movie I wanted to watch, but I really didn’t care, and I didn’t want to impose.

The blood tests Dr. Bauer had ordered right before I left indicated a very low platelet count. A platelet is part of the blood cell that helps the blood clot normally. A healthy range is 150,000 to 400,00 per mm. Mine was 50,000, which explained both the bruising and the “leaking,” which were piticheai, a spontaneous seepage of blood. Soon after my return home, Dr. Bauer called.

- It’s very dangerous. I want you off that diet.

- No, it’s not the diet causing it.

- I want you eating real food, and you must get to a doctor right away.

- It’s all right. I just need some sleep.

- Janet, I cannot impress upon you enough how dangerous this is.

She was right. She couldn’t.

Dr. Coblyn ordered more blood tests. I sighed and said he could do the blood tests, but I was not going off my diet and I did not agree with the principles of Western medicine. He called me from home the next evening. My platelet count had dropped below 11,000. Anything below 20,000 is potentially life-threatening. At that level, I was right: my blood was not holding together. At that level, you can bleed internally. You can get brain damage from blood leaking into the brain. Your internal organs can bleed. You can die.

- OK, I said, using anger to cover my worry, what do we do?

- Prednisone, he said.

I felt a tremor run through me. I had spent the last few years aggressively avoiding steroids. I had read and heard just enough about them to know how awful they were. I had met many people in clinics and waiting rooms who were on it and hated it being on it. I had seen the pictures of Flannery O’Connor near the end of her life, when her steroid-swollen cheeks overran her nose. This was failure. I had failed. I had tried everything, and failed. All this work, and now I was being threatened with steroids. All a waste.

- No, I said. Oops. Sorry. Not being very reasonable. What are the other options?

He sighed. He didn’t want to use other options, but,

- Well, there’s danozol, a male hormone with essentially the same side effects.

- No.

- Chemotherapy.

- No.

- Intravenous glamoglobulin transfusions, which is a transfusion made up of platelets, or a spleenectomy, since, sometimes, especially with lupus it has gone awry and is chewing up the platelets before it releases the blood back into the blood stream.

- That’s disgusting. Western medicine is so disgusting. It’s all dangerous and – ick. When it can do what it does without being intrusive and dangerous, I’ll be impressed. I need some time to think about it.

- You don’t have much time. This is officially an emergency.

I told him I’d call him in the morning.

I called the chiropractor in Boston, and he had me talk to the acupuncturist and we all agreed that it was toxins leaving the body and that the gammoglobulin infusion was the least offensive. I called my therapist in New York and sobbed into the phone,

- What am I doing to perpetuate this?

- ‘Perpetuate’ is a judgement, as if something is not the way it should be.

- It’s not, I insisted.

- No. Each life is perfect, and God is present, and when we learn acceptance we realize that God is within and everywhere, and everything is perfect.

I wrote that down, which is good, because I didn’t hear it. I spent the night on the phone with friends who agreed with me, and heard my Dad come home late. I was in bed. I was so glad he didn't know about this. He might have been pushy about going to the Emergency Room, and he wouldn't have had any luck at all and we would have had a blow-out. It was a long night.

In the morning, I called Dr. Coblyn and told him that I had decided that the gammoglobulin transfusion was the least offensive option, so we could go with that.

Now it was his turn to say "no."

- What? Why not?

- Because they won't try gammoglobulin unless the steroids don't work.

I broke a sound barrier.

- Why didn't you tell me that? Why did you tell me the options if you weren't actually going to do anything but prednisone?

- We have to go with the most time-tested method.

- I would hardly call prednisone time-tested. It's been in use, what, twenty years?

I was comparing it to homeopathy and Christ.

- I think I know a little bit more about medicine than you do.

That was really about the dumbest thing he could have said. I would need a new doctor, that was for sure. He said next that this was out of the realm of his expertise, and he would call a hematologist colleague of his to find out what to do. I called a friend and he called back 20 minutes later on an "emergency interrupt" (I detested his penchant for drama; leave that to the professionals). His friend said I should get to the hospital right away, this morning, now. He was affiliated with Brigham & Women's, one of our fine Boston hospitals, but I was in Abington and didn't want to do anything he said anyway.

- I’m out in Abington and I have no way to get there. My Dad’s in Boston and there’s no one else to give me a ride.

- You have to. You have to get to the hospital. You are in great danger.

- Ach. I can see if I can get a taxi to the train.

At that time, the nearest train into the city was in Braintree, about 9 miles away.

- No.

- What?

- I’d rather someone drive you.

Could he be serious about the danger? I looked at my arm; new bruises. I pressed the inside of my forearm. Speckles. Blood. One finger, minimal pressure, blood. Finally, I backed off and called my Dad and he drove back to Abington as fast as he could.

We arrived at Brigham & Women’s at around noon. I immediately hated the friend of Dr. Coblyn’s. He seemed a carbon copy. I pictured the two of them playing golf over the weekend, conspiring to put as many people on steroids as possible. He told me that Jon was a very good doctor and he was concerned about me. I guess my claws were coming out, so at this point, another colleague who was present, Dr. Phil McCarthy, interrupted. He said,

- She’s angry because she’s sick. I don’t blame her.

From then on, he was the only one who could talk to me. He looked Korean-American, and he was probably nearing thirty, so he was closer to my own age than these supercilious over-paid freaks. He was also cute, with thick black hair and pretty blue almond-shaped eyes. The other doctor was smart enough to leave the room and leave me to Dr. McCarthy. We chatted. I told him about everything I’d done in New York and he admired my tenacity and courage, which also didn’t hurt his case. Then he was ready to get down to business.

- Did Dr. Coblyn explain a bone marrow extraction to you?

Pause.

- If you were Dr. Coblyn, would you have explained “bone marrow extraction” to me *before* you got me in here?

He laughed. He dared laugh in my presence. I smiled.

- No, I would not have. We have to check the platelets you do have to make sure they’re valid, few in number, but healthy. We’ll take a little bit of bone marrow out and get a look at it.

Due to the miracles of modern medicine, they can get bone marrow out, but really, it’s not like skin or an eyelash – it should stay inside where it belongs. It was the most gruesome procedure I’d endured yet, and, yes, my suspicion about it was right: it was just the beginning of a life time of gruesome procedures.

I lay on my stomach and he shot my hip full of lidocaine. Lidocaine numbs the area, but it feels like hell in a needle going in. Another shot of lidocaine. Then he suctioned the marrow from the bone with a third needle. It was so intense I felt sure that my spine would crack. I screamed at each new assault and Dr. McCarthy, whose bedside manner was good in crisis, too, kept saying,

- Are you with me? Are you there? You OK?

When he finished, he asked the nurse who was assisting to check the fluid.

- Is it OK, or do we need more?

I barked a laugh.

- Don’t even think about it, I said.

Doctor McCarthy, having helped me sit up, held my hand, coaxing me gently back into contact with him.

- How is it? How are you? You did great.

- I want something to throw.

So he wadded up a sheet and left a banshee in the room. On his way out, I stopped him.

- Thanks. You handled me very well.

He smiled again. Then he chuckled.

- Oh, my God. Imagine if I hadn’t.

After a while, I had had time to calm down (tired? thirsty? Not to be believed.) and both hematologists came back in. They should have brought a whip and a chair. Jon’s friend did the talking this time.

- This condition is called *idiopathic thrombocina purpora*. In English, that means a sudden acute drop in platelets for reasons unknown – “idio” means unknown. The first course of treatment is prednisone, because it will bring the platelet count back up to a safe level quickly. If that doesn’t work, we have to go to a spleenectomy.

- That is not an option, I said.

Certainly no one would cut this poor body open while I was still in it. The very idea of surgery repulsed me, and, what? take out an organ? A whole organ? That’s ridiculous. You need your organs, right? And, now that I knew what was wrong, I could deal with it myself: tell my body to knock it off. Make some platelets.

- This is an emergency, and we’ll probably need to operate, but we can’t even do that now. You’d bleed to death. We have to get you on steroids first, and get the blood count up –

- No.

- Sorry?

- No steroids.

- Janet. You could die, Dr. McCarthy said.

So, in what felt like the ultimate failure, I took steroids. I was on a dose of 80 milligrams. Anything above fifteen makes me both suicidal and homicidal. I shake and jump like I’m wired. I cry a lot. I yell a lot. I clean a lot. I eat a lot. I gained about 60 pounds in the few months it took to get my platelet count to level out for the first time. A steroid, according to Wikipedia, is a “biologically active organic compound with four rings arranged in a specific molecular configuration.” Which means nothing to me. It’s an artificial cortisol. Cortisol is produced in the brain. It is anti-inflammatory and immune-suppressive. When the body is not creating enough, or when, in crisis, more is needed, steroids can supplement the body’s own supply. I was left alone with Dr. McCarthy so he could rattle off the list of side effects, all of which I knew.

Dr. McCarthy tried to assure me though, that most of the side effects occur only after long-term use, and this would be temporary.

- Are you listening to yourself? Do you understand how awful this stuff is?

- I do, but this is an emergency.

Well, I thought. I guess it is an emergency. I guess the day had managed to convince me of that. And it's only temporary. In a month, I can get this under control and I'll be out of trouble. OK. I can handle it. Then he made his first mistake of the day.

- Of course, you might look like a chipmunk for a while.

I was inconsolable. He paced the room, daring touch me only once in a while on the shoulder or arm and say,

- Oh, my God, I can't believe I said that. What a stupid thing to say.

- Only a man would say a thing like that, I told him.

- You're right. You're right. Only a man. Only a stupid man. Oh, God, I'm so sorry.

My poor Dad waited all this time outside in the office. All I could say when I came out was,

- Get me out of here.

On the way home I did my best, in between sobs, to explain.

When he was going to bed that night, he came up and kissed me on the head and said,

- Poor baby. You had a rough day.

I wanted to crawl into his arms and be five.

1987

High Street in the Fall

That photo of Flannery O’Connor. She was using walking sticks, not just a cane. Her thick, black framed glasses sit pat on her cheeks, which are so bloated they look like they might burst. My heart breaks when I see this photo of her. When I see that photo, I think:

80 milligrams. It’s gotta be. 60, minimum.

And she died at 39 anyway.

I prayed over the prednisone, and I took it. I’m sensitive, and I could feel it within the hour: a frantic, gnawing squirrel; an exposed electrical wire flapping in a rough wind during an ice storm. It also gave me a terrible feeling of foreboding. Something’s wrong, something’s terribly wrong - but what is it? It’s an accurate feeling of doom, because if you’re on that level of steroids, there’s something terribly wrong, but, even though you know what it is, you can’t put your finger on it.

I had a sleepless night because of the steroids. You can’t get comfortable and you can’t settle down. I caught a few hours of sleep in the morning. When the phone rang, I didn’t want to get it. It might be Dr. Coblyn. I might have to kill him.

It was Phil McCarthy. He called himself “Phil,” knowing the word “doctor” made me crazy. He asked how I was, and I told him I’d not slept. I also had new bruises. He wasn’t surprised by either.

- Your count is 1,000.

- Wow. That’s almost none. Yikes. What do we do?

Finally, there was a “we,” thanks to him.

- There’s a conference at the hospital this morning on your behalf. We’re trying to decide whether or not to put you in the hospital. I’ll call you back, OK?

- OK, I said and hung up and decided I would not go to the hospital. Luckily, when Phil called back, he told me they had decided not to put me in the hospital just then - probably they were afraid for the nurses’ safety - but he told me to watch for a bunch things: spontaneous nose bleeds, numbness, anything unusual at all. No aspirin, no football, no kidding.

I assured him that my Dad and I had arranged to check in with each other every few hours till this settled down. Then I called my Dad at work and told him we were checking in every few hours till this settled down.

Every morning, I’d go downstairs, having popped up to kiss my father good-bye for the day, (I still picked out his tie) then go back to bed till 10 or so. When I finally did get up, I’d head down to the kitchen, which was unchanged, same ugly Colonial wallpaper, all the cabinets dark and full of stuff I couldn’t eat. I’d have the chiropractor’s tea, pray over and take the prednisone, and go back to bed. When I finally got up for real I’d pull on a lovely outfit of leggings and a man’s over-sized shirt, Timberland boots. It was sort of “in” at the time, but I don’t know where. Most days, I’d walk for hours. There are two options right near the house: High Street or Groveland Street. We lived on Groveland Street, but it has no sidewalks and runs parallel to a major state road, so people tear down it at 70 or more miles an hour, heading for the highway, driving like they’re already on it. The other option, High Street, had an enormous canopy of trees, and it was much quieter, so I usually did that first. Because Groveland Street was so dangerous, as kids, we were encouraged towards High

Street, and there were lots of kids, so the childhood that wasn’t spent in my own yard was spent hanging out with, then, later, babysitting the kids on High Street. Most had stayed local, and I felt superior to them for leaving, so I kept a low profile. It was the foliage, mainly, that drew and soothed me.

Walking on Groveland Street left my nerves jangled, but it was where the ponds were. They were just wild marshes really, and there was a lot of overgrowth and invasive species. I had a monkey chattering in my brain: gotta get a job; can’t hang around the house forever; gotta move back into, at least, Boston; I’ve already gained about twenty pounds; wonder what my platelet count is; maybe this’ll kill me; chat, chat, and I’d try to let the sky and earth and the water I’d find at the ponds quiet me.

One afternoon, I sat on a rock and took off my shoes and let my feet sink half an inch into the mud. I closed my eyes and absorbed strength from the earth, from its coolness and depth. I pictured a band of light, the earth’s light, running up through my feet into my beleaguered body, my body gratefully absorbing it. I sprouted wings and soared above the pond. I noticed from a great height that my corpse was not concerned at being left behind, and I didn’t mind leaving it there. Below, the pond was beautiful: wet and unassuming. Just frogs and marsh grasses, nothing special, but awe-inspiring just the same. When I opened my eyes, my feet were cold so I put my shoes back on and headed home, taking my corpse with me.

I got my old bike cleaned up and oiled. I loved being able to cover a lot of ground and having some sense of self-direction. With all this rest and fresh air and exercise, I felt that, surely, under all these illusions of illness, these drugs, the drama, surely, I was getting stronger. I felt that this “bout,” as I called it, with the blood, this “blood episode,” was the illness’ last gasp. That when this mess cleared, I’d be well for good and for all.

My brothers were busy with their own lives, so that left Dad to deal with me. Some days were tender and dear; some nights were ugly. Some days I’d clean his medicine cabinet or the scary area below the kitchen sink, or the linen closet. Cleaning keeps me in one piece when I’m on steroids; if I’m on a high dose after a flare I clean *everything*. The furniture gets moved. Then it gets moved back. If you want your house cleaned, get a friend with lupus and wait till she has a flare.

Some days I’d be well enough to cook him a nice dinner when he got home. One night he let me tend his sore knee; he had some arthritis himself and, with old hockey injuries, and needed a knee replacement. I just put some menthol on it and massaged it and then put a hot towel on it, like that. Of course, I did Reike.

Then some nights were ugly. He had slipped quite heavily into drinking after Mom died and I was terrified of him drunk, and furious with him for being so. In my mother’s absence, he found companionship in a small local bar, and I hated the thought of him slumming around that dump. If he was out late, I didn’t see him at all, and that meant I was alone twenty-four hours a day. If he came home and he’d been drinking, I’d go upstairs to hide from him while he watched TV, which was even more lonely, the two of us needing one another, separated by our illnesses and terrible sadness.

Most weekends we had fun. We went grocery shopping and he bought anything I wanted especially for me. Over the years, cooking for me would be his solution to every medical emergency. We ran errands. Just as when I was a child, I’d be happy just to go to the hardware store with him while he picked out screws for a project he was working on. We’d grill. When I was a kid, I'd stand by the grill and watch him cook. I was chef Pierre, and he was my Meagre Assistant. I didn't do much but brush on the barbecue sauce and talk to him. That was still wonderful, but now it drove him crazy that he couldn't put barbecue sauce on my food because it had sugar in it.

- It'll burn.

- Don't burn it, then

- The grill will burn it.

- Hey. I'm the Chef.

- Ach.

We watched a lot of TV. It was always on. I don't own one now. I'm easily visually overwhelmed, I hate that all the commercials for crime shows have dead females on them, and it's too noisy. But, also, maybe it's because I'm afraid I'll never shut it off. If I were alone, I'd watch old episodes of "Bonanza." I liked "MacGyver," because Richard Dean Anderson had a swell head of hair and lots of clever ideas, but Dad teased me about it, and, indeed, I was embarrassed to watch it, miss college graduate.

I slept a lot, cried a lot, wrote a lot. I was in Dr. Seuss's Waiting Place, from *Oh! The Places You'll Go!* I was waiting for my blood to grow, or the lupus to go, or the steroids to stop, or a sign from my Pop. I was just waiting.

I spent one day a week in Boston at the hospital and seeing the chiropractor. The hospital depressed me terribly. Everyone hated me. With good reason, sure, but it still felt awful. After a month of steroids, forty pounds later, my doctors were happy with the platelets, which meant I wanted off the steroids, but my platelets dipped every time we tried and, mad with frustration, I had to go back up. My face was almost without a nose because my cheeks rose to meet it. I can’t imagine what my Dad saw, his once beautiful daughter, hanging on by a thread, looking like a, well, Phil was right: a chipmunk.

As this dragged on, my Dad and I were more inclined to fight. We started fighting over the position of the shower head and whether or not you can run back into the store to get popcorn when you’re already in line at the check out (you can’t). After a lovely evening together, he’d slip out to say good night to his friends at the local watering hole, and I’d hate him. We were not either in any shape to break out of harmful old patterns, so, though we often enjoyed each other, we spent more time hurting each other than was good for either of us.

I decided that my only hope was to win the Lottery. That way, no matter what happened, I would never be financially dependent (thus, powerless) again. I started buying tickets every week, praying on them, writing over and over and over the affirmations that would bring wealth my way:

I am wealthy and prosperous. I am wealthy and prosperous.

I can afford everything I need. I can afford everything I need.

Hundreds and hundreds of times. Week after week, I was amazed to see that I hadn’t won the Lottery. Wasn’t I doing everything that I could? Truly, I felt was dumbfounded that The Universe was not sending it my way when I so desperately needed it.

I also became aware, by December, that I had been crying since June. This was, maybe, my first bout with Clinical Depression. It would be many years before anyone could convince me that there was any such thing as Clinical Depression, but, yes, maybe, this was it. I really was not sure if I wanted to go on living.

Thank God, at about this time, I found a therapist, Bobbie Colasante. She had been recommended by the Boston chiropractor, who had soothed and embraced me one day and said,

- You're so brave. You move me. Don't go through this alone.

Bobbie would turn out to be one of the most influential and important people to ever touch my life. She is a strikingly beautiful Italian-American woman with a shining smile and an enormous curiosity about God and the Universe. I felt my relationship with God, who'd let me down so dreadfully, was in peril, and I was desperate for someone who was as interested as I was in exploring that relationship. Bobbie's main emphasis, for our many years of practice together, was mindfulness: whatever is going on now, is what is going on now, and that's what we focus on. *This is what life is offering me Now*. One "now" after another; she could go back with me to explore my past, and forward with me to explore my dreams and hopes, but, always we came back to now, and here, and mindfulness. She was to inspire me for my lifetime to try, as hard as it is, to stay present.

Immediately, Bobbie began a discussion of the legal and financial ramifications of disability. That was the "now." It certainly would appear to any sensible person that I was presently just a little bit on the disabled side, and I was frantic to move out of my father's house and have my own home again. She saw disability as a way out. A disability payment would allow me to rent a small apartment with a roommate or two. It was only based on this discussion that I realized I wasn’t ready to leave my Dad yet. I launched into my opening monologue, so different from the one I’d done two years ago in New York:

- I have nothing to look forward to. Someone has me mistaken for someone who has any patience for this kind of thing. I’m almost thirty. I expected to be so much further along by now. I expected to be in New York, acting my head off, and here I am, I can barely feed myself, no, I can’t feed myself, I’d be starving without my Dad. I don’t want to be a TV movie.

- Pardon?

- You know, this person goes through an awful thing and she learns from it and gets some kind of reward, and, no, no, I don’t want the reward, don’t want the lesson, disease, the whatever - I don’t want any of this. I don’t want to be brave. People assume because I’m sick that I’m courageous. They have this huge expectation of me that I’m going to act a certain way, and I guess I do, too, because I’m always disappointed and ashamed of myself, the way I act at the hospital, you know, so angry and upset and like a lunatic. I can feel them all put their guards up when I walk in and I don’t blame them - I’m such a bitch, I yell at everyone - but it makes me feel really sad and lonely, like I would like them to like me, it seems it would make all this easier but I can’t seem to stop hating them because they’re all about this illness, it’s all they know, and, you know, honestly, I’m afraid I’ll hurt someone.

I had to breathe a moment. The front of my shirt was soaked with fallen tears.

- All I am because I’m sick, is sick. I don’t feel brave and I don’t want people, including and especially me, to expect that of me because it’s wearing me down. I’m exhausted. I’m just exhausted. I can’t do this anymore.

I stopped, finally, and let my head fall onto the back of the couch. I put my hand on my stomach to keep my guts in. Bobbie waited a respectful moment.

- Can’t do what, specifically, anymore?

I took my time answering. I knew it was the key question. Finally, I said:

- Fight. I can’t fight this anymore. I just can’t.

- Then don’t.

- I’ll be dead in a week if I don’t.

- You’ll be dead in a week if you’re supposed to be dead in a week. You won’t know that till then. Right now, what you know, is that you have lupus. You act like you’re in a war.

I flashed on an image: me, blindfolded, bound, gagged, being led to my death by firing squad, but struggling with the guards who surrounded me. Going, but not going gracefully.

Goodness, she had a lot of work to do.

Sewing is always a comfort, and during the fall I had a few quilt projects going, one of which I only worked on during the day because it was my Christmas present for Dad. There’s a style of quilt called “watercolor.” With this technique, very clever people use small squares of fabric in light, medium and dark tones to create, from a distance, an image. Like those images assembled from photos of people, the watercolor quilts delight with their individual pieces, and with the image they finally form. The problem is, I stink at it. So when I presented his watercolor quilt to him for Christmas, hard as he tried, Dad couldn’t figure out what it was.

- The Grand Canyon?

- No.

- A river?

- No.

The family came and took a shot at it. It was made of reds, yellows, golds, oranges – how could they not see this? Down the middle of the image, there was grey fabric shaped like, sort of, a river.

- A fire? A - something on fire?

- No.

- A log in the woods.

- No.

Finally, they gave up, and I threatened to never tell them, but I soon gave in.

- “High Street in the Fall.”

Oh, they murmured, ah, High Street in the Fall, yeah, of course, oh, yeah, there it is...

1988

Sarah Janet

Because trucking into Boston was a bad idea, I took a little job in Abington. In 1988, VCR's were new: the thought that you could take a major movie home with you was still pretty amazing and, given my background and obsession with movies, I was a good employee. I knew every movie anyone was looking for, even if they couldn't remember the name. If they could only give me one hint, I could get it. The people who worked there were loads of fun, all of us movie freaks. It was good for me to get out of the house, nice to make a little money, and great to see people. I was on my feet for 5-7 hours at a time, so my knees swelled to grapefruit-size and my feet ached, but I didn't care.

Mike, the boss, had some sense that I might not stick around that long. I told him,

- You're right. I can't guarantee much. But every day I work here I'll work really hard, and you'll never regret hiring me. I promise.

Dad told me I didn't have to work if it was too much, which was sweet, but I was working to keep my sanity and get ready to move on. I began to wonder if my spleen *wanted* to come out. Was it damaged? Was it the root of illness? It pulsed and kicked like a baby; did it want to be out of the body? Nothing was getting better. So it was bad that one afternoon, when I was biking away from work, I got hit by a car and broke my foot. Dr. McCarthy told me that lupus and car accidents are not a good mix. He was right: the platelets crashed.

He had been pushing for a splenectomy for the last few months. The fact that the platelets wouldn't stabilize told him that they couldn't, wouldn't stabilize while the spleen was getting at them. The spleen is one of those evolutionary left-overs - not quite as useless as the appendix, but you can live without it. It primarily filters blood, and other organs can pick up its function. For reasons unknown, if the spleen goes haywire, as it can and often does with lupus, it takes in the blood to filter, and doesn't release the platelets back into the blood stream. The only way to really get it to stop that is to remove it.

Dr. McCarthy said we just couldn't risk any more crashes and falls and flares. I was in too much danger with that organ doing all the damage it was doing. He told me the only thing to do was to remove the spleen. I told him I'd get back to him.

He called Dr. Bauer in New York, and she wrote to me saying "you have become very ill with your lupus and your life is at risk." I found her concern touching, but annoying.

Dr. Coblyn explained that it's the nature of lupus: the immune system attacks the body. If the spleen doesn't come out, and soon, he told me, I could very well die. I told him,

- I'll think about it.

I stalled. I bled. I bruised. I looked like a leopard. The marks all over my body were brown and purple, aubergine. I believed that once they started cutting me open, it would never stop. (I was right about that.) As we started to increase the steroids yet again, I could hear a quiet little voice in my body plead, *stop it, stop it, stop it*.

I saw an herbalist who knew someone who lived in South Boston who was doing some mad healing work, Evae. This third person had set the whole thing up, so I hadn't actually spoken to her on the phone, so I was surprised when I arrived at her door and she took one look at me, stared at my belly and said, in a vicious Boston accent,

- That spleen has to go, dahlin.

I looked down at my belly.

- What are you looking at?

- Ya spleen, dahlin. It’s this big, black, pussy glob. Geez, it’s ready to blow. You’re gonna die. You wanna die?

- I don’t know.

- Come in, dahlin. Have tea.

Her story was that she was an angelic walk-in. That meant that, at some point, the original spirit that had been in her body had sort of stepped aside so that an angel could inhabit the body and could do the work that the angel wanted to do. Her angel-name was different than her birth name. In the years that I worked with her she’d change several times.

Evea’s healing sessions involved the client lying on a massage table in the middle of her sunny living room. She chanted in a deep, vibrating waves. She used touch. She lay crystals. Lots of crystals. She was expert at which one did what: rose quartz for detox and heart chakra; black amethyst for pain; sodalite for immune system, and dozens more.

My whole body shook and rattled. I writhed. The pain swelled like an aria and when she finished, I had to lie on the table for twenty minutes before I could get up.

We sat in the kitchen drinking tea and smoking marijuana. She nearly chain-smoked the stuff. Though I tried a little bit to be polite, it only made me cough and gave me a headache.

She’d formerly been a nurse, so she understood my situation on many levels. She listened so patiently and had that gorgeous accent that still wipes me out. Finally, she said,

- It’s OK to die, you know? I don’t feel like you’re dying soon - that’s not what I’m feeling - but it’s nonna my business. You do what you want. But I will tell you this: it’s maybe a terrible thing to return the gift of life, to see it as worthless when it’s the greatest gift we get. But you do what you have to do, and I’ll support you.

With permission to die, I had to re-think the whole thing. My problems with the surgery were, in order: 1. there'd be nothing for me to eat in the hospital; 2. it feels awful to be in a hospital; 3. bedpans; 4. scars; 5. pain; 6. feeling like shit for however long afterwards. The larger issue - that I had failed to cure myself - was the biggest block. But, then, to the extent that I could get it through my head that if this kept up, I would probably die, there was this: how could I do that to my Dad?

I called Phil that day and told him,

- OK, all right we can do, you know, it's Ok to, you know, I'll do the thing.

- Sorry?

- The thing! (*How stupid are these people??*) The thing! The splenectomy.

- Thank God, he said, and he had me meet with the surgeon within days. It would take several weeks of a killer dose of steroids - it might have been as high as a hundred, but I can't remember - to get the platelet count up enough to safely operate, so we had some time. Evea and I would take all the pain and fear and panic and illness and gather it into that spleen, and when it came out, all this crap would come out with it. It was a sacrificial organ, and its loss would mean the end of the illness phase of my life.

I woke up with a tube in my throat that was intended to fit into a carburetor. I felt, I have to admit, saved. At the cost of only one organ, I had bought a new life. A friend brought an anatomy coloring book and I colored the spleen black and then scribbled it out. I felt the other organs shifting around, breathing again, their poisonous neighbor gone. I was wondering if I should do work with pre-operative patients when I was well enough, to calm and reassure them. I felt I had fallen so completely back into the arms of God that I would never doubt His presence again.

The day after I returned home from the hospital, I walked four miles. I had to have blood drawn and could do it at the local hospital, Brockton Hospital, which is two miles from the house. The early spring weather was a miracle, and I was a little powerhouse.

Every day, I walked. I walked to the video store and my co-workers nearly fell over. They were bringing VCR tapes to the house at my bidding, but then I went down (show-off) to see them anyway. My platelet count was 273,000. I could have sold them on the black market, and I wondered if I'd be able to donate blood someday.

I got subliminal tapes that played ocean sounds but were saying, "I am strong and healthy." That's what they said they were saying, anyway.

I had no inclination to go back to New York. I had missed Boston. It's a beautiful city, a city for people who need trees in order to live. And I did like being close to my family. Though we had our moments, my Dad and I were now an awkward and incompetent medical team, but a team, nonetheless. I knew I needed him nearby. Having been through this transformative process, and left so much behind, I changed my name. "Janet" was a person who had lupus; I would be "Sarah." I asked Dad to call me Sarah.

- Sarah? Why?

- I'm changing my name.

- Why?

- I like it. It's legal. If it's not for criminal purposes, you can just do it. I checked.

- But why? Janet's a nice name.

- No. I never liked it.

I would be Sarah, and Sarah would be healthy.

After the steroid weight mostly came off, I got new headshots by a popular Boston photographer, and had the name “Sarah Janet Kenney” printed on the 8 x 10’s. Luckily, I can’t find any copies of those. My friends tried hard to call me Sarah; my family didn’t try very hard, but I wrote it off to their stubbornness. I’m sure this was a stingingly clear metaphor for anyone who wanted to notice that I did not like “Janet,” as in, me, myself and I, but I am happy to report that, years later, I like my name, and am pleased when I’m walking down the street and someone calls it, though they usually call, “Gracie!” and I am acknowledged after the dog.

Sarah Janet walked and walked, until she saw Evea the next week and got reamed.

- You’re about two days away from being back in the hospital! You’re doing too much, there is no need to walk that much, you’re supposed to be resting! Do you want to kill yourself?

- Uh, no.

- Then, rest.

Dad kept encouraging me to write, not just in my journal, but, you know, something. A lover of the printed word in any form and, he felt it was a path I should check out. I had had a story published in the school paper when I was sixth grade, but that could have been a fluke. I started working on a short story, and again picked up the play I’d started in college.

For about two months after the surgery, I was high as a kite. With the cesspool of disease gone, I was free of my past terrors, errors, sins and the sins of others.

Then I got bored. It was lonely out there in Abington, and, though afraid to move on, I was really starting to climb the walls. I still had no money, though, and wasn't sure exactly how to move on.

One night at dinner, Dad said,

- Maybe we should sue.

- What?

When the car accident happened, we hadn't even discussed that because he heartily disapproved of the litigious nature of our society. This was before people started suing because the coffee in the coffee cup was hot, but it was getting out of hand already.

- I can't believe you said that.

- Well. How else are you going to get yourself started? It'd give you something to help you get on your feet.

I called a lawyer, a friend of my Dad's, the next day.

- If you had called right away, you'd have $60,000 by now.

- Well. I was having surgery, you know? Can you get me anything?

I couldn't admit my Daddy wouldn't let me sue.

- Oh, sure. Minimum a coupla grand. Six at best, I think. Wish you'da called me right away.

After the high of surviving the surgery, putting the illness phase of my life behind me, I didn't really know what to do. I desperately wanted to go back to acting but didn't know if I could do it. I had no place to live in the city and was afraid to move in with perfect strangers, etc. I was digging a little hole in the ground with my spinning. So I did the the only sensible thing and had a horrible fight with my Dad.

It started one morning when he was complaining about having to buy all these vitamins and special teas for me, and, even though I heard it coming out of my mouth and could have stopped it, I said,

- Do you think we'll have to sell the house?

He said things, I said things. The family had been holding its collective breath for eight months in fear of this: THE BIG ONE. He didn't speak to me for days, and I deserved it. Finally, about a week later, he asked me to fix some buttons on a shirt, and we were okay. But clearly, it was time to go.

As actors often do, I took two part time jobs so I could have flexible hours. I went back to the Ritz Carlton to work in The Club Lounge. This was a new thing; an exclusive lounge for guests above the 14th floor. This was the top of the Ritz, mind, so Senators and TV hosts would come in, and we'd know how they took their coffee because you were not supposed to ask them twice, so we had notes in the back as to who liked what and how they liked it. As with waitressing in New York, I liked tending people, and at the Ritz you could really do it right. It pushed against my socialist tendencies, but it was fun. I also took a job as the personal assistant for an architect. I just ran errands and filed and answered the phone. All the skills I had learned in New York.

After my usual crashing with friends and a failed attempt, I found my home for the next several years in a big old brick three-story on the main street in the Coolidge Corner section of Brookline. I moved into 340 Harvard Street, and, I would be able to pay for it. I had received $6,000 from my little lawsuit.

That summer, The Names Project - the AIDS Memorial Quilt - made a stop in Boston in its travels. I went to see it and was blown away. The panels are made in and with the name of someone who died of AIDS, and the Project was begun by some folks who'd lost people when nobody mentioned "AIDS" in the obituary. The panels are grave-sized, six feet by three feet. Some are elaborate, some simple, all astonishing and raw. Everyone there was crying. There were volunteers giving out hugs and tissues. I took both and gave my name for the volunteer list to help people make panels. It was the beginning of a dozen-year association.

That July, I lost an entire day. I woke up Saturday morning with no recollection of Friday. I had a relatively new perm but couldn't remember when I got it. I thought I had worked at the Ritz in the morning, but, no, it *was* morning, so it must have been yesterday. I called the hotel to see if I had worked the day before. This made no sense to anyone. My still-dear friend Donald finally dashed up the Lounge to check my schedule; I was scheduled to work the next day, Sunday, so I didn't have to work Saturday. OK. Good. So at least I wasn't late for work.

A short story I was working on had many new pages typed, so I must have gone into the architect's office to use his computer. I found a deposit slip for $1,381, and I was pretty sure I didn't have money like that, so it must have been for him. I found a receipt for film, and the camera shop was near his office, so I must have dropped that off, too. After a week or so, I sort of let it go. The chemicals from the perm? Something I ate? I had purchased an obsidian necklace. Obsidian, a dark crystal with yellow veins in it, is supposed to draw out toxins, emotional and physical, and I had put it under my pillow, so I figured that was it, and I’d have to be more careful with it.

Update

Winter 2008

- You have the whole room to yourself, my beautiful young nurse Meghan says. You scored.

Meghan opens the blinds and the two of us stand at the window for a moment watching the end of a snowstorm that had caused 8-hour commutes, and will probably strand her in the hospital for the next shift, as no one can get in. There is a recent issue of *Vanity Fair* on the windowsill. Julia Roberts is on the cover. My friend Jenny and I had poked through magazines at the CVS a few days before, so I said,

- Oh! Look at this.

I poke through the book to find the photos of Ms. Roberts in an embroidered lace gown. So gorgeous, and we *ooh* and *aahh* the way women do when another woman is truly worth admiring.

- Ach, Meghan laments, None of the actresses in my generation can act. And they don't have any class.

My generation?

Oh. Right. She's twenty years younger than I am. I am no longer the youngest person on the floor, nor am I the same age as the nurses who work overnight. They were my age or close to it. Now I'm part of a generation that came at least one generation before them. And, certainly, if I make it to memoir age, I'll be the old lady on the floor, but I hope I'm lucid, and I hope I'm nice, because everyone responds to that, and they really do take better care of you if you're nice, because they don't mind coming in. I tell her,

- Don't worry. They're learning on the job. Julia Roberts wasn't very good when she started. Nicole Kidman wasn't very good at first. They don't do stage work anymore to learn the ropes, so they have to learn while we wince. And, no, Britney Spears isn't an actress, so you don't have to worry about that. You have to think of Natalie Portman instead, and Kate Hudson. They'll be OK, but I don't think there's any hope for Kiera Knightly, who acts with her bottom teeth and is just too thin.

She leaves the magazine with me and tells me to call if I needed anything. I'm always deeply grateful for those quiet moments nurses give you when you know they don't have time.

I had waited till 8 that morning to actually get myself out the door and to the hospital. I fed the dog. Put fresh water in her bowl. Put her sweater out. This is the second flare I've had since I got her. The last time, I had no ability to walk, because my joints were just too awful. At a certain level of pain, the brain just refuses to cooperate. It says, No. No. No pressure there. So even if I wanted to walk through the pain, I wouldn't get any cooperation from my brain, and my feet and knees and ankles and hips are in cahoots. For this flare, I was able to walk. That may be because of the methotrexate, which I'm tolerating well, or it may just be luck, or the exigencies of this particular flare, as they're all slightly different. I call Jenny.

- I have to go to the hospital. Can you get Grace?

- I'll be there in an hour. Do you want a ride?

- No, thanks. I'll call an ambulance.

- I can give you a ride.

- You get better service if you come in on an ambulance.

- OK. I'll give you a ride home.

- You're a doll. I'll call you later.

I call Tim and Kim. I'm supposed to walk their dog that day and babysit their kid that night.

- I have to go to the hospital. Can you get Meredith to walk the dog?

- Sure. What do you need?

- Nothing. I can't watch the squirt tonight.

- That's fine. I think we're skipping it anyway because of the storm. Who has Grace?

- Jenny.

- OK. Call us.

When I call 9-1-1, I tell them I'll meet them downstairs.

- No, no, honey, stay right where you are.

- No, it's OK. I can walk. I don't know why, but I can walk.

- You should wait right there.

- Nah, that'll frighten my dog.

I can picture it: two strange men come in, they're not there to visit her, which is bad enough, because every doorbell ring brings excruciating excitement (she has to "sit to greet, please"), and then they take me away? No, that wouldn't work. A year ago, as a true puppy, she wouldn't really have noticed that something was out of the ordinary, but her sense of *normal* is very powerful now, and her devotion is appalling, so, no, the elevator's working, and I'll get myself downstairs.

I take my big heavy bag and hold up two fingers. Two fingers means, "I'm going out, you stay here." I wave and blow her a kiss as I always do, telling her to be good. That used to be a plea, but now I just assume that she will be.

Update

Spring 2008

The methotrexate seems to be helping a bit, and I just increased it slightly, but my hair feels thinner. My hairdresser assures me it’s not falling out, just changing texture, and she can cut around that.

- You just take your medicine. Let me worry about your hair.

The dog has taken to sleeping with me. She prefers her den under my bed but knows there’s a change in my sleep pattern. I have to get off the sleep medicine I’ve been on for almost ten years. It has been making me stupid and crazy, and I wake up and find empty pints of ice cream that I don’t remember enjoying. Terrifying to find a broken cup in the kitchen in the morning, and not know how that happened. I check the puppy’s feet for damage. She’s fine, but if I can’t remember what I do after I take the sleep medicine, I’m a danger to both of us. I stop taking it and do crossword puzzles to try to heal my brain, but now there’s no chance of sleeping.

At midnight or one, I get into the bed under the sheets and turn out the light, knowing I won’t sleep. She scampers up and crawls under my arm.

- Thanks, buddy, I tell her, and rest my arm on her small, strong back.

When I do finally feel myself dozing off at about four, she hops off and goes to her own bed.

I'm going to try a sleep study to see why it is my body has no idea how to sleep. We have some idea, of course: lupus messes up your circadian rhythm. But can it really destroy sleep?

You go into a dark place at night. The place is bustling during the day, but there's a night staff of three. They put you into what looks like a motel room. The bed is so soft it's like one of those moonwalks they blow up for kids at parties. You put on your pajamas. Not the ones you usually wear, the purple top with the red and black bottoms that are neither a set nor really pajamas, but the ones you got for Christmas that actually match. You watch a video about sleep apnea. It's really creepy and keeps showing animated sketches of peoples' throats closing up. The losers who have apnea have to wear a WWII style gas mask to bed. In the film, they seem to be happy about it, but I'm not buying it.

The nice people who work there spend almost an hour hooking you up to about 200 wires. They're attached all over the place: several on the scalp, the feet, the legs, the throat, the temples, the side. Now, they tell me I must sleep. I tell them I don't do that. They say, well, then this will be a waste of time. So I take enough sleep medicine to kill a bear and get a little sleepy. I do manage to sleep for enough hours for them to get data. They wake me at 5:30, take all those wires off, and send me out into the cold, dark morning. The hospital is in a nearly-industrial zone on the top of a big hill. I'm deeply suspicious of the whole thing, and I think it may explain alien abductions.

When I see the doctor two weeks later - it takes that long, apparently, to process the 800 pages of data they generated overnight - he tells me I have quite a profound case of sleep apnea, interrupting my sleep cycle every minute and a half to gasp for air. I explain to him that that is the one thing I didn't have because I don't sleep, but he's got 800 pages of data that say otherwise. When he tells me I'll have to wear one of those masks, I start to cry. Something about it terrifies me: I'll drown, I'll choke, I'll die. Plus, I won't look good. I know I say I've given up on getting a man, but do I have to get more unappealing every week? How do I put that in an internet dating site ad? Should I put that before the cast, or after the cane?

1988 - 1989

Sweet Bird

Brookline is full of three-story brick buildings that were mostly built in the ‘forties and are full of endearing woodwork. When they were built, one family would inhabit all three floors, but they’re all broken up now, and full of quirks, like tiny extra rooms behind the kitchen that were the maid’s room and half-baths in the back with just a sink and a defunct shower stall. The street trees are old, mostly black locust and maple, and if you’re on the third floor, you are almost entirely surrounded by green.

My bedroom was a converted dining room, in the front of the apartment, right on the very busy main street. That would end up driving me insane, and eventually, drive me to the next rental, but for a long time I didn’t mind it. We had a living room, which was mostly used for friends of friends crashing for a while, so we socialized in the kitchen, just like everyone else in the world. The kitchen floor was a yicky old brown linoleum that had a four-foot square chunk that ripped or rotted and had been replaced by another yicky brown, but different; we called it “the dance floor.” It wasn’t much to look at, but we sure had a lot of long nights and big laughs and deep stories in that kitchen.

Roommates are funny things. Generally, you move in with people you’ve never met. They meet you one time, you take a look at the place, at the room that’s available, check out the neighborhood, and move in. That’s just looking for trouble, yet, usually, it works. You tend to be the same age, in about the same place in your life, busy, broke, but reasonably responsible. You just have to put up with other people’s boyfriends and hour-long showers and midnight curry-cooking. But they are available when your aunt on the West Coast dies or your friend gets his girlfriend pregnant and you don't like this girl at all. You go through breakups and new beaus and, more than once, bats in the apartment. You can walk away with a few friends for life.

Right down the block from my apartment, I found a brilliant acupuncturist, Dr. K.S. Tsay. He said if he couldn't cure me, he would cut off his head. I worked with him for several years and every time he saw me, he did the same thing: checked my pulse(s) for whatever he checked for, slapped my hand gently and said,

- Slow down.

The only scary thing going on, and I didn't even mention it to my doctors, were these weird spells I got when falling asleep: I'd get disoriented, and feel like I was, not falling asleep, but slipping away. I'd sit up quickly, running my fingers over my arms and legs in compulsive Reiki-like sweepings. Sometimes I'd panic as I slipped away and would sit up and say, "No!" nice and loud to my consciousness, or sometimes, with a growl: "Get *back* here," and it did, so I let it go.

I saw Evea and she said that this was likely me being "walked into" and how did I feel about that? I didn't want to be rude, but it didn't appeal to me. I'd already changed my name once and everyone just called me Janet, anyway, and, to my credit, it was only a few months before I gave up. I told Evea that I guess I would be OK with it if that were God's will, but the truth is that I didn't like it when God's will didn't suit mine. God's will to me, at the time, had something to do with acting.

With home and work under control, I started auditioning again. My worst fear was that three years away had left me incapable. And I did stink. I was stiff and afraid, not joyous and alive, as you must be to do theater. I went through several auditions that left me depressed because I knew I had fallen flat. Part of the problem was that I was doing monologues from three years ago, and they really didn't suit me anymore. I was bored with them, but they were safe, because familiar, which is the definite sign to pick up new monologues.

Finally, I had an audition that excited me because it was all improvisation, which meant I didn't have time to be frozen with fear. The piece was a feminist diatribe that had been mounted originally in the 70's. It was the story of a woman who had been a maverick, a star in the feminist movement. She'd sold out and fallen apart. But, ah, she was back. The show was very silly, and wildly physical. Some nights I came out of rehearsal really dinged up. I'd get knocked over jumping on or off a chair, or one of the girls would hit me with a broom handle she was using as a prop. I had to seriously wonder if acting would be too dangerous.

In the meantime, I was studying with Judy Braha, who had directed me in *Fifth of July*. She is a task-master, and would put up with none of my nonsense.

- What if I can't do it? I'd wail, What if I stink?

- Oh, stop it. It's a muscle you haven't used in a long time. Get to work.

And the sessions were awful, because I was a novice again, but I was a battle-scarred, terrified novice. In only a few months, though, she had me back in working order.

I had quit the architect's office before he drove me insane and I'd had to quit the Ritz because it was just too much on my feet (I didn't have lupus; I had sensitive feet) and I was working part time for a small non-profit that had offered me insurance even with the pre-existing condition.

The next time I saw Evae, after a particularly disorienting night, she was giggly and conspiratorial. She said my name was now Nezet and I was a walk-in. It made sense of all the stuff that was going on at night; she said it was the body releasing the soul, and the new energy shifting in.

That night, as I lay there, blasting off the bed again, I said to God:

- OK, do what you need to do, but leave me out of it tonight. I need to get some sleep.

Much to my surprise, I turned 30.

Judy offered me a role in a show called *Quilters*, by Molly Newman and Barbara Damask. It's a musical pastiche of diary entries of women from the American pioneer period. The quilts they made figured prominently in the script, the beauty they managed to carve out of unthinkably difficult lives, and, as we know, many of the quilts survive as testament to their skill and artistry. As with *Godspell*, I didn't have the difficult songs, but I had a pretty one about falling in love while quilting. Judy told me she wanted to hire me because she was giving me the hardest monologues, so that did it. Again, I struggled with rehearsals physically, but the joy of working got me through. She had, indeed, given me the toughest monologues. Judy and I drew blood to get them right, and we finally did, and it was good.

I barely paused after *Quilters* before the next show, Tennessee Williams' *Sweet Bird of Youth*. It's not his finest play, but anything of his is worth doing, and any actor jumps at the chance to try his poetry on stage. It's the story of an aging actress who is dragged back to her young lover-boy's hometown so he can finish some unfinished business. Chance Wayne was, it seems, chased out of town because of his relationship with me, Heavenly Finley, the daughter of the local political boss. It seems that lover boy may have been run out of town by Heavenly's powerful family when Heavenly became pregnant and was forced to get an abortion. That's what we went with, anyway.

We were back at the mouse-dropping covered basement of the theatre in Inman Square, but with a different company and a wonderful director and a very exciting group of new people to work with. I had two crushes going on, and two swell costumes.

One was a bathing suit, a bright turquoise number from the fifties, and, because Heavenly was a modest girl, and, in so many ways, was kept tightly under wraps, we covered it with a sheer dress. One night before the show, I was getting dressed, and I turned to the mirror to see myself in the blue bathing suit. I looked lovely. I remember thinking:

Thank God. The illness didn't get my looks.

Towards the end of the play, the big political party takes place, and as Chance disrupts it, Heavenly sees him, wants to go to him, and is hauled off by her political thug brother and his political thug friends, at the direction of their political thug boss father. Though carefully choreographed with my safety the first concern, it appeared I was getting hurt when the boys carried me off. I was bruising. My friend John, who was doing most of the hauling, noticed them.

- Oh, my God! Did we do that?

They were big bruises. Dark. Brown and spreading.

- No, no. I bruise easily. You're fine.

I'd had my platelets checked and they were back down to 17,000.

We re-rehearsed so we could be sure I was not being accidentally manhandled. The bruises persisted.

At around this time, I was due to see my hematologist, Phil McCarthy, for a check-up. I cancelled the appointment. His office called, and said he felt it was important to follow up. I told them, Fine. And I re-scheduled. For just after the show closed.

The pitichaei re-appeared. My chest and arms were especially exposed in the white gown I wore in the second act. I used thick, disgusting grease paint (sort of like my Nana) to cover the damage. By the end of the run, we had so adjusted the hauling off that I practically carried myself, struggling, reaching for Chance, offstage. My friend John plunked me down off stage and waited there, expecting me to faint. I was in no danger of fainting, though I knew for sure I was in danger of bleeding.

The little part-time job I had ran out of money for the position, so they'd have to let me go, but they'd let me keep the insurance till December. Soon I got another job at a major hotel in Boston, as the Administrative Assistant to the Administrative Assistant to the General Manager. I was jumping from one little insurance bridge to the next. I was having intense pain in my chest - sort of like a heart attack but only on the right side. I finally called Dr. Coblyn and he said it was probably pleurisy, an inflammation of the lining of the lungs. He convinced me to take an anti-inflammatory till it quieted down. Much to my surprise, the anti-inflammatory quieted it down. He said to come on in and see him, but I politely declined.

Within a week after *Sweet Bird*, closed, too, I had already picked up a part in a lesbian romance. We were just about to go into rehearsal when disaster struck: I kept my appointment with Dr. McCarthy.

- Good Lord! Look at these!

He had my hands and arms in his, tenderly turning them this way and that. He looked at me with his sad, sincere look.

- How long has this been going on?

- I was doing a show.

- How long?

- A month? About a month.

- A month, he sighed. You know you should have called.

- I know.

- Do you know you could have died?

- Oh, well, no, not, probably not. I doubt it. No.

- Look at these - remember these?

He was tapping at the pitichaie.

- Yeah, I remember. I'm not going back on steroids. I have another show to do. Maybe after that.

- Maybe we'll check your platelet count, and see what's what, hmm?

My platelet count was well below the safe level - 11,000. Because my insurance would change to an HMO the first of the year, Dr. McCarthy had to send me to different people. This was devastating. I was in beast mode again, stranded with doctors who couldn't get real jobs, so had to work at HMO’s. I ended up seeing a guy who’d gone to high school with Dr. McCarthy. My platelets had dropped to 10,000 and he wanted me admitted immediately. But I had dinner plans. He was shocked, but I was intractable. He told me to call him in the morning. I reached his nurse.

- Dr. Kaye will be happy to meet with you at the Emergency Room.

- He told me to call him.

- He wants you admitted.

- That’s very manipulative. He should at least get on the phone with me.

- He wanted you admitted yesterday. He feels it can’t wait any longer.

I called Dr. McCarthy and said his friend was a jerk.

- Oh, dear. Do you want me to call him?

- No, you’ve done enough. You’ll get yourself into trouble. Should I go?

- That would be really great. If you tell him you’ll take steroids, maybe he’ll let you go home.

- You can be sure he’ll “let” me go home.

- Be nice, he said. Which was exactly what Dad had said. He asked me to give this guy a break and reminded me that I hated Doctors McCarthy and Coblyn at first.

Dr. Kaye did meet me at the Emergency Room and wanted to start gammoglobulin transfusions right away. I refused. That was just gross. He made me sign a release that I was being discharged against medical advice (AMA). He managed to get me back on 60 mg of steroids. I must have had enough clarity of thought to finally be nervous. I was frustrated by the feeling that I didn’t have any control over what was going on, but I did have a sneaking suspicion that that was I was supposed to be noticing that. I wondered if could I possibly have any grace in this situation, or did I have to be an absolute bear?

We had another lovely Christmas. My Dad and I were becoming a well-oiled machine and feeding twenty-something people was easy. My sister-in-law was beautifully pregnant with my first niece or nephew. I got my mother’s recipe for apple pies exactly right. I was on a high dose of steroids and losing my mind. My platelets had stabilized, but I had “fired” the first doctor and was in the process of trying to find someone at the HMO whom I could stand. Against his last words of advice, I lowered my dose to 10 and felt better.

Finally, in early January, I saw a surgeon. I snarled at him:

- Why don’t you take the spleen out again, since it worked so well the first time?

His eyes lit up.

- Do you have another one?

- What?

- That’s possible.

- What??

He ordered a liver/spleen scan. I was such a wreck about the scan that I asked my Dad to come with me. He said,

- No, I have to work.

- It won’t take that long.

- Well, if you really need me to go with you –

- Well, that’s OK –

- I’d be hitting awful traffic.

- No, that’s OK. Never mind.

I came home later to a message and called him back:

- I’m going with you tomorrow.

- You don’t have to do that. Awful traffic. I’ll be all right.

- No. Friends do that. I’ll be there. I felt like a rat all day for telling you ‘no.’ You don’t have to go through everything alone. You should have a friend there.

The liver/spleen scan comes back quickly, so I was still in the room when the radiologist came back in, shaking his head and with a big grin.

- You have 2! An extra spleen.

- Can I see it?

I pointed to a place under my ribs where I thought it was.

- Son of a gun. That’s exactly right.

And there it was: the second spleen. Even I had to laugh. I walked out into the waiting room shaking my head. My Dad looked up.

- Oh, my God. You’re kidding.

This is a mystery. It happens either because the first spleen, or one stem cell or other, grows back, or in some cases, a person can be born with two spleens, and the second one is hidden under the rib cage when they go in the first time. I’m not sure if it’s more likely to happen with a lupus patient, but the first makes the most sense: the impulse is still there - they couldn’t remove the errant immune system’s impulse to kill me one way or another. ITP and spleen problems seemed the most expeditious, apparently.

Still, I couldn’t believe it. If surgery had been a good idea, if it had been something that would have helped, it would have helped the first time. Nothing, absolutely nothing, could get me back into an operating room. Except, maybe, Dad.

- Don’t do this to me.

- What?

- Don’t die.

He got me again.

1990

Decade

I'd done the best I could to stay calm the day before, which would be the first time I'd be at home the night before a surgery, because HMO's didn't cover that night before anymore. I'd gone jogging, settled my taxes, cleaned my room and done my laundry. I'd thought I could handle it, but an unexpected party my roommate had knocked me down. I was disappointed in myself. I was tired of being the Tasmanian Devil. Funny cartoon; bad life. I finished clear liquids at midnight and prayed for courage. I felt certain that things had to change: that life gets weird, gets bad, gets worse, gets even worse, then: boom. Something changes. As Bobbie said,

- You can panic, or you can not panic.

Maybe because it had not been long since the last one, this splenectomy was worse than the first. I was much sicker and weaker. I asked to the surgeon if I were dying, or if this was normal.

- BIG operation, Miss Kenney.

- When you were on spleen patrol, did you move things around in there?

- Oh, sure. We couldn't find it. It was way under the rib.

It would be a slow ride back.

When I was ready to look at it, I found the scar fabulous. It cut straight down the middle of my belly. The other scar was horizontal. My stomach, once pretty and curved, looked like the deteriorated tracks in an ancient railroad yard. I made Dad take Polaroids of it, in case it was not convenient to pull my shirt up at a given moment. Diana called from

New York and wanted to see it, so we took another and I sent it to her. Dad could not believe how disgusting we were. But it amazed me that, looking at my belly in the big mirror above the bureau in my parents' bedroom, that I'd survived this. Twice. I was genuinely surprised at how ill I was, but, gee: I was tough.

In March, I had a full flare, with high fever and arthritis and an ancillary infection and etc., and, because Dr. Coblyn could not accept my current insurance, I met the poor man who would be my rheumatologist for the rest of his tortured professional life, Dr. Robert Sands. I was furious to be forced to choose a new doctor and, as little as I had liked him at first, sad to let go of Dr. Coblyn. Doctor Sands had deep brown eyes and a full head of brown hair that I, personally, have turned gray over the years. It was a full year before I could see or even talk to him without my eyes filling up with blood and daggers popping out of my fingers. I vaguely but permanently remember one particularly frustrating afternoon when I yelled at him to get his fucking rich white hands off of me. I blush. I hated him because he couldn't cure me, couldn't fix anything and, usually, could not even determine even what might be wrong. Through all this, he was patient and compassionate and professional, which I resented.

After that flare, Dad said,

- I've been thinking. I have a plan. You have to slow down. You were planning on going back to work end of this week, beginning of next. No. Everything has to be pushed back. Stay here for a month. Get going in April.

Much to his surprise, that sounded good to me.

That night, he knocked on my door. He wondered, when we had done yard work over the weekend, if I'd gotten too much sun. I remembered my fingers swelling up at the time, which I ignored and, yes, it was that night that I began to feel ill. I didn't want him to feel badly so I said, Oh, doubt it. Probably not.

But, yes, probably.

So I was still at his house on March 22nd, the second anniversary of first splenectomy, as opposed to the first anniversary of the second one, but six weeks after the second one, by which time, I'd been sure, I'd be recovered. Dr. Sands asked if I had "become totally disabled from your lupus?" I was shocked.

- What? What makes you think that?

- Because you're not working?

- I'm just taking a break.

What a rude thing to say. Of course I was not totally disabled from "my" lupus. Who is this guy to tell me I'm disabled? Jerk. But I had to cancel two job interviews and started to worry that I really was permanently disabled from my lupus. What if that were true? Dad took it in stride.

- Then you'll live here. We'll have a helluva time.

Dad's new girlfriend was around a lot, and he was much happier, which helped make this second stay nicer. I was trying so hard to be patient and calm, and relax into being sick, a little. I coulda stayed forever. I started doing the Jane Fonda workouts again to build up my strength (not as much fun without twenty people watching my gorgeous self) and trying to come up with a strategy for the next phase.

I woke up one morning after a night of “spells” and had a huge lump on my forehead. Either there was a lump for no reason, or I don’t remember doing it: not good either way. I spent the day admiring it and when Dad came home, we made arrangements to see Dr. Sands the next day. Dr. Sands said he’d never seen anything like it, and called in a dermatologist who’d seen it, but never on a forehead. Dr. Sands wondered,

- Could you be expecting too much too soon? It might be too much to ask for perfect health without medication at this time.

Although I figured he was wrong, I left back on Clinoral, the anti-inflammatory. The lump started to decrease almost immediately. It was just something swelling in my head. Very scary. Bobbie urged me to be calm, to let my Dad take care of me, as he was obviously enjoying it this time.

But I was worried. I was beginning to wonder if all this talk of “chronic” over the years might be true. It had been a decade. A *decade*. I had not beaten it down in that first year or two. Or the next year or two. Or the next five. It hadn’t stopped. It hadn’t even let up. ‘Lupus” was a meaningless label assigned by others. But “chronic” was chronic. I could no longer think of myself as a healthy person going through a difficult phase. A phase doesn’t last ten years. A phase doesn’t change all of your relationships, move you from one city to another, destroy your hopes, rebuild your days, so you don’t run from audition to audition; you run from doctor to doctor. I was flirting with acceptance, but it felt dangerous. I couldn’t quite distinguish it from resignation. And I would always be ill? Always? No. I did not want to live a life of illness. I just did not.

Bobbie suggested I work with an affirmation that was actually true. I’d always written *into* affirmations: trying forcing things into existence by the power of will and the use of ink, paper and repetition. But Bobbie asked me to write many times: “I have lupus. I have a chronic disease and I don’t know what will happen.” I couldn’t do it. I put pen to paper, but I sobbed instead of wrote. I tried saying it out loud but sobbed instead. This body was, and is, an unworthy vessel for me. And to *not* live was easy: all I had to do was stop trying. Skip the next surgery, skip the steroids and the doctors’ appointments and let my immune system have its way.

My brother admitted that he dreaded talking to me because I was so miserable and he didn’t know what to do about it. Everyone who knew me had become afraid of me, of my rage and disappointment. I felt two things about that: 1) Fuck you. Go through what I’ve been through and see how you do; and, 2) Forgive me, I’m so sorry, I can’t apologize deeply or quickly enough. I wanted to be noble and elegant in my suffering, but I just didn’t have it in me. I was tortured by insomnia, making the fatigue worse, and worse, not giving me a break from my body. Dr. Sands mentioned anti-depressants and got his head good and chopped off for that one.

I needed distraction, and nothing else in my Dad’s house could tolerate another cleaning. It was time to move back into the city.

I settled back into my apartment and quickly picked up a temp job and went with friends to see plays but didn’t give a thought to auditioning. I enjoyed grossing people out with my scars and one night, out for a play and drinks with friends, I spent half the night in the ladies’ room with my shirt up and a bunch of squealing girls. Scars aren’t chronic. They’re already a thing of the past. Any day I wasn’t temping, I was at the place I used to work using their computers to work on short stories and plays. And if I was spending all this time writing, did that make me a writer? I'd broken my heart on acting. If I "became" a writer, and that didn't work out, whatever that meant, I couldn't survive.

I woke up one morning looking like I'd been in a bar fight, my face and head covered with lumps and bruises. Doctor Sands ordered an MRI and I met Doctor David Pilgrim, my going-on twenty-something years now neurologist. I liked him right away. For one thing, he was black. I was so sick of white men telling me what to do. And he had a mouthful of braces, which didn't hurt him. I'd had braces as an adult; we had something in common.

He said that my brain scan looked normal, and the bruises were likely a combination of lupus, medications, trauma.

- Let's not do anything about it yet.

I liked that plan.

I had the nerve to mention my "spells," which were becoming day-time events, too.

He said they might be *jamais vu* or "never seen," a little breakdown in the sensory system.

- Let's keep an eye on them.

Again, a good plan.

As to the bar fight, we guessed that the steroids had burst a bunch of blood vessels, and it would stop when it stopped. I woke up with new black eyes for a month.

Bobbie managed to convince me to take a class she and her colleagues had developed just as the mind/body connection was becoming of interest to Western medicine. To my disappointment, it would be taught, not by Bobbie, but by her colleague, Doctor Matthew

Budd. I didn’t want to, of course. Ways to Wellness classes were for sick people. But lacking auditions, acting classes, shows or an international lecture series about my recovery from lupus, it was something to do.

Their basic premise was that you had not necessarily much control over what your body was doing, but you did have a fair amount of say over how you reacted to it. The kind of life you chose to live was still up to you, even with a chronic illness. The trick was to learn to observe the observer that you are: how do you process things? What old conversations are affecting your new conversations, and are they still useful? Changing the way you see things allows you to take new actions, and these new actions, grounded in reality rather than opinions and assessments, can make profound changes in your life. It was the stuff Bobbie had been teaching me for years, but in a classroom.

I wasn’t into it at first. Matt told a story about a friend of his who had lost his sight and now, as I wrote in my journal, was “some fucking national chairman of some fucking thing for fucking blind people! Oh! Look! This is the way to be sick! This is the way to act if something horrible happens to you! Fuck him.”

I went to an American Lupus Foundation meeting. I dragged my brother, or he dragged me, I don’t know. I walked into a room full of women with fat faces. I know that I’d have left at that sight a few years earlier, but I stayed. I met Val, who lived down the street from me and Kim, who would become a good friend, and I had that rare feeling of belonging somewhere. I decided to start my own support group called LupuShare; we’d meet in my apartment and talk and write. Two people came. Twice.

After a year, the temp job at State Street became a real job, because I was bleeding to death paying for insurance, and the people there were so very nice. Patsy, one of the salespeople whom I assisted, did what Bette did in New York, which was to convince me that I was loved and needed and it was ridiculous to pay for insurance when I could get it through a company. State Street became my home, my headquarters, my social life and my torment for the next decade.

The *jamais vu* spells continued to happen and the staff at State Street became expert at dealing with them. Rita, a girl so lovely I looked forward to her outfit every day, ran over to my desk and placed her hand firmly on my back. I found out years later that that's a valid technique. I don't know how Rita knew that. Mary would stay at her desk and watch Rita's, mine, and her own phone lines. Suzanne brought water and clapped her hands in my face. No one questioned the spells; they were part of the package. Usually, I was glad to be at work, worked very hard, did a great job. When I was sick, Patsy threw me out. Just as at CBS Magazines in New York, I'd found myself surrounded by people who took me "as is."

I was having fun at State Street, and writing in every spare moment, in case I ever wanted to be a writer. My platelets slipped again but I didn't panic. There was pain under my rib that no one could explain. Somehow, I managed to not blame Dr. Sands for all this. Indeed, it was time to apologize for the way I'd been taking out my problems on him.

- Tell me the truth. You dread the sight of me.

- That's not true.

- I'm so mean to you.

- Well, there's a natural human reaction to being yelled at. But, no, I don't dread seeing you.

- I won’t yell at you anymore.

- OK.

- I’m sorry.

- That’s OK.

A month later, the platelets crashed again.

- Oh, my God. We have to do this without steroids.

- There are other options. We both want to keep you off steroids.

- You just don’t want to start wearing your battle armor again.

- You’re fine either way.

Liar.

I kept my focus on the work I was doing on a play, and the platelets came back up when they felt like it. They also crashed again when they felt like it, but I knew not to be too impressed by either.

One of my classmates in Ways to Wellness chided Matt and reminded him that we can’t all be Nelson Mandela. But he said he was as impressed by me wondering how my doctor might feel and that he might have feelings, and even flirting with acceptance, as he was by Mandela. He grew on me.

That spring, Alison Patricia Kenney was born. I was an aunt. Maybe all I needed to “be” was an aunt. And who would Alison be? She was already way too much fun. She’d only get more interesting as she grew. I hated to miss a show like that. She nudged me gently into the future, even though I wasn’t sure I wanted to come.

1992

How to Write

I wonder why Rita keeps hitting me in the face. Out of the corner of my eye I can see her always beautifully manicured red nails coming at me again.

- Where's your gum?

- What?

She slapped me again.

This is odd. She's usually so nice to me. Rita says to someone,

- She was chewing gum, but I can't get her mouth open.

- OK, we got it, says a male voice Then, to me:

- Do you have gum, sweetie?

Two men in uniform. Police? No. EMT's. But Rita was not ready to let up yet and used her two strong hands to pull at my jaw and managed to open it.

- I don't see it, she told them.

- Where's your gum?

- I swallowed it.

And I had. I was sitting at my desk, exactly like any other May day, then my head began to separate from my body; my body sank into my chair, but not all in one piece. By this point, I'd had so many "spells" that I knew I had one coming on. I also somehow knew that this one would be awful. This *jamais vu* was fast, intense. I didn't know quite what was happening, but I remember thinking I'd better get rid of the gum, so I swallowed it. Our mothers used to tell us that swallowed gum sat in your stomach for seven years. Still, I didn't have time to get it out and I didn't want to choke.

When I woke up, I was lying on the dirty carpeted floor near my desk. I took a look up: Patsy was there, and Rita, and Suzanne and Randy and Michael. Yes, all the guys from the farm. My friends were all talking to the guys, but I couldn't make sense of what they were saying. This is called aphasia. It's a break in the language center in the brain. I knew I was on the floor, and thought it needed a vacuuming, but wasn't sure why I was on the floor. I assumed I'd passed out, but hadn't ever had what I'd just had: a *gran mal* seizure. *Gran mal* means "big bad" seizure, as opposed to the thousands of *petit mal* (small bad) seizures that we would now know my spells were. I don't know why the French got to name all this stuff. I've been assured that most people don't remember much after waking from seizures, but I caught much of what followed. The EMT's were checking my vital signs as my friends told them I made an odd sort of laughing sound, then sighed, and then fell back off my chair.

- Think we'd better take her to the hospital, said one of the EMT's.

But I didn't want to go to the hospital. Just my usual orneriness, I guess, or confusion.

- No, no hospital.

- We can't take her without permission. She's awake.

Rita tapped at my cheek, shook me by the chin.

- Say 'yes.'

- Yes.

EMT's have to take you to one of the two nearest hospitals and they have to give you a choice.

- Mass General or New England Medical?

- Brigham, I managed. Of course, Brigham. I always went to Brigham to have my organs removed.

- No, they said to the gang, only those two.

So, of course, Rita went after me again.

- Say ‘Mass General.’

- Mass General.

At Mass General, they did all kinds of X-rays and CT scans of my neck and brain, and, worst of all - ick - a spinal tap.

The next day I called in sick. At noon. Of course, they were all eager to tell me what had happened and they put me on speaker phone. I described the bruises that had come up overnight. I must have hit my face on the way down - big bruise and a rug burn on one side of my face, my arms were bruised, and, of course, after all those tests, my veins were held together with string and masking tape.

Dr. Sands told me over the phone that, Yes, unfortunately, this is the lupus at work. I now had Central Nervous System (CNS) lupus as part of my systemic lupus. The most common manifestation of CNS lupus is seizures, so the spells were seizures and we had to treat the lupus aggressively right now.

- 40 milligrams of steroids, he had the nerve to say.

- 40 milligrams! How about 5?

- Come see me tomorrow.

At Mass General, they’d written a prescription for Dilantin. It is supposed to prevent seizures. But I knew that any medicine that could prevent a seizure would be a really tough medicine. I would hold off for now. Dr. Sands was not happy.

- You’re not doing very well.

- I know.

- The problem with a chronically low platelet count and seizures is that you have a seizure, you fall and hit your head, you get bleeding in the head. You don't want that.

- Will you still be my doctor if I don't do exactly what you tell me?

- You mean, Will I fire you? No. I'm just worried. I know it's awful, and I can't think of anyone who deserves good health more, but right now, that's the scoop. Your lupus is very active. Look at your face.

- I see it.

It had a marked rash, the one that spreads over the nose to both cheeks. It's worse when your lupus is active. It's called the "butterfly rash," but lupus was originally named "lupus" after the rash. It was said, in harsher times, to look like a wolf bite.

But I wouldn't go up to 40, and I was stalling on the Dilantin. He said,

- I feel like you're driving the boat and I'm just in the back seat.

I sent a note saying that he was at least in the passenger seat and, oh, by the way: I drive with my eyes closed.

Even though I was now a person with seizures who was struggling to tolerate Dilantin (I don't know how they talked me into it), which made me spacey, woozy and cranky, life went on as it does. Work was work. Our department had no cubicles, so we really did spend our days together, and about once a week we made a point of eating lunch together in the small conference room. No one could eat for the laughing. Probably I remember so much about the seizure because I heard the story so many times.

I began the long process of writing a full-length screenplay which would eventually be called *Crying Wolf*, about a young actress who comes down with lupus. I finished it, but never sent it out. I didn't want to be known as someone who had lupus. I had an image in my head for lupus as a water serpent, slithering darkly beneath algae-thickened waters. It moves all the time, imperceptibly, and then rears its ugly serpent head, screeches, spits some venom, retreats with a dark splat back into the water, hidden.

Whenever I took a day off to rest, I'd come back into State Street and everyone would say cheerily,

- Feel better?

- Yeah, I'd say, though I'd want to say: 'Shitty. Just like every other day. My organs rattle around in there like they're trying to get out. My feet are swollen and sore and the swelling is creeping up into my legs and my face hurts because it's never gotten used to the steroid stretch and the last time I looked good was *Sweet Bird of Youth,* and my heart breaks every minute because I wanted to be an actress and I've lost my dream, and wonder if I want to write but I'm not sure if that will ever compensate, or - could it? - even be better and I have failed at thirty-something and I hate my body with a rage that terrifies me.'

But I'd say, "Yeah, better, thanks."

I was becoming close to Kim, whom I'd met at the Lupus Foundation meetings and learning an important lesson: that you had to have more in common than the same disease to be friends. We liked the same movies, adventures, spent time walking more than once in the wonderful "Garden in the Woods" in Framingham, a 35-acre collection of wildflowers, many of them rare or endangered. She was much sicker than I was. She'd developed lupus in her teens, which is usually a much more serious case. Her lungs were in trouble, her liver wasn't holding on at all. Still, she wanted to have fun, and she wouldn't stay out of the sun. She did, however, wear really cool hats.

In the fall, I went into back-to-back *petit mal* seizures. I had thirty a day. Dr. Sands suggested I might be having an adverse reaction to Dilantin, that people with lupus often have "paradoxical" reactions, and maybe cutting down a bit would help. I'd rather have a splenectomy every year than have seizures. Cutting down on the Dilantin helped, so I took myself off of it entirely and felt better.

There was this little issue with dryness in my mouth and eyes. Dr. Sands suggested I probably had Sjogren's Syndrome.

- And what the heck is that?

- It's a chronic autoimmune system disease –

- What? You're not serious –

- Your white blood cells attack the moisture-producing glands - it affects your eyes, mouth. It tends to not be serious. Certainly manageable.

- With what?

- Uh, steroids.

Such a look he got.

- Oh, right. I'm taking more steroids.

- You don't have to. We'll just keep an eye on it.

- Sjogren's. Ha. What do I need, 12 diseases? That's stupid.

It was the first of what are called “secondary” conditions. Sjogren’s is mainly a danger to your teeth, because they don’t get enough saliva, which is loaded with minerals. It causes terrible dry eye and we’ve since put small plugs into my tear ducts (really small) to try to keep some of the moisture in, but my eyes are still dry.

I decided that if I were going to be a writer, I had better learn how to write - how *I* write. I’m in love with paper, always have been, so I work with pen and paper till I have to go to the computer. There are 12 large notebooks for 1992 and they’re mostly full of writing practices. I took classes at the Boston Center for Adult Education in spontaneous writing, in screenwriting, personal writing, short story writing. I read dozens of writing books. I did all the exercises recommended by Natalie Goldberg in her wonderful, *Writing Down the Bones*.

Mostly, I wrote. I wrote about having lupus, getting lupus, already trying to sort through what had happened in New York, and still so angry I tore through pages in my notebooks with my pens. I wrote about acting: the soft heat as I moved my head into the lights, the lights in my eyes so I know I’m lit, taking in light and throwing light, the stage under my feet, my feet slightly into the boards and slightly above them, both grounded and floating, like a figure skater on her ice...as Thalia, in TheaterWorks’ remarkable *Me and My Shadow*, tapping the cymbal on my finger at just the right second, leaning back and peeking through the crystal beaded stage to see the audience, seeing the audience and pulling them back behind the crystal curtain by my presence.

I made lists that started, ‘I want to write about...” and the page would have four columns full of little words and phrases:quilting/breath/bridges/feathers/grass/weather/colonic/the office/Pres. Bush/jazz/shirt/Dad/floss/... an entire page like that, then I'd write pages and pages using these kinds of things as a starting point. Then I'd make a page: one half nouns, the other half verbs or adjectives:

"the withered dandelion" hung gamely in the child's hands she'd been at it all morning just as the noon bell rang in her head and she ran home to forage for food the dandelion crashed lay limp on a rock in the center of a field like so much nothing He used to live in the field...he wants an aspirin, he's dying to death, stuck to a rock by his own glue, like to kill that kid...

And this delights me because it's sad and funny and something only I would write.

I was just working to learn and learning to work. Because the job at State Street took up my best energy, I got up at 5 a.m. so I could hang out at a coffee shop near work and write for an hour before going to the bank.

I began to wonder if I should wonder about grad school. Working at the bank would not be enough, and it wouldn't last. Already I took one or two "short term disability" leaves per year, and I didn't know if they would have put up with that forever, though they were never anything less than generous and loving. If I went to grad school, I could teach. I'd love that. But how? I had enough money saved for 25 minutes of school. I had lupus and unpredictable seizures. Then, there were these tests you had to take. The GRE's. Math. I cannot do math.

I loved the show *Quantum Leap* and so decided to write a TV script. It was a fairly minor adjustment from a full-length screenplay: it was broken into four acts with breaks for commercials. I taped *Quantum Leap* episodes and, using the “Pause” button a lot, wrote minute-by-minute breakdowns of scenes and timed everything and did this over and over until I had the structure right. I spent months on a “treatment,” which is a detailed story line, and had just begun working on it when a show aired which used one of my basic ideas. Oh, my God, what horror. I felt that nothing ever would or could go right for me. Loser, loser, loser. I mourned for weeks. Then I wrote another one. I still love it, but I was very much to learn that it is just about impossible to get a television drama script looked at without an agent. They would have been lucky to get it.

The script was an unsent, unread love letter to the actor Scott Bakula, and to the character he played, Sam Beckett. This was not a valid avenue to pursue for a love life, I knew. And I fussed at Dr. Sands because, no matter how lousy I felt, he couldn’t define anything and, worse: by then, I had gone from hating him to having a little crush on him. This is not good because you can’t quite get enough from him: he has to be your doctor and your boyfriend, and he really is only the one. It didn’t help, though, that Dr. Sands bore an eerie resemblance to Scott Bakula, so I couldn’t actually place the crush properly. Was it my rheumatologist or a television star I longed for? Either way, I was in no danger of having actual contact with a real man. How could I, with bruises and seizures and rolls of fat where my waistline used to be, and a terrible illness? What man would even look? “Not tonight; I have a headache,” would happen every night.

One summer afternoon, we were all at Bud’s house. The boys were working in the yard. Dad was working on the loose slats on the sun deck. They were painting and fixing and hauling, all out in the yard. In the sun. I sat on the porch watching, but that would not do.

How could I include myself without being in the sun or, worse, hanging around in the shade just watching or worse, annoying hot, hard-working people by chatting. After a bit, I decided to clean the door between the porch and the kitchen. Who cleans doors? It hadn’t been given a good cleaning in a long time. I got into each little nook and cranny with a wet paper towel and my fingernails. It was sparkling white when I finished a few hours later. I was exhausted from the exertion, but the door was stunning. I had worked as hard as everyone else.

1993-1994

The Playwright

And then I did what I'm pretty sure will be my last acting job. My old pal, Paul Dervis, who had directed me a few times, including in one of my favorite experiences (Tom Eyen's hilarious *Women Behind Bars*), called one night to ask how I was feeling. A mutual friend had seen me recently and told him I was feeling well these days. I confirmed that I was, indeed. I'd even managed to get off prednisone, but there was that little problem with seizures. Not good on stage. Very unprofessional.

- It takes place at an AA meeting. It's 11 monologues. If something happened, you could skip a night.

The script was seizure-proof?

He came over the next night to let me read it. He said it was an audition, but when you've worked with an actor several times, it's just a chance to see if the actor and the script like each other. Paul was willing to make any accommodation: skip rehearsals if you have to, we'll schedule separately if you have to do that, anything you need. It was flattering, of course, but I was also curious. Could I still do it? Was it still in my body? I had to see.

I would not tell many people I was doing it. I didn't want anyone, especially me, to think that I'd returned to acting. I knew most people didn't appreciate a missing actor, even if this script could handle it. And I was more worried about getting a *Northern Exposure* script I was working on right than a little play in a church in Cambridge.

I did the show. I had bronchitis within a week of the beginning of rehearsal and I was, as we say, "over the top," - trying too hard, emoting, faking. Stinkin' up the room. It felt awful, and Paul was appropriately hard on me. I'd drag myself into rehearsal after a full day at State Street and grab a cup of cappuccino on the way in. Drinking a few shots of espresso at 8:00 p.m. isn’t a good way to get to sleep by midnight if you have to get up at 5:00 a.m. to write so your writing isn’t completely neglected while you’re doing a show.

What I remember most about going in each weekend night to do the show was that I would rather have been heading home. If it was a Thursday or Friday, I was coming from work, sore, tired, frazzled. By the time I did my thorough warm-up and got into the mood of work, I was fine, and I was eventually pleased with my work. Still, it felt tangential. The writing mattered more to me, because there was no limit to what I could do it with it, and, if vanity goes late, ambition goes last. I knew, by the way I felt, that I didn’t have the energy to pursue theater in the way I had wanted to. This was a near-deadly wound, but I’d been living with it for a long time. The show closed quietly and I tip-toed away from the dream that had driven me for most of my life.

That spring, Emma Anne Kenney burst onto the scene. I wondered how I could ever love another child as much as I loved Ali. But my heart got larger, growing inside its cage like the Grinch’s, and my little Goddaughter filled the new, light space. I was an auntie for the second time, which made me a deeper form of auntie.

Kim started coughing up blood, but it stopped in a day or two.

One of the girls in Human Resources instigated a Family and Medical Leave plan for me. The Clinton Administration had just passed a law that meant people who had a family emergency could leave for a certain number of days (or months, depending on length of service) and their job, or an equivalent, would have to be kept open. Mary Ellen from HR actually read the law and realized it could be broken up in a case like mine. It meant that I could take Wednesdays off to rest and keep my full pay.

The production of *Lucy's Attire* in New York was going along without me, except for annoying and unhelpful phone calls from the director, and I'd recently found out that a new company in Boston, CentaStage, which would focus entirely on new plays, was interested in doing it. A four-day work week and two productions of my first play? This might work.

But not for long. I didn't like being "the playwright." I went down to New York the week before the show opened but I was not welcomed or needed. I holed up at a friend's townhouse and listened to the Indigo Girls' *Closer to Fine* album compulsively and worked on a short story. Back at the theatre, I didn't like the interpretation of one of the characters, and I know now that the character was not clear enough in the script to not let someone get that far off, but I didn't know that at the time. I glanced over at the director's copy of the script and he had blacked out all my beautiful stage directions so they wouldn't influence his brilliant impulses. I've since learned to write almost entirely without stage directions, I think the script, being a first, and having been worked on for too long, was pretty flat, and mostly they missed the humor, which is the life of it. But the fellow who played Dracula was wonderful, and he thought it was the funniest script he'd ever read. He gave me the one glimmer of what it was to be a happy playwright. As for the playwright, there were moments; there were moments when the script worked like a well-oiled machine, and I liked it.

The production process in Boston was even worse. I was told by the director that I was welcome to attend as many rehearsals as I liked. But I was the skunk at the lawn party from the minute the thing started. It ended up with her screaming at me:

- Do you have ANY IDEA what a play is? DO YOU HAVE ANY FUCKING IDEA WHAT A FUCKING PLAY EVEN IS????

So that was not good. She ended up quitting about a week in advance of the opening and taking the cast with her. We replaced her and the cast and the thing went up and I survived it, but that's about all that can be said about it, except that the CentaStage folks remain good friends and have produced three of my plays over the years.

During the run of the Boston show, niece #3 came along, Kristen Elizabeth, with the wildest blue eyes anyone had ever seen and auntie's heart grew again. Unfortunately, that big new heart was pushing against my lung and I was in agony. Dr. Sands gave me a prescription for a new and stronger anti-inflammatory, which I didn't really intend to take, but I took the paper so he wouldn't feel useless. He took some X-rays, just to be sure, and a few days later I got a call from one of his staff members.

- Dr. Sands has scheduled an emergency appointment with a pulmonary specialist at Brigham & Women's.

- Oh. Any reason?

- Pardon?

- This is the first I've heard of it. What's it for?

I was getting so slick with this stuff. But the poor guy felt awful.

- Oh. Uh. Oh, geez. I'm sorry. I'll have Dr. Sands call you right back.

The X-ray showed some scarring or lumps of tissue or something, and he thought I should see a specialist, which I did. He wasn't too worried about it, either. He said that lots of people with lupus get a disease called Sarcoidosis, which is an auto-immune disease whereby inflammatory cells form clumps (granulomas) in certain organs, especially the lungs. It didn't sound particularly dangerous, just another “secondary” disease which would, of course, be treated with steroids if it got out of hand.

We did a bronchoscopy, which involves taking a bit of tissue out of the lungs so they can biopsy it.

I remember coughing a lot. Probably because there was a tube down my throat. The doctor kept saying,

- Don’t cough, OK? Try not to cough, all right?

I did my best, but they ended up giving me additional morphine, which, in a case like that, is used as a cough suppressant.

When they were finishing up, I asked to see what they got. I wanted a glimpse at the tissue that came out of my lung. I don’t tend to be as interested in that kind of stuff anymore.

Recovery went fine till I tried to get up. I headed into the bathroom to change and immediately became violently nauseous. I turned back and I guess I didn’t look very good because three nurses came rushing over and set me back on the gurney.

- It’s that damned morphine, I heard one of them say.

By then, my Dad (who was on prednisone for horrible poison ivy ha ha see how he liked it) was sitting in the chair beside me and had to watch three nurses grab his swooning child.

They gave me a shot in the butt for nausea and I slept for another hour, then tried to dress again. This time I did throw up. Violently and copiously, though I hadn’t eaten. I do remember thinking, when I finally got dressed, that I looked very slim and tidy in the blue and green top I wore and my favorite jeans, which were *real* button-fly Levi’s.

The bronchoscopy didn’t work, meaning that they didn’t find conclusive evidence of sarcoid. They could only tell that it was “inflammatory tissue,” but since everything that’s wrong with me is essentially swelling in all the wrong places, I wasn’t too worried about it. But they, meaning Dr. Sands and the pulmonary specialist, were. They wanted to do a further procedure called a mediastinoscopy, in which a small incision is made in the throat and they actually take out one of the swollen nodes I told Dr. Sands,

- Ah, let’s skip it. It’s just lupus. Or it’s sarcoid-whatever-it-is. It’s just swelling.

- I don’t trust your body. I want to know what it is.

I could certainly see where he could feel that way. I felt stupid about the whole thing, though. Was I looking for more of that nice attention I got when I had the bronchoscopy? I felt like hell every day, had since the 80’s, but people don’t normally bring me plants, as my brother did, and make toast for me, as Bud did. I think, finally, I did it because Dr. Sands was just the tiniest bit worried that it could have been lymphoma.

The night before my procedure, Jackie Kennedy Onassis died of lymphoma. As we sat in the waiting room at 8 in the morning, Bud confessed he’d been up all night, worried about that. We watched the pictures of beautiful, gracious Jackie flashing on the television: Jackie at the funeral, Jackie on the Onassis yacht.

- I don’t have that, I told him.

- I know, he said.

But, still. He’d been up all night.

I was right: it was stupid. My back got hurt during the procedure, and, of course, it was just sarcoidosis. A week later, I took the tape off my neck, admired a really globby-looking scar across my throat, and went to see some friends in a play. I'd put a band-aid across it so it wouldn't gross anyone out, but as soon as my friend Paula came out from backstage, she said,

- Oh, cool. Can I see it?

Which is why she's still my friend.

One evening, Dad and I were grocery shopping, and I wondered aloud how different my life would be if I hadn't gotten sick. Certainly, I'd still be in New York acting; maybe I'd be a really, truly working actor. But, you wouldn't be as close to the babies, he offered. Well, that was true, and they were - and remain, even as they all start high school and college and get drivers' licenses, the centers of my love. But, I countered, they might not have been as important to me; I'd be so involved in my career that they'd maybe not be as crucial. He pointed out that that didn't sound very good. But maybe, too, I wouldn't have finished that play. The way the productions had gone, that seemed a desirable thing. I pondered the nature of gratitude for what is, not what could have been. I was not at all ready to offer thanks for lupus. I worried, too, that if I were grateful for it and some compassionate universal force were listening, I might be offered more of it.

The request to God, for which/whom I had absolutely no definition at the moment, becoming, not so much: make me a great actress, or: make me a great writer, but, more sensibly and wisely: show me the right path and I will try to follow it. I thought, if I can pray for grace and strength, for good "listening" skills so I can figure out what I'm supposed to do with this remnant of a life, maybe there's not an answer; maybe there's just more prayer, and less asking that big white guy on the ceiling of the Sistine Chapel for favors.

For that night, puttering among the grocery aisles with my best guy, it was enough for us to understand that your life takes the path it takes, and the best you can do is good.

Update

Summer 2008

Just before my family heads *en masse* down to our favorite house in the world, my cousin's house in Harwichport, on Cape Cod, I get bronchitis and sinusitis. I saw it coming. I got a steroid shot in my left hip and took the methotrexate on the same day that I woke up with a sore throat and a slight pain in my ear. The legs are just awful so I needed the shot because if I can't lift my left leg walking on the cast becomes ridiculous, and I'm finally back up to a dose on the methotrexate that will probably help, so I took a calculated risk and paid for it. Both my brother and sister-in-law can hear how sick I am (all the hacking, probably).

- You sound awful, they say, don't go.

- No, no, I'm coming, I insist, and I do.

We arrive at Harwichport and I greet my aunt and cousins and extended family members warmly, then go up and take a nap while everyone else goes to the beach. I'm up for dinner, and they come back with fabulous pictures of the sand sharks they caught and the running around they did. I'm used to missing the "day" beach time, so I don't mind, and I had a great nap (as did Grace).

At 7 pm or so, I organize the second beach walk. This is the best time for the beach anyway; it's so cool and lovely and you get to watch the sun go down over the water. I leave my cast by the fence where the beach starts and head down to the water. Grace adores the ocean, though she doesn't seem to quite understand it, but once I set my feet in, she's in. We throw in shells and tell her to go get them.

Watching her dog paddle in waves is surely one of my great delights in life. When she comes out, wet and crazy, my brother and niece chase her up and down the beach. We all make our way down to the jetty off of which, I've made it clear, I want my ashes thrown, and sit while a wildly orange harvest moon comes up. I sit with Jessie, 12, while the others, including the dog, are climbing up and around the jetty. My girls, in their early teens now, have become intuitive about when I need a little help. If there's a rock that's large, or a hill of sand that's wide or tall, they quietly take my elbow and make sure I'm over it safely. When did they learn this?

About half-way back down the beach, holding hands and talking about God with Colleen, I realize I'm not going to be able to make it back to the house on my own. I tell her that.

- I'll ask Dad to go get the car.

Back at the house, I take two painkillers because I've way over-done it and sit in the den with three of the girls and watch "The Sound of Music" and talk and work on crafts, tying dozens of tiny ribbons that will eventually become something. Grace lies, absolutely exhausted, at my feet. I think, as the Percocet kicks in and my legs begin to settle down, I must have done something right if my girls would just as soon sit in the den with me and tie ribbons while the party's still going on in the kitchen. This isn't too bad at all.

1993-1994

A Stillness in the Room

I woke up on a Wednesday morning. I was not due at work because of the Family/Medical leave thing so no one was looking for me when I didn't show up. I wasn't even sure where I worked; it's that basic knowledge that you wake up without: name, rank and serial number. No idea. But, with that strange ability of physical habits to burn past the cloud, I managed to dial Dad's work number. Claire, the long-time operator at his office, immediately picked up something in my voice and said,

- Are you OK, Jan?

- I don't think so.

- I'll go get him.

Dad came on the line and I said,

- What day is it?

- Wednesday.

- But, no, what day? What month and stuff?

He told me and I looked in my date book to see if I was supposed to be anywhere. My schedule was clear; my head was not.

- Eat something and call me back. Have some orange juice and an English muffin and call me back.

That seemed like a good idea, and I was glad I knew what an English muffin was. My back ached violently, and what I think happened was that I had a *gran mal* seizure overnight and lost consciousness in a way that was not good for my back.

I vaguely recall waking up and clawing at my arms. I'd often get up with seizures and turn on a light, so I wouldn't pass out in the dark, or so the light could scare the seizure away, but there was no light on in the morning. After I ate my English muffin as instructed, I called back and he still didn't like the way I sounded and told me to call Dr. Sands. In the days before cell phones, you had to actually dial the numbers, and my fingers knew these phone numbers. The administrator at his office, Helen, didn't like the sound of my voice either and pulled Dr. Sands out of a room with a patient. He got on the phone and asked those annoying: Who's the president? What year is it? questions, which are annoying if you don't know the answers. He told Helen to call an ambulance and stay on the phone until they got there.

I can't imagine what we talked about. After a while, she said she heard a siren, and the doorbell rang. I opened the door and fell over and the fireman practically carried me to the couch.

The EMT's started poking around my head and my apartment.

- Who's the President?

- Uh. Reagan?

It was Bush.

- What year is it?

- '95?

It was '94.

- Guess again, said one of the EMT's. I couldn't understand much of what they were saying, but I caught the conversation they were having:

- Can't find any pills. Did you find any syringes? She's whacked.

I was injecting methotrexate at the time, and ever the cooperative gal, I was desperately trying to tell them that the syringes were in the top drawer, but, though I could see the words in my head, and knew how to spell them, I couldn't get the muscles in and around my mouth to connect to the part of my brain that had that information; I'd experienced aphasia before, but never at this level.

It's good that I didn't help them find the needles, because they already thought I was a drug addict. When they asked me if I wanted to go to the hospital, I couldn't answer. They told me they didn't have all day for me to make up my mind. I guess they thought it was OK to be rude to drug addicts. They tossed me into an ambulance, tearing my back yet again and we went to Brigham & Women's.

At triage, the nurse also wanted to know what year it was (I couldn't believe that *none* of these people knew what year it was) and she set me out in the lobby to wait hours and hours. In walked Bud. He had his horrifying summer "tan" (burn) so he was red and brown-skinned and was wearing a brown and white-striped shirt and brown slacks. He was the most beautiful thing I'd ever seen. I was shivering, a solid, deeply physical shuddering, so he found me a nice warm blanket and we sat for hours and I rested my head on his shoulder.

Eventually, we were called into a secondary triage, and the nurse filled out some paperwork that she wanted me to sign. She gave me the pen. We waited. Waited. I couldn't do it. I could *see* my signature; knew exactly what it looked like when I did it. I'd been perfecting my autograph since sixth grade, but the part of my brain that signs my name couldn't reach my hand or arm. Finally, Dad said,

- Want me to sign it, kid?

I pushed the form over to him.

Dr. Sands arrived in the evening, told me I was being admitted and told Bud to go get some rest. Knowing I was safe, the poor man finally went home. I rarely want to stay in the hospital, but just that night, I didn't mind. I was still a little confused, and I was terrified that it would happen again.

One of the problems with Boston hospitals is that they're all "teaching" hospitals, so you have gangs of interns roaming around, and I couldn't stand to be touched. I thought I was just tired, but, looking back, I think my nervous system was so shot that any touch - even a familiar one like Dr. Sands' or a gentle one like the nurses' - sent me shaking and rockin' and rollin' half-way off the bed. By three in the morning, Thursday, I knew what year it was, and who the president was, but you couldn't touch me.

The next evening, Dad picked me up and I spent the weekend with him. State Street told me not to show my face for at least a week, and the long, slow healing cycle began again. That weekend we were all invited to a cousin's party. I couldn't go, of course, and none of my brothers could make it and Dad told me he was very disappointed.

- I like to show you guys off.

- Ha! What can you show off about me? Look at me! I can barely walk, I'm covered with IV bruises and I have a pimple the size of a tooth on my chin. Yeah. Show *me* off.

- Are you kidding me? I'm very proud of you. Very proud. You're a tough guy. You're a survivor. You kidding? You're tougher than all of us put together. And, I'll tell you what, I still think you're going to do something, you know, accomplish something in spite of all these set-backs. Don't tell me I can't show you off. I'll show you off anytime I want.

Despite what he said, I was tormented because, at age 35, I had accomplished nothing. I had always succeeded academically but had been rejected by two writing programs. Both the Iowa Writer's Workshop and Sarah Lawrence would have focused on short story writing, so I was definitely heading into playwriting, and just would have to learn to manage the agony of watching healthy strong actors do what I couldn't do. I was enjoying hours of research at the library for my next full-length play, *The Last Work of Saint Peter the Great,* about a young man in late stages of AIDS who gets stuck with his sister as a caretaker. Invariably, next to the AIDS books would be lupus books, which I aggressively ignored.

Partly, I was working on this new play because of my work at the Names Project. By the early 90's, there were hundreds of thousands dead, and no talk of a cure, or even an effective treatment, and the panels were a collective yowl. At The Names Project sewing room we had lots of people coming in; some sewing for their friends, Mom's sewing for sons, a few sewing panels for themselves. Always, hovering behind our chatting and joking and pauses to cry, there was a sense of death. It was just part of the room. Peter's "Last Breath" hovers in the back of the room being a nuisance.

In the fall, I started studying at Harvard Extension with Kate Snodgrass, who is the Producing Artistic Director of Boston Playwrights' Theatre and sort of the queen of new plays in Boston, of which, partly thanks to her efforts, there are lots. For me, it was love at first sight. She's a beautiful woman with reddish-blond hair and green eyes. But, more than that, I could see immediately how smart she was. And when she covered the first draft of my first ten-minute play with "NO NO NO NO and NO. You are the genuine article and I am going to let you get away with nothing. Fix this!" I was on board. I was working on a ten-minute play for her, a one-act she wanted by semester's end and my own full-length play. I was content in all that work.

She had assigned a monologue that would generate a very specific feeling in the listener and I had her read to the class a monologue from Joan, the sister from *Saint Peter*. I loved it. The class loved it. Kate loved it. There was a stillness in the room while she was reading it; I didn't know what it was, but I know now that it's *focus*. It's better than a laugh: a group of people intensely listening. It is stunning.

By mid-semester, I had a viral infection that turned into a lupus flare that triggered a probable bacterial infection. I didn't catch it until my skin felt like it had been burned off, and my temperature shot up and I was shaking with chills. They put me in the hospital for a few days because the combination of a flare and a viral situation can be a little dangerous - the virus, whatever it is, can spread while the immune system is busy trying to pry off your nose. My platelets crashed again, for no particular reason.

With my roommate snoring away, I was awake all the time.

Late at night, a nurse named Mary came in and sat on my bed and said,

- Oh, poor thing. Know what you need? You need a boyfriend. I prayed to Saint Joseph that I'd get a boyfriend and I got a carpenter - isn't that funny? I'll pray for you. What kind of boyfriend do you want?

- Anyone with health insurance. I'll marry him.

- Ok. Listen, I have some other patients to check on, and then I'll come back in here and sit on your bed and we'll talk all night, all right?

She left, and I fell asleep.

I left the hospital a few days later with a “long line” in my arm – an IV that can be left in so they don’t have to keep sticking you (Peter, in the play, ended up with one of those...) and began the process of falling apart at home, post-flare being even harder than flare.

I had to call Kate and tell her I was missing class because she told us we could miss class only if we were in hospitalized. I hadn’t wanted her to know that I had a chronic illness, but there was nothing else for it: I didn’t want her to think I had missed class for nothing. When I crawled back in, still exhausted, I found myself walking back to the bus through Harvard Yard helping one of my classmates to understand the concepts Kate was discussing. It seemed I loved teaching. Back at the bank I was teaching people who worked in other offices how to use a new piece of software that the bank was using and, though I found those full-day sessions exhausting, the students came away competent and happy.

At about this same time, Emma started dragging toilet paper all over the house and patting baby lotion on every inch of her body after a bath, so there was plenty to come back to, even though I’d been in the hospital four times that year and everything in the world was jumping on my last good nerve. I took a small dose of Serax, a mild sedative, most evenings to keep me from killing someone, and mostly I wondered how I managed anything at all.

Putting Emma to bed one night, I was aware of her body on mine; her head against my left arm, her legs against my right. I didn’t even sing to her. The silence was enough. I watched her eyelids slip and flutter as she struggled to stay awake. I put my hand near hers and she grabbed my index finger and fell asleep holding my finger in her powerful little hand. I told myself: pay attention. This is life in a body, too.

1994-95

Freeman Street

I kept up a steady stream of *petit mal* seizures while I finished the two plays for Kate's class, worked at the bank and worked very hard on *The Last Work of Saint Peter the Great*. My baby clock was ticking but there was nothing I could do about it. My brother and sister-in-law announced a second pregnancy, and she complained to me a lot about nausea and swollen feet. I had to ask her to stop. I explained that it was beginning to look like I wouldn't be able to have babies, and a little nausea seemed worth it.

In December of that year, *Boston* magazine published my short story *Gizelle*. It was about a young woman with rheumatoid arthritis who met the man of her dreams while the two of them watched a box turtle lay eggs on the side of the Muddy River. The Riverway is part Boston's famous Emerald Necklace, a series of green spaces, which was conceived by Edward Olmsted in the late 1800's. It travels all the way from downtown Boston out to Roslindale. The story starts, "My face looks like everything I lost..." and it was, so far, my truest thing. I wrote about pain, and the girl's loving relationship with her father, and falling in love with a good man and a friend, and, yes, I did see a little box turtle lay her eggs on the bank of the Muddy River one night when I was out running, but no cute herpetologist showed up to enjoy it with me or marry me. It was a full-color, glossy, nicely-done magazine and the story looked great. I felt the thrill of having other people work on my work: the editor, the graphic designer who made the beautiful opening photo; the decision someone made to print the first page white on black. And, yes, there was my name in print. I had now two productions and a published story behind me. My brother bought eight copies. My friends all read it and called. State Street Cash Management gave out its first, and, to my knowledge, only Pulitzer Prize. And Dad loved it. He got a big kick out of seeing the name of his “authoress” (working on that) daughter in print. His secretary had run out to get him a copy the day it came out. He called me that afternoon.

- It’s beautiful. It’s really beautiful. There are some descriptions here that are about as good as writing gets.

I was on the other end of the line, tearing up. He started quoting lines from the story. My Dad quoting my lines back to me. He promised to take a deeper look at it that night, and make notes, and underline the parts he really loved. He called later that night and read off his favorite lines: “Instead, I let my head fall back; flecks of paint hang suspended from the ceiling like falling leaves that slipped through the roof and were trapped.” “Her dress fit her like a fine coat of dust.” And, I knew he’d like it: the frustration the father feels when his daughter suffers and he can’t fix it: “No band-aid, no nickel, no kiss.” He said I captured his feelings really well, the frustration he feels around my illness, seeing me suffer when he’d rather I just get on with my life like anyone else. After all I’d put him through, to have him be so proud of me, to see that I could and did work even with all the nonsense my body put me through gave us both hope and strength. And I was aware that some adults never feel deep pride from their parents, and here it was, and I was so grateful.

Several months later, I was sifting through the mound of loose paper he always had on his kitchen table. He would get to them, he said, but they drove me crazy: kitchen tables are meant for a small but tasteful vase of flowers, or a nice centerpiece - not piles of collected junk mail and random pieces of paper. Whenever I went home, I took care of it. He sat in the living room complaining I was throwing away stuff he needed, but I ignored him. I let him keep it if he proved to me that he needed it. I found his notes on the story on a yellow-lined sheet of paper, his Catholic school-boy handwriting tracking the details he liked. I asked him if I could keep it.

- Whattya want that for?

- I just want it.

I still have it.

In February of ’95, Matthew Richard Kenney blessed us with his arrival. After three girls, we had a boy. Finally: teeny-tiny dungarees and buffalo plaid work shirts and teeny-tiny construction boots. I began to think that the flood of children my brothers and sisters-in law were producing might have to be enough. Everyone can use a single auntie. You don’t have to share her with her children. The weekend gatherings at Bud’s had all levels of talking and babbling and walking and crawling and there was always a baby to hold.

Then, thanks to Dr. Sand’s annoying habit of going to medical conferences, he came up with another diagnosis: fibromyalgia. Never heard of it, though, years later, people have. I understand it can be as devastating as lupus, but in my case, I can’t tell them apart, so I’ve defined it for myself as a kind of “lupus of the muscles.” He poked at several spots on my body - the seven points that indicate fibromyalgia is present: the inner sides of my knees, just above my ankles, just above the breasts, etc., each time I jumped, flinched and told him,

- Ow, quit it.

- Ow, quit it.

He explained its nature, which was similar to lupus in that it was an autoimmune disease that attacked the muscles, and had similar range of effects: muscle pain, chronic fatigue (so this is layers of chronic fatigue? How does that work?), headaches, muscle pain and, of course, sleep disorder. But, seriously, another cause of chronic fatigue caused sleep disruption? That made sense. If you get too tired, and you’re in too much pain, there’s just no way to sleep.

- What could I possibly need with another disease? Don’t tell me about them and stop going to these stupid conferences. Just stay here and work.

I wanted to know *why*? The big why. Why, with all my ambition and will to live and have a great life, why was I trapped in a body that was clearly unsuitable for living? This is a recurrent and dangerous feeling that I just don’t have a body that can survive in the world. I was profoundly sad, so I dashed to the mall across the street from his office and scribbled in my notebook for hours then bought a pair of earrings in the style that Kate Snodgrass wears, though they didn’t suit me at all.

Finally, Harvard Street noise became too much and in March I found the new place I’d been looking for. Freeman Street was further into Brookline, on a quiet tree-lined street, overlooking one park and half-way down the street from another, it seemed green and quiet and it was filled with grown-ups and a bunny named Savannah. She was allowed to hop around the apartment only when someone was supervising her because of her tendency to chew wires and anything else she got hold of; all the buttons on the remote were gone, so you had to wriggle your finger into the nubs she’d left behind. I loved her little presence, loved having a roommate who just did her own thing (nibbled) and that surprise, in the city, of a live animal. The building was another old triple-decker in Brookline, and it was another second-floor unit, but this one was clean, and had some matching furniture in it, and nothing was draped in Indian fabric. Some of the dishes matched, and there was a big kitchen table around which we could, and often did, gather.

Jackie, Karen and Paula would be my very fun, affectionate roommates for the next three years or so, until they all wandered off to get married or move to the suburbs and I was ready to flee young replacements. Two of them were special ed teachers, and would be a big help with my seizures, talking me back from small ones, un-phased by the larger ones and everything else my body did during this period. These poor girls had no idea what they were getting into.

In April, Timothy McVeigh blew up the Federal Building in Oklahoma City and we started to live with home-grown terrorism. On the other hand, we started to live with Jessica Lee Kenney, who blessed us with her arrived that same month. Another little lollipop floppy head gently breaking open my skin, giving me a glimpse of what was inside.

That spring, I was accepted to Boston University's Master's in Playwriting program with a ten thousand-dollar scholarship.

Waiting for school to start, the notebooks from the summer of 1995 read like one deep scratch of long fingernails on a very large blackboard. I was sleep-deprived, and therefore, sleep-obsessed. As I moved towards juggling a Masters' program with work at the bank, I was terrified. Even with the scholarship, after I had a Masters, I'd also have a little problem of $10,000 debt. I knew a siezure or a flare could occur anytime. I kept dreaming of dropping the babies. Maybe one good thing was that I saw a play and the acting was terrible, and I didn't miss acting. I took it as sign of maturity, of wisdom. I'm sure I was premature with that, but now, to this day, only really stunning actors give me that ferocious ache. Unfortunately, I know a lot of really good actors.

The only good thing about being so raw was that I was becoming more sensitive to human beings and their frailties. I could walk by someone eating lunch by himself and it would catch my breath: the simple human need to eat, the mechanics of chewing, the sense of his alone-ness: did he want to be alone? Was he missing someone? Is there someone he'd rather eat lunch with, than just himself? I had to catch tears on my fingertips. A mother and baby waiting for a bus. Tears. A perfect apple; a grey sky; landscaping - flowers in the city. Everything. I felt connected to everyone and everything; I seemed to have dug down to another layer in myself. I was deeply happy, and deeply sad.

There was talk of the "d" word again: Depression. Some clinician whose name and face I can't remember said I was so busy pushing away Depression that I couldn't feel it. I was sure it was, at the least, a harsh judgement, at worst, an excuse to put me on more medication, and one that would affect my brain, at that. I hated all my doctors for being in cahoots with her. If Dr. Sands asked me to call Ms. Colasante one more time, I'd have had to kill him. In June, I made a journal entry that said this:

I can't stand it. I can't stand it. I can't stand it.

How could anyone suggest I was depressed?

Val and Kim and I occasionally graced a Lupus Foundation meeting with our presence (we were always the youngest ones there), but mostly when we hung out, we went to the movies or something. I was getting annoyed with both of them. Val was thinking about going on disability. It seemed early to me, and she didn't seem to really have much of job to leave, and, though I didn’t say anything, I thought it was giving in to the disease to take disability already. Kim, on the other hand, was trying to kill herself. She spent entire days lying out in the sun to get a little tan on her Nordic blonde self, but she’d usually have a ferocious flare right after. She was such a maniac on the infamous roads of Boston that I had stopped driving with her. If we were going somewhere together, I’d make up a story about a previous commitment and meet here there. It seemed to me that she had a death wish, and Val had a sick wish, and I was the only one who was being chronically ill properly.

In July, we had our annual volleyball/pool party/cookout with 50 or more people at Bud’s house. By then, I’d gotten used to not playing volleyball, but to watching it, and sometimes being the referee, even though I didn’t know the rules, and I hadn’t usually seen the play. I was too busy running the party with Dad, anyway. Even in our rough patches, we were good at that. In the evening, after almost everyone was gone, I lay on the hammock with Emma half asleep on my chest and Ali curled up at the top of the ropes and we sang to the cicadas: *In the jungle, the mighty jungle, the lion sleeps tonight...*

As school approached, I alternated between reading a bunch of plays by the same playwright and reading all the classics I hadn’t read in high school because I had no idea what we had read. I was coming into a writing program with a Theater Arts major behind me; I had not read nearly enough, though I read all the time (what *did* we read in high school?). I wanted to be in as good a form as possible before school started, scholastically, physically and mentally.

To my horror, I was making lots of mistakes at work. I was screwing up a complicated system of adding and delineating accounts that I had helped to create. I guessed it was some combination of school-distraction and general fuzziness left over from the last seizure. I saw Avea in August. It was at some sort of new age healing get-together at the Cape. As I approached, she said,

- Havin' trouble with ya brain, dahlin'?

- What's causing it?

- Has it affected yah balance yet?

- Definitely. It's from the seizures?

- Nah. The prednisone. Little bitta brain damage. We'll take care of it afta dinnah.

So, she did. We did a little healing after lobsters and corn, and my brain was in its finest possible shape just in time for school.

1995-96

Master's in Playwriting

At 35, I was sure I was the world's oldest living graduate student, but few things thrill me like school, and scribbling, scribbling, scribbling. It was what I'd been doing for years, but now there were deadlines every week. I love deadlines. It's the only way to guarantee I'll ever get anything done.

Derek Walcott, who wrote his first play the year I was born and founded the Boston Playwrights' Theater in 1981, had recently won the Nobel Prize for Literature for his work, *Omeros*, a Caribbean re-telling of Homer's *Odyssey* that is far beyond my describing. I was duly impressed by his accomplishments, and I liked and admired him, but I really went there to study with Kate. Again, she was a perfect teacher: demanding, perceptive, generous. She had us get right to work. The first week, she assigned us monologues wherein a particular emotion could be plainly perceived, as she'd done at Harvard Extension. Since she assigned two, I wrote about a dozen, one of which would become the basis of a new play that I would finish post-graduate school. In it, a woman told a story about how beautiful babies are, and how delicate they are, and what happens if you drop them. On their heads. And brain damage looks sure. Kate's comment, when she began using the nickname she uses today: "Gianetta, Terrifying. Don't even know what to say. Yikes."

So this is what writers did: they wrote. They wrote all the time, even more than before. They had assignments and did them on time. They hung out with other writers. I hadn't really had an artistic community since I stopped acting, and this was nice. I did notice that, like grade school and high school, grad school had "mean girls." I worked, maybe, under the circumstances, harder than I ever had. If we had to write one scene, I wrote five and had my favorite read in class. If we were asked to read a play, I read everything that playwright ever wrote and his or her biography, autobiography and/or collections of letters. At the end of the semester, we had a ten-page research paper due. I didn’t realize, not having been near a college in 15 years, that it was supposed to be double-spaced, so I handed in a twenty-page analysis of quotes by and about Edward Albee, a three-time Pulitzer Prize winning playwright. I’d sit in the library at BU after class and all weekend, literally holding my eyes open with my fingertips, looking at pages that were blurring in and out focus. Great, great fun.

Mondays, we had Derek and he’d comment on full-length works in progress. On Tuesdays, we worked with Kate on scenes, structure, arc, play elements, etc. The bank was letting me take a combination of vacation and some other nebulous days to keep my insurance, so the other three days a week I worked like a maniac at State Street. The *petit mal* seizures buzzed around like huge, annoying mosquitos, but I ignored them. We did Strindberg and Chekhov one week, Wilde and Shaw the next. O.J. Simpson was busy mocking the American justice system while the victims’ families grieved in public. Synge and O’Casey one week, Mamet and Woyschek the next.

When Derek Walcott was preparing for his first look at *St. Peter*, he looked over at me first and said, in his lovely Saint Lucian accent:

- Take some deep breaths.

- OK. Yessir. Thank you, sir.

I did my best.

Like all drafts, it was a little bit long. We were an hour or so into it when he whispered,

- How much longer for Act I?

- Ah, about half an hour?

- For Act I?

He chuckled and told me to find a place to stop.

I stopped at the end of the scene we were in. I waited. He seemed to gather his thoughts for about a week. Finally:

- This is gorgeous, gorgeous, gorgeous writing.

My chest released.

- It must be cut.

He talked about bladders. In Shakespeare’s day, they came and went as they pleased, and went outside. In Chekhov’s day, they had long intermissions and tight undergarments and were used to it. Now we’re spoiled; we must have access to a bathroom every hour. He said again,

- So, it must be cut. You must cut it. But if you *hack* it, you will answer to me.

Some seizures are more important than others. Even among *gran mals*, there are rarely long-term repercussions, except for whatever will happen in the future when all those concussions add up. The symptoms among retired football players make me nervous.

On October 27, I took the train to meet my Dad in Braintree so we could go to the McCabe’s 40th wedding anniversary party. The McCabe’s had been our next-door neighbors for my entire childhood. I’d spoken to him that morning and told him I didn’t feel very well. No surprise.

- You shouldn’t go.

- No, no. It’s the McCabe’s. I’ll go.

That was the last he heard from me till about five hours later.

I remember the train coming above ground at the J.F.K./UMass station. It used to just be UMass, but then they put up a great museum in honor of on one of our greatest presidents and put it so far away from the center of anything that it’s almost impossible to get to. It’s where the train goes from underground to above-ground. It’s hard to say what brings on a seizure. There are so many factors involved, and, then, really there are none. They just happen. But I’ve wondered if the sudden shift from the dark of the underground to the bright daylight set it off. I remember that light, and it makes me queazy all these years later, so maybe that was it. I remember grabbing one of the poles, though I was sitting, and saying,

- Fuck.

And that was it. I’m sure there were some passengers who were heroic and helpful, and some who arrived late to their destinations and had a bad ride: *there was a lady on the subway...*

I woke up in a dark, speeding vehicle. There was a bit of bright light in spots and corners, so I couldn’t really see what was what. But I knew this: I was lying down; one man was holding my feet down. Another was holding my shoulders down. I couldn’t move my hands because I was handcuffed to a railing. I screeched, I screamed, begged them to let me go. I struggled so hard to break the handcuffs the bruises took a month to heal. Kidnap? No. Rape. I was going to be raped by these guys. I struggled screamed and then passed out again.

Meanwhile, back at Braintree station, Dad was waiting, and waiting. My Father told me the story later, and this is what he said happened (and you have to add a really thick Boston accent to hear it properly):

- ‘So, I’m waitin theah, and at first I think the trains ah runnin late. But three trains empty out, and then, I’m thinkin, you’re in trouble. Then I just knew. I figured you had a seizuh somewheah, but what could I do? I couldn’t go back to the house. What if you showed up? What good would that do? Had to stay theah.

So, I’m waitin, getting pretty worried, and I see a police officah with one of those beautiful Shepid dogs. He’s takin him up the hill to have a pee, so I followed him.

‘Nice dog, officah,’ I said.

‘Thank you, sir.’

‘Let me ask you something.

‘Yessir.’

‘Well, I’m waitin for my daughtah. She was supposed to be here an hour ago.’

Then Dad used his standard phrase:

‘She’s not the healthiest person in the world.’

‘Oh,’ said the Officer. ‘Is she a little brunette?’

‘Oh, Jesus. Where is she?’

I woke up again in a lighted room; I recognized it as an Emergency Room, but didn’t know what I was doing there. There was a nurse doing a little tending, but she was gruff, and she wasn’t doing much. The handcuffs were still on and I couldn’t remember anyone’s phone number. I meant to ask her to take them off, but I couldn’t remember how to do that.

Back at the train station, the officer had called to see if I was still at Quincy City Hospital, then told my Dad to follow him in his car. They came in with lights flashing and sirens blaring. I think they got the word that my Dad was coming, and I had a seizure disorder, because they finally, cautiously, took off the handcuffs.

They were much nicer to me after he showed up. He was always calm in an emergency, but if he'd seen me handcuffed, heads might have rolled. I was awake enough to feel the goose-egg rising on my forehead. I had a knack for landing face-first on the hardest of floors, like subway trains.

This is the repercussion from that one: though I'd been fighting him on it for years, Dad finally insisted I get a Medic-Alert bracelet. Since I couldn't go missing on him again like that, and since he paid for it, I got it. At first it seemed like a flashing red neon sign on my wrist, but I got used to it.

On Monday, I went back to school shaky and sick and looking like I'd been in a bar fight.

- Good God. What happened? asked Kate.

She'd been warned.

Ten-minute plays were coming into fashion. They're cheaper to produce and you have almost a guaranteed audience if you do a bunch of them and the playwrights have any friends at all, but I didn't approve of them. They seemed to me to be giving in to what we could already see was a diminished attention span because of the internet. But it was an assignment, so I did it. By then, the girls on Freeman Street had let me take over part of the storage room (which used to be the maid's room when this was a one-family house) as a writing space, so I spent my weekends in the hovel working away.

My ten-minute piece, *What Mother Knows*, was a love song to my Mom. In it, a 17-year old girl breaks up with her boyfriend right before the prom, after they had her prom dress altered, because the boyfriend saw her Mother drunk. At the end, the Mother, who really is a good mother, a wise and loving mother, asks for a kiss goodnight, and the child gives it to her. She can't resist her mom. It was produced a few years later as part of an evening of plays, and one of my brothers said,

- Will you get over it?

- I did, I said. I had.

She was lovely, and I wrote that down.

We also worked on a one-act, which would be our "final" for that first semester. Though I worked and worked and read and wrote and did all the research I could find, the piece about the old man and the young man and the sea and whales and whalers never did work. I got an A anyway, because Kate knows a good failure when she sees it. The old man, years later, ended up in another play. I loved him, and that kind of love lasts.

Bud celebrated the completion of my first semester of grad school by posting my report card up on the fridge, as he'd done since first grade. I celebrated the completion of my first semester of grad school by coming down with Shingles. I had to re-learn pain, again. Early in January, I experienced extraordinary back pain, but nothing appeared to be wrong, so they sent me home with a pamphlet about back pain. When, a few days later, a nasty red rash ran all the way from upper right back to just above my right knee, my doctor actually gasped, and said,

- Shingles! Oh, God - there's the rash. Wow. That's the biggest shingles rash I've ever seen. Have you been under stress lately?

Shingles is caused by the re-awakening of the *varicella zoster* virus that's been sitting in your nerve cells since you had chicken pox as a kid. In severe cases - and, of course, mine was severe - it can cause permanent nerve damage. The entire right side of my body has never been the same because of post-herpatetic neuralgia.

I spent most of the break that should have been spent working on the full-length play that was my graduate thesis on my back, or rather, on my side, because I couldn't lie on my back because it was covered with horrid red pustules and it was on fire. The rash, so, the pain and itch, started on my back then traveled down to inside of my thigh and down almost to my knee. We tried a few anti-virals that didn't help at all.

During the weeks I was bed-bound with an agonizing recovery, Kim was up in Vermont dying. She'd moved up there in the Fall. She had stopped seeing her doctors. She stopped calling them. Her lungs and her kidneys were shot, and when, over the summer, they had tried to biopsy her liver, it was so far gone it was like wet sponge. They just closed her back up. And she picks this time to start a new life? We knew what she was up to, but who could tell her what to do? She was a grown woman. We had talked over Christmas. It was a nice talk, and I'm glad now that I didn't tell her what to do. For once, I kept my opinion to myself.

By the time her roommate called an ambulance, Kim's bedroom was littered with the bloody tissues she'd been coughing into. She could have called for help anytime. She knew we would know what that meant. I wondered, and wonder, how many days of that? Did she reach for the phone? Did she cry? Pray? Write? Probably she was in and out of clarity, waiting, finally, to leave that body behind.

Back in my bedroom, the pain had become coupled with an itch. Itch might be worse than pain. You can't get at it; if you scratch, the rash will bleed and it's the nerves themselves that are itchy; they're hiding underneath layers of skin. The anti-itch medications made me sleepy, but the itch would not let me sleep; 24 hour a day itch and pain. The only thing that helped at all was ice, and even that only took it down a notch or two, until the hot rash melted the ice and I needed more. I went through ice bags so fast I kept running out of proper ice bags and used frozen peas, corn, and even frozen sticks of butter that eventually melted, which was gross. Finally, after weeks of that, some combination of anti-viral, anti-itch, anti-pain thing that, in an afternoon, calmed the worst of it. I was breathing again. I got up off the bed to go watch *Seinfeld* with my roommates and threw up all over the bedroom. Jackie got me back into bed and put cold cloths on my face while Paula ran and replenished them every time I burned through one, and Karen cleaned up the vomit (these were amazing roommates.)

In her final days, Kim was in the hospital in Vermont. The family had honored her wishes of no extraordinary measures, and her Mom and sisters kept sacred vigil by her bed. One night, her sisters called and, though she was in a coma by then, they were letting her friends talk to her. I don't know what I said: I love you, good-bye, good luck, I love you. Nothing to say, but her sisters said she moved her head. She died a few days later.

A lifetime of this kind of illness is, must be, accompanied by a lifetime of healing, again. The bruises fade, the muscles mend, even nerves quiet down, and the body fills in the space where the organ used to be. I started to walk in the park, then walk a bit quickly, then more jog than walk. Looking for another avenue for faith in the wake of pain and loss, I discovered Paulist Masses in downtown Boston. This is an Evangelical branch of the Catholic Church. Very smart, often radical. I liked the Masses; they were intimate and comfortable. They reminded me of the 70’s in the Catholic Church, when the Church wanted to be hip and suddenly all the nuns could play guitar. It gave me a sense of community, and a weekly reminder to seek joy, to contribute, to know peace.

1996

Baby Girl Kenney

School started too quickly for my taste. I was scheduled to have the full draft of *Saint Peter* read as soon we re-grouped. A week before, I had a meeting with Kate. I was going to talk her into waiting because I'd been ill. No good. She had scheduled seven very busy actors and we had to go on time and could I please cut those 5 extra characters by Monday? I sat and tried desperately to pay attention to her. I had two cans of Coke between my legs. They were ice-cold out of the vending machine, and I put my notebook on my lap so she wouldn't notice them. That would turn out to be a good trick, because we had vending machines at State Street, too, and whenever I was tired the itch started again and it was a really bad place to scratch in public.

I filled up a couple of notebooks with scenes and ideas and questions about the new full-length play, *My Heart & My Flesh.* It's the story of a brain-damaged woman and a man with severe learning disabilities and behavioral maladjustments who get pregnant. I marveled, again, at how incredibly difficult it is to write a play. Soon (always too soon), I was back at work at State Street, writing at lunch and before and after work, healing still.

By mid-February, I was back on my shaky feet. One day I went to the library and hand-wrote 49 consecutive pages about *Saint Peter*. I wonder now why I didn't do 50.

At State Street, I was going mad. I was working on accounts that moved cash to the Caymen Islands over-night. This was all rich white guys moving money around so they didn't have to pay taxes; my job was to make sure it worked. This moving around of money is, of course, automatic now, but in 1996 we were figuring it out, and it was going from manual to electronic, and it was easy to have something go wrong, and one mistake would blow the whole account batch. It was a lot of pressure for a sick girl who was trying to get a Master's. When the system didn't work and wires didn't go through, all hell broke loose. With the help of an incompetent co-worker, the batches blew up fairly often. It made for a lot of late nights at the bank while we mopped up an explosion. One particularly long evening, we had a Senior Executive Vice President giving a verbal OK over the phone to ask the Fed - The Federal Reserve System of the United States, mind you - to hold their lines open so we could get a payment through. I wondered how and why I'd become so good at my job. Surely, it couldn't be good for me.

Our thesis project was a fully staged reading of the play we had completed that year, *The Last Work of Saint Peter the Great*. The actors carry the script so you can make changes on it till just about the time they walk on stage.

Since I had had nothing but bad experiences with directors, I was a wreck. I wondered if it would always be horrible to be "the playwright," though I knew from my early training and experiences that everyone should have a blast. The director who had been hired for my play, Bruce Ward, had been warned that I was nervous. I walked into the first rehearsal with a water balloon in my chest, trying to figure out which of the people gathered was the director, when Bruce came over and threw his arms around me. That was how the whole rehearsal went. It was a joy: intense and fruitful. It was the first time I felt like the playwright I wanted to be. The play was funny and fierce. It was theater. I had made theater.

There were three readings over the weekend and each one was followed by a discussion with the audience. My family came to the Saturday night reading. I was a mess with them there. I developed a nasty habit that weekend: sitting on the stairs. Sitting near the lighting booth. Sitting under a chair. Anything to hide. I pretended I thought they wouldn't enjoy the play as much with the playwright sitting near them, but, no, I was too nervous to sit near them. I'm getting better about that, but it's only because they've been annoyed with me a few times: *What's the matter with you? We come all the way to see your play and you won't even talk to us?*

The audience loved it, laughing in all the right places, being still in the all right places. I have no idea what anyone said that night specifically, though the audience loved it. I do remember what I was wearing: my pretty Pier I mustard-toned floral swingy dress and a matching silk jacket and my coolest lace-up boots. And I remember where Dad was sitting: way up at the top, three seats in. When I headed on stage to do the talk-back, we locked eyes and I blew him a kiss. He lifted his hand slightly to acknowledge it. That would be our "thing," like Carol Burnett tugging on her ear to say hello to her grandmother.

So, in April of 1996, the magical year of playwriting ended. Kate played a tape of Steve Winwood's *Back in the High Life Again:* the worst is over; you can relax.

Relax? I had used up all my vacation and sick days and personal days and a few we made up for going to school. I'd never have another day off from the bank again. I had four literature classes to take to complete my Master's and the scholarship money was gone. Relax? But I had what I needed: I was a playwright. It was, as I never thought anything would be, as much fun as acting. Every play you start is a hopeless endeavor - it might not work. It won't work. You can't get it. It doesn't mean anything. And then it doesn't thoroughly stink. Then it's good. Then it's as good as you can get it. And I was looking forward to experiencing that, because it's delightful.

I spent the summer working at the bank and doing that crazy five in the morning schedule to write and, as I'd done for years, walked most of the way home. I walked from the Financial district, through the Commons and the Public Garden, down the Commonwealth Mall, whose enormous trees shaded benches and statues. I'd stop to write on the mall, and then walk to where the trains went above ground. It's a distance of about four miles, but walking had taken the place of running permanently. The walk cleared my head from work and gave me time to write when I was relaxed. I worked on the new play and some short stories and sent *Saint Peter* out to every theater that seemed even remotely a good fit. No takers. Lots of letters praising the play, but none offering to produce it. Well, playwrights had to get used that, too. (I'll never get used to that.)

I soon had to admit that Dad was right about the Medic Alert bracelet. When I woke up lying on the famous cobblestone bricks at Faneuil Hall, the EMT was holding my hand, speaking gently to me.

- You're all right, hon. You had a seizure. We're gonna get you to Mass General for a check, but you're fine.

This was so much better than being handcuffed, I couldn't even believe it.

Dr. Pilgrim insisted I try yet another seizure drug, Gabopentin. I stayed on it for a few months, then took myself off of it. I was still having *petit mals*, and I felt lousy. Another failed experiment.

The Jacobean period occurred between 1603 and 1625, when James I ruled England. To prepare for Jacobean Literature, I read ten books over the summer. The class was split between Master's and PhD candidates, so I knew right away I was in over my head. Our grade was largely based on a 25-page research paper in MLA format. I kept a straight face, but I thought: what the heck is MLA? How do you fill 25 pages with research? The Professor gave us a reading packet that was about 4 inches thick, plus books and plays and we had to choose a book to read and present the material to the class. I spent every available minute reading, reading, researching, researching. After all the hard work I did, I recovered from the horror of an A- (as opposed to an A) by hosting a great Christmas. Dad and I served an enormous turkey dinner; Spaghettio's and hot dogs were also on hand, and Krissy grabbed a stick of butter, popped the whole thing into her mouth and got a big chunk of it before I could stop laughing long enough to grab it.

Dad found a newspaper article about Lupus that scared him; he sent it to my brothers. It made it very clear that there was no cure in sight, and ineffective treatments were the only ones available, but they were dangerous - steroids did most of the damage, but also kept patients alive.

- Don't read that stuff, Dad. It's going to make you nervous.

- I want to know what you're go through. Your brothers should have some idea, too.

- They don't *want* to know. (That's still true.)

The article said that the normal length of life prognosis was about 4 to 5 years after diagnosis.

- See? They're exaggerating. It's been 17.

- You're so brave. I don't think I could do it. I just don't know how you do it.

I didn't want to blow my cover, but it's really not brave. It's just, Tuesday, then Wednesday, and there it is again the next week and you're still going. That's not brave. That's just Wednesdays, every week.

On April 5, I was heading towards to Riverway for a jog and I had taken the Kent Street route to get there. Kent Street is the last thing I saw. I mean, actually, the street. Cement. Oh, shit. I got my five second *jamais vu*, and I knew I would land hard on cement. Dad always asked, in frustration: *why don't you sit down when that happens? Then you won't fall on things*! I tried to explain, but it's hard to understand that, once that *jamais vu* happens, you don't know how to "sit" or even, what "sit" means. So I did not sit down on a sidewalk near a street. I remember grabbing on to a tree, which explained the scrape that ran half-way down my face.

Doctors Sands and Pilgrim were so angry with me.

- You have to stop hitting your head!

- That would be good.

- How long have you been off Gabapentin?

- A while.

- Don't *do* that!

They seriously suggested wearing a helmet. I thought they were kidding, but, no, they meant it. Frequent concussions are dangerous.

- Lamictal.

- No.

- Miss Kenney --

- No. These drugs all suck. They make me feel worse than I already do and they don’t stop the seizures. Why would I want to take them?

- Because one of these days you are not going to wake up, or, if you do, you’ll be a vegetable.

All right. One more try.

My second literature class seemed like it would be a cakewalk, because I would be doing it without also managing State Street hours. I’d been put on long-term disability at the bank. By late fall, it was clear I was falling apart again, and my manager and Mary Ellen in HR started talking about disability options that were available through State Street. I’d paid out a little extra in each paycheck to have a long-term disability option, although even I never thought I’d need it. But maybe I did. It had been 17 years since I’d been healthy. Yes, I had a chronic illness; I had come to accept that, which seemed to be half the battle. But trying to live in peace with it didn’t meant I didn’t feel like hell all the time, every day, every minute. I was physically, mentally, spiritually exhausted.

There were several delays from paperwork that hadn’t gone through yet, signatures that had to be found again, silly stuff, but word got out and everyone came around to wish me well. Since there were three final days preempted by three delays, there were three good-bye parties for me. It got to where I couldn’t walk by a conference room with some people in it without thinking they were waiting to surprise me again.

- For *me*?? I’d say, and they’d just shake their heads and toss me out, trying to have a meeting or something stupid.

- Not today, Jan.

- There must be an error.

- I'm sure there is. Close the door, will you?

I wrote every day. I rested, I walked, I ate a healthy diet, and, within a week, I was lonely. But I didn't care. I meditated for long periods by the side of the Muddy River on the Riverway and wrote there for hours. I worked on *My Heart & My Flesh*, spending hours and hours researching brain-damaged children and adults, adults with severe learning disabilities and behavioral issues that could only be tracked back to the brain, but not understood. Some people I read about had permanent brain damage after seizures.

I was still happy at the Paulist Center. I'd go in an hour early and sit and meditate on a beautiful portrait of The Blessed Mother. For me, she's a role model, a feminine symbol of strength, of persistence, of survival. How could she survive the death of her Son? The way anyone survives anything, I guess. I get her slightly tangled up with my Mom, who also has no physical presence here on earth, but who once did. I felt afraid much of the time: how would my body continue to fall apart? How would I continue to stand it? Mother Mary come to me. Let it be.

It took about two classes of the mandatory Translation seminar to know I was in trouble. I'd be lucky to pass. The professor was impossible. He gave out assignments, we did them, and then he forgot about them. He assigned a reading then spent the class talking about famous literary figures he'd met, someone he saw at a party. We had famous authors in every other week to speak about having their works translated, or famous translators to talk about how they did it. I did enjoy them tremendously. I enjoyed translating and found mine to be just a bit superior to the ones done by the official translators for the estates of, say, Rilke, but they kept coming back with A-, and comments that made no sense to me.

In mid-February, my sister-in-law and brother invited me to be present for the birth of their second child. I was sitting with them one night, watching logs burn in the fireplace and admiring my sister's beautiful pregnant belly. Having long since let go of the hope of having 6 kids of my own, I was still startled by this thought:

- Oh, my God! I'm never even going to *see* a birth!

I did a lot of writing on that, processing another loss from the future I had imagined. In my notebooks, I reminded myself to trust God, to trust that my life had some sort of momentum no matter how it appeared to me. That, no, after all these years, I did not know God's will for me, and sure couldn't even take a guess at it. Is that what the lesson was? Could I just learn it and make this stop? But wouldn't that be sort of just pretending to learn it and then my life wouldn't change, because God would know I was just pretending to trust His will, just putting on an act He could see straight through? Hopeless. Or maybe not. Maybe, probably, if I'd ever entirely let go of hope, I wouldn't still be here. I like to say that vanity is the last thing to go, but probably it's hope. Hope is a real stinker.

A few weeks later, at a gathering at another brother's house (probably a child's birthday) my sister-in-law called me into the bedroom and asked me to come see the birth of the child. To this day, when so many people go so far out of their way to help me, it's still one of the most generous gifts I’ve ever been given. In exchange, all she wanted was a narrative of the event, to be given to the baby when she was eighteen.

In late February, my brother called: Get down here. I took the train down to southern Massachusetts and arrived in time to see my sister-in-law getting pretty uncomfortable. A few hours later, I was in the back of the room, keeping quiet and out of the way as much as possible. The doctor sounded like a college cheerleader: *Come on! You can do it!!! I wanna see this beautiful girl! Yay, here we go!!*, which is exactly what I think an obstetrician should sound like. Then, finally, here is a head. Coming out of a body. The black stuff was hair. Human hair? How is such a thing possible? I thought: oh, no. This is a problem. That’s not gonna fit. Oh, geez. Tempted to warn, to ask, to see how they were going to fix this terrible dilemma, I shut up anyway. And then, the miracle: out she came. Limbs flailing and flying - four of them - a head, a neck, a back, a person. My brother grabbed her and comforted her while they cleaned her throat and tested her lungs. She cried when they stuck a hose down her little throat. Her daddy said,

- Yeah, you tell them you don’t like that. Tell them, ‘don’t do that to me.’

His wife needed some tending, so less than 15 seconds after her arrival, here was my beautiful “baby girl Kenney” in my arms. I gave her my index finger and her tiny hand curled around it. The narrative is in an envelope, waiting for her. It’s 9 pages long.

Summer 1997

My patient

In May, we found out that Dad had a major arterial blockage and would need a triple bypass. I had planned to take my third literature course that summer, meaning I would finish my Master's in January, but dropped it when I found out about this, because we knew he would need a few weeks of care at home. He fussed like crazy.

- Don't skip your class!

- I can take one in the Fall; it's no big deal.

- What is it?

- Irish Literature.

- Oh! You'll love that. Don't skip it.

- You'll need a nurse.

- That's a whole month after. Take it.

- Ok, Ok, I'll take it.

- Really?

- Yeah.

I had my fingers crossed. After twenty years of prime nursing from him, I could spare a little time to help him recover. I was still on disability from State Street. After several months of rest, I really did feel better. On the day of the surgery, I asked Jesus to come; to please settle His beautiful presence in the operating room and be there and keep an eye on my Dad. I could see it clearly: a white light in the room, vibrant, amorphous. Present.

We were all relieved that he would have a 24/7 nurse, but I was nervous about getting it right: should I assure him that I understood pain and frustration, or leave him alone and let him experience his own? No one can possibly “get” another person’s pain and suffering; each body is different, each pain is different. “I get it, yeah, I hear you,” from other people feels dismissive. I didn’t want to do that to him; I hadn’t had heart surgery. I could only hear what he could find words for. Should I try to be Nurse of the Year and drive him crazy? Should I do everything, or let him do what he could? I understood, though, that I couldn’t possibly know what to do until the situation presented itself.

We also had a knot in our collective stomachs: would we fight like we had when I was first ill? Like when he was drinking, which he’d stopped long ago? In my body, I still reacted the way I did when I was 16 or 22 and he barked or snapped at me; my heart skipped, my face heated up. Would that happen? A lot? Plus, before I left to start his care, I had one of my special ed teacher roommates review CPR with me, which I had trained in at State Street but never actually used.

In that part of my family’s history, we couldn’t seem to get anything done without having a baby in between. Days after the surgery, I got to tell Dad the news:

- Hey. You’re a Grampy again. Christopher Thomas.

- Oh, God. Everyone OK? Mom’s fine? He’s healthy?

- He’s healthy. She’s healthy. Everyone’s fine.

If he was a Grampy again, that meant I was an auntie again. Gosh.

Dad had a terrible time with recovery. He kept running fevers, his lungs had fluid around them, and his heartbeat was irregular. Between the cracked sternum, the raw new pieces of his heart, the eight-inch gash and the train-wreck of a surgery, he was in agony. It was too painful for him to lie down in his bed, so he settled in his chair in the living room and that’s where he stayed. That first long night, I took the cushions off the couch and lay on the floor beside him. We didn’t talk. We just waited it out. And when I saw the first streak of pink in the sky, I said,

- Oh, look. It’s dawn, and we both fell asleep for a few hours.

It was almost a week before we were not awake all the time, together. As a kid, I was his champion back scratcher, and he the most grateful of scratch-ees, so I’d do that on and off all night. After a few days, one of my brothers brought a Lazy-Boy chair, and we could position it that so he could half lie, half sit up, and we could at least make him a little comfortable. I moved the couch cushions back to the couch and we slept a foot apart.

I did the laundry and organized his pills and followed up on his appointments. The boys grilled meat, cut his grass, washed his car and kept the pool in the Caribbean-blue state he always had it in. They ran errands, since I hadn't driven in years and Dad couldn’t drive for several weeks. The boys or their wives brought the babies by to soothe and entertain us.

Our first major crisis came about a week after he got home. We were pulling another all-nighter, he in the “flower” chair that was my mother’s, and I on the ottoman beside him. At about five in the morning, while laughing at some Comedy Central thing, he finally fell asleep. His head was back, and he was breathing pretty well. But. His foot was down. The left one, the one with the gash. And. He wasn’t wearing an embolism stocking. Should I wake him? Get him to move to his Lazy-Boy, so we could get the leg up? He was so peaceful, and he was so tired. I tucked a blanket around him and crept upstairs to the middle bedroom. I slept for about two hours, then:

- Jan! Jan!

I bolted to the end of the hall. He’d made it up to the end bedroom on his way to the bathroom, figured he’d better sit down before he fainted, and his leg, as I had feared it would, exploded. The chair he was sitting in had a puddle of blood under it. Anything he had touched in the room, or on the way up, was doused with blood.

- OK, OK. You’re all right. Lemme call an ambulance.

- No, no ambulance!

Is he insane? I asked him what the heck he was thinking? He insisted I find the “envelope.”

- What envelope?

- It’s from the doctah.

- We don’t need a doctor. We need an ambulance!

I said that, but, daughter, I ran to the kitchen anyway. He was upstairs howling hints and guesses as to where this famous envelope might be. I found something and brought it up.

- No. no! Not that one! The one with the doctah’s numbah -

- I’m calling an ambulance! You’re bleeding--

- No, no!

Now, I’m pretty good in a crisis. I have them all the time, so when they happen to me, I’m calm. When they happen to someone else, out in the world, say, a person falls in the street, I’m calm. But I was not calm. I was not calm *not* because of the blood, and the wound, and the terror of heart trouble. I was not calm because he was yelling at me. If he had just let me call an ambulance, I would have been perfectly happy. I would have sat on the bed beside him, maybe run down to get him some juice. Instead, he had me running up and down the stairs like an idiot. Finally, I brought up the information for the visiting nurse. Yes, I had permission to call the visiting nurses. Thank God. There was a woman there in ten minutes.

- OK. This is settling down nicely. Is that your bed?

- No. Down the hall.

- OK. I want you to get to your bed.

- I can’t walk.

- Yes, you can. There are stitches under the staples. They’ll hold. Come on.

He sent me to find crutches, which we did not have. He sent me to get a cane. We don’t have a cane, I insisted.

- It’s in the closet. I got it for a retirement present.

OK, there’s the cane. With this tougher-than-the-other-nurses nurse, he got himself down the hall and onto his bed. We put all the pillows in the house behind him, and he was sitting comfortably, and we were both calming down. The nurse fussed with his leg and I ran and got him his favorite breakfast: apples, grapes, cantaloupe and banana all cut up nicely and served in a small bowl.

Exhausted, relieved, still angry, I sat at the end of the bed - the very spot I’d sat on while I helped him pick out his ties - while he ate and the nurse wrapped his leg. He said to me,

- Oh, poor kid. It’s OK. I’m all right.

I burst into tears.

- No, no, it’s Ok. I’m OK.

Big moment for me. Big confession:

- I’m not upset about your leg. I’m upset because you yelled at me.

- Oh, my God, what am I doing yellin at you! Oh, geez, I wouldna made it through the week without you and I'm yellin at you? Whattsamatta with me?

- Don't yell at her, said the nurse. She's working her butt off here.

- I know, I know, oh, geez, I'm a rat...

That night, though I always just quilted while he watched a ballgame, he insisted I pick a movie, and I let him insist. We watched *Indiana Jones and The Temple of Doom*.

By mid-July, Tiger Woods was blazing a trail in the golf world, and Dad's lungs were a mess. They made ghastly wheezing noises and he choked when he slept and we nagged his doctors enough that they put him back in the local hospital to have them drained. His problem was a pleural effusion - fluid in the lining around the lungs, between the inner and outer wall of the lungs. It causes terrible pain and pressure and shortness of breath. A few times over the summer he had to do this. When he was in the hospital overnight, I'd sleep twelve hours. He'd been given an Ambien prescription for sleep, but he didn't want it. I didn't like him to take it because his breathing made me so nervous, but it worked great for me. Unfortunately, I'm still on it.

He listened to the visiting nurses better than he listened to me. I'd been asking him for weeks to let me massage his feet, which were so swollen they looked clubbed. I told him,

- It's not good to let the fluid settle down there.

- No, no. I don't want you touchin my feet.

- Why not?

- Only your doctah should touch your feet.

Until a visiting nurse came by. I said to her:

- He won’t let me massage his feet.

- Why not?

- I don’t know. It would be really good for him, right? Look how swollen they are.

- They’re very swollen.

Then she told Bud:

- Let her massage your feet.

- Every night, I said.

- Every night, she said.

Every night I massaged I feet. It came to be a favorite time for both of us.

On a bad day - not health stuff, but “I’m going to tear out his esophagus with my bare hands” stuff - I’d run out to the yard and say a bunch of *Hail Mary’*s and take a whole lot of deep breaths. I took the pruning shears out and went after all the bushes. I weeded and fussed with the flower beds and brought in a bouquet.

His doctors were useless. I was so accustomed to my doctors being careful and compassionate and, well, competent. His crew left me distracted. They didn’t return calls, they didn’t order tests, they didn’t put him in the hospital when it was clear that he had pneumonia.

One morning after a brief hospital stay when he was given a new drug or two, I gave him a handful of pills. I had made a chart by then, and the information changed at least every week. He broke out into a sweat, became bleary-eyed, dropped into shallow breathing, had trouble keeping his head up. He was groggy and disoriented. He fell asleep or, maybe passed out? I waited for him to wake up, wondering if I should call an ambulance. Sure, he'd kill me, but he could be dying. He woke up shortly afterwards and I begged him to call his doctor.

- Ah, no, don't bother them.

- They make fifty billion a year. You can call them.

But he said, no, so I didn't. It drove me crazy all day. Was I ten? Was I twelve? I remembered that the silly New Age healing books said that lupus was a problem with "rather die than stand up for myself." I could see where that was still a problem, but I'd rather not have it kill him.

At quarter to five, running out of time and not wanting to see that show again tomorrow morning, I headed to the kitchen while he told me NOT to call the doctor. I said,

- I'm calling the pharmacist. That was a drug reaction.

- It was not.

- I know a drug reaction when I see it.

- Oh, listen to the phahmacist ovah heah.

He nagged the whole time I was on the phone, this little running monologue of 'it's nothing…I just didn't feel well...get offa the phone…'

I got hold of a nice lady. I told her what he was on, and what had happened. I told her what I suspected had happened - a blood pressure crash. Of course, I was right. She said it was very serious and we must call the doctor. The longer I stayed on the phone with the pharmacist, the more he quieted down. When I got off the phone, I told him,

- You had a blood pressure crash. It’s very dangerous for a guy in your condition. I’m calling the surgeon. Do you want to talk to him or should I?

- No, you go ahead. You’re doing a good job.

When he was at least able to drive but still breathing like an old dog, we went over to the local hospital to get some chest X-rays. We got them done and drove over to the doctor’s office to tell them. I jumped out of the car before we really even pulled in.

- I’ll be right back.

Ignoring his protests, I barged into the office. The doctor was not available.

- My father’s been sick for two months and we’re getting nothing for help. I’ll wait.

The doctor came out.

- I want his meds checked. They’re crashing into each other. He’s got fluid all over and I’m worried it’s going to seep into his stomach next, and why are we not concerned that the wound in his leg still looks awful, and if it’s not infected why is it still full of fluid, even though I don’t feel heat, but it shouldn’t be full of fluid like that and he’s not made much progress at all for over a month. I’m pulling staples out myself because the nurses can’t see them there’s so much swelling, and if the first two effusion treatments don’t work, don’t you try something else?

Pause.

- Are you a nurse?

Sigh. Idiot.

- I’ve had lupus for twenty years.

- Oh.

He tried to sell me on his concern for my Dad, and he had three or four other things he would try, etc. Not convinced, but a little bit hopeful, I went back out.

- What were you doing in there?

- What? I was waiting for the doctor.

- Did you talk to him?

- What? I just told him we did the X-rays.

- Oh, geez. Is he all right?

- He’s fine.

One afternoon, he was particularly down. It’s so very depressing to cycle like that: to think the last horror you went through will finally set you on the right path, then it doesn’t help at all. So I did the only thing that could be done.

- *Scrabble*?

- Ah, no. No, thanks.

- You’re afraid.

- Hah.

- You’re chicken. ‘Cause I’m getting a Master’s. So you know I’ll kick your butt.

- I don’t think so.

That first afternoon, he won. I’ve always insisted I did that on purpose, to cheer him up, but really, we were perfectly-matched adversaries. I (might) know words he didn’t know, not just because I’m a writer, but because I read the Dictionary for fun.

- ‘Trill?’ What’s ‘trill’?

- It’s a bird sound. It’s a light bird song.

- It’s a misspelling of “thrill.”

- You challenging?

- I think I will.

- You sure?

Long pause.

− I’ll let it go.

On the other hand, he could “see” the board from upside down, backwards, diagonally either way and up and back, and he remembered everything he ever read starting in grade school. Each game was ugly. 182-180. 175-179. 156-164. We are sore winners in my family.

- Ach! This is embarrassing! Miss Master’s! Ha! I’m killin you!

- You’re two points ahead.

- This is awful! Oh, I feel terrible.

Then I’d get “triangle;” 8 letters and a 50-point bonus for using up all my letters.

- Ah, geez, I feel badly with you so sick and all - embarrassing you like this.

A nurse noticed an irregular heartbeat and she called the doctor and they listened to her. They sent him to the hospital to do Electric Shock Therapy. Very scary, but it should level out his heartbeat, finally. He was in the hospital by noon, and they were to do the procedure the next morning.

He called me after the therapy to tell me it went well, and he would be coming home that night.

That night? They're sending a guy home hours after Electric Shock Therapy, and I'm supposed to be in the same house with him to make sure his heart's working? The nice thing about him not being around was that I could call his doctors without being pestered.

- You can't possibly send him home.

- Oh, six hours is enough to monitor the result.

- Not for me. I don't trust you guys. I want him in the hospital another night. He's been through enough. We need this to work.

Bud called later.

- Have you been on the phone?

- Me?

The next night, he slept in his own bed for the first time in months. I checked on him.

- Dad? Bud? I whispered. He was breathing gently. His feet were twitching, as they often did when he slept. He was sleeping softly in his own bed. A small miracle, a major milestone. He slept better after that, and mostly at night.

1998

Pahty

In April, having gone an entire year without a seizure, I walked out of my last class at BU. Someone forgot to drop the balloons from the ceiling. I went home and went to work the next day. I could teach now. I had some stuff to finish up at State Street, but I knew that was my next step. In early July, my Uncle Frankie died. He was an uncle who was not really an uncle, but a man Bud grew up with. His health had been an issue for a while because he had diabetes, but it was still a shock because he was only in his late sixties. His five sons were considered cousins, as we'd all grown up together at parties and family gatherings. And, though I wasn't particularly close to him, I wept at his funeral. My cousin Lesley put her arm around me. My Dad, next to me, nudged me, offered his handkerchief. After Mass, on the way to the funeral, he teased me:

- Geez. I thought I was an old softie. You're worse than I am.

- But, Dad, I said, The Gropman's don't have *any* parents.

Their mother had died several years earlier.

- They have none! They're orphans. They're not really even children anymore.

- Guess so.

- That's terrible.

- It is.

- You have to be careful. You have to take care of yourself. You're not going anywhere anytime soon. We'd be lost.

- Hah! Don't worry about that.

I was wracked with roommate troubles and I know also that I was just too old to be living with roommates. I didn't *want* to find other peoples' pubic hair in the bathtub; I didn't *want* to find underwear on the divan. It took on heavy significance: had I not been ill, I could have afforded my own place by now. In New York. No, Boston. I wanted to stay here, where some people were making a good living acting. I wanted to be one of them. Or teaching. Teaching and writing. I could do that.

In July, Grampy Bud turned 68 and Christopher turned one. They were both adorable. Christopher wore his cake well, and Bud received a box of Viagra from my sister-in-law's 89-year old Grampa. It was empty. Not sure what the story was, but we all had a great time. I gave Dad a brochure for a Whale Watch trips; I would take him on a Whale Watch for his birthday.

- No, that's too much sun for you!

- I'll wear sunblock. Parts of the boats are shady.

Sun Protective clothing had been invented and I had a few pieces. I managed to convince him it was fine, but he was "booking" into early October. I worried about missing the whales for the season, but we could go in the spring, I guess.

We got busy with plans for my graduation party. Since we had a yearly cook out anyway, we just made it in honor of my Master's, which, even I had to admit, was quite an achievement under the circumstances. I made invitations at work after hours. The invitations had lots of tacky clip art on them: "sailing" (in the pool); free parking (on Davis Street.) games (volleyball), etc. About 100 people were coming.

We sure knew how to pull off a party. We were backing out of the driveway on another errand when I happened to look down and notice his hand on the gear shift. It was old. It was plump. It had some gray hairs on it. Freckles. Some liver spots. It was an old man's hand, and it startled me. I marveled at how far we'd come, from snapping and gnashing all the time, to mutual respect and true friendship. I patted that hand and said,

- I *love* you.

Boston, Irish, Catholic, male; from another day. He said:

- Of couhse you love me. I'm god damn good to you, throwing you this nice pahty...

Later that day, July 24, 1998, at about 4 in the afternoon, Dad died almost instantly from a pulmonary embolism.

I knew he would want his “authoress” “Master’s’” daughter to write his eulogy, so I did. Somehow, I managed to deliver it. Just as I approached the podium, I touched the foot of the statue of the Blessed Mother, gathered strength.

Thank you for coming out here today to celebrate this wonderful man.
He was, for all of us, someone to emulate, someone to imitate.
We have enough material on him to last for generations.
He was someone who understood that life was in the love you generate,
in the details. Bud was a man of real, almost embarrassing generosity,
wisdom, mischief. A man who took deep pleasure in life, in the only things
That matter: his four children, his seven grandchildren.
Nothing meant more to him than his late wife, Helen,
his friend Jane, his sister Lois, his nieces and nephews, The Mazzotta’s,
the co-workers who shared Chicken Caesar lunches with him for years -
the friends and family on whom the quality of his life was built.
He loved the sea, Archie Bunker, the birds who hung out in his yard.
I have lost my best friend.
I’ve heard that from each of my brothers.
I know I’ve heard it from many of you: I’ve lost my best friend.
But how is that possible?

How could one man belong to so many people in that exclusive way?

Because he was Bud. Because he was the best guy. Bud was the best guy.

Now, I know he is with Christ.

And the Blessed Mother took him home.

But I'd like to quote from Shakespeare to finish:

this is Hamlet, mourning his father, knowing him, loving him. He says:

"He was a man, take him for all and all/I shall not look upon his like again."

God bless you, Bud.

Update

Winter 2014

Everything’s different now. For one thing, I’m 55. I didn’t plan to make it to 50, but nothing seems to kill me.

The garden I built is thriving, though the April flowers now bloom in March and the summer perennials are gone by the end of July. Gardeners use lots of annuals and plant seeds so something will be new and blooming in August. Now that my garden is gorgeous, and people in the area have changed their walking routes to be able to see it every day, I’ve worked to beautify the whole of Cleveland Circle. For the last few years, I have been my own community service group. I have worked with or against absentee landlords around the neighborhood to get them to plant gardens, or at least clean up and keep the weeds from growing to thigh-height. The threat of Small Claims Court comes up sometimes. Either the bad (inexpensive) landscapers leave a job un-done or the disgusting property owners don’t want to pay the good (expensive) landscapers. I’ve taken to cleaning up the sites myself. Grace’s excellent digging skills comes in handy when dealing with soil that is nearly cement because it hasn’t been worked for fifty years. I need to break it up and turn it over, so I throw a rock down in the yard and let her dig a hole for it, and I do that over and over until I have some soft soil to work with.

I work at Berklee College of Music as a writing tutor. These brilliant musicians have to take Liberal Arts courses, so they need help with English and Psychology and Surreal Literature. They need help with scholarship applications and resumes and artist bios, housing waivers, etc. In a one-to-one format, I get people in tears because they are working so deeply they surprise themselves with what they know, what they remember, what they think. It’s when I’m teaching that I think my brain is still working, and that’s good, because I often think it’s not. It’s also when I feel most useful and that’s the most important thing for anyone, to be of use to someone else.

I’m on significant pain medicines now (fentanyl and oxycodone) and I ask my pain specialist:

- Are you *sure* I’m on pain killers? You’re absolutely certain?

We have a terrible problem with prescription pain pill addiction in Massachusetts, so it’s a nuisance to be on them, to get them, and it feels a little shameful to be on them, but I could not walk otherwise.

Timothy McVeigh was just the start. There was 9/11. There were the Iraq and Afghanistan wars, from which, it seems, we’ll never extricate ourselves, and our soldiers are coming home with more atrocious wounds to body and soul than have ever been seen. In Boston, we survived, with the help of our own sense of identity, David Ortiz and the other members of the Red Sox, and our beloved Mayor Thomas M. Menino (God rest him), the Marathon Bombings. The Red Sox won the World Series that year - a gift to the city.

Some of my plays have been produced and some have sat for years un-produced. Just when I got on a roll with new plays being produced just weeks apart, I started on this book. Might have shot myself in the foot there.

A young man comes to the apartment once a week to clean. I can do most things myself, but it helps me save a little energy for other things. Plus, the stairs to the basement are narrow and crooked. I couldn’t make it down those stairs carrying laundry and come up in one piece. He’s from Haiti, so I practice French and I’m making feeble attempts at Spanish. My neighbors do so many things for me: run errands, watch the dog, grab things at the grocery store, change lightbulbs, fix and open things. I call when I come in from the garden ill and shaking and can’t get dinner for Grace because I’m about to faint. It could be low blood sugar or dehydration; I’m so fragile. They come upstairs to feed the dog and get juice for me, maybe an ice bag, then they run down to the garden to shut off the water I left running. When I have a flare and can’t walk at 9:00 at night, I text one of them and she takes Grace for her last walk. They call and ask to take her for overnights and feed her when I’m at work because my shifts start at 1 and I get home late. One is about the earliest I can be sure to be on time. The neighbors bring me to doctors’ appointments and pain shots and surgeries. I try to be available for any little thing they need, but I could never equal the things they do.

Grace will be 9 in October. She’s developed a thunder-phobia that seems to get worse with each storm. Now it’s fireworks, too. She’s starting in on bubble-wrap. No. I will not tolerate bubble-wrap phobia. One massive clap of thunder while we were sitting under an awning waiting for a storm to pass did it. Around the neighborhood, she’s almost always off leash. I always wanted her to be off leash. I saw a magnificent boxer when she was just a puppy. He was walking calmly, no leash in sight, between his owners. I asked the owner how this could be.

- He knows the rules.

So she does, too. (Though sometimes she likes to break them.) We read each other’s minds: I point my head to the left and we go that way; she pulls her head back on a Sunday and that means she wants to go to the Reservoir. She’s well-trained and very fresh and way too smart, but she tries to be good.

On a snowy afternoon, Grace and I go to Coolidge Corner. The snow becomes a light rain and, when the sun goes down, it turns to solid ice in half an hour. We have to walk on the street because the sidewalks are dense, wet ice.

When we finally made it back to Strathmore, I am across the street from my door, soaked to the knees. The knees were both frozen and raging. Between me and my door, there are about a dozen slush ridges. A sludge ridge happens when cars and trucks push the ice and snow and sludge around to make ridges that are as high as two feet. To move, I would have to lift my walker and, then, my legs over the slush. I can’t do it. I just stand there, looking at them. Nothing like a plan emerges from my exhausted, terrified brain. I have been doing this all afternoon: find something that is at least the lowest ridge, look for the area where there seems to be little or no ice, move toward it, lift my walker over it, fight to push the walker through it, keep my balance without my walker under me, because it’s just in front of me as I try to jam it through nearly solid ice and snow. The dog is leashed beside me, also miserable. The weather has caught me by surprise, and now I’m stuck. Really stuck. I suppose I hoped one of the neighbors would come by, but, no, so I stand there. I get a little weepy. There is nothing else to do. I cannot lift that walker.

- Come here.

An accent. Russian? One of my neighbors is Russian. Is it she? I glance up. I don't know this woman.

- Come. Come to me.

- No, no. I can't.

- Where you live?

I point to the door with the maroon awning.

- Give me the leash.

I give her the leash. She walks Grace across the street and deposits her in the foyer of the building. She's safe. She certainly won't leave. All she wants is to go home. The lady works her way back across the street. She's middle-aged? Is she fifty something? Sixty something? She's wearing a thick, faux-fur lined hood, so I can't see much of her face. Not heavy, but sturdy. She's reaching for me.

- Come, give me your hand.

I shake my head. She grabs my walker and drags it through the ice mound. She takes my hand.

- Come over.

So I do. Her grip is not hard, but she has me. She coaches and coaxes me through the next several sludge ridges. I'm whimpering. We cross the center four feet of street that is, because of no traffic, clear of slush. On the other side of the street, there are more ice ridges. I want so badly to be home, I just let her drag me. Grace is waiting patiently. The Russian lady gets me all the way across the street.

- Here. Here you are.

There are a few stairs to get over, but we do it. We're in. We're in the foyer. She takes the walker up to the top step, just outside the inner door and I fish for the keys in my pocket. I hand them to her and she fiddles with the lock, which is tricky. I'm trying to be helpful.

- Can you get it? Uh. It turns to the left -

She opens my door and lugs the walker inside. She takes my hand again and helps me into the lobby.

- Thank you. You're so kind. You're so kind.

- You in?

- Yeah. You're so sweet --

But she's already on her way out the door, then gone.

This sort of thing happens to me all the time.

And I know this, hauling myself to the elevator, trembling:
that right knee has to go.

But let me back up.

1999

Groveland Street

Men grieve differently than women. My brothers, who are men, wanted to sell the house the week Dad died. I wanted to sit in Dad's chair for six months and smell it. I wanted to lie on his bed and wait out the stomach cramps. We had to wait, as it turns out. The town was building a sewer system and no one would buy the house until that was done.

I know that the heart does break; that muscles tighten and pull at the skin inside; I could feel an actual sensation of cracking. I could feel his absence on my skin. The lack of his skin, his voice, his hair, his body, that little personal scent that everyone has, was with me all the time. Once, when Colleen (Baby Girl Kenney) was about 5, she came into my apartment, smushed her face into the bed and inhaled deeply. She came up satisfied:

- Ahhh. Smells like Auntie Janet.

I wore his watch, which fit on the middle of my forearm. I would imitate him looking at it: an enormous watch, with huge numbers, and he would have to hold it far away to see it.

I had conversations with him all the time, sometimes in my head, and sometimes whispered. He got a lot of vicious scoldings and endured raw wailing. I suddenly believed in something like Purgatory, the Catholic notion of a kind of "waiting place." I thought, he shouldn't "leave" - whatever that meant - until I was ready for that and, more - he must have missed me as much as I missed him. He just must have missed me.

I realized slowly that his death would not kill me, and I didn't have to get sick to prove how sad I was. I wandered around in a fog, nothing seemed to be exactly what it appeared to be, but there I was: wandering anyway. I can see myself now, on a lunch break from work. Walking in the little park near the office. Green grass. Grape vines. Birds. There are birds. Friends took me away for weekends down the Cape or to the Berkshires, to a tiny cabin whose water reeked of sulfur. We didn't talk about it.

I craved the house. The boys all had homes in the suburbs, but I only had an apartment that had become repugnant to me, and a house that he lived in, that I grew up in. The house that, for all of my urgency to leave when I was out of high school, I'd gone back to hundreds of times to recover from something or just to be with him and, then, with the kids. That was my house, my only home, and I was going to lose it.

If he told me once, he me fifty times:

- Now, when I go ("go" is Irish Catholic for "die"), I want you to take your shayr of the house. Take all the money that you get from the sale and plunk it all down on a condo in the city. Your brothahs will tell you to move to the suburbs. Don't listen to them. You're a city girl. Buy a small place so you can't have roommates. You're sick of roommates. Plunk it all down so you'll have a small mortgage. Keep it low, so no matter how sick you get - I'm sorry to have to say that, but this will get worse before it gets better, or it won't get better - but if you have a low mortgage, no one can throw you out of there. That's what you do.

He gave me that speech, again, about a half an hour before he died.

About six weeks after his death, I took trains and the only cab in Abington to get there. I walked around the yard then lay on the grass in the front yard for more than an hour. Even lying on the ground in front of the house was soothing. I was looking up through our magnolia tree whose branches spread almost entirely over the front yard. From the big picture window in the living room, it was all you could see. I lay on the grass, telling myself I was calm, noticing, that, really, I was calm. When nature called, I headed into the house. A little panic; a little joy. It would always be that way.

After the first time, I went to the house every chance I got. I felt at peace there. I said good-bye to him, to the child that grew up there, those children, that mother. I used a large, beautiful notebook with dried and hand-pressed wildflowers to build a story: In This House. I went from room to room, tried to recall everything I could in this house, these rooms. We had the basinet in that room; the New Years' Eve party there, the kitchen had the mark of thousands of meals from sloppy joe's to the fine, fancy roast beast dinners we had on Sundays. "In this house there was a family..."

At first, I stayed for the day and cleaned. An un-used house gets dusty very quickly. There was never a speck in that house. I started staying longer and it wasn't long before I was staying overnight. We'd already moved the headboard somewhere, so I slept on the bare mattress in his bare room. It was just quiet. No ghosts. They'd left. In this room...I watched him get dressed. And snap the elastics on his boots. In this room, he finally slept on his bed weeks after his heart surgery. In this room, his scent lingered.

Glancing back at my notebook from this period, I just cringe. I was miserable. At work, State Street's latest attempt not to kill me was killing me. My apartment was a madhouse. The two girls who had been subletting wanted to stay but the lease was expiring and all the original tenants were gone or going. Because I was the last remaining tenant on the lease, they wanted me to sign the lease for a year and they'd pay me after I paid the monthly rent. Probably not. Leases were taken and altered, tantrums were thrown. And my stupid stupid stupid immune system never stopped and, just to tie things up nicely, I was going through menopause. Lupus patients, for reasons, unknown, of course, start menopause early, so at 38 at I had nights sweats and hot flashes.

I had colds and sore throats and fevers and pain everywhere all the time and no one to take care of me, ever again. All of my doctors were worried and there was talk of anti-depressants from all of them. Even Bobbie, who seemed to know the secrets of the Universe, was leaning in that direction. How could I need anti-depressants? Finally, an acupuncturist I was seeing helped me have a clear thought:

- It’s just a chance to get out of a sinking boat.

Well, the boat was certainly sinking. So. Paxil. A little bit. Just for a try.

One of my neighbors names all of her dogs after anti-depressants. So every day I greet little Paxil. We call him Pax. I think I live with at least part of the boat underwater at all times.

After a particularly tough week at the apartment of pounding on my door at 11 pm drama, I took the things I valued - little things: my nana’s diamond and a ring, and the first quilt I had made, the quilt I’d made for Dad, and brought them out to the house and, slowly, dodging realtors and my brothers, moved in. About a week after I sidled in, all the boxes were gone from the living room and the dust was gone and the spiders that had spun cobwebs in just hours were out. The place looked like his again, ours again.

Bud was a Depression child. Born in 1930, he understood early on that food and other necessities were unreliable things. He kept everything. I’d call and ask my brothers what to do with an entire bookcase’s worth of extra basement tiles. I can hear Dad’s defense:

- What if one rips? You’d have to replace it.

So we had two thousand of them in case one ever ripped. Some things had been too much for him to throw out: my mother's hair curlers were still in the drawers. He had 67 pairs of earphones so he could listen to the radio at night (the way I do now). I threw out the grooming stuff in the medicine cabinet and the seven back-ups in the linen closet. I thought: it's OK; you don't need this stuff anymore. You are free from a body.

I called the boys one night and said,

- I hate to say, it: we can only have four bottles of black pepper each. Each.

They gave me permission to throw them all out. (But what are you gonna do when you need pepper? hmm?) Nobody wanted the six cans of Spam, either.

I spent 1999 cleaning all day, every weekend. When I left work, I had already decided what area I'd go after that night. I took the commuter rail into Boston because, by then, I had made the dumb move of buying a car. A tomato-red Toyota Corolla zipped me to and from the commuter rail to get to South Station to get to the office - just like the thousands of commuters working their 9-5 jobs then commuting home to the suburbs. Me? Last time I checked I was an actress in New York. Then I was the author of a New Age-style book called, *I Cured My Immune System Problem and You Can, Too*. Then I was a published authoress, then a grad student, then a playwright. But a "commuter?" I was so far off track.

I was, however, learning to teach. I volunteered with a group called Tremont Street Project that was inspired by the 52nd Street Project in New York. They work with kids from the Hell's Kitchen neighborhood and pair them with playwrights. They build short plays together that are eventually performed. We taught 7-12 year olds, inner city kids, from a towering housing complex in Copley Square. They were sweet and smart and very physically challenging. By this point, I couldn't remember when my back didn't hurt awfully. It was like wallpaper, that pain, just there in the background all the time. Still, I was not taught to work sitting around: you work on your feet. I taught on my feet, and ran after them on my feet, and talked them through their thoughts on my nasty, raw feet until they had written little plays that delighted them.

And I was working on a new play. I could hear it in my head, see some of it, but I was having trouble getting to it, so I took a Linklater voice class. Kristen Linklater is the author of *Freeing the Natural Voice*, which took voice training for actors to a deeply physical and spiritual level. The teacher, Deborah, had played my Mom in *Fifth of July* many years ago, when the only thing I had to struggle with was pain from my braces. The class, because the voice sits in and, is mostly trapped inside the body, is intensely physical. I knew that the agony from Bud's loss was a living thing, and it needed tending and releasing if I were to be able to work again. I thought my inability to work on the new play would be released. It was. I finished that play, *The Mark of The Lord*, that year. It's a 40-minute piece about a woman who wakes up with Stigmata, the wounds of Christ, and this is a problem for her. It was inspired by a C.S. Lewis quote: "a miracle is anything that falls outside of our understanding." My father's death, truly, was a miracle. It would forever be outside my understanding. Surely, then, by that token, lupus was a miracle, too.

I received the good news that *Down*, a short piece I'd scratched out on Bud's porch that summer he'd been ill, had been accepted for The Boston Theatre Marathon Festival, which I've now done more than a dozen times. It's a collection of 50 ten-minute plays produced consecutively over ten hours. A long, marvelous day. *Down* was produced twice in Boston and again in Seattle. This was about eight or nine months after his death, so friends were telling me that a little angel was looking over my shoulder. I told them they should remind the angel that I had a full-length that needed producing.

- You're flying out from Boston to see a production of a ten-minute play?

- Sure, why not? I've always wanted to see Seattle.

My director introduced me as "my playwright," which I liked, and he put me up at his home for the week. It was a garage-turned guest house that smelled of cats, but it didn't have any plumbing, so if I had to use the bathroom, I had to tramp across the yard at whatever hour. From someone who had travelled cross-country by bus with a backpack and a gym bag, I was now into 400 count sheet linens and, at the very least, a nearby toilet. But the production was a blast. And I was now officially, a "nationally-produced playwright."

And there was this about all of these productions: he wasn't there. At the reading of *Saint Peter*, when I found him in the audience and blew him a kiss, and decided that that would be our "thing," how could I have possibly imagined that would be the only time I used our thing?

I was working on a ten-minute play, *Debt*, that would take almost a year to get right. Yes, a ten-minute play can take a year to get right. Thanks to the endless patience of my playwriting group, *Debt* was included in the next Boston Theatre Marathon. That year, I started to manage the Green Room. This is where the actors hang out and dress and do their make-up and generally prepare to go on and unwind after they finish. My penchant for taking care of people made this the famous Ritz Carlton of Green Rooms. I took to wearing a tiara so no one could doubt who was in charge. We got, on average, 120 actors in, fed, tended and safely in and out the door. It was a non-stop 15-hour day and I couldn't get out of bed the next day so I scheduled a personal day.

In May, now that I was a millionaire, for Bud, with no training but lots of brain, had done very well in the 1990's stock market, I accepted an invitation to have my one-act *The Devil on This Earth,* read at the prestigious Last Frontier Edward Albee National Theatre Conference in Alaska in Valdez, AK. I had always wanted to go to Alaska, so, using another week of vacation time about two months after my last vacation from my endlessly patient employers, I flew off to Alaska. Ever the good girl, I spent most of the week actually inside the Conference Center instead of taking off to see Alaska. I arrived in Anchorage in the early evening on Summer Solstice. I walked the Coastal Trail. Though you're only seeing the tiniest bit of the thing, you can feel the immensity of Alaska all around you. An image lingers: Sleeping Lady Mountain, or The Lady. There's a mountain across the Cook Inlet on the Susitana River that looks like a recumbent woman. There are many versions of myths. My B&B host told me a race of giant people had lived there, and two lovers were separated by war. The woman waited for her lover to come back, but he never did. Eventually, the grass and meadows grew over her, and then the snow came, and there she is still, waiting. It's easy, without trying too hard, to see it.

Anyone who's been to a conference of any kind knows what happens from here. You start meetings at ten in the morning, drinking terrible coffee from styrofoam cups lightened with that gross powder and you do that until ten o'clock at night and then you don't sleep and then you get up and do it again. It was very hard and very fun. The highlights were: 1) meeting Joseph Chaiken, whose book, *The Open Theatre* is a classic. By the time I met him, he had had a few strokes and worked with aphasia, that disconnection between the brain and the mouth that I often endured after seizures; 2) Despite a discussion of my play, *The Devil on This Earth*, that was louder, more raucous, contained more foul language and verbal violence and was almost twice as long as my play, I didn't win. What I wrote in my journal cannot be repeated here; 3) I developed a terrible sinus and ear infection and needed to see the only doctor in Valdez. This was handled immediately by the organizer of the event, whose mother had had lupus.

After taking a short kayak trip around the bay on Sunday morning, I flew home with only a "Panelists' Choice Special Recognition" (I heard that there was a brawl over that, too) and a fever, a terrible canker, a deep, ugly foul-tasting cough and the lesson that you should never fly with an ear and sinus infection because your head will explode.

A little package arrived that summer: the last of the litter, Joseph Mark Kenney, was born on August 4th.

Then a strange thing happened in the front of the yard: A FOR SALE sign went up. When the sewer lines were set in the town, and the house would not have survived another cleaning anyway, and all the cabinets were empty, it was time to close up shop. When potential buyers came by, there were little cinnamon-scented votives that had been recently burning on the mantel piece, there were fresh flowers from the yard on the perfectly polished dining room table, there was a "coffee table" book of American quilts open by my mother's chair, as if we read that in the evening.

It became, not exactly a rush, but a good time to find myself a new place to live. I had been looking. I tried Quincy, Braintree - suburbs between the city and the family, but they were so, I don't know - suburban. The Brighton section of Boston was right over the

Brookline line, where I'd rented for ten years, so I looked there. I looked at two places, then I said this thing which is not smart to say to a realtor as soon as you pull up to the curb:

- I'll take it.

And when you do get out of the car, the first thing you notice is a filthy, trash-strewn, weed-clogged and run-down tangle of dead trees kind of courtyard. Strathmore Court.

- Is that the courtyard?

- They're working on it.

- I'm sure.

One look at the original 1927 log cabin style ceramic tiles on the bathroom floor, and I was done for. It was an entirely too emotional decision, but you know home when you see it. I would be living, for the next chunk of my life, at Strathmore Court.

I celebrated the year's end by attending a beautiful reading of my Master's thesis and full-length play, *The Last Work of Saint Peter the Great*, which had won the Provincetown Theater Award. I showed up with a lingering sinus infection, but had a great time with a responsive, grateful audience.

We had a final Christmas gathering at the house with some of my cousins, and I shoveled the driveway one more time, delighted with the crunching and the sprinkling snow, knowing it would be maybe the last time in my life I ever shoveled snow. Since the closing on the place was December 31, 1999, I arranged mine for December 30, 1999, and fled just ahead of the new owners.

2000-2002

Professor Kenney

52 Strathmore Road has a Northeast exposure, which is on the cool side, which I like. It has hard wood floors throughout, including the one under the six layers of linoleum in the little kitchen that I dug through with bare hands the first day I owned it. It feels like a cottage, especially when the Boston Ivy that clings to and covers the windows make the view green and leafy. I loved my little studio. But it stunk. My pretty little apartment smelled of animal carcasses. I know many people whose apartments don't reek. Why not mine? With no immune system and without health and unable to buy a condo that doesn't stink, I had that conversation that haunts me: I'm not fit to live in this world. I traced the stench as far as the kitchen, and the plumbers came one day and tore out the wall but couldn't find it. For my birthday that year, six of my gay male friends had a goddess-worshipping party and they all gave me scented soaps, scented candles, candle holders, incense and yummy scented body lotion.

Dad made frequent appearances in dreams and he was always in some sort of trouble; his clothes were blood-stained, there was a wound on his neck; he was missing. I attended a few masses at the Paulist Center and an Episcopal church me and I left them all in the middle and wept outside. I was so angry at God, because we lost Dad when he was happiest and that made me sick. A priest told me God had big shoulders and didn't mind my anger. I guess that was right. But the only comfort I found was in a tiny miracle of a book, C.S. Lewis' *A Grief Observed*. After just a short marriage, Lewis had lost his wife and, unlike me, who tore things apart and cleaned them, he had the presence of mind to pay attention to it and report on it. I was startled to read, "Nobody told me grief would feel so much like fear." That was the problem. I was afraid. Not even terrified in a grand, operatic way. It was a knot in my stomach that spread to my thighs that never went away. All these years, when I'm tired and quiet, I still get it.

I was cleaning again. Not Bud's house this time, or even mine, but the trash pit of a courtyard that I had remarked on that first night. It's about a thousand square feet, and when spring warmed it up, the weeds grew thigh-high, and I could see that there was garbage strewn about from years of neglect and the trees were past saving. I was moving chunks of metal and cement and brick that were entirely too heavy for me to handle. Tree branches and roots that were six feet long were no match for my crazed self. Adrenaline. My muscles and joints were not happy with this project, but they didn't get a vote.

I was working on *The Queen of Braintree*, a full-length screenplay set in the Depression, based on a story Dad had told me about himself as a child. I was blessed with a good production of *What Mother Knows* in a collected evening of plays by Boston-based playwrights. I was welcome at rehearsal and got to see the ladies take over the piece and leave me behind to enjoy it.

Ever since I'd been there for a site visit with the Names Project, I'd been trying to finagle a teaching gig at Framingham Women's Prison, the first women's prison in the country. My hope was to help them write the way I write: all the time, rain or shine, wherever you are in your life, even if you are in prison. This is where you are right now, so write it down because it's precious. I had six to ten regular ladies, though their attendance was not regular because they have no control over their schedules, and sometimes they're in

Solitary. I gave them starting points: The first kitchen I remember; my favorite outfit junior year in high school; my room (we don’t say “cell”); My father’s hair...” anything to get started. We’d read things aloud and I coached them to say, “I heard you say...,” and noted how spectacular it was when one person hears another person. Write for ten minutes. Don’t stop. The ladies were in there for blown parole, minor or major drug offenses, assault and battery, murder. Of course, they didn’t tell me that, but it came out in their writing. By the end of eight weeks together, we had someone run to the bathroom to get toilet paper for tissues because the writing was so ferocious, we’d all be in tears.

Being an aunt was the center of my life. How do you get a petulant three-year old to put the buckle on when riding in his stroller? You become The Leaf Monster, and you run, screaming, at high speeds through thick piles of leaves. You spend that night on your back on the floor in the baby’s room in agony. One day Krissy and Colleen and I were sent out to run some errands for the pumpkin-carving party that was to take place at their house the next day. I insisted we stop at David’s Bridal shop in Attleboro so they could try on flower girl dresses. We spent two hours. They were so well-behaved and lovely that brides sought their advice on the gowns they were trying on. This is before the phone was also a camera. I have this image: Krissy dashing through the flower girls’ dresses section suddenly turning around, stopping and saying, “I love you!” Better than a photo, indelible.

For the first time, someone could call me “Professor” and not be making fun of me. I was hired by the University of Massachusetts at Boston to teach Screenwriting. That’s where I had earned my B.A., (that didn’t hurt my job chances). Immediately, I adored the role of teacher: the work of organizing a class, the joy of the performance needed to hold people’s attention for 90 minutes, the rapport that I quickly developed with my students. When teaching screenwriting, I'd break down *Casablanca* scene by scene to demonstrate classic structure and spread the thing over three blackboards even if I had to crawl on chairs to do it. I took several screenplays and analyzed those crucial first ten minutes by the moments. Just a few images at a time. Once the class started reading their own material, my sessions were so raucous my boss snuck over to close the door. But there was something that tortured me: Dad would never be able to call me "Professah Kenney." Good ol' Professah Kenney."

I won the Women's Playwriting Festival award at Perishable Theatre in Providence, RI for my one-act, *Extraordinare*, and had another wonderful rehearsal process. As after any good rehearsal process, I came away with a much better play and audiences loved it.

April, 2002. For the first time since Dad died, Spring felt like Spring. I'm not fond of a blue sky because it means the sun's out, but I enjoyed it this time and every glimpse of leaf or bud made me happy. And I was seeing signs of life in the garden. Just a few daffodils, just tough little guys like that. Mostly bare dirt and plans. Since we were scheduling major work on the brick and windows, I could only plant annuals and seeds for the first few years, meaning anything I did for the first few years would be all gone the next year. The yard was full of bachelor buttons and marigolds, celosia and Morning glory vines. But it wasn't a waste; in those few years, the formerly grungy space became a garden.

I had finally found out the cause of the stench. It was the "chase." A chase is a wide space between the inner walls in the building and the outer walls. Inside the chase are all the wires and plumbing and anything else that is required to run the building. It should be sealed at the source because it works as a wind tunnel if it’s open, which it was. I had finally hired an environmental company that specialized in air quality. They sent a guy out who traced it in about five minutes. He explained it was a terrible fire hazard because air is drawn upward. In this case, what there was a two-foot opening in the ceiling in the basement that was sending warm air up and dragging with it a hundred years’ worth of dust and dirt and dead rodents and general behind-the-walls filth. It took eight seconds for a test smoke to get from the basement to my apartment. A very real danger in case of a fire. After I’d been fighting with the board for two years, it took 15 minutes to fix it. My pretty little apartment smelled like a pretty little apartment.

Then: the jig was up. There was new management at State Street. A guy who used to be a good buddy when he was a salesperson had slipped into a management position. He came to me one day and asked what this “arrangement” I had was. I was working on site just three days a week but still getting full pay. I took one of those “Family and Medical Leave” days every week, then another sort of amorphous “working from home/personal day.” The first time he brought it up, I was doubled over in pain. I was on my way to the doctor with the first significant subluxation of my left lower rib. That happens when the cartilage and the bone separate due to some sort of blow. I couldn’t remember receiving a blow at my ribs, but I couldn’t breathe for the pain, and my doctor couldn’t touch me until she had given me Tylenol and waited half an hour for it to kick in. There’s nothing for it but to wait. I get them all the time now, leaning over the tub giving Grace a bath, ripping out an ivy root in the garden, leaning over anything to reach something. I feel this little “pop” and I can barely move for a week.

The next time he caught me he mentioned it again. It was hard to explain. He didn't want to hear the explanation. He was giving me a month before it ended and I would be officially part-time and financially destroyed. I'd asked God to help me get out of there, but I was thinking of a nice new job offer, not a kick on the butt on the way out. I panicked because, as much as I enjoyed teaching, I'd already figured out that, between the time spent in class, preparing for class and grading papers, it paid about fifty-two cents an hour. It didn't seem likely I'd get a full-time position anywhere. Those are reserved for the PhD's. I'd barely made it through a Master's. Because I was going into reduced funds, after the transmission blew for a second time, I got rid of the car. I wouldn't be making enough money to buy a new transmission every six months.

I had a solution to the insurance problem: now that I was a part-time worker with no money to speak of, I was eligible for the state's Mass Health system, an insurance program for children, the elderly, disabled and poor. The problem with it was that it was dreadful. I had had years of top-notch insurance so I wasn't used to having to get everything pre-approved, of errors made, of things denied, of paperwork and copies of things that took weeks to assemble and then were rejected entirely because one thing was missing or otherwise inadequate. I was dropped entirely from the program all the time, and I'm sad to say I was hysterical when that happened. They just made me crazy. It was the start of ten years of frustration and rage when I couldn't get what I needed even when I fought for it, the unfairness of which made me cry.

In my notebooks was the first appearance of a play that had something to do with garbage, that turned into a play about water and dirt. There was also a ten-minute play called

More Than What almost entirely intact in a few passes. It's about a bride who just sort of kissed her bridesmaid in the Ladies Room. But it's not what it seems. It's much more than that. And it would be included in the that spring's Boston Theatre Marathon in a beautiful production that I snuck in to watch from the Green Room. All this new work was tumbling out like water heading down hill, but I don't mean to make it sound easy. After hours and hours and months and months of hard work, when I finally start to get it right, I feel I'm channeling. The characters exist in some kind of Universal swath of energy and my job, as I do my hard grunt work, is to listen for that character, that story and the most perfect version of the work until I get it right, do it justice. It's an honor and a burden, and a spiritual undertaking.

In my ignorance, I was sure I could get a teaching gig over the summer. I couldn't, didn't. I was lucky enough to get a job as the third person on a costume crew. Commonwealth Shakespeare Company is one of the oldest "Free Shakespeare in the Park" companies in the country. This production was *Henry V*, when Henry goes from a rascal in the last play to a warrior king who whips France's butt and gets the girl in this play. Since it was out on Boston Common, we had trailers for dressing rooms. I was in charge of the men's dressing room: 32 guys, all of whom had several complete costume changes. I've always been as happy backstage as on. When I studied at UMass Boston, before we set foot on stage we were required to work backstage for a few semesters. I especially love costumes. For one scene, we had to get eight guys out of court wear and into battle gear in under eight minutes. We had it down to four minutes by the end of the run. Sweeping the floor of the trailer was a thrill because it kept the room nice for the guys. Spraying the frizz down from under the Cardinal's huge three-pointed biretta made me happy because the actor didn't want a sticky neck so I sprayed my fingers first then worked them up under the hat. 32 of those. The show was so physical with its battle scenes and brawls that the guys often ran into the dressing room having torn their costumes from top to bottom and we fixed them while they paced, and then headed back out the door.

Between prep and clean-up, I never stopped moving for 4 hours. The afternoon shows were often performed in 90 degree-plus heat, and I did the same dashing around, sometimes in the sun. I could hear Bud: “you’re ovah doin it, Janet,” “Get outta the sun, Jan.” I tried, but I couldn’t do my job and worry about that at the same time. It was a glorious run, and on the last night, I came up to the front of the backstage area to watch the curtain call. If I made it through this run, could I make it through another? Could I take a small part in a small production? Could I?

A week after we closed I was in the hospital with the worst flare I’d had in some time: full body pain to the point of not being able to move at all, 105 degree temperature, swelling around my lungs and stomach, skin made of burning parchment paper. I spent all night feeling the bumps on my mattress with my foot. But I had had a ball. I even told Dr. Sands that it was worth it. A job well done. And I miss acting. But I miss it the way I miss my health or Mom or my Dad. Gone is gone.

2003-2004

My Heart

I received an invitation from Theater Emory in Atlanta to show my one-act, *The Mark of the Lord*. The invitation was especially meaningful because it came from one of my mentors from my time as a student at U Mass, Vinnie Murphy, a sharp, gifted director and one of the Artistic Directors at Theater Works, my first theater experience out of college, and, still, one of my most profound. This is the company I was with when I almost exploded my spleen on stage.

It was a wonderful reading, with a ton of work done on the script. The only glitch was that, having breathed in “plane air,” I had bronchitis, so I spent half an afternoon trying to get to a doctor, finally gave up and got my doctor to call an antibiotic prescription in to Atlanta. The Stage Manager had to take me to CVS to get them because Stage Managers do everything. Shortly after the reading, the theater commissioned my next play, the most significant award I’d had so far. That would mean I’d finish the play about dirt and water and garbage, *Globus Hystericus,* and be able to skip temping over the summer on their dime.

In the Fall semester, I started to teach the theater class for Berklee College of Music. The “those who can’t, teach” axiom came to mind. But it wasn’t that I couldn’t act, only that I wasn’t able to. I certainly knew my stuff. I taught what I was taught, that the essence of fine acting is being present in that moment, which means you’re more present in daily life. I taught it for a few years and, only in the last course, when one of my favorite students asked why I didn’t perform anymore, did I tell them why. It made some of them teary, and all of them very quiet. A rare public display for me, but it seemed right. It was a very physical three-hour class and it got so that I had to take a Percocet or two to get through it.

In the garden, I was trying, quite unsuccessfully, to build a stone wall on the side of the property and had the gaul to take a "job" as a garden designer and landscaper for a man who admired the garden. I even wondered if I should do that for money in the summer because I can never find teaching work. This, even though I can't be in the sun. I would call myself "Sun Shy Landscapers." But the deer ate all the flowers I had planted for my one and only customer, who was very unhappy. I let that go. I'm not sure how I get myself into these things. I did manage to plant a tree on the side of the property, a Persian Perottia, a tree with spectacular fall foliage. It's thirty feet high and thriving.

I was diagnosed with severe osteoporosis. This is something we saw coming, but it still hit me hard. All those years on prednisone had caught up with me. I remembered, years ago, screaming at my doctors, hating them for prescribing it, hating myself for taking it. Maybe they were right; I was still alive, but maybe I was right: I was going to fall apart. Though I wept at the time, the word "osteoporosis" wouldn't have any actual meaning for several years.

In the summer, I brought *Globus Hystericus* to a workshop that I took through the Ensemble Studio Theater in New York with playwright Romulus Linney. For the first time, I had special needs: I needed a room to myself because I might need extra sleep. I had to be on the first floor because the stairs are hard. Didn't phase them. This difficult task of asking for what I need paid off when I got it what I needed, and it helped. But I had other weird experiences there: people didn't "get" my play. To be sure, it's a little odd. Set in the "days after the Resource Wars," and peopled with remnants of human beings and an ancient mariner, it left people confused. My work had been so well received so far; it was a shock.

And, for the first time, when we all read each others' work, I was cast as the mother, or the aunt or the old lady next door. Not the ingenue anymore.

At the beginning of 2004**,** though I couldn't handle any more work, I did need more money, so I began to work as a union usher in Boston's historic Shubert theater. It hosts most of the operas and some dance companies. It's a sad statement that most of the ushers had full-time jobs as teachers. I ran around like a maniac, walking people to their seats rather than pointing them towards them, tearing around taking especial care of our many elderly guests. My boss sometimes found me, long after the other ushers were gone, sitting in the lobby holding the hands of some elderly couple who were having a small crisis. He encouraged me to let him shut up the theater on time so we could all go home. As always, I adored the work, but it was hard on my body, especially after I slipped on a set of wooden stairs and acquired a hair line fracture in my already-disastrous right foot.

One winter day, we planned an ice-skating party on a pond near my brother's house. The kids were at various levels of skating and sliding on bums. Unable to even put a skate on my fragile, swollen foot, or to trust my ankle to hold my body up, I walked around all day in a pair of my brother's boots and held on to a milk crate to push myself around. It wasn't long before I became The Great Zamboni, the master of ice cleaning and pushing small ones around on the ice before hurling them, sled and all, into a snowbank. Later, destroyed, I snuggled sleepily in the den with the kids while they tried to instruct me on the basic points of football.

Sometime over the winter, without me noticing it, a viral wart had covered the entire bottom of my foot. I thought it was a corn, or just roughened skin at first, but then it spread and the whole bottom of my foot had a living thing on it. I went to the doctor when it became so thick it was hard to walk. The podiatrist explained that we're all covered with viruses, but a lazy immune system can let it get out of control. He injected some prednisone solution directly *into* the bottom of my foot. For months, I had to soak my foot every night in 120-degree water. This is hot. Hot enough to kill a virus. And I know it was a 120-degrees because he made me get a candy thermometer to check it. It was six months of that before the virus retreated. I guess it's sitting in my body, still, waiting to pounce.

For the 2004 Boston Theatre Marathon, I ran *Ma in Her Kerchief*, the second play having something to do with the marriage of Jack and Andrea. This was Andrea and her new mother-in-law. I was reminded that reviews only count if they're good: The Boston Globe's reviewer wrote that, "Just when I thought ten minutes were not enough to dig into deep feelings, along comes Janet Kenney with 'Ma in Her Kerchief.'" They count because they're encouraging, and it takes courage to write, then share, plays. I found myself getting near the "it" list in Boston theater circles. I wrote another short play connected to *More Than What* for what was now sure to be a cycle, *The Space Beside Me*. This was Andrea's sister and their uncle. The family was spreading, just as mine had been doing for years.

2005 opened with a Playwright-in-Residence gig at Theater Emory in Atlanta. The play they commissioned was ready for a reading. I asked that it be staged, rather than just read. A good reading is a great way to work on a script, but, at some point, you need to see a physical thing. These physical things, except for ten-minute productions, are rare things for "emerging" (*read: unknown, not yet known*) playwrights. I asked for what I needed and got what I wanted. The script asks for live music but doesn’t specify which instrument; they got me a drummer who added a raw spinal nerve. A fine group of actors and a smart director is all I ever need to make me happy. I was also to speak at a symposium. I found, at the last minute, to my horror, that a symposium was just me. I’d thought of my whole cast, Vinnie, a dramaturg, etc. No. Me. Yikes.

I had a ball. A natural born ham, I had them howling. What I said, mostly, was that you have to write every day, no matter what. But I think now that I was arrogant. I’ve been through times when no writing was done for weeks and, sometimes, when the lupus is very active and the depression is bad, and the pain is spirit-crushing, even months. It makes it very unlikely that you’ll ever finish anything if you don’t work every day. I was right, but I haven’t been able to always follow my own advice.

Nothing was happening with *My Heart & My Flesh*. I needed that physical thing again, so I decided to produce it myself. I still had money left over from Dad’s estate and, long before Go Fund Me existed, I wrote letters to all my friends and family and had them go fund me till, combined, I had $13,000. That’s not a lot of money to have when mounting a production when you just have to have the two actors you want even though they’re Equity actors because you need exactly those people. I also paid the director, my buddy Courtney, and the Stage Manager. That didn’t leave much for a marketing person, which, knowing better, would be the first person I’d hire if I were crazy enough and wealthy enough to do that again.

After a wonderful rehearsal that gave me a much better script, we opened. To three people. We’d been late with our bits of marketing stuff and had worked on the script till the last minute, so we had people in the first weekend without even charging them, just thanking them for their presence and their attention. So much for making any money back, but it was a good run anyway. The reviews and word-of-mouth were swell, so by closing night we packed the house, including all the Kenney boys and their wives. How wonderful to be able to discern all three different laughs. Only Dad was missing, but it wouldn't have happened without him.

I received a Tanne Foundation award of $4,000, which meant I could take the summer off and finish *Globus*. In August, I went up to Arthur's Place in New Hampshire - part of the prize was a trip up to the cabin - with the goal of finishing *Globus*. Arthur's still has Arthur's truck from when he farmed the place sitting at the top of a hill near the driveway. It overlooks miles and miles of the Osipee mountains. Nothing but trees. There's a meadow at the back of the little cabin and the deer come out to feed at 4 pm, at which time, you just have to take a break and watch. I had a dazzling flare, a real humdinger, and it had repercussions.

Late in the afternoon on a cloudy day, I walked the mile it took to get to Lake Winnipesauke, New Hampshire's most famous lake. The entrance nearest me was speckled with a few rental cabins and nothing else. The lake was still and smooth, with a little dock anchored about twenty feet from the tiny, pebbly shore. Always a good swimmer, I dove and swirled and got near enough to ducks to swim beside them for a bit. I caught glimpses of sun through the clouds, but let it go. Because I was in a lake. A real body of water. There was sand under my feet and water giving me wings and I swam for more than an hour. I was a mermaid. I swam using only my feet as propellors and my hair grew to my toes and my gills were shiny and I was supple and strong. I thought to myself, "Yes, this is right. I'm not a land creature. I'm made for water, where gravity and pain don't wear me down." Mermaid.

After a while, I climbed up on to the dock to jump off and fell off instead. The sharp pain in my legs startled me and I found myself underwater again. Which is where, I decided, I belonged, so I stayed there. In a while, I tried it again. Spectacular pain. I slipped back into the water and began to wonder: am I OK? Lemme try this again. Again, splash. Getting nervous now because, when trying to reach up for the ladder on the dock, my arms had not responded. I couldn’t lift them for the pain. And, finally, I noticed: my jaw was locked. This is something that comes at the peak of a flare, when everything else has already given out, the jaw locks. Uh oh.

There was no one around at almost 6 o’clock in the evening. I took my time getting out of the water, knowing now what I was in for pain-wise. When I finally got to the water’s edge, I had to combat crawl, a few inches at a time, stopping to gasp and pull myself together for the next few feet until I hit a little log that marked the end of the beach and the beginning of the parking lot. I hoped someone might come out of one the cabins to offer some help. No one. I lay there for quite a while, no plan.

A white jeep. I’d seen it earlier, because the driver had a little pit bull with him so I stopped to say hello. He was coming down to the beach. I was almost at the edge and I wanted to catch him before he took off. I called “hello” and “hello” again and I got his attention. I told him the quick version, and I’d need to get back to the cabin, could he help? And, by the way, I don’t know where the cabin is, and you’ll have to wait ten minutes while I crawl over to your car and hoist myself in, which I eventually did.

He was a good sport and we drove around for forty minutes, up one hill and down another, me saying I was pretty sure it would be the very next hill and he waiting patiently for one of them to be the correct hill. Finally, we came to it and I somehow got myself inside while he went off, very late, to his original destination. I called 9-1-1.

- I'm having a bad lupus flare. I'll need you to come get me in about an hour.

- An hour? Why not now?

- I'm good. I can still breathe. My lungs will get tight in an hour or so, and my stomach lining will swell up, but I'm not in any danger right now.

I was just out of my ever-living brain.

- Well, we could come get you now so you'll be all set when your lungs shut down.

- Ah, it's fine. No rush. I'm going to take some prednisone and lie down.

- Where are you, honey?

- Arthur's Place. I'm not sure where it is. It's surrounded by hills.

In New Hampshire, this is not helpful. The lady who owned the place was away for the weekend so I didn't have access to this information. They talked me into calling Dr. Sands and he ganged up on me and thought I should have them come right away,

- Are you in the old Arthur Davis place? The one with the red truck at the top of the hill?

- Yeah! That's exactly where I am! How did you know that?

- We traced the number. We know the place. So, we can come get you, right?

Oh, fine. I was brought to the Wolfboro Hospital Emergency Room, where the nice young doctor had never treated a lupus flare before so I asked for solumedrol (a potent liquid steroid) and saline to lower the body temperature and an anti-inflammatory, Toridol and Tylenol and double Percocet for the pain. OK. Go. I stayed most of the night and Ernie, the town's taxi driver, gave me a ride back to the cabin - he knew where it was, too - and in the afternoon I called Dr. Sands.

- You can kill me. That was stupid. I thought it was cloudier than it was. I guess the sun gets stronger when it bounces back off the sand below.

- It sure does.

- Stupid.

- You want me to be mad because you had a flare?

- You have full teasing rights.

- No, no. You just wanted to be free.

- Oh, God! I did! And I was! For an hour, I was completely free! I was a mermaid! It was the best swim I ever had! For an hour, I didn't have lupus. When I got out of the water, I sure did. Water creature, indeed.

- Sounds like it was worth it.

The problem with a problem like this was that there was no Dad to drive up and get me. I wasn't any near strong enough to take a bus, which is what I had planned. With only three busy brothers who had small children at home, there was no one willing to help. They didn't even call to see how I was. A few days later, I got a terse call from my brother with an expected pick up time on Saturday. He forgot to ask how I was, though. Dad would have come up as soon as he could. He would have come up for me himself, or coordinated the rescue trip. I was waiting by the phone with all the success that usually entails. I called Bobbie, my by-then former therapist, and she told me that this was a skill my brothers would need. I had to teach them what to do. I did eventually manage to talk to all three of them and make requests: If I have a major flare and you know about it, could you please call me and ask how I am. That’s all. I rarely need a ride back from New Hampshire, but flares are not Dad’s problem anymore. Tell me honestly, the minimum I can expect from you, and that’s what I’ll expect. We all agreed that a few phone calls after a flare was sufficient. That would do. With Dad gone, I wasn’t ever going to be anyone’s priority again.

Back at home, the bills were piling up. Summers were times of scarcely living on a disability check and some babysitting cash. Unable to take on too much work because of how fragile I am in the summer, I thought about re-financing the mortgage again just for spending money, but my prudence kept me from doing that. Until I had more work coming in, money would go as soon as I got it, and, aside from a few temp jobs, there would be no money till Fall.

2006

Grace

I had always joked, as I grew older and there was no husband in sight, that if I were still single at 45, I'd get a dog. Then I turned 45. The joke was not so funny anymore. First, I blew it off. I just could barely take care of myself. But I have never been able to walk by a dog without stopping to chat. I was busy with openings and gardening and writing and teaching, but I was terribly lonely. My friends were all married and I didn't see them as much as I used to; half of them were in the suburbs. So, days were full, but nights, I hung out in a cottage-style void with my tired, aching body. Would a soft, pretty face looking at me the way dogs look at people make it easier to be in the world? I know myself well enough to know this would be a very well-cared for dog. My illness was what it had been for the last several years and, though it wouldn't necessarily get better, it wouldn't necessarily get worse, either. Everything seemed OK. But nobody needed me, and that's not good. I got the dog.

People try to tell you. They tell you that a puppy is a lot of work. I heard that phrase a hundred times: "a lot of work," but, somehow, I didn't get it. It's like when people have a baby, and they've been warned that they'll be tired. But they had no idea what "tired" meant until they had a baby. This is true for puppies. To say that they are "a lot of work," is to say that lupus is a kind of a pain. In the days before I was to pick her up at the airport, I was desperate to find a way out of it. I'd even gone to the pet store to get toys and food and puppy regalia and still I hoped it would fall through.

When, a few days after I got her, I brought her to the Vet for her "well puppy" check, I prayed she had no liver or something so I could send her back. She was gorgeous: two pounds of silky puppy coat, with intense brown eyes and skin so thin her ears were almost translucent. There was no arguing she was beautiful dog. But no one ever suffered as I did. The apartment was covered with stickies: “You’re the Alpha dog;” “She’s on YOUR schedule;” “She’s cute. She’d be adopted in five minutes.”

I owned her for almost a month before I finally named her. I was thinking of pretty old-fashioned names like Sadie (my grandmother’s name) or Mae (but, “Mae! Stay!” sounded bad) or Grace. I finally was sure it was Grace: Gracie Allen should not be lost from memory, and every night for almost two years, when I put her in her crate at night, I’d say, “Goodnight, Gracie.” She never once got it. “Hail Mary, full of Grace,” is a favorite prayer and, then, her legs, in proportion to her body, are ridiculously long. She’s the fastest dog for miles around now, but when she was little, she tripped all the time. So, Grace.

One of my playwright friends, on hearing the name, said,

- Of course. That’s what all your work is about.

- Is it? Huh.

Well, what else is there?

The first year was one frustrating disaster after another: escapes and near-escapes, hoped-for escapes and training at the local chain store that hardly helped at all. Everything you’re asking them to do is completely contrary to everything they want to do. I asked every dog owner in the neighborhood: Does this get better?? Yes, they said, it gets much better. WHEN??? About a year. Maybe two. Knowing I’d never make it that long without killing her, I loaned her out to friends and family a lot so they could get a puppy fix and I could have a break. This turned out to be a good thing, because she’s a gypsy traveling girl and with issues and surgeries coming up all the time, I don’t see that changing.

I had my first major flare as her parent in the summer, and I had to deal with her before I could get help. I couldn’t put pressure on my legs, so I crawled to the kitchen on my elbows and got her breakfast. As soon as she ate, I called the doggie-day care store in the neighborhood, where I had never even taken her for day care, and asked if they could send someone to come get her. Bless them, they obliged. I had only then to call an ambulance and arrange to have a friend pick up Grace take her for a few days. I had been wondering how we’d manage when I had a flare. So, I could manage. And she could manage. And she does. And we do.

My knees, especially the right, were ready to fall apart, swollen and full of fluid all the time, not responsive to the knee drains, which were excruciating. There was talk of knee replacement, but with Dad gone, I’d have no place to go to recover. The pain of my entire body was destroying my mood, even though I was beginning to be obsessed with the puppy. I was still on Paxil, but we probably didn’t have the dose right. Chronic pain and Chronic Depression feed on each other. My doctor frequently explains, whenever I forget it and feel like a wounded butterfly for no reason, that the mood track and the pain track are right next to each other in the brain, and if one is inflamed and irritated all the time, the other one gets irritated as well. This theory makes the most sense to me. As usual, though, Dr. Sands wanted to know why I was in so much pain so he ordered an MRI of my knees and I got a call one morning:

\- There’s a thing on your right knee. Be very careful. It looks like necrosis.

\- That sounds awful. “Necro?”

- It’s dead bone. Not getting any oxygen. It could snap. Don’t put weight on it. Let’s get a biopsy.

I didn’t think a biopsy would be much of a problem - quick, numb it up, grab some tissue, move on with it. Wrong. They had me strapped to a table when, inserting the needle to get some tissue, they caught a nerve and I screeched and nearly went flying. It is that thing that nerves do so well. They had to keep injecting me with pain meds, which were useless, for the next half hour while they got what they needed. I am no match for an assaulted nerve. In the Recovery Room, I was in shock. Too upset and distracted to keep my mouth shut, I let go with,

- I can’t stand my life. I can’t bear it. It’s just not worth it.

That’s not the kind of thing you should say to a room full of nurses. They kept me for hours until I convinced them I wouldn’t hurt myself. I had to sell the puppy pretty hard, and the joy and responsibility of that (I didn’t mention the occasional nightmare). But this was sickening pain, and I was sick of it.

The tests came back as being of no concern. I did not have dead bones that could snap at any moment, just benign tumors, and yucky looking cartilage and bones.

Dr. Sands managed to get me to try a cane. I didn’t like it, but I didn’t hate it. I wasn’t religious about using it, but I did find it helped as I was puttering around the city: people were quick to open doors, give up seats on the train and not knock me over on their way by. But here was a new thing: I was visibly damaged. I didn’t like it. Disabled? Nah.

Early in 2006, I left Grace with my brother’s family and spent another week in the cabin in New Hampshire. I brought all the books I could get hold of on W.B. Yeats and his long-time friend/probably mistress, actress Maud Gonne. I spent the week doing research; I knew everything, but felt nothing. But the night I got home, I was in the bathtub and suddenly knew the premise of the next new play entirely. I can’t prove it, but I think I was rewarded with a new idea by all that hard work leading nowhere. *Theresa at Home*, set in 1956, is the story of a former novice nun who has to find a way to live a happy, faithful life in the real world. A year later I had a draft.

I was invited to workshop it with Village Theater Company of Groton, MA. They gave me a chance to work on *Theresa* with two weeks in the farm country of Ayer, MA, a director and some actors. Boston Playwrights’ Theater and Village Theater offered to co-produce it the next spring.

Over the last two years or so I had added four more plays to the *More Than What* cycle of seven short plays that were all stand-alone, but, when performed together resonated with each other. It’s a very satisfying piece of theater. I had had an offer: my old friend Joe Antoun, Producing Artistic Director at CentaStage, who’d had the mercy to produce my first full-length play, said he’d produce an evening if I wrote seven of them. So I did, and he did, and I started 2007 with a wonderful show and another one coming.

At a year and half, Grace was better, and I was a pretty good dog owner, but her pulling on the leash was killing me. This is certainly the hardest thing we ask of dogs. The interesting things that lie everywhere on the ground, in the air and down the road yank them every which way and, pity, that’s what she did to me. The problem, aside from the difficulty of training anyway, was that I didn’t have the strength for it. I was struggling to walk to begin with and having a little force of nature dragging me along with her was unbearable. I tried all kinds of collars, hired a trainer, read manuals, worked with folks at the dog park, practiced and practiced and practiced. All of it worked. It just took three years, rather than the one I'd prepared for. And there was no secret to it but training: when she pulls, stop. When she twists, stop. When she yanks, stop. It's awful. I can say that it paid off because now I loop one finger through the leash and place that on the walker and walk along with her, but it was a long haul.

Right after the New Year, we held auditions for *More Than What* and assembled a fine cast. The play was very well received. That means that the reviews were good and audiences loved it. And that means full houses, and they all came expecting a good time. The whole family came and the coolest thing: my oldest niece, Alison, came. She gave me a two thumbs up.

I didn't know it at the time, but I was teaching my very last class at Berklee. I'd failed to show up for the first day of class when I got the address mixed up and, walking with a cane all the time now, couldn't make it back to the correct one before my students left. I'd become so slow, puttering around on my cane and in raging pain. I never had even a moment without terrible discomfort of one kind or another. I wrote in my journal that I didn't recognize myself for pain.

- DO something, I told Dr. Sands, so he prescribed Cellcept. Just another drug approved for R.A. Not excited about it. Nothing else to do.

The play I had produced in Boston, My *Heart & My Flesh*, was contracted for a full run at the Sonora, CA theater that had done a reading of it and would run in the spring there, at the same *Theresa* was running.

Theresa at Home started out as a one woman show. I couldn't do it. I heard other people in her life on stage and they were as interesting to me as Theresa was, and, also, I love actors so much that I'd rather hire three than one. Now it's "A One Woman Show for Three or More Actresses." What I had were a series of monologues that were directed at the other characters, but there's only one character on stage at a time. I knew that the audience could fill in the little gaps, answer the questions asked, guess the question by the answer. It would be a fun, attentive, collaborative ride.

Rehearsals for *Theresa at Home* were just revelatory. Vinnie Murphy came up from Atlanta for the gig. Because he'd been so much a part of my theater training, Vinnie's techniques for training the actors for this particular piece were at once familiar and startling. My ear was razor-sharp as to where cuts needed to be made so we cut and worked and mined whatever was in the text. By then, I was happier being the playwright than an actor. Never thought I'd see that. But when Vinnie asked the actors to think about "what contributed to the Janet Kenney quality of the thing," I wondered if there was a Janet Kenney quality to a thing.

A few weeks before we opened, I was profiled in the Arts section of the *Boston Globe*. The article was called, "Two Weddings and a Breakthrough," and it discussed my background of acting and my transition into playwriting, including - I let them put it in the paper - lupus. The article mentioned that I'd been to most of the pain clinics in the city and, it must be my strong constitution, but I made light of it. I assured her that when I said, 'Oy,' I meant, 'Oy' and I had earned that. It came out the week we opened and had two photos, mainly a close up that made my breasts look like the Osipee mountains. I got a load of abuse about that. Of course, no Dad to delight in that, but Dr. Sands was teary.

- You did this, anyway, he said.

I was pleased with the production, but the critics were not. I thought their points were petty and catty, but it still hurts feelings and houses, so it was sparsely attended all through the run. Part of the problem, I'm sure, was that, though I was picking up a bit of a following, I didn't have enough of a following to drag crowds into two different theaters three weeks apart. It was just bad timing, but that blew it for the awards I was hoping for for *Theresa* and me. I'd expected *Theresa* to be a launch pad, but, because of a lackluster reception, it hadn't taken me to the next step, whatever that should have been. Instead, I went into a Depression and waited only for each day to be over. The drug-of-the moment, Cellcept, wasn't helping at all, which just made everything worse because it left me feeling hopeless. At Berklee, I kept forgetting what I'd just said so the kids looked around uncomfortably and said,

- Uh, Miss Kenney, you just said that.

- I did? Oh, right. [pause] What did I say just before that?

And I really couldn't get their names straight. I was just too distracted by pain. Knees, feet, back just ached every minute and I was exhausted. As the semester wound down, I told them,

- Get your final papers in on time. I think this is it.

I told Dr. Sands,

- Something's gonna blow. I can feel it.

- Can we catch it? What can we do?

- Nah. We're just gonna have to let it blow.

The day after the semester ended, I went to the hospital with one of the worst flares I've ever had. We hadn't seen blood tests like that in twenty years. A few days later, I left the hospital very sore and tired and with lots of drugs. I got ready to do my annual Green Room Queen thing, which we'd have to modify with extra help so I'd get through the day in more of an honorary role. But I woke up the day after that with the feeling that two strong men were clasping their hands around my throat. I called Dr. Sands to ask about it and he said,

- Get off the phone. Call 9-1-1. You're having an anaphylactic reaction.

I was right in the middle of explaining to the Boston Theater Marathon guys that I'd have to get the shopping done by someone else, and we'd need a kid who could do the running around for me during --

- Oh, shit. The doorbell. That's the ambulance.

- Did you just say, 'Oh shit the doorbell that's the ambulance?'

- Oh, brother. What a pain. I'll email the grocery list to Valerie, OK?

At the hospital, they just gave me some IV benadryl and told me to see an allergist. The problem was that the new drug I was allergic to was an anti-inflammatory, so we had to find one I wasn't allergic to that didn't aggravate the ulcer. Running out of options. And, even though I had a play running in the Marathon that year, I didn't see it and I wasn't the Green Room Queen.

In the summer, I was at dinner one night with friends Larry and Joe. Larry, who is a minister who specializes in helping people adjust their personal narratives as their lives change, advised me to take a look at my own narrative, and maybe write a book.

I had one more major flare that year, in October, and an amazing thing happened. Grace spotted it. I was irritable and muddy-headed, as I am always in the very early stages of a flare, and I realize I was that way after the flare has been identified, but, at the time, I'm in the dark.

It was time for Grace's final pee at 9:30. That's a two-minute foray, unless I feel like going for a walk. I didn't. I couldn't wait to get to bed, maybe take some steroids because the pain was bad for some reason.

She wouldn't pee. She just stood there. I told her to go pee. She wandered away, meandered up a little hill.

- Come on, let’s go.

A neighbor walked by and she went up to say hello. I had to be civilized and say hello, too, though I had no genuine desire to be sociable.

The neighbor walked away and I told her again,

- Come on. Gotta go pee, bud. Let’s go.

Nothing. She’s staring at me.

Now she’s in trouble. She’s about to get a scolding. I’m ready to fall over I’m so uncomfortable and she is just doing the vampire stare she does when she wants something.

What’s the matter with you? Come on, I gotta go upstairs let’s go I’m gonna go inside without you i swear come on go *pee*...

And this goes on for a minute or two till I’m ready to brain her and she’s just staring. And I think: I have to go lie down.

Wait. I have to go lie down?

- I have to go lie down, you know. Let’s go. What are you doing? What?

My legs are sore. My hands are sore. And my arms. I check my forehead. Am I warm? My lungs are cranky. Oh, wait. Wait. Am I sick? Am I?

- Am I sick?

Vampire stare.

- Is mum sick?

Vampire stare.

Oh, geez. I am sick. This little son of a gun knows I’m sick. Yeah, I’m definitely sick. She has this command for when she’s barking at something silly and I want to acknowledge her concern so she can stop barking at it:

- I heard it. Good girl. I heard it.

She pees. We go upstairs. I take some steroids. A pretty high dose. Then I go to bed and, when I get up in the morning, I am definitely having a flare, but I don’t have to go to the hospital. I just take some more steroids and call Doctor Sands and tell him what happened.

- Good girl, he says, and I’m not even sure he believes me, because it’s pretty strange, but it’s cool, and my odd little girl has given me warning on flares ever since.

Update

Spring 2009

Because I'm getting some work as an infant nanny, I take an infant/child CPR class at a local hospital. It's a slow night: a very pregnant woman, her very nice husband, the instructor and me. We practice the simple but brilliant routine for a few hours, learn the difference between adult and infant breathing problems (usually with an adult, it's the heart; usually with an infant, it's the breathing) and in our practices, which include made-up scenarios we pick up from a prepared instruction video, I do about 150 of the compressions that are the most important part of keeping oxygen and blood in the heart and brain until help arrives. I get my certificate and look forward to calling my agency and telling them I have this skill.

When I get home, I'm sore. Hmm, I think, must have used a strange muscle. Though I walk many miles every week and do yoga and/or Physical Therapy exercises most nights, I rarely do compressions, which involves a very vigorous pushing and pumping on dummy babies and children with little metal braces in their chests. I don't think much of it - just play with the dog, go to bed. The next morning it's much worse. It gets worse and worse till I see Dr. Cunningham on Thursday.

She pokes around and can't feel much, though it's clear I'm in agony. I'm taking two Percocet at a time without making a dent in it. The X-ray shows nothing other than the usual scarring and lesions from so many bouts of bronchitis and the history of sarcoidosis.

- OK, here's my best guess, she says. You hurt your rib, pulled a muscle or something. I'm going to give you a muscle relaxant. Take it right before bed because it'll make you sleepy (*Yeah, right, I think*) and let's keep an eye on it. If it's no better by Monday, call me and we'll do a CT scan.

- But I was going to go away for the weekend, go see my friend Suzanne.

- Then go. Distraction, my dear, distraction.

At Suzanne's house, I'm pathetic, but she's used to that, and it doesn't faze her. We watch a wonderful movie, chat, she cooks for me (she's a gourmet cook, and she loves to feed me, because she knows I don't eat enough) and she sets pillow after pillow behind my back in an attempt to make me more comfortable. It's a snowy weekend, yet another storm hitting a storm-weary populace, and I take Grace out for one last pee and go flying on some ice that was beneath the snow. Suzanne scolds me soundly for going outside when she offered to do it, but she's my dog - I try to be responsible for her. I hit the icy ground in my nice sleep-over PJ's, and the pain is, to say the least, aggravated.

The next evening, I check my messages. It's Urgent Care, please call. Suzanne and I have already determined that, based on the pain and the cracking and rattling I'm hearing in there, it's pneumonia. Except I'm not coughing, but nothing ever makes sense with me. The nurse calls back and says the radiologist took a look at the X-ray and diagnosed pneumonia, and how quickly can I get to the drug store? In a couple of feet of snow, Suzanne drives over to CVS where I get meds and Oreo's, and I go to bed expecting relief soon.

By Tuesday, it's no better. Either it's the wrong antibiotic or something else is wrong. Meanwhile, I can barely walk because the pain radiates out from my chest and surrounds me like an aura. Dr. Cunningham arranges for a CT scan, which should finally tell us for sure what the heck is going on. She calls that night.

- Very interesting CT scan. You've got a broken rib in the back there, where the pain is coming from, and it bled, so you've got a hematoma there which is why the radiologist thought she saw fluid - it's just blood. You can stop taking the antibiotic. There's no reason to brace it, and it's a nice clean break, so it should heal pretty well.

Dr. Sands considers this a "spontaneous" fracture, meaning nothing happened to break it, it just sort of broke. But I tell him he's not quite right.

Anytime anyone takes a CPR class, there's a discussion: what if you break a person's rib while doing compressions? People, even those concerned enough about their fellows to take a CPR class in the first place, worry a little bit about being sued if they break a bone. The instructor assures us that that almost never happens, and no one's ever been successfully sued for that. But I've got a new one on him: I may be the only person in history to break a rib DOING compressions. I try to decide whether or not to sue myself.

This spring, I write a new ten-minute play. It's called *Rosie's Things* and it's about a couple who really can't go on - and they might have made it to the altar - after his dog accidentally, in a bizarre moment of beastliness, kills her little dog. The nice thing is, I like it. Even though I'm working on a memoir about illness that is taking forever because of the illness, I can still write a play that pleases me.

The big news is that the family I babysit for has received a new child, and they'll adopt her in the fall, which, in our under-staffed adoption system, is about as fast as they can do it. She's six and been through more than that many homes, between her original one and the potential adoptions and group homes, etc. It will take at least a year to convince her she has a family. For me, it's love at first sight and I'm energized by her presence, thrilled and humbled to be playing with her. She'll be the first Puerto Rican-crack-baby-adopted-by-two-men-tended-by-a-crippled-nanny-President of the United States. I take enough Percocet and steroids to make it through our four hours together. You'd think I'd get fuzzy, but it's the pain that makes me fuzzy; pain relief is clarifying.

May 13. I turn 50. Amazing. To commemorate the day properly, I take a bad fall the day before. The fatigue this spring has been devastating, and I'm easily worn out. So, after a day of running errands then babysitting, it's not hard to understand how, while we're in front of the kids' house, with one of the kids holding the dog's leash about a foot off the ground, and the neighbors all talking at once and all over each other, and I turn around without paying sufficient attention, and bam. I twist to the right, landing soundly on my left knee and smash both hands against the ground. Grace licks me when I'm down.

I tell the Physical Therapist, whom I've seen several times,

- I'd blame the dog and the kids, but I know I'm just falling a lot.

- Your doctors know this, right?

- Yeah.

She gently reminds me that I have a cane and it wouldn't kill me to use it. She measures these things and notices a marked loss of strength in my legs. She gives me leg exercises, and I'll do them, but I tell her, no, it's not just muscles. It's something deep in my body that means moving forward takes conscious effort.
I'm very sad that she can actually measure the weakness.

Once again, Grace comes through. When I begin to heal, we go for a long walk. We roam the hills of Brookline, which has very strict leash laws, but I really don't care about that and we're so isolated up there on these little side streets that I drop her leash and let her wander along near me, smelling everything. At a park we find, I throw treats into the grass and she blazes around finding them and on the way home, I buy her something she's wanted for a long time: a Red Sox collar.

The next day, I beg to see Dr. Sands though I have no appointment because I need a steroid shot in my hip before I go insane. He wonders aloud,

- Are you sure you're strong enough for physical therapy? If it's killing you, it might not be the right time.

- Don't know what else to do. I just need a steroid shot in my hip. That'll quiet that down. Then we'll figure things out one by one. You know my left foot is still numb, right? Did I tell you that? Doctor Pilgrim is having it checked.

Dr. Sands checks with pins and gadgets and observes that, indeed, the front of my left foot has lost some feeling.

- You're getting more complicated. Can't you get something simple once in a while?

- Can’t you guys fix something once in a while?

He stops typing so he can have a quick laugh and hang his head in shame.

For my birthday present, I track down my old acupuncturist, Dr. Tsai. I’m so happy to see him I nearly swoon. I’m sitting in his tiny office filling out a form for symptoms and history, but it’s stupid; he hasn’t seen me for ten years, but he sees what he sees, and he thinks in Chinese. I hand it to him, and say,

- You don’t need this. You see.

- Yes, yes, I see. 50, like 88. 50, like 88.

Update

Fall 2009

The children I care for go back to school, and they'll be in after-school programs more than they were last year, so I need to look for work but I'm not going to do that till I figure out what's going on with my legs. I have a bad few weeks with way too many doctors' appointments - sometimes three a day - but I'm not budging till we figure this out. It's got to be something besides just everything.

Finally, in early September, they do an electromyogram, or EMG. It checks to see that the muscles and nerves are talking to one another. I sit up to watch while the quiet, serious doctor sticks large needles in my calves and feet and moves them around till a muscle reacts. The needles are so large I bleed a lot, and he asks if I'm on blood thinner.

- No, I've just had a lot of needles stuck into me, you know?

He doesn't, and I'm disappointed to find that the results look normal. Always a dilemma if they're normal. That's good, right? Not if it doesn't lead to a solution.

I go down to the hospital cafeteria and write for a few hours, hoping to see my Neurologist that day so I can skip coming to the hospital next week. Also, I need an answer soon, and I think he's the one who has it. I think this horrible pain I've been in is my nerves. It has to be. Dr. Pilgrim's assistant calls to say he's available and I bolt - to the best of my ability - upstairs.

- I hear you're disappointed, he says.

- I have no answer, still.

- OK, what's going on?

- Can you show me a picture of the nerves in my legs?

- Sure, he says, and dashes out of the room. He comes back a minute later with a textbook - a beautiful old thing, large and masterfully bound, gold lettering on a textured beige cover. I bet it's from graduate school. He flips through and plops the book open on the table in front of me.

There on the page, in this lovely old book, is my pain. The nerves in the legs run up from the feet, up past the hips, into the thighs and culminate just above the knee. It's a hand drawn illustration, this picture of my pain. My mind switches quickly from the simple drawing of the nerve system in white to a raging, raw red. I get a little weepy and point to the picture.

- There. Yes, that's it.

- What? That?

- Yes. What's that?

- The whole thing?

- Yes.

- Yikes. That's what hurts?

- Months. Since, like, spring. Do something.

- Geez. Well. Tell you what, I'll have you in the pain clinic tomorrow.

- Is this my central nervous system?

- No, it's your peripheral.

- What's that?

- Anything that's not central - in your spine or head.

I’m sad because I don’t think the lupus has gone after this before, and I don’t want to know what else it could be up to.

I haul myself to a family party over the weekend but all I can think about is my poor napalmed legs. I think what happened was, when we lowered the dose on my methotrexate to give the side effects a chance to calm down, my immune system saw a little opening and went after my peripheral nervous system.

Update

Winter 2010

A few weeks after the latest epidural does its work, I take a bad fall. It's night-time, I'm walking home, more tired than usual after the last time I will babysit a particular child since he threw soup in my hair and I have to draw the line somewhere, and down I go. Of course, I'm furious at myself for falling. I didn't hear anything crack, but I know I'll be sore for days, at a minimum. At worst, I have broken something hard or torn something soft. I go in to get it checked and the nice P.A. gives me a two-foot long brace that goes around my knee. It has two metal wheels inside the black foam that allow the knee joint to move, but they squeak and I am no longer able to sneak up on anyone. Now I'm walking around with about an eight-pound brace on my left knee and the usual eight-pound cast on my right foot. I think it's kind of funny, it's so ridiculous. I'm starting to look like I owe Tony Soprano money.

A few days later, a nice man in the Orthopedics department pulls and yanks at my leg and when I threaten to kill him, he's found the spot.

- That's your MCL – medial collateral ligament. We'll call it a sprain, because part of it's intact.

- It feels torn.

- It is. But not entirely. Normally, I'd tell you to take Advil, but with your history, I can't touch it. You'll have to call your Primary Care for that.

A council is required. Because of the ulcer, I shouldn't really take anti-inflammatories at all. The rheumatologist is called just to let him know there's been another fall. Doctor Sands' nurse emphatically advises me to stop falling. The gastroenterologist is called to see what can keep the ulcer under control while I'm taking anti-inflammatories. All agree that this particular injury is one of the most painful. As the tissue comes out of shock and begins to heal, and, because this is what I do, I start walking around on it, the pain becomes, oh, Lord, a new ten. A seventeen. I'm giving birth through the side of my leg.

I get a "pain plan" memo from Dr. Cunningham. Oxycodone, which is the stuff people get high on and has become hard to get, is the best thing to use for now, because I'm mixing it with Advil and Tylenol. It's two oxycodone every four - six hours, followed a few hours later by either Advil or Tylenol. My poor liver - but it can't be helped. I sleep for, at most, two hours, then wake up with a gasp, panting. I apply ice but it actually makes it feel worse. If it's only been three hours since I took oxycodone. Sometimes I wait an hour, and sometimes I don't.

Dr. Cunningham had given me a week's worth of oxy and by Friday morning, I notice I am down to six or eight. I call in a panic looking for her. I'm trembling all day from pain and the fear that I'll have nothing for the pain. I feel like an addict. I *am* an addict. We established that a few years ago, when I asked Dr. C. if I was addicted to Percocet.

- Yeah, sure. But, what else have we got for you? If you ever get off of it, we'll manage it slowly, but don't worry about it for now, OK?

I'm aware that it's the only way I manage to move around at all, so, yeah, I have to live with that.

The dog's getting on my nerves. I can't take care of her properly; we usually walk miles a day, but I can't go far. She hurt her leg about a week after I did and she's supposed to be on "leg rest," too, but it makes us both cranky. I'm changing her diet, too, so she is way off her regular schedule, so she's spending two hours at night before she does her business and every step, and standing, is ripping my knee apart. She's whiny, but so am I. I drop her off at my friends' house and give myself a fun day at the movies. The movie was good, but I was not. I finally reached Dr. Cunningham late in the afternoon, from the lobby of the movie theater.

- Are you telling me that you have gone through 80 oxycodone in 5 days? How bad can it be that you're putting yourself in danger?

- What danger? What are you yelling at me for?

- You are taking way too much of this stuff. I am trying to manage a very dangerous drug.

- I know that.

But really, I don't care about her problems. I'm afraid. I'm afraid, as I am once in a while, that a nice bridge could tempt me. I couldn't do that to my nieces and nephews, my family, but it crosses my mind, because I know this: this is just now. This is how much it hurts right *now*. But after this, when this knee settles down, there will be something else. There will be another fall, or an infection or swine flu or a brain tumor or *something*; I will go from one pain to another for the rest of my life. It leaves me discouraged – which I see as being, "without courage." I know this mood; it's despair. Oh, damn. It'll take me weeks to dig myself out of it.

In the movie lobby, I'm so furious with Dr. Cunningham I can't even be civil.

- If you have a better idea, then do it. If you don't, then just help me.

` - I'll give you some oxycodone, but only two weeks worth and I am *not* writing it again before two weeks are up.

I'm sitting in an (I hope) inconspicuous spot in the lobby weeping copiously:

- I can't help it if the pain has been this bad. What are you thinking?

- I don't know, just worried.

- You're treating me like a junkie.

- I'll write it for you but be careful. Did they do an MRI?

- No, they said they would schedule that if it's not healing and they have to operate.

- That's nonsense. I'm scheduling one. Let's find out what's going on in there.

- I don't know. It feels like it's quieting down a little. It's probably healing.

- I still want to know what the problem is.

- Fine, I say, but I mean: *Fuck you*.

Now, this is a woman I like very much, and we've been through a lot, and we are at an impasse. I'm in agony and she's not responding the way I need her to.

I want to be in bed, but in bed, because of the pain, I'm just miserable. I want to be asleep, but once in a while, I wake up anyway. I take care of the dog in a minimal way. I see and talk to a few of my doctors and they say: GET OFF THAT LEG. It won't heal if you don't rest it.

I give up the dog for a week - she goes on vacation with her favorite playmate (my brother) and two of my nieces to tend and wait on her. I spend a week either at the doctor's office or in bed. Asleep. It's exhaustion and avoidance, healing and hiding. By the end of the week, I'm nervous about Grace coming back. I don't want to hurt that knee again just when it's starting to quiet down. I don't want to have to feed her, play with her, love her, care for her. I don't have anything to give her.

She comes back anyway. The first night, we're strange to each other. She's exhausted, so sleeps while I cut up ribbons for these silly but really pretty Christmas trees I make. At 6 a.m., she's banging at the door to go out. In my pj's, even though it's light out and the neighbors are surely up and about, I throw on a coat and take her out. She doesn't even pee. I take her back upstairs, go back to bed, and ignore her. Eventually, she climbs onto the bed and sleeps near my leg till a reasonable hour for someone who could sleep for a year. By the next morning, she has remembered what time we get up.

I've had to hit my pension to pay bills, and just hope I don't live too long, because I'll have nothing to live on.

Update

Winter 2011

Sometime in the middle of February, my back collapses. I suffer my first, and, hopefully, last, spontaneous compression fracture in my spine. It's "spontaneous," meaning I didn't do anything that caused it to break; it just broke. I function - and teach - for two weeks with a broken back, wondering what could possibly be wrong. One morning, I take three Percocet and the pain goes from 10 to 9.5. Finally, Dr. Sands takes an X-ray that shocks us both. It's *my* spine, he assures me, but it's all crooked. He sends me to a lumbar guy, and this guy calls the next day to tell me what it is. It's a compression fracture of the L2, the second bone in the lumbar group, just above my lumbar/pelvic region. It's caved in on itself. Now, "osteoporosis" means something. Because, at the same time, one of our fine teaching hospitals missed an intestinal infection even though they did a CT scan three weeks in a row in the exact spot where I said it hurt, I end up in the hospital for eight days with lots of antibiotics and a low dose of morphine and a broken back. Grace is with Sarah and I miss her at night, so one of the nurses gives me a warm pack and wraps it in a soft blanket and snuggles it beside me, and I cry. Compression fractures can happen when you're sleeping or moving or sitting. Although I don't know exactly when or how it happened, Grace and I had been rolling in snowbanks a few weeks earlier, and I will always believe it was that so, at least, I had fun doing it.

When they try to get to me to walk at the end of the week, I fall over. For the first time, I'm sent to Rehab. Rehab? With Dad gone, there is no "home" to go to.

None of my brothers' families can manage 24-hour care. I have to go to Rehab, which is where people go when they don't have fathers.

The place looks like a nasty motel room from the seventies; the bedspreads are that weird shiny stuff with a bit of machine quilting. They're that ferocious orange/rust theme that was popular in upholstery at the time. It's dark enough to not show dirt and I wonder how much is under there. I am really lucky because there is no one in the room with me. I have a television. I have not owned a television since I moved into my condo. CNN. There are thousands and thousands of people in Tahrir Square, and Egypt is imploding, and the Arab world is - doing what? Arab Spring? I know we won't know what that means - if it means anything - for years.

In rehab, we build the strength in my core muscles, work on my balance and teach me to negotiate space with the new delicacy of my back. I have to re-learn to take a shower with the addition of a shower chair. I learn to work a stove while holding onto the counter for balance. I teach myself how to eat lying down because it hurts too much to sit up. I wear a tiny little fabric brace that fastens with Velcro. There's nothing to it. In about three weeks, I'm out and learning to walk around in the world again, but I still have a broken back.

And now, wow: I use a walker. It's black and maroon and has a seat in case I need it and a basket and four wheels and two handles and I use it. To walk. I go through another level of "visibility." If people can tell that I might have a medical problem because I'm walking with a cane and wearing a huge knee brace or using...a walker? Definitely visible.

Grace sleeps, as she has since late February, with her spine pressed up against mine.

In April, they do a kyphoplasty. I am told the success rate is over ninety percent rate, that the pain is ninety percent better the next day. I am excited to be waiting for that rare thing: something that will help. This is a procedure in which they inflate the bone and fill it with what is, basically, rubber glue and cement. But my bones are so delicate they can’t support the little gadget and my spine falls over on its side. The L3 bone falls and crash lands on top of the L2 nerve - a big, busy nerve that starts in the back and travels half-way down the leg, almost to the knee. The next bone falls over, and the next, till my spine looks like a train wreck in the Swiss Alps: in snow-covered mountains, all the trains are off the rail; I see them as being different colors, faded primaries, all of them tilted and touching each other on the corners, on the sides. So my spine is perched on top of my L2 nerve. The pain moves up several notches, and still there are no words that work for me. A bloody gasp, a pause in the sun’s orbit, a fire in the brain.

I’m in and out of the Emergency Room and with back and side pain, and, finally, after a few months spent fooling around and being mistreated and upset by one of our fine Boston hospitals (such letters they got), I switch to New England Baptist (NEB) and hook up with a surgeon, a Nigerian spine artist, Dr. Ohaegbalum (it’s easy, he says, the “g” is silent). New England Baptist is world-renowned and deserves to be. Their specialty is spine and orthopedic work. When you pull up to the building for the first time, you may be either amused or scared to see a huge silver sculpture of two spines crossing one another looking like a DNA strand.

This handsome Nigerian fellow in a multi-thousand-dollar suit wonders aloud why they did a kyphoplasty. *Wonder why they did that?* he says to himself. *I wouldn't have done that*, he murmurs. That's not really what you want to hear from your back surgeon. He is actually talking about fusing my spine together. I've heard of that, but that is definitely for other people. When I ask him if that's what he's actually talking about he sighs, shakes his head and says,

\- I don't see any other way out of this.

But we have to wait. After thirty years, the lupus has destroyed the ligaments and cartilage and, much worse, both it and the steroids have destroyed the bones. The titanium screws used to stabilize the spine would push through the bones as if they were cookie dough.

He tells me to wear a Boston Brace. This thing starts at the upper chest and goes down, around, back and down to the pelvic bone. It's made of a hard plastic called polypropylene, has a huge molded protrusion for the breasts. It fastens back to front on the sides with Velcro tabs. If worn properly, it's tight. It's supposed to be very lightweight, but it doesn't feel like it is when you wear it all day. You also have to wear a white cotton tank top under it to prevent skin irritations.

He insists that I use the brace whenever I'm upright.

\- Upright? That's a lot of time!

\- Yes.

I ask him how I’m going to garden with the brace on.

- Must you?

- Of course. Your garden doesn’t go away because your back breaks.

- Uh. Crouch. No bending. Be careful.

- OK.

I wear the Wonder Woman brace. After a few months, I switch to regular tank tops that match whatever shirt I’m wearing over the brace. And we wait. I work on this book. Because I can’t work at Berklee for the semester, the bills are late. I’m using my pension money to pay them. I take a Star Wars medicine, Forteo, that, with a small injection each night, should find holes in the bones and latch on to become bone - not something *like* bone, but bone. The back brace is supposed to help, too. But I have to wait to grow a backbone. I hadn't realized people could walk around with a broken back.

2011 Spring/Summer

Life went on. I continued to garden, crouching or crawling, did my babysitting and nanny work, annoyed the dog with my usual grouchiness in the face of terrible pain. I guess she's used to it because she bopped along with me wherever I went, and I did go, still walking around on errands and making sure we got our exercise. But my neighbors did everything else. Sarah took Grace for long walks so she'd come home tired. She also did my laundry a few times a week because, in the hot summer, wearing a plastic back brace, you go through three shirts a day. The kids across the hall, while earning their degrees from Boston College, vacuumed and cleaned. Jenny took the dog many mornings so I could sleep in. My brother attached a grab bar to the back wall of the shower and clamped a grab bar on to the side of the tub. My youngest niece, Colleen, (baby girl Kenney) came to clean the apartment, twice. The kids I babysit showed off their cooking skills with scrambled eggs and sauteed broccoli. Kate Snodgrass, my teacher from Boston University, cleaned and crafted a fresh mozzarella and basil salad and was the person who actually forced me to put the brace on. I'd been admiring it from afar for a week. A whole gang of Kenney's came and cleaned out the garden just in time for the tulips to burst.

I was on Dilaudid for pain, which is about twice as strong as Percocet, and it made a little dent. Physical Therapy helped me strengthen my core muscles so I could take some pressure off my back. We did this for several months till my PT told me there was nothing more she could do. I just needed surgery. I couldn't simply do anything with pleasure; everything hurt and frightened me. Dr. Cunningham said,

- When's the surgery? It's the only way you're going to get your life back.

- Still waiting. Growing bones.

And I was aware that she was right; that there is only surgery, and my surgeon didn’t want to do it. Because my spine collapsed to the left, my left side had burning knives poking into it, as did the whole path of that nerve, back to knee.

I hooked up with a pain specialist who seemed to hate me because I was a junkie. I couldn’t handle her paranoia about her patients just wanting to get drugs and I stopped seeing her after a few years. By the time I stopped, though, she had me on the best possible regimen of oxycodone for “break-through” pain (it all breaks through, all the time) and Fentanyl patches that seep medication 24 hours and get at the background pain. Such harsh drugs. Horrifying.

The most important thing was that I had to re-learn dog play. Because I didn’t want Grace to be afraid of the walker, I roared and charged at her with it and she soon took it to be a new toy for her enjoyment. We still went up to the Reservoir, where my walker rattled and bumped over the tattered path, but we didn’t climb up to the top of the hill anymore. Of course, she took it in stride because dinner was on time and I could still get down on all fours to play with her.

- This is very tricky surgery. Can you live with this?

The person asking this insane question was my back surgeon. I told him there’s no way I can live with this. He just didn’t want to operate.

- I’m worried because the bone quality is so bad. I’ll have to graft some bone from your hip, and that’s not great bone quality either. So it’s risky. I’m not certain it’ll work.

But, really, I couldn’t live like this. I could function. I function in all kinds of circumstances, but, no. I couldn’t live like this.

- How about steroid shots for the pain, and we’ll give it more time to see if the brace helps. Maybe it will settle down on its own.

That didn’t sound like a good plan at all, but I couldn’t do the operation without him.

Update

Fall 2011

Here’s where it starts to sound like a Monty Python skit.

I have broken my arms. I have two broken arms. I must get some help. I will scream. I scream. It doesn’t have any particular shape to it, I don’t say “help,” or call “fire,” or anything. Just this brain-cooking scream explodes, and I wait.

Oh, God. Help me. I will scream again.

And I do. I have no pain. I know I have two broken arms, so I will have pain soon, but I figure I must be in shock, because I just saw the bone that goes from my elbow to my shoulder (which will turn out to be my humorous) ripple up then split in two. The other arm is under my body; it is stuck between cement, a plastic body cast, and a body. I didn’t see that break, but I know for sure that it did. I know, too, that you only have shock if you’re in really big trouble; people in war movies go into shock; on *Bonanza* someone was always going into shock. I’m wearing a light green shirt with horizontal stripes. The bone did not go through it, or the skin. It just, sort of, popped. *No one has come. It’s been a minute. I’ll scream again.* And I do.

It’s early November, and we have just set the clocks back. Fall backward. It takes a week or so for the eyes to adjust to the new hue of dusk. I’m thinking I’ll catch the end of the Patriot’s game. I’ve been in a cafe all day working on this book. I’ve broken my good glasses so I’m wearing my nasty old back-ups from three prescriptions ago that look like the ones Uncle Junior wore on *The Soprano’s*. I had told my right foot to move, but it doesn’t always listen to me. I looked down. If I look over the handles of my walker, I can’t see my feet, so I look down. I tell the foot: Move. It doesn’t. I can see them not move apart when I just told them to and my knees are frozen and I can’t lift my walker because it’s heavy with nice groceries (I’m told later the basket’s not for groceries; I want to know: then why is it there?) And then, and, this is it, and I know it: my walker starts to tilt to the right and I try to push it to the left because there are about 9 cement steps below me on the right. I go to grab the brake - my last chance to stabilize the thing and - and the brake pops off. I can feel the wire under my hand, as opposed to under the handle where it should be, and I say to myself: *You’re going down.* And I do.

I’ve been told I did well. I threw myself over to the left, avoided the stairs and hit a flat surface instead. In my mind’s eye, I was way over to the left, but when I look, months later, I realize it might have been only a little bit over to the left. My left hand hit the brick wall with such force that, though my wrist was intact, the impact travelled up my arm and cut the humorous bone in half. I saw the ripple travel up, the split, when part of my inner arm went one way and another part went another way. It turns out that my right humorous shot up and out of place entirely and shattered the right shoulder, leaving nothing circular of the shoulder socket. All angles and sharp edges. It reminds me of a plate of chicken wing remains, the ones the kids around here get at 3 in the morning when they’ve been drinking all night and they toss them all over the neighborhood. Grace gets them before I even see them, so I have to stick my hand into her mouth and get what I can of it because chicken bones snap and can pierce a dog’s internal organs. Anyway, that’s what my right shoulder looks like.

In these slowed-down moments, I’m really sad about this: Grace is home. I’m lying just outside the back door to my apartment building, and our apartment is about twenty yards around the corner and I know she can hear me, and I know she knows who it is. If she’s in the apartment, she’s usually under the bed. Or, having heard her best pal scream, she’d be at the window.

- Hi. Uh, hi. My name is Mike. I called the police.

- Thanks.

- Uh. I don’t think you’re supposed to move.

- I can’t move. I got two broken arms.

- Geez.

- Can you do me a favor? Reach into my right pocket and get my cell and call Jenny. It says, “Jenny/H.” Jenny. Home. Tell them there’s been a terrible accident, I have two broken arms, come get Grace. Tell them please come before the ambulance does. I don’t want her to hear the ambulance.

He’s talking over me, talking to Jenny, telling her that I don’t want the dog to hear the ambulance.

The paramedics show up. They’re sad that I have a back brace on, and that there’s a walker sprawled beside me. The one who’s dealing with me primarily is Brian.

- What’s your name, hon? What’s with the back brace?

Lucid as you please, I rattle off my entire medical history in two minutes and tell him my name.

- Can I call you Jan?

Family members and close friends call me that. Yes, Jan.

- Brian. Both arms are broken. I saw the left one break and the other one is broken, too. You can’t see it, but it’s broken.

- I believe you, says Brian.

Brian is now my friend.

- I don’t have any pain, Brian. That’s not good, right? That’s shock, right?

- Right. Tell me when you have pain, all right?

- OK.

- This is gonna take a while, Jan. We can’t rush this, OK?

- Yup.

My poor neighbor Lindsay comes out just to do her grocery shopping and finds me sprawled in the doorway and nearly falls over the walker. She takes it upstairs. She told me later that Grace growled at her. I torture myself when I think what I’ve put that dog through.

I hear Rucca from the apartment next to mine, whose window is almost directly above where I am, come on the scene. She’s a very dear friend and when I hear her voice, I keep calling her name, and she tells me, in her pretty Mumbai accent:

- I am here, Janet. You are in good hands, Janet. These people are wonderful, darling, all right? I’m right here, *bita*.

Bita is nice. It’s what you affectionately call a child, a small loved one, in Hindustani.

Though I'm face-down and can't move, I can feel a small crowd gathering and the young man who called Jenny to come get Grace says she has her. Good. She's down the street. She can't hear this. Maybe.

- We're going to cut your jacket off, OK, Jan?

- Oh, shoot.

A well-worn denim jacket that I've decorated over the years with just the right pins: The Red Sox, Catholic Parents of Gay Children, AIDS ribbon, Obama 2008. I never see it again.

- Shirt, Jan, OK?

- Yup.

I just bought it.

Uh oh.

- Brian?

- Yes, hon?

- Tingling.

- Where?

- Right elbow. Left arm. Where it split. Suppose my right elbow's broken?

- Don't know. We're moving. Keep me posted.

- The tingling is pain coming, right?

- Right.

And it was, and it did. It hit suddenly, as if it had been holding its breath, and finally gasped. It was not limited to my arm. It filled my body, larger than the outline, larger than the organs and cells. I scream, pausing only long enough to catch my breath, for the next, roughly two hours. Now, every time they touch or move me, every little finger's touch, blows off the top of my head. My body is not *in* pain; it *is* pain. My arms fill with hot, racing fluid. It's erratic and mis-directed, bouncing all over the place.

- OK, that's it, hon. Let it rip. Don't try to hold it back. We're doing your pants.

I picture my underwear exposed to my small audience. How could I be modest at a moment like that?

- You won't be uncovered at all, OK? We'll keep you covered, OK?

I mean to answer him and scream instead. The cold air hits the smelted iron heat of my body. A few grunts in response to Brian's questions, but nothing sensible. Rucha's pretty voice floats over my wounded bear noises.

- I'm right here, Janet. Do you hear me?

The EMT's are talking, but not to me. They're whispering semi-secret plans to one another, and to Rucca. They have corralled Rucca. How do they know she can handle it, I don't know. Has she told them she has an M.D.?

- Jan? Here we go. There is no way to make this easy. This is gonna hurt.

- Rucca!

- Yes, darling. I'm here.

Brian says to his partner and Rucca and me:

- OK. We're good? On three. One. Two. Three.

Oh, my God. My body is a cartoon body: it's in pieces, raw and tangled and lifeless on the ground. I can feel movement, tearing at me, but I can't quite locate it, or myself. I think that my right arm fell off.

- Rucca! Where's my arm?

- It's right here, *bita.*

That's not correct. I have a picture of it hanging off the gurney, dangling.

- Rucca! Where's my arm?

- Right here, darling.

- Keep it up, Jan. You're doing great.

They're so broken. How could they ever be just arms again? My teeth are chattering, though I have blankets. Backboard. Night sky. Teeth. Top tapping the bottom. Why am I still conscious? I will myself to pass out, but I don't.

Then, the bounce of the gurney as they raise it to ambulance height. Whup, whup, whup, and now it can reach the door. Now we're inside the ambulance with its creepy prison-night light look. Another blanket. I can only look up because I'm in a neck brace and a back brace and if I move my arms will fall off.

- Brian? Brian. Come here.

- What, hon?

- Come over here. I need to see your face.

- Why do you want to see that thing?

- I need to.

And I did, so he did. He smiled at me. A nice smile. A good man.

I had to make a decision (ha!) between the nearest hospital, Saint Elizabeth's, which is very good, and one of Our Fine Teaching Hospitals (OFTH), which Harvard Vanguard had just affiliated itself with. This is the one I'd had all that trouble with, including the blown kyphoplasty, and the mean doctors and crabby burned-out M.A.S.H. unit nurses. Still, I was thinking my doctors would have easy access to the X-rays. I hate to think I was being polite, doing what I was supposed to. I hope not. Brian is on the phone with the folks in the ER.

- Why am I still awake? Brian? Can you give me something that would knock me? I can't pass out. Why can't I pass out?

- I have no idea why you're awake. Just keep screaming. We're almost there.

- Give me something!

- I can't do that, hon.

I realized later, either, a) he was not at a level where he could administer drugs or, b) the ER was telling him to hold off till they got me in there. Probably both.

We travelled for a long time. At one point, I became interested in the screams themselves, and I spent the latter half of the ride trying to match my screams to the pitch and volume of the wail of the siren.

Stranger than fiction: Because Grace was at the beach, I took off for the whole day to write. The section I worked on that very afternoon had been the story of the bizarre hand-cuffed seizure ambulance ride from 1995. When I came home, I broke my arms and had another really weird ambulance ride.

Dr. Rand

The first New England Baptist spine surgeon, who had recommended Dr. Ross for my arms when he got a ridiculous phone call, decided he'd rather not do it, it's too complicated. My back had more twists and turns than ever and he handed me over to Dr. Frank Rand. Dr. Rand is world-famous. He's a specialist in spinal deformity and scoliosis. Deformity? Me? Just the word made me weepy. He was nice enough, and had the cool, calm demeanor I have come to like in surgeons. He told me a thing I needed to know. As we discussed the surgery - a two-level fusion to re-build the second and third lumbar section of my back - I was a little horrified. Just a bit. I sighed and said,

- Well, what choice do I have?

- Surgery is always optional.

I thought about that for a moment.

- Life or death?

- Even then.

That way, I think, he gets patients to buy in more deeply. They have options. A broken back and permanent disfigurement, or surgery. Not a pleasant choice, but, certainly, a choice.

His assistant spent a good enough chunk of time with me to make me feel tended and as safe as I can feel with people who are going to open my back and screw around in there. During the exam, he tapped my right knee with that little tuning fork thing and I yelped.

- My knees have been acting a little funny since I fell.

- You should have that looked at.

He ordered diagnostic tests: first, a Myelogram. Immediately, I didn’t like the sound of this thing. They inject contrast dye into your spinal column. This is one of those areas that already has enough fluid in it, and you shouldn’t add more. They need you awake so you can turn to the left, the right, stand up. They strap you to a table that tips and suddenly your head is near the floor, then you’re on your side, a few feet from the floor. Then you’re vertical, and you stand and hold onto the handles and twist to the right and left.

There was a transition away from just unpleasant and upside-down, someone said I did a great job and suddenly there was an anaconda in my spine. They tossed me onto a gurney and paged the pain nurse. Late-labor breathing. No nurse.

- You paged her?

- Yeah, she’ll be here soon.

- Why is she not *here*?

- She’s with a cardiac patient.

I didn’t say it, but I thought:

I don’t care if she’s with Christ. Get her down here.

I was huffing and puffing, trying deep breathing, but I couldn’t catch my breath. I kicked at the gurney and smashed my arms against the sides, so I was physically battling the raging serpent. How long was this? Ten minutes? Five hours? Finally, Mary, the pain nurse, came.

- Mary! Come come come come come.

- Oooh -- problem?

- Hurry, hurry, hurry.

She quickly checks my meds list.

- You take too many drugs, my dear!

- Go go go go go.

She readied a huge needle.

- Big owie.

- Owie? Go ahead.

She gave me an impressive shot of Toradol, a very powerful anti-inflammatory used, in my case, for lupus flares. In minutes, I was quiet. They sent me to a recovery room next door and gave me lunch and sent me home. I told them I should be admitted, and I was right because I collapsed that night, fell over when my knees buckled and hit my head on the floor. My head hurt for days, big lump for weeks. The fluid they put in my back slipped out my bladder and splashed under me. I call the emergency after-hours number and they told me to go to an Emergency Room, but I don’t even remember hanging up the phone. I fell asleep almost immediately.

The next day, the Guantanamo radiologist called.

- Heard you had some trouble. Did you go to the hospital?

- No. I fell asleep.

- How are you now?

- Horrible.

- Do you want to go the hospital now?

- No. I’m in a cab on Brookline Ave. I’m going to a Red Sox game.

- Oh. Then you can’t be too bad.

Tim Wakefield tribute day at Fenway and I'm going to miss it? Wake - one of greatest knuckleballers of all time - would be on the field for his retirement celebration. Go to the hospital? Is he crazy?

One more quick thing before the surgery: an electromyogram (EMG) which will test the nerves for quality. A very nice Indian doctor shot electrical currents up and down my legs and back and told me the good news: nerve damage is mild.

- This is mild? Are you kidding?

- Oh, yes. You don't want "severe." Can't walk.

Still, I hated to think the pain I've endured can in any way be called "mild."

- The surgeon needs to know this. The nerve can be saved.

- Oh. That is great news.

- Your pain tolerance is amazing.

I laughed, just a little. And a good thing.

Three weeks later, I was back at the spine surgeon's office. He had some screens he was looking at, some reports.

The reason I had so much trouble with the Myelogram is now clear to him. They found "three episodes of severe stenosis." Stenosis is a narrowing of the spinal column that can cause many of the symptoms I'd experienced since my back broke: pain (natch) and numbness, tingling, etc. My entire right leg doesn't send or receive signals properly. I already knew this. Although it's never been right since the Shingles episode, it's been much worse since my back broke. I can't put it in bath water first, before the left: the water could be scalding and the right leg wouldn't know it. It's also, oddly, extremely sensitive. When Grace and I play "kill the guy with the bunny," I have to maneuver both of us to keep her off that side, as any touch sends pain into my stomach. She's grown up being allowed to fight with that foot and pull the sock off, it so it's confusing. I shifted her attack to the left foot. Too late, in one way: the right foot has a permanent bruise. She must have broken vessels. At 7, she was so pretty I could hardly take my eyes off her. I was much more at peace with her dirt. She was pretty anyway. What I used to think smelled like a dirty dog I inhaled, because it smelled like Grace.

Anywhere you go in New England Baptist - the pain clinic or the cafeteria where you accidentally hear everything everyone says, or visiting my high school friend Christa, who had a knee replaced (I told her if she liked it, I'd do it, too) people hear Dr. Rand's name and say he's the Miracle Worker, or he's the master or, as Christa's nurse did, whistle and say,

- Ooh. You're complicated.

- Very.

- He's the best.

- I've heard that.

- Here's what I'll tell you: We usually put Dr. Rand's patients in ICU for a couple of days. The first few days, you have to keep telling yourself: It's worth it. It'll be worth it. It'll change my life. Just keep telling yourself that, OK?

- OK, I said.

But that's probably more difficult than it sounds.

Update

Summer 2012

In the meantime, Dr. Sands is waiting for results from an MRI of the right knee, so we look at the X-ray of the left knee.

- See? This black space? That's where the cartilage is supposed to be.

The next week, he calls about the right knee.

- That is not a happy knee. It has to go. It's gotta be replaced. The left knee is just as bad.

Right first. Then the back. The left has to take a number.

They're both bone-on-bone, but the right one is buckling and freezing and locking and otherwise making a nuisance of itself. They can't do the back surgery until the knee is stable. Everyone wants to get to the back, so we do an Arthroscopy, a simple procedure meant to clean up all the loose and dangling cartilage junk to see if the right knee will behave for a year or so while we do my back. The arthroscopy is easy. I stay at my brother's house for a few days and my nieces, who were just born last week and are now 15 and 18, remove the bandages. Krissy takes a look and pronounces,

- That looks good. Just a little swelling. Not red. Good.

She gets a few damp paper towels and cleans the bit of blood on the skin around the little incisions. Growing up with Auntie Janet prepares you for this.

The Arthroscopy stabilized it slightly, but the doctor said it was too far gone, and he wouldn't bother with another one because I'm a high-risk general anesthesia patient. He does a steroid shot to try to keep it stable and minimize the pain for six or eight months.

I understand this: this is what it costs to live with lupus for over thirty years. You lose your kidneys and go on dialysis or die. You lose your liver and no one wants to replace it because your immune system will just go after it again. Your heart goes. You lose control of your nervous system. You lose something and can't get it back. In my case, the entire lower half of my body needs to be replaced or re-built. Plus, my back, which needs to be partly re-built and partly replaced.

Though I never expected to make it to 50, I find myself at 53 starting a whole new phase of my life. The motor's still running, but the chassis is gone. Although pain has been a constant for my entire adult life, this new level is impossible to live with. I take enough pain killers to dope a Marine, but they just barely register. I miss the days of just taking a few Percocet to keep things under control. Years ago, I was at a play with Suzanne and told her:

- OK. Here we go. I'm taking a Percocet because I'm in terrible pain. You watch and see if I get goofy, OK?

Always game, she says, Sure. Later she said she had not noticed anything, and I remember a moment when I felt like the Percocet "kicked in" and I felt some relief. No weird behavior (Suzanne would have noticed, even with me) and some pain relief. That seems like an innocent time, when I thought I'd seen the worst of it.

In November of 2012, we do the successful eight-hour re-build of my spine. After eight hours on the table, I wake up temporarily blind because I was face-down all that time and I then develop a horrid rash on my back, which we find out is Dermatographia, a condition with a raw, burning rash brought on by trauma and stress and, after six days in ICU, I walk out with a new back. Grace and I stay with my friend Christa and her husband Brad and their horses and dogs for a few months till I am ready to go back to work. Immediately, people start calling me “bionic,” which I hate, not because it hurts my feelings but because it’s so corny.

2013 - 2014

Knees and Feet

In the winter, I find out I have another painful syndrome: Allodynia. That's Latin for "Pain from nothing." It's caused by pain medicines. I've been trying to figure out what's up with my hands. I don't have bad arthritis in them. They're not like my legs and feet - just fried. But over the last several months, they have this mysterious amorphous pain. It seems that when you're chronically on pain meds, you can get this over-reaction to nothing at all. Allodynia. Swell. I'd thought maybe I'd done them in with so much gardening, but, no, they just hurt. And, anyway, they're not as bad as my knees. I'm ready to rip them apart with my bare hands, replace them with paper clips and some string. I can feel things move around when I walk.

Sometimes, I have to walk up four flights of stairs with them. The elevator frequently goes out, to the point where I'm just about to call Inspectional Services Department on my own building, because my pleas are being ignored and I'm lugging my legs up four flights of stairs couple of times a day for days at a time. That means, I get home in the evening and I have to leave the walker on the first floor, go step by careful step up four floors and get myself all sore and crazy while Grace runs up and down stairs over and over, trying to see what exactly takes me so long.

Hynes/Auditorium, the subway stop nearest Berklee has no elevator. It doesn't have to have an elevator because it's an historic landmark. I'm all in favor of historic landmarks, but it seems rather an easy way to save money in this case. That means, if I either didn't book The Ride, or have given up waiting for them, and don't, as usual, have money for a cab and don't, as is often true, have the energy to walk to Copley Square, which is accessible, I'm stuck. I have to get myself down three flights of stairs that are historically beautiful and crooked and small. That means I have to stand at the top of the stairs near the entrance and look like I need a hand. The walker is a dead give-away. Some people walk quickly by. Others pause, and the minute I catch their eye, I got ‘em. I’ve never had anyone turn me down, when I ask,

- Think you could handle carrying this down?

- Oh, sure! No problem.

And I take one terrifying step at a time and he or she might chat a bit, though I’d just as soon focus on getting downstairs in one piece. To be polite, I chat. Invariably, the person stays with me through both flights of stairs and gets only a sincere and hearty thanks for their trouble. Walkers bring out the best in most people and I’m so grateful all the time. But trying to do this with knees that are done for this world is just too awful.

I wrote a new ten-minute play, *Things to do on Saturday*, and it will run in the Boston Theater Marathon next year.

And then the Boston Marathon bombing happened and Boston was tested, and shone. You know who a city is in crisis. Berklee was closed for a week because some of our buildings are on Boylston, right near the crime scene. It stopped on the corner of Mass Ave and Boylston, which is where I work. We had fragile, upset kids over the next weeks, supported by upset, slightly less fragile teachers. I was reminded of teaching the day after 9/11, that weird sense of having to be the grown up because I was teaching. So that’s what we did, and it was a comfort to be of comfort.

At the end of the summer, I got clearance from Dr. Rand to travel and went out San Francisco to visit the family I used the work for - the two men with two adopted children who had moved out there two years earlier. It was my first air travel attempt since my back broke, and I was still wearing the big back brace. Getting all that metal thorough Security was a breeze because, with the walker, you have an assigned person who plops you into a wheelchair and scoots you right through. I had a problem on the plane, though: they wouldn't move me to a seat with more leg room because we had not reserved that, not knowing such a thing existed and would be a help. The crew member said, nice and loud for everyone to hear: Do you really want to be the person responsible for all of these people missing their connections? I did not, but I couldn’t fit my poor, angry knees into the standard 4 inches allotted for that. Eventually, a woman traded with me and saved the day, but I was very embarrassed. And Berkley Hills, where my friends lived, is nothing but, yes, hills. So we visited - except for side trips to see the bridge and San Francisco - in the house.

In the Fall, my back broke again. I thought I was going insane: I must be imagining it. It’s wired and screwed together, how can it break? But, no, it broke again. A less complicated “end plate fracture,” which is the bit of bone at the very end of each spinal bone. The tiniest little fracture there is a big problem, and there it was again, on my nice (nearly) straight back, a broken bone on an X-ray. There’s nothing to do for it but wait for it to heal.

One night I left Grace with Sarah and told her, “Can she stay overnight? I’m going out to get arrested.” I tried to get arrested on one of my problem properties. My plan was to call the local paper with a potential headline: “disabled lady arrested cleaning up after slum lord.” His neglect and filthy habits diminish the whole street because he owns three properties. I stayed on the property till way late, trimming and tidying, till the cousin of the owner came out to try to chase me off. He eventually did call the police, but the nice policeman wouldn’t arrest me even though I begged him. After telling him what I was doing while carefully taking my pruning shears and scissors out of my back brace, where I found they stored nicely, I explained my “Clean Cleveland Circle” mission and why I was particularly going after this guy. He had a nice chuckle for himself.

- I think you’re wonderful! I really do. I’m from this area. These landlords are disgusting. But I am not arresting you.

- No, please, please. You have to.

- They’ll kill me.

- I don’t know how to get to this guy.

- You Tube.

- Sorry?

- Make a You Tube video. You can use the same name: “Disabled Lady Cleaning Up After Slumlord.” It would be a hit. I just can’t arrest you.

Ignoring my protests, he talked me into showing him my garden, and that adventure led nowhere. It’s not possible to shame some people. On another block, one of my worst problem properties got a garden. I got the property manager to cough up a thousand dollars, hired help and bought plants. I had to bring gallons of water over every day, but I hoped it would be worth it someday. Unfortunately, there’s no requirement of any kind to put “landscaper” on the back of a truck and the guys I hired had no idea what they were doing. They didn’t plant the shrubs properly and they were all dead by next summer even though I did, indeed, bring gallons of water over every day. The walker doubles as a wheelbarrow.

I was suffering from my end of summer/beginning of fall money draught. Berklee checks arrived at random, so you could work all the way into October without seeing a check. I had $1.72 in the bank. Being that poor gives you, not only the daily emergencies of food and basic supplies, but a vague sense of panic. You keep thinking something is wrong, even when you're not thinking of it. And then you remember it. If you have $20 in the bank, you buy toilet paper and Sudafed before the bills arrive, so you can pay them without feeling deprived and guilty for indulging in such extravagance.

The Red Sox won the World Series that year. Some say the bombing solidified them, that they wanted it so badly for the city, but the Red Sox became an insurmountable force. Halloween night - game 6, best of 7, I had a feeling. I knew it would be the last game. And a great game. So I crawled up Sarah's three flights of stairs and we watched that beautiful game together.

In January of 2014, I finally had that right knee removed.

A few months after my "I'm not having surgery for at least three years because I'm all set for now!" right knee triumph, my right foot started to fall apart. This foot has been a problem for years. Even when I was young and healthy, I kept spraining it. And now, after many, many doctors and specialists and several different iterations of boots and casts and braces, including the walking boot that fell apart every three months and a Darth Vader brace, it was really going. I'd had to let go of the DV brace because all the straps and metal were too hard on my neuropathy-ragged right leg, so I was just wearing ankle boots to hold the bones together, but that was no longer working either. Walking was sickening. It made me shake and I had such sharp pain sometimes that I had to stop and pull myself together before I could go on. I'd waited several months till Medicare would cover new orthotics, and had hoped it would help, but it didn't. I wrapped the foot up every night so it wouldn't wake me when I turned over and it hit the sheets and things inside slid around. I had my always-accurate sense that something was very wrong.

And this is how Grace Mae Elizabeth Ann Mary Kenney (the kids all gave her middle names) became an Assistive Animal. I was craving grapes. Not just average grapes: beautiful, firm, juicy, lovely grapes - the ones that have a little pop when you bite into them. The only way I could be sure to get the best grapes is to go all the way down to the Whole Foods. Technically, there's one closer to my house than the one at St. Mary's stop in Brookline, but the C train goes right there and I couldn't be sure how much I could walk. I wanted Grace to get lots of exercise so she'd be good and tired when we got home. I knew that I'd be good and tired from breaking in the new knee and wondering what's going on with the crabby foot. She was, as usual on Beacon Street's wide sidewalks, off-leash. I had the joy of walking 10-15 feet behind her, watching her skinny, impudent white butt (she has no bum) paddling happily along: she was enjoying herself so much that I couldn't get the dumb smile off my face. And we walked and walked. And walked. I started to calculate: was it worth getting on the train for just two stops? Was it worth getting on the train for just one? I wasn't doing well, but we were almost there. A little cold drizzle had started to fall. Normally, I like that, but that night it was just hitting me too hard, and it was too cold. But, finally, we made it there. My knee was swelling, my foot was furious, I had a headache and I was a nervous wreck for some reason, maybe because I had just had major surgery three months earlier. I couldn't move. Not without Grace. I just needed her. I just did. With the Wonder Woman brace and the walker there's no way I don't look disabled.

- She's Assistive, I said, breezing inside.

And the young woman who approached us near the door nodded and smiled and said, OK. She smiled at Grace. She walked away.

That was too easy.

Just to be sure, I wrote to my wonderful District Legislator, Senator Will Brownsberger. I'd met him at craft fairs, "C" line meetings, whatever neighborhood affairs I can get myself to go to, and I like him. I explained the back brace and walker and foot and drizzle and asked him if that was sleazy, or not? I was, am, confused by the rules. He had his assistant get back to me that very afternoon. She sent a copy of page nine of the ADA guidelines on the subject of Assistive Animals:

- Here are the most relevant points to your situation. The ADA is very strict about this." And she listed the rules, which are very much in favor of people who have a disability that you can see, and she concluded:

- You do have the right to have the dog accompany you.

I don't take advantage of it. She's not Rin Tin Tin. I'd never take her to a movie or a play. She'd never be able to be still for that long. She doesn't come to work with me because I couldn't expect her to lie still for 6 hours. I can barely sit that long. But I've always taken her into stores of every kind if I thought I could get away with it, so she has excellent indoor manners ("In-doors," I tell her before we go in: I want no fussing or barking. Bee-have.) and seems to know how to act in most situations because she's been exposed to so much. I take her with me just about everywhere, and we're both happier for it.

UPDATE

Spring 2014

After two years and eleven months, I get rid of the Boston Brace. The new cotton brace is so light I would like to say I can't feel it, but if it isn't breath-depriving, it doesn't protect my back which, for a change, is not broken. It's so tight that it cinches my waist a bit, so, for the first time in years, I have a waist. I look great. I am almost 55 and this is the best I've looked in years. I've lost twenty-something pounds over the last few years; I did nothing drastic. I just changed the way I eat. *In Defense of Food* by Michael Pollan was a turning point: "Eat food; not too much; mostly plants." I'm solidly vegetarian now. I've never been a meat-lover, so it was easy to do. Then I read autistic animal researcher and professor Temple Granden's books and learned too much about the meat industry, especially the buckets of antibiotics they use to fatten up the cattle. I'm at risk for a resistant bacteria, so the fewer antibiotics I have in my system, the just slightly better chance I have of surviving one. I'd be vegan if I had the time, energy and money to let go of dairy entirely. The food at the Rehab was so gross it was like being at an old fashioned "fat farm." So, in my mid-fifties, I look darn good. And now I'm wearing a corset. Ladies: we may have over shot on that one, too. It pushes my boobs up, makes my back straight and flattens my stomach. I'm delighted whenever I look in a mirror. I still don't have a mirror in my house, but the one in the lobby is no longer a daily prod to be someone else. Indeed, I pause at the door. I can see the heart-breaking jiggle in my neck. The little softness my arms have - though my arms are pretty good because of the walker. My arms, at times, are almost carrying the weight of my body, if I'm trying to somehow walk without using my legs or feet. And, here it is: with the brace gone, a nice haircut and a bit of make up on, I look pretty good. For 55. I have to throw some kind of caveat in there: For 55. For a middle-aged lady. For all I've been through. Or, I could just say, I look good. And leave it at that.

The funny thing is, the people in my neighborhood and at work, the people I see all the time, don't notice that my brace is gone. I hold my arms up so they can see me in all my glory and they look at me quizzically until I finally, say,

- My brace! It's gone!

- Oh! That's great! You look great - etc.

At first, I think they're not paying attention, that we stop looking at what we see every day, but then I think it may be this: they weren't looking at my brace; they were looking at their friend. I have to get used to wearing a bra again (still a raw deal). I can't imagine, after what I've been through with this back, that I would take this small brace off, even if someone (Dr. Rand, for instance) told me to take it off. Why risk that? The pay-off is that I look good, and it might just keep my back from breaking again. A bra and oxygen deprivation are a small price to pay for a back that's in one piece.

A week or two after it's gone, I have a strange moment in supermarket. I'm dressed like a regular person. There's no evidence of a brace under my shirt. I don't have my walker. Because I need a lot of stuff for the Boston Theatre Marathon Green Room, I leave my walker at the Courtesy Desk and have a shopping cart. I'm roaming around, hungry. I head for the “a la carte” counter. I look around. No one’s looking at me, or busy looking away from me. I look like a well-kept soccer mom. I don’t know how I feel about this. What if I need something? Will someone jump? Reach? Make pleasant conversation while he or she gets something for me? This is weird. I order some stuff to eat while I shop and I find I must tell the girl at the counter that I normally wear a back brace and I don’t have my walker and it’s strange. She tells me I look good. Tells me I do not at all look 55. She’s thinking more like, thirty something. She’s a very nice girl. Men stop me on the street to ask me what time it is. It occurs to me that the chest to hip 8 pound-back brace might not have been alluring.

Update

Spring 2014

I'm doing really well with my knee recovery at New England Physical Therapy. I cannot believe this thing is getting stronger all the time. It's rock-solid and it responds to the requests my PT, Jamie, makes. We work all parts of my body so I can manage better overall, but, increasingly, I cannot do the ankle lifts and holds. After almost two months of PT, I say to Jamie one day:

- Watch me walk. My gait has changed since I've been working with you.

She watches me.

- Go make an appointment with the foot surgeon upstairs. Today.

Several weeks later, I meet with Dr. Jockel, a very young man with a reputation as a hot surgeon. He's got long, delicate surgeon's hands.

He fools around with my foot, points to the X-ray.

- See that space there? That's where the ligament was.

The ligament that was nibbled away at by swelling and shrinking and years of prednisone. That's let the bone go and, over the spring, the bone wandered over to the side of my foot.

- That's the navicular bone. It's supposed to be here. It's here.

It's supposed to be on top of the foot. It's on the inner part of the side of the foot, where I'm not supposed to have an ankle.

He pulls a bone out of my foot. I mean: out. I let out a yelp.

- Oh, sorry.

He takes another bone and coaxes it back to its original place and it lands with a pop.

- Ach! Don’t move my bones unless you tell me first!

- Sorry.

I ask him if we can’t do some arthroscopy; put something in? Take something out? Not just leave it all hanging on by a thread, skip surgery.

- Oh, no. They’re all broken. No, no arthroscopy.

He pokes and pulls then settles against a counter with his arms across his stomach, the way Dr. Sands does.

- I’m a surgeon. I love surgery. But I don’t want to open up that foot. I don’t know if I can get it back together.

I picture a foot avalanche. All the bones tumble to the bottom of my foot and land in a pile in my sock.

- But what should I do? I can’t *walk* on this thing.

- Arizona brace. Let’s try that.

Although I was expecting a high-tech solution, the Arizona Brace looks like an ice skate without the blade; it’s the same quaint lace-up as a skate. It looks like one of those ice skates on which I whirled and wheeled around on long winter days. In pre-litigious times, everyone went to Greenfield’s Pond to skate. It was called Greenfield’s Pond because the pond was on the Greenfield’s property. There were fifty kids on that pond on a nice winter day. If you fell in the water, you didn’t sue; you got out. It wasn’t deep. There was always a little cocoa to be found. The boys played hockey and the girls imitated Peggy Fleming, who had won the Olympic Gold in 1968. I was quite a good skater. When I started to lose my ability to walk without a limp or pain, I dreamed often of ice skating: leg out, arms properly extended, turning, stopping on a dime with my toe-blade in the ice, loving the sound that made. But mostly this: I was strong and supple. Graceful. I was Pegging Fleming. I don't remember skating *with* anyone. I was in training for the Olympics.

I get the brace, which is not much help at all and Dr. Jockel moves to Colorado to practice with his twin brother.

Next I see a Dr. Kelly from another hospital. He tells me,

- You understand it's very complicated. If anything goes wrong - I mean, anything - you might lose the foot.

This is the first time I've heard a doctor say that. It spooks me for sure, and I go looking for another surgeon.

Update

Winter 2014-2015

I wait over two hours for this surgeon. This is appalling to me, but he's a big shot and I'm in a roomful of people who don't mind. They say this is normal, and they would not be walking without him, and they advise patience.

I love him on sight. He's loud and boisterous, and I feel he can almost shout the foot down. He's excited about the surgery, which he can schedule in a few months. First, I need to go to PT and learn how to walk on one leg and use a knee bike and get up and down from chairs and beds without putting any weight on my foot. When I finish my training, he'll have a cast put on my foot. If I step on the cast, he won't do the surgery.

- I can't rush this! This has ENORMOUS IMPLICATIONS!! FOR BOTH OF US!! It'll be months! THIS IS MONUMENTAL SURGERY!! For you, and for me!

But I'm thinking: Oh my God. More *months* of this pain? I'll never make it.

- What's your support system like? Who can take care of you for three months?

For the spinal fusion, I had two weeks in rehab then left with all kinds of gadgets and braces that stimulate bone growth and went to Christa's house for about two months. This time, Christa's moved to Vermont where there's not, she assures me, an inch of flat ground. My cousin has sold her condo and is living with her father. There's no easy place for me to go. I'll have two nights in the hospital and then three months of waiting with no weight-bearing on that foot.

It’s not great, I say, but my brother can probably take me in.

But nobody’s home at my brother’s house. And when they are home, they’re resting from their overwhelming days, and the kids are wildly busy with last year of high school or second year of college. I’d be thoroughly in the way, all alone and miserable and, with no one to help me, unsafe. When I carefully mention the discussion with the surgeon, my brother says,

- I don’t know. We’ll work it out. We’ll figure something out.

I heard: *Sure. No problem. We’ll take you in for three months.*

- Your brother’s taking you in. That’s good. I need to see him. I gotta get the whole family involved.

I don’t say anything, knowing my whole family doesn’t want to be involved.

In order to cover living expenses while not working for the three months, I have to rent out my apartment. This is Dad being forward-thinking. I own it. I can rent it. An associate of my neighbor’s will be in town from Germany for a few months and, via email and recommendation, she’ll do fine.

When my brother finds out the doctor wants to see him, he freaks. He never promised that, I hear half of what he says and make up the rest, etc., I start conjuring other alternatives: a person who’s a frequent church-goer who will take me in as a charity case? A friend of a friend of a friend who’s a retired nurse and has an extra room on the first floor and no stairs into the house and wouldn’t mind a little company for a few months? Facebook. I could post a notice asking anyone to ask anyone they could think of, or maybe someone has an idea. Catholic Charities? I still like a nice Mass once in a while. Maybe a Catholic would take me in.

I just go ahead and schedule everything anyway. Because I had asked:

- The pain level now is so far beyond a ten on that dumb pain scale I can't even use a number. It's just extraordinary. What will the pain level be like when we finish?

- NOTHING!! ZERO!

Is he talking about this foot? This one, at the bottom of my leg? Let's do it.

2015 is the worst winter anyone can remember. It's historic; a real Climate Change winter. At over 100 inches of snow, it breaks every record for as long as they've been keeping records. The snowbanks on both sides of every road are ten feet high. The sidewalks, where they've been shoveled at all, are about twelve inches wide. And even that's covered with snow. It's just enough for one person to walk, one foot in front of the other. There is absolutely no space for two shattered, cold wet feet, four wheels and a dog.

One night, I'm just trying to walk Grace, but I can't do it. It's been weeks of traveling like this: tromping on slippery ice and snow, knowing what's at stake if I slip. I pick up the walker, lift it as high as I can, put it down as far away from me as I can, wrestle with it over packed snow and ice so it's somewhat stable, take a step, take a breath, pick it up and reach it as far as I can. Stop. Lift. Place. Stabilize. Step. Stop. Lift. Place. Stabilize. Step. Miss my spot, sway, grab the walker just in time. Lift. Place. Stop. Stabilize.

I try walking in the middle of the street, which has become an impromptu sidewalk with honking cars, but after all this snow, it’s covered with rock salt, the stuff they use to melt snow. Rock salt is torture on dogs’ feet. When Grace steps on it, she lifts her leg and makes a pathetic screechy sound reserved only for rock salt. I grab a handful of clean snow and rub it on her burned paw till she sets it back down. She can’t go four steps without this happening, and it’s often more than one paw so she really can’t move, and we have to go back to the sidewalk. I can’t turn around because getting this far down the block was so dangerous. I stand at the corner. Behind me the block that almost just took me down; ahead of me, more snowbanks. I can’t turn left or right because of the snowbanks. Grace looks up at me, expectant, but I have no idea what to do.

- Janet?

I hear a soft female voice, but the only person I can see is a young black man. This makes no sense. I must be getting ready to faint. After a moment, he manages to get himself out of my line of vision and I see my neighbor from down the hall.

- Do you need help?

- I can’t move. I can’t go any further. And I can’t go back.

- Do you want me to take Grace for a walk?

Nodding, I reach over a snowbank and hand her the leash. She coaxes Grace up over the snowbank.

- I’ll take her down the street, OK?

I nod and stretch my hand out with a “doggie” bag in it.

- Can you get back home on your own? Stay on the street. Skip the sidewalk.

I wrangle my way back to the middle of the street where I don’t have to deal with Grace’s poor paws and head home. I’m supposed to use a knee bike in this stuff? I’m supposed to wear a cast and keep it from touching the ground?

The training doesn’t go well. My arms are so damaged from the breaks, especially the right, and I can barely open a door with my left hand. I’m supposed to learn how to lift myself up a practice set of stairs, but my hands aren’t strong and they hurt too much. The PT is not especially patient or sensitive and she doesn’t hear what I’m telling her: I can’t do this. Yes, I can work a knee bike - a little scooter with a knee pad so you can keep your foot up while you scoot around, but after a few minutes, my hip is raw and I have to get off it. I pretend things are not what they are: I am strong enough to manage. I have a place to stay for three months even though I have no one to help me, nowhere to go and a dog to care for. Desperation is making me stupid.

Secretary of the Treasury Steven Lew is in town to visit to some of the poverty-service agencies. My buddy Angie, who’d helped me out of a dreadful tax mess and coached and tried to calm me through bankruptcy, invited me to speak to him about my experience with her agency and about life below the poverty line. After talking about how wonderful Angie was, I tell him that I’m having another surgery and that, after the surgery I’d be out of work again for three months, then for a longer time because I’d miss the next semester entirely and hit the gap between semesters and have to go through my post-surgical hunger horror, where there’s never enough to eat and the bills devour my Social Security check and then school starts and I catch my breath and then I have more surgery and it starts again and I’m looking at major surgery in the next few weeks and...here we go again and it so disheartening. I can’t work many hours at anything - certainly not enough to keep myself out of poverty - and I wasn’t raised to be poor, but I think that’s true of a lot of people who find themselves in the downward spiral of want. He is gently silent. He nods. When he leaves (we all have to stay in the room and let the Secret Service get him out of there before we move - very cool) he shakes my hand warmly and says,

- Good luck with your surgery.

And, easy as you please, as if I’ve done it a hundred times:

- Thank you, Mr. Secretary.

After almost fruitless hours and hours of research and digging around for options, I find out I can stay at Epoch for a few weeks - the worst of recovery will be over, so I’ll have some strength to be alone at my brother’s house, even though we all think it’s a terrible idea.

At my pre-screening visit, just about a week before the surgery, the Case Worker says, with a weird smile:

- I hate to be Debbie Downer, but you can’t stay at Epoch Rehab. It’s not covered unless you’re in the hospital for three nights, and you’ll be in for two.

- Can’t he let me stay another night?

- No. Insurance.

- I’ve got a very long history. He could use that, ask.

- No.

The surgeon calls again.

- I’m seeing a bunch of red flags here! You promised your brother was going to take care of you!

- He was, but he changed his mind, I sort of lied. I don’t usually lie, but I’m afraid of this guy and I’m afraid he won’t do the surgery.

- You said you’d take care of this! You get two nights in the hospital and that is it! I don’t want you making a big stink over the weekend because you want to go to Rehab and you can’t. If you don’t get me a note from your brother saying he will take care of you for three months - and I want it signed - if you can’t do that, I am *not* doing this operation!

When he’s got me good and weepy, he gets off the phone. Mauret, the young man who cleans the apartment stands beside me, patting my knee.

- Oh, poor miss. God is good. So sorry. Poor miss.

It turns out the secretary at Epoch who told me I could stay was mistaken about the two-night stay, versus a three-night stay; she apologizes. My brother and I spend the week making calls, trying for some kind of insurance miracle. But, nothing.

Five days before the scheduled surgery, I’m up all night. I spent less than ten minutes on a knee bike and I don’t think it would work for a few months. If the knee bike supports my right foot, what the heck is going to support my left side? How is my nasty, tattered left leg supposed to support my whole body? What did he say about a cast? I have a plastic thing that goes over the cast when you shower. I don’t think he meant that. There's a metallic taste in my mouth. I call his office in the morning and tell the receptionist I don't have a cast and I haven't really used a knee bike. Shouldn't I have a cast? He calls back. He's furious.

- Do you have that letter from your brother? You should have been on a knee bike for weeks! You never even got a cast? Look, I'm not spending five hours of my time performing a very complicated operation only to have you destroy it!

I call close friends and doctors. They say it's OK to back out; you have to feel good about this. Dr. Sands tells me to be cautious. If he pulls this off, he gets to write an article in a medical journal. He gets his office re-done.

I call my brother. Can I stay if I can walk? He says, of course. So, four days in advance, I cancel the surgery. I don't talk to the surgeon. I call the office and the receptionist says to call back when I'm ready, but I know I'll never be ready for this surgery unless I have - by some miracle - a place to stay. And I'll never be ready for this surgeon.

I spend this shocking winter hiding in my brother's basement bedroom. I sleep 18 hours a day. Sometimes I go upstairs and snuggle with Finn, their delightful and delicious cockapoo. I'm happy when folks come home and we eat dinner together. We watch *Seinfeld* and *Modern Family* and chat. I get some writing done, but not much. They let me watch too many *Downton Abby* episodes and I tell Colleen, who's graduating from high school in the spring, that I'll be Anna the housekeeper and she can be Lady Mary. I'm happy helping her get through her wild end-of-senior-year thing with a school play and dance competitions where she has three solos and several group numbers by doing her laundry and cleaning her room and having snacks ready when she runs home between various rehearsals. Krissy comes home for her semester break and I'm so happy with the two of them around. I walk softly and never forget I'm in someone else's home, but it's nice to have family around. We've lost this in our culture. Was it so bad to have aunties down the street or upstairs? Or in the basement?

But the larger issues linger: what to do with this body, which is falling apart faster than it can be fixed? What to do with Grace? She's better off with our friends for the two months I'm hiding, but she's mine and I need to be able to take care of her. I never have enough money. The foot seems to get more deformed every week. Stalling for two months in the basement isn't going to change anything. I can't live like this. I think a lot about not living. It's a really passive thought, but it's persistent. Is there hope? Not really. Will the pain ever stop? No. Not ever.

I keep thinking of the scene in *The Hours* when Virginia Wolff/Nicole Kidman walks into a picture-perfect British country side stream. A Downton Abby stream. She's wearing a celery-green hat, natch, and a celery-green coat. As she steps into the stream, she's reaching into the water putting rocks in her pockets. She gets deeper into the water and reaches down when she sees one on the bottom of the stream. She puts that one in her pocket, too...

Sometimes, I can see myself. Probably just wearing my denim jacket, with the Boston Red Sox and Boston Strong pins, a bit of rhinestone. I would go in the evening. Sit by the stream a while. I'd have left Grace with a friend, I think. My cousin will take her, "In the event that..." She'll be fine. I love rocks. I'll take some from my garden. Some from the river's edge. Go down to the quiet end of the river, where Fenway Drive curves near Longwood Ave. I don't think I'd ever do it, but this lingers in my darkest corners.

Besides being broken, my right foot is cold all the time because of neuropathy and neuralgia. It's as if my lower leg is chunk of solid ice surrounded by a slowly burning fire that has no impact on the ice. It's covered by gray, leathery skin that's not really skin anymore because it's been frozen then burned. At home, I use a hot water bottle and hand towels heated in the microwave to try to warm it. I can't use a heating pad because my outlets are not to be trusted with heating elements, and there's nowhere to put it where I wouldn't trip on it. But at my brother's, the electrical system is not a hundred years old and the outlet is at the end of the bed. I set the heating pad on top of the puffy quilt and it keeps the end of the bed warm and my feet feel good. Too hot is awful; too cold is awful. Just warm is good. Every night, in my hideout, with some family around, my feet are warm.

2016

Grays

I didn’t know if I could actually do the surgery for my left knee. Certainly, it needed to be done. There wasn’t much left of it, and it was acting that way. But I just couldn’t bear to do my usual “surgery to poverty” cycle and I had just had surgery on the left foot in the summer and there it is fall and I’m scheduling again. I do not know if I can make it through another five-hour surgery; I could die from the sedation alone. This is always the last thing they say to you before they wheel you to the OR. From the anesthesia,

- ... you could wake up blind or you could die. OK. Here we go.

I know the sedation itself is very dangerous, but I don’t want to stay awake for surgery either. They all tell me it takes about a year to recover from the surgery and recovering from the anesthesia is part of that year. When I’m in the OR, I fight the sedation for as long as I can. I’m not afraid. I just don’t want to miss anything.

There are, maybe, 15 people in the room. Some of them I met in pre-op, but not all. They’re all wearing face masks and hair covers, so it’s hard to tell what sex they are. The room itself is cold to inhibit germ growth, and almost entirely chrome. And the people are so very busy. They all smile and nod as I come in and I lift a sleepy hand to wave. I feel, post-muscle relaxer, pre-release to unconsciousness, so blessed. So well cared for. These people are so smart, I think, and they’ve worked so very hard to do what they do. And here they are, and they’re all giving it all they’ve got - full attention and intelligence and precision and skill and, yes, I think, love - and they’re expending it all on *me*. Amazing. I thank God for that and that’s usually my last thought.

But I know this anesthesia. It's very powerful. It is going to keep me "asleep" while these smart people cut and spread skin, then pin it back the way a hairdresser clips one part of your hair up so she can work on another. Then they'll push things aside, kneecaps and remaining ligament and cartilage and such and they'll recycle the blood that's coming from my knee into the rest of my body. They'll cut dead ligaments and use a saw to remove the irreparably damaged bone. They'll put in a thing that sort of looks like the original thing and they'll screw it in using screws that are several inches long. Eventually, they toss parts of my body into the trash (or the incinerator? Where the heck does that stuff go? I must ask.) and puts lots of stitches in and close it on up.

And I "sleep" through that? No. I'm in something near the same state as poor Wesley in *The Princess Bride* when Prince Humperdinck turns "The Machine" all the way up to punish him for Buttercup's love. It leaves him, according to Miracle Max, "mostly dead." I am, if not mostly, at least, a little bit, dead. And it's a long way to come back, to fight my way up through that thick navy haze. I picture an old stone well. The farm's abandoned so the well is covered with moss and slime. I can see the top, but it's a long way up. I could slip and that would be it. I hear them call my name, and I know they're looking for me, and I'm looking for them, but they're very far away. When I do finally come back, I'm annoyed because I'm sleepy and these people are pestering me.

Diana suggested a Go Fund Me campaign for this surgery. My friends and family might pay for me to eat until school started up again? That could work.

I wrote a full-page draft of the GFM "script" that I thought I would either post or read. My friend Zahili looked at it and gently said,

- Uh, no, hon.

She built a script that followed a sequence of images: some film she shot of Grace and me puttering around Cleveland Circle, some pictures from my phone, some photographs of pictures in my apartment. She spent hours and hours recording my voice and syncing it to the images to make a fine little presentation. I explained the situation and set a goal $3,000. I got $5,000. I lived comfortably on that for six months.

Just before her tenth birthday, Grace gave a squirrel a run for its money and came up limping. She must have caught her paw on rock or something and twisted her hip. She was in agony. It was clear she didn't want to walk, but when I tried to pick her up, she screeched. There's a sound a wounded dog makes that particular to dogs. It's ghastly. I was going to put her in the walker and walk her home, but, no good. My neighbor tried to pick her up and got the same reaction. It was good luck I had some cheese with me. I don't even know why I had it; it's not our usual "walking around the neighborhood" treat. I managed to lure her home a few steps at a time. The vet didn't feel any major break so thought it was just a sprain in her hip, which made sense and, better, would heal in time. She prescribed anti-inflammatory and we went home. 12 hours later, about three in the morning, Grace started hurling and it was a very long night. I gave her sips of water but she couldn't keep it down and when she went out for her morning walk, she kept going for the snow in the neighbor's yards, licking a bit of it then vomiting. I took her to Angell Memorial Animal Hospital, the local emergency vet clinic that looks almost exactly like an ER for people. I sat on the floor with her. She was so exhausted she looked slightly drunk. The doctor came in and sat on the floor, too. She ordered IV fluids because Grace was very dehydrated and wrote a few prescriptions for stomach issues. I brought her home in a cab (she threw up a tiny bit in the cab, but I caught it with my towel). When we got home, she wanted WATER. NOW. I couldn't give it to her. She'd just throw it up and her stomach, the doctor said, was traumatized and needed to get some medicine and some rest before she could eat or drink anything. She kept hovering around her water bowl, even after I took it up. Finally, knowing how tired she must be, I put the Super Bowl on the radio, got out the spongy yoga mat that she loves, lay down on it and pretended to fall asleep. For a few torturous minutes, she moaned and whined, then she curled up beside me and fell asleep. Because, clearly, she couldn't tolerate anti-inflammatories for pain, she'd have to use Gabapentin, one of the drugs we tried for my seizures. It works great. I could afford all this because of the Go Fund Me campaign.

I'd been suffering with leg spasms at night for the last few years. It started out with garden-variety Restless Leg Syndrome, a feeling that the legs have ants crawling around in them and it usually quieted with Advil or some homeopathic stuff available at CVS. At first, that helped, but not for long. Soon we were trying muscle relaxers like Flexoral and Atavan, but nothing helped and I was up all night with my legs flailing and flying. I think it's related to the nerve damage from the Shingles episode, and exhaustion or stress triggers it. The only thing that calmed it at all was warm towels from the microwave, and then they just have to be waited out. But here's the weirdest thing: they stop at 4 am. On the dot.

For the first time in many years, I wasn't the Green Room Queen in the spring of 2016. The program used only to have a Master's and now they have a Master of Fine Arts. The graduate students run the Green Room for the Boston Theater Marathon. I'm sure they don't do nearly as good a job. I'm sure no one wears a tiara (how are you going to know who’s in charge, hmm?). It was my last connection to Boston theater. That is, until I write another play. It was quite a blow.

I often feel I should be exempt from the normal trials and tribulations of daily life. I shouldn’t have to shower or do the dishes. I shouldn’t have to pay taxes. I certainly shouldn’t be behind in them. I shouldn’t get old. I didn’t expect to. But there it is, anyway: gray hair. Just a bit of it. It didn’t even appear till I was into my ‘fifties, so maybe I caught a break. I always said that when my hair turned gray I was just going to let it go. Grow it long and learn to style it into pretty up-do’s. But I have no hair skills, no innate talent. My mother wasn’t one of those mothers who sent me to school in cute little buns and braids. She could handle a headband or a set of pigtails. That was about it. I got a little further than that, but not much. So it went up in nice buns, a few braids, nothing fancy. But I did not like the whispering gray.

Then it started to fall out. Not exactly in clumps. More like, light handfuls. But definitely falling out. It got so thin I could see that the parts in my hair had changed. They looked like the produce aisle at Stah Mahket, as we say about Star Market. Maybe the heat? It was a terribly hot summer. Climate Change just makes everything different. Summers and winters are both worse. The pain all over left me weepy, the heat left me exhausted. Maybe that? I told Dr. Sands my hair was coming out in not-quite clumps.

- Well, you know.

- What?

- You know...You are a woman...

- I am.

-... you know, over the, over the age of fifty.

- What does that mean?

- Hair thins.

- Not on me, it doesn't, sir. Oh, no. Something's wrong.

I went to see my dermatologist, who saw it and wanted a biopsy. Their office is across the street from a Marshall's and I planned to go there after the little procedure. She numbed up my scalp and then I felt her poking around up there, but it didn't hurt. I was very aware that she was putting in some stitches, but it didn't hurt, either. When I went to sit up the entire room tipped over.

- Whoa. Whoa. I'll be OK in a minute --

But I stayed down. And stayed. And ate the crackers they brought. Then I moved to the waiting area. My eyes were still not focusing well. I'd have to wait another bit to go to Marshall's. Maybe for another hour. Till finally the doctor came out to see me and I asked if she'd prefer I go shopping another day. She would. She sent me home with packets of Vaseline ("Moist wounds heal!") and a promise to take a Lyft, rather than the train.

Later that night, Christopher, 19, came to crash at my place for the weekend to pick up shifts at the restaurant where he works. I called to him from the bathroom:

- Buddy. Can you come here for a sec? I can't find the stitches.

He padded in, located them and showed me where they were so I could find them next time, then he slathered Vaseline on my scalp.

The biopsy came back showing not the dangerous kind, but the garden variety "telogen effluvium;" it can be caused stress, trauma, surgery or other contributing factors, such as immune system disorders. That sounds right. It usually lasts nine to ten months. It was ten. My hair has never been quite the same, but, much to my surprise, I am, indeed, aging. I henna. (That's not really a verb). I use a henna rinse in my hair and the hair absorbs it and it thickens and the gray hair absorbs it and goes auburn-brown, very much like my original color. I like it because it's cheap, I can do it myself and it's all natural. I know that anything I put into or on my body is going to end up in the ocean, and this will do no harm.

Prince died of a Fentanyl overdose. I listen to the BBC every night and Europeans are less pain-med obsessed than Americans are, so they're a little judgmental about it. The doctor they had speaking told us that it's "fifty times more powerful than heroin" and I wept because I'm on it. The prescription for my other main pain killer, oxycodone, was lost somewhere in the mail and it'll be late and I'll be out before I get it and I was upset but then I realized it's OK because I'm on fentanyl and I won't go into withdrawal and this is truly disturbing. "100 times more powerful than morphine," said the BBC, and I'm juggling these monsters.

Shortly after this, I dislocated my right shoulder, the one that was so badly broken in 2011. I started to slip, slapped my hand on a chair and, POP. I felt it go. Five tendons ruptured. I had filthy dark bruises all up and down my arms and on my back. Now, it's never been the same again, again.

Update

Summer 2016

- I gotta give you a leg to stand on, don't I? First, we'll do the left foot, then we'll do the left knee and then we can do the right foot, Ok? Dr. Zarin did your right knee? You like Dr. Zarin? I'll see him tomorrow. I'll tell him, OK?

This makes more sense. Dr. Slavonkai is the fifth surgeon I've talked to about my foot. He had looked at my feet and said softly,

- Wow.

My right foot has two more years of damage accumulated and the left foot is a mess, too. It has just what is called a bunion, an abnormal extension of the bone at the base of the big toe and it's made of bone and soft tissue. It's often caused by wearing too-tight shoes or heredity, but mine's caused by swelling around the bone and the loss of connective tissue that leaves it to stick way out to the side. The bone has started to curl under and it hurts to walk on it. My foot looks like it belongs to an elderly male elf.

For his sixteenth birthday, I had sent Christopher a photo of it.

- Oh my God that's disturbing, he had texted. Fresh.

I'm back at New England Baptist for a Great Toe Fusion. It's only one bone that has to fuse, so I'll be up in a walking cast the next day and up and about in a week. Everything goes fine - and here's the fun part: my nieces come to the hospital to pick me up.

I wake up from a little nap to see pretty Colleen sitting beside me. Krissy, radiant, is on the other side. This is very nice. I guess they grew up knowing I'd need them sometimes. But anyway, that's done, so now it's time to schedule the left knee.

Update

Winter 2016

The left knee replacement was fine. I say that likes it's no big deal, but it is a big deal. It just gets buried under the things that hurt more: my left side hip and back area; my ankles; my feet. Always, always, the feet. I went back to Epoch for the rehab on the left knee. This was just after Christmas. I worked until December 23, spent Christmas day asleep in my niece's bed with Grace, hoping no one minded my rude behavior, then did the surgery on December 28. Note to self: don't do major surgery three days after a major holiday and a week before another one. I did my best for holiday shopping. Of course, even though I have no money, I'd like to give some presents to my loved ones, and I have a nice recipe for baby oil and rose petal sugar scrub so the kitchen is sticky with my mixing, but it smells good. This winter is nothing like the last one. A few storms, but no knee-deep mounds of snow on the sidewalks. Grace and I are still mostly able to get around safely. For the surgery and rehab she stays with her usual aunties and does fine. She comes to visit a few times. Epoch is pushing protein even though I make them feed me mostly produce, mostly unprocessed, so they bring celery and peanut butter for two meals a day. When she visits, Grace licks a tiny tub's worth of peanut butter off my finger and scours the floor looking for a crumb from four years ago.

The actual rehab, as usual, is heartbreaking, then surprising. For the first few days, I'm faced with the holiday staff. These are not familiar faces. Lots of them are day-to-day workers and they're not sure what they're doing. They don't smile, which means, to my tired, anesthetized brain, they don't like me. But then, a CNA I don't know brings me some Haitian New Year's soup. I've heard about this soup from friends and acquaintances. It's a yellow squash soup that's made each New Year. I asked her about it, so she brought some in for me and then we're friends. She calls me, "Boo boo." And when people come back to work after the long, lonely weekend, we start the rehab.

This nice young PT helps me get onto the low padded table. I know this room so well. How much time have I spent in this room with its full-view window panes looking onto busy Route 9 in Chestnut Hill. She tells me to bend my knee and I try and can't and then gasp and tears seep and I gasp and I cannot believe I let this happen again. I also cannot believe that this crazy thing works. How can it be connected to my brain? When my brain tells this thing to move, what, exactly, is responding? Not the knee. The knee is a chunk of titanium and some plastic. It's the muscles and nerves around the middle of my leg where my knee used to be. That's rehab: getting this titanium thing to become a knee. We work for about twenty minutes because that's all I can do. I bend it a little bit. It seems more painful than the other one. Is that possible? My surgeon tells me it might be.

- There were a *ton* of bone spurs in there. It took ages to clean them out.

Bone spurs. They're kind of a mini-bone that the bone produces to protect itself when all the cartilage is gone. I picture a little mushroom-like outcropping and when my brother tracks down the image on Google, I find, of course, I am right. Then he finds a picture of knee replacement surgery and offers his phone to me.

- Yick, I say. It looks like a gutted fish.

- It looks like a vagina, he says, and his wife laughs and tells him to be quiet.

I tell them they’re both disgusting and can we please get back to my bone spurs.

Opiod crisis: I leave with all the drugs that are signed out in my name including three sheets of oxycontin. At two a day, that’s about a 3-month supply of the long-lasting stuff that addicts crush and melt and inhale or otherwise get in to their bodies. And they send me out needing a hand cart for the extra opioids and that is exactly how the opioid crisis began. I tell the nurse,

- I don’t need these. I’ll only take this for about three or four more nights.

- That’s OK. You can just take them.

- But I won’t use them.

- That’s OK. They’re signed out in your name. They’re yours.

- What should I do with them?

- Grind them up and put them in a bag with coffee grounds and just throw them in the trash.

Seriously? She’s serious.

I don’t do that, but I keep meaning to drop them off at the police station where there’s a kiosk you can leave them in while you remain unseen and anonymous, but, one thing and another. I’ll get around to it one of these days.

Dr. Sands finally meets the famous Grace Kenney. I wake up with just enough time to get The Ride to my appointment, but not enough time to get her outside for business and back inside, so I have to take her with me. They are immediately old friends. While he checks my lungs to see if they have any air left in them, he reaches down and puts his hand on her little head at the same time.

- She loves you so much, he says.

- I have treats.

- You have treats? Why don't you give her one? Grace, want a treat?

- Oh, you're a big help.

Update

Spring 2016

A few nights ago, I almost stayed at a hotel. I was in Kenmore Square. Like many parts of Boston, it's been cleaned up quite a bit in the last few years. The scary nightclubs have been replaced by Chipotle and Starbucks. Decent restaurants. It's only a five-minute walk to Fenway Park, so it's the first thing many tourists see. And it's a major terminus for the subway and bus systems. And there's a nice hotel. It was constructed by gutting a dirty old apartment building that took up half a block, and, in keeping with older city's desire to preserve edifices, it's charming and it looks like it would be nice. I was going to stay there because I could not take one more step, and because I felt that if I did the same thing I did every day, nothing would change, and something just had to change.

I had recently bought new shoes. Different L.L. Bean styles because they don't make the one style I've been wearing since I have to fit my shoes over an Arizona brace. I don't "break in" shoes; they break in my feet. I had had a long day at Berklee. Whenever I go in sick and shaky, I say my own personal Lord's prayer, the one that says, *This is all on you, Lord. I got nothing. Thank you*. Then I make it through the day.

After leaving Berklee, I had tried to go to Trader Joe's, just down the street, but I couldn't do it. I panicked. I stood still, looked around. Walked. Not sure where I was going but heading in the general direction of home. But not. When I got to Kenmore Square, I sat on the steps of a brownstone that was probably a frat house and wept. I talked to God. Why? What's the point of this? I know I'm sick. I'm broken in many ways. But, why? What else can be learned from more pain and more weakness and, while we’re at it, poverty. That night, I had a bit of money. Enough for maybe one night’s stay at the hotel. That would clean me out, but I didn’t care. I was crying so hard I was shaking, and young men walked in and out of the frat house, facing away, stealthy. I called Sarah. I had to interrupt us a bunch of times to just sob, or to catch my breath.

- I’m staying at the hotel.

- Which hotel?

- The one across the street. It’s nice.

- You don’t have clothes with you.

- I’ll wear these. It’s fine.

- You don’t have any toiletries. You need soap and stuff.

- They have those little hotel soaps. I’ll take a shower there.

I was picturing a beautifully renovated sparkling white bathroom. A mattress full of air, a down spread, fluff and volume, air. Space all around me.

- Can you keep Grace?

- Yeah, but I think you should go home.

- *Why?* Nothing changes. Nothing gets better. I can’t live like this.

- Are you going to hurt yourself?

- No. I’m just going to stay at the hotel.

Eventually, she talks me out of it. Without hope, I head home. It takes over an hour to get a cab, but by then I’m exhausted and calm so I don’t care. Grace stays at

Sarah’s. I have a crying hangover the next day. I thank Sarah. I get new shoes and they work out better. I haven’t stayed at the hotel. Yet.

Update

2017

Starting around the middle of 2016, I settle into a funk. Six surgeries and thirty-something years of relentless illness and poverty and loneliness and too many cares for one tired person have dug out my core. I'm looking back at this time a year or more later, so it's not really a proper "update," but I just couldn't do anything, including write, at the time. I'm having some guilt because of the time wasted, but if I'm compassionate with myself, I see I just didn't have anything left. Now that the kids are getting older and facing some life crises and hard facts, they ask me if it gets any easier. I have to tell them, sorry, no, it doesn't. Maybe you acquire some grace, maybe. And I tell them: If you are shooting for more compassion for yourself and others, then I think you're at least moving in the right direction.

I show up at Berklee twice a week and do my same hard work, but, in private, my enjoyment level has dropped. After seven years without a raise, I am aware that I will always be poor if I stay and I can't justify that anymore and have any respect for myself, but I'm sad. I feel driven out. I show up for my doctors' appointments, but just barely. I make sure Grace gets everything she needs, including lots of exercise, and I garden, guerilla and home as an obligation, not a joy, and days I don't have to be anywhere on time go like this:

I set the alarm for 9:00 a.m. and drag myself out of bed. I keep changing my "wake up" music because I keep choosing blues to wake up to and it's not helping. I kiss the dog and throw her three tiny treats for "good morning sunshine." Then I get some coconut oil and melt it for 5 to 10 seconds and swish that in my mouth for ten minutes because it's great for your teeth. It's supposed to clean out your liver and detox your kidneys, but I don't know about that. "Pulling oil" feels like it's great for my teeth and hygienists have confirmed this. With the Sjogren's Syndrome, the one that dries up all your glands, I have to really watch my oral care. Then I have some warm water with lemon, a little iced espresso, then rouse her majesty before the dog walker comes. I eat something. I make whatever calls I have to make and when Grace comes back, we crawl back into bed till as late as two, though I might set the alarm for two and sleep through it.

We go out at 3:00 or 4:00 and roam for about three hours. She sees the world as a place in which to chase treats. She's allowed a certain small amount each day and I parse them carefully so we get the timing right and she always has a task waiting. We stop at the neighborhood stores, starting with the hardware store, where a treat awaits if she guesses the correct hand. We go to Starbucks if I want tea. If it's a weekend, and weather permits, we go to the Reservoir or just CVS, which has turned itself into a Store 24 and carries too much, makes it too easy to spend money. Then we go to the park and she smells things and runs or walks around, and we get a nice long walk in, and though it's agonizing, not walking is worse.

My limp is appalling; I walk all bent over from the back and tilting to the right, trying to walk without stepping on my feet. I still use a walker and I limp when on that, too. I'm a three-legged goat. The pain is new every night, when I massage the poor nasty-looking thing and try to get it to calm down. The navicular bone, which has been hanging off to the side all these years now looks like an extra ankle. I can't ice because it's just too sensitive because of the neuropathy, so I have limited options, but I can't stay off of it because I have the little things of life to do. I have to put Grace's eye medicine, clean her teeth, give her her meds if she needs them for pain (because sometimes we have matching limps) and brush her. Maybe play a little "kill the guy with the bunny," then she's all set. I get myself set by preparing some coffee for the morning because I like it cold, juicing and any other minor prep things. This is where I wonder if it's fair that I have to take a shower. My body is throbbing and my foot is bloody jagged glass. When I get into bed it takes hours to get to sleep because I'm so uncomfortable. And this is the best I can do. And it's been going on for way too long.

- My DNA hurts, I say. My cells hurt.

How else to describe the depth of the pain to Dr. Sands?

I've been on the methotrexate so long that my body is bored with it. It has stopped helping much. In addition to the one hundred mechanical things that are just permanently wrong, I am distraught with depression and fatigue and deep, systemic pain. It's all the surgeries. They all worked. They all did what they were supposed to do, but all of the trauma has done nothing to calm my lunatic immune system. I can feel it quietly rumbling and grumbling, getting dangerous.

He orders Rituxan, one of those biologic drugs whose workings elude me. It calms the immune system, but I don't understand why. You get two infusions, six hours each, two weeks apart, and they load you up with benadryl and anti-emetic stuff and whatever all else you get to hold off a reaction because you can die from that. My friend works as a pharmacist at the Infusion Center so I get to see them mix up the batch for me. A person in surgical gear handles it all in the sterile mixing unit while he calls the names of the solutions and my friend and I watch him on a camera from about thirty feet away. Very cool.

We wait to see if it helps. We wait and wait. It takes a month or two, usually. In late February, I wake up with the worst full-blown flare I've had in ages. Grace was sleeping over at Sarah's the night before, so she missed it and I didn't take any prednisone to head it off. In the ER, I fall apart entirely and say something stupid like, "I've got way too many drugs in the house for someone who feels this way." The Psychiatrist is called. They call my brother, but by then I'm calm. I just tell him to say if I haven't done it by now, I won't. He tells me that's what he said and we dodged that, but he advises me to keep my mouth shut if I don't want to end up in the Psych Ward. I receive Confession from the priest. It feels nice. I should investigate that further. I haven't done it in years. Couldn't hurt. I have this terrible image. There's a story that goes like this: a man dies and he comes to a beach where there are two sets of footprints in the sand - his and the Lord's. The man notices that sometimes there is only one set of footprints, and this during the most difficult times in his life. He asks the Lord about it, who assures him, "My child. It was then that I carried you." I can't get the image straight. I see myself lying face down on the shore. The tide is coming in. Nobody is carrying me.

I'm in Dr. Sands' office, weeping again.

- You're out of options. That was it. You've tried everything.

- I’m never out of options.

And, somehow, he gets me to try a medicine that’s just now being used for lupus, Leflumonide. We wait. Then, maybe, in June. One day in June I don’t feel so awful. Just for a few days. Then, not as bad. Not as bad as it’s been for a few years. Then I start to wake up in the morning without wanting to go right back to bed. I get up. It hurts to do that, so I get back to bed to get the heck off my feet and tortured back. But I stay awake and write. And that continues all through the God-awful hot months of summer. Gardening is tough because it hurts so much to walk, especially on uneven ground, and I often fall, and break toes and metatarsals and slip and land on my butt, shaken. But it’s not as bad. My DNA cools off. And when September comes and it’s not so hot, I feel actually...not horrible. Still sick. But not horrible. Yeah is the last thing to go.

.

2018

Memoir Now

Finally, the right foot is done. The surgeon had pointed at me and said,

-I'm not touching you unless you get three months in a nursing home.

That's because the titanium plate in the left toe fusion split in half horizontally. It's not the fusion itself, but the titanium plate inside my toe. We were checking it on an X-ray and Dr. Slavankai was amazed. He whispered:

- What'd you do?

- Me? I didn't do anything.

- It's broken! You must have done something.

- That's titanium, right? Superman can't crack that, right?

- That's what it is. You cracked it! It's split right in half.

- I see it. That's amazing.

- I've never seen anything like that. Never seen it.

- Oh. Stuff like that happens to me all the time.

The problem is that the plate cracked before the fusion was fully set, so now I have a broken titanium plate in an un-fused toe. We'll only deal with it if we absolutely have to.

So, after years of debilitating pain and two tries and lots of last-minute drama around insurance that involved a two-week postponement and a last-minute cancellation that was cancelled, for which, I'm happy to say, I remained calm, we finally did the three-layer fusion and the great toe fusion and a toe-straightening to re-build the right foot. It helps me, in a case like the postponement and the cancellation, to think of the worst-case scenario and talk myself through that, because I’ve probably been through something like it and survived. I can barely remember a time when this foot didn’t cause me heartache, and now it should be better. Not good, but better. I’ll have to learn to walk again. Again.

I’m back at Epoch, now called Wingate, for the fifth time. There are nurses and aides here I’ve known for seven years. The first day, as always, I’m sad to leave the Disneyland of hospitals, New England Baptist, so have my usual weepiness. I’ll be here for at least three months, maybe close to four. That’s a long time without Grace who is, of course, at my brother’s house with his family. An enormous gift from them, but they want me to be as comfortable as possible. And if you already have one dog, you might as well have two.

I can’t sleep without her. I need that little weight on the end of the bed. The lady in the beauty salon (yes, there’s a beauty salon in here) gives me a big stuffed dog to put there. It doesn’t really help. I had a fun roommate in the beginning, then had the room to myself for weeks and weeks and then got a roommate. Uh oh. Of course, she was nice. Of course, I didn’t feel uncomfortable with how sick she was, how confused. She had me up every night to find her call button or to talk her out of getting out of bed on her own. All that was easy. But I was a mess because I lost my privacy. My freedom to come and go as I please, to use the bathroom when I want without worry of waking her up. To not sleep with a stranger four feet away and to hear her body noises and to have her share mine. That’s where the difficulty came in and the perpetual “if I had more money, I’d [fill in blank...get a private room],” stuff and I had my shorts in a knot for a few days. A real bitch. Then I gave myself a talk and said: Stop it. Can you have some class around this? I guess I can try. Yes, I can try to have some class around this. I was just trying to get used to it and be a good roommate when a private room opened up and she took it. But I’m still trying to release those invasion feelings because I could get another roommate at any time; it’s not my room, it belongs to Wingate. My insurance won’t cover a private room and I can’t afford one, so I hope only to be better about it if it happens again.

My next roommate was a delightful 85-year old pediatric oncologist from Moscow. She called me a “woman of steel,” which I much preferred to “bionic” and when she left I was sad.

The work when I first got to Rehab was to figure out how to manage everything in a wheelchair while wearing a ginormous cast - a specialty of Dr. Slavankai’s - to keep the surgical site supremely safe for the first few weeks. It was well over five pounds, but if I hadn’t had it, I might have smashed the new surgical site the morning, a week after I came, that I slipped in the bathroom and tapped it on the floor. Right away, we started mat leg exercises so my muscles didn’t atrophy too much during three months of non-weight bearing. (With the two surgeries it would end up being five months and 5 days.) Also, right away, we started to strengthen my arms so they could support my upper body while I transferred from bed to chair and back or toilet to chair and back. My shoulder is not happy about this. It’s creaking and scrunching and throbbing and making “rocks and sand in a glass bottle” noises. Other than that, because I’m not putting any particular weight on my body, I feel great. I’m hardly in any pain. We managed to cut my fentanyl almost in half and I went a week or two without any oxycodone at all. Until my shoulder got news of the exercise bike and didn’t like it. That’s been the main source of pain, not my foot at all. I’ll take one oxycodone once in while, and that’s down from about four a day. I know I’ll be on more again when I go home and start gardening the whole neighborhood and walking with the dog, but it’s a nice break, and maybe I’ll take less when I get out.

The first good news is that the new bones are coming in. That’s astonishing. I’m not the most reliable producer of new bone, but I know they put some bone growth medicine into the site when they operate. I can’t make them out in the X-ray at all, but the surgeon’s assistant assures me they’re there. The hardware in the foot is impressive. Three really large coarse-thread screws, about two inches, and a little gadget that looks like a penguin. Then, at 9 weeks, the bones I still can’t see are starting to latch onto the hardware. And this is a fusion.

- Geez, I say to his assistant. He must have used some serious bone-growth stuff.

- He used everything he’s got, she says.

And after I recovered from surgery and finished my PT and OT work, I worked every day and finished this book. Surely, few memoirs ever took longer. If not for five months in rehab, I never would have finished it. But that’s the way my life goes: time flies and everything else takes forever.

At Dad’s wake, my sister-in-law and I were standing near the coffin. A nice mahogany thing, closed, with the incredibly detailed model ship he was working on on top. I tapped the wood. Long before this thought hit my brain, it came out of my mouth.

- Oh, shit. I’ll have to get married.

We laughed till we were weepy, the way people laugh at wakes.

By now, I might have been living with him. He’d be in his eighties, and the care-taking would be mutual. He’d need someone, I’d need someone. My brothers would have to be running in and out of the Kenney Nursing Home in Abington, MA all the time. I think we'd have fun, and I know he'd adore Grace. He was a world-class napper, and so is she. He was silly and brave and good, and so is she. He adored me, and so does she. I can hear it playing live, in his thick West End of Boston speech:

- Good ol' Grace. Gracie Girl.

- Don't give her steak.

- She likes it.

- Of course, she likes it. She's a dog. She's had enough.

- Sit. Good girl - See? She likes it.

- I know she does, but don't give it to her unless you wanna clean up.

- Send her into the field.

- She'll get fat.

- Don't call her fat. You'll hurt her feelings. Oh, Grace. Poor Grace. What a mean Mommy you have.

He'd give her some steak to console her for having such a mean mommy. I'd spend the rest of her life trying to keep her weight down.

It takes fifty people to do what he was doing, but, indeed, I do have people to take care of me. I have that nice man through a state agency who comes in and cleans once a week. I always wanted a "cleaning lady," because I was one. I thought I'd be rich enough to afford it, not sick enough to need it. When I first broke my back, the couple I used to babysit for asked their dog-walker, Kelly, who owns a dog-care business, to walk Grace for a couple of weeks and they would pay her. After a few weeks, when I cautiously asked her if they had finished paying for the walks, she said,

- Don’t be ridiculous. I’m not charging you.

She sends one of her folks out to walk Grace Monday through Friday in the morning for free. For going on five years. Once in a while, when we’re chatting on text and I have some more bad news, a new break or symptom, she writes,

- Oh, God. I wish there were something I could do.

I write back:

- You mean like, walking the dog five days a week for free? OK, I’ll think of something else you can do. Then I put one of those stupid :) things at the end.

Friends with Cars (FWC) take turns taking me to the pain clinic for my spine shots. You need a ride home because of the mild sedation, which keeps me on the table when they start sticking needles in my spine. Jenny says she likes doing that; it takes three hours out of her day, but she knows it’s the only thing that helps, and she likes to see a result once in a while. I come home to warm rolls and organic bread or whatever was on sale at the grocery store left on the basket outside my door. The neighbors change lightbulbs and hang pictures and take stuff down to the basement. Talented playwrights do laundry and others come to see me almost every night in Rehab. Singer-songwriter Barbara does 5 loads of laundry in one day and, by herself, flips my mattress. Christa brings tons of home-made frozen vegan food and tears apart the closets and we have four huge bags of donations in one day: clothes from parts of my life that are long gone - State Street, temping; I always dress comfortably now. And then there are my brothers, who do whatever they can, and my sisters-in-law who do whatever they can. And then there are all my family and friends; some take on more than others, and I try to distribute my calls for help evenly, but I get help, and I'm so grateful for it.

Years and years ago, when we were out running errands on a Saturday afternoon, Dad and I were having one of our deep talks and I asked him,

- What's Grace? You know, "Hail Mary, Full of Grace..." God. What *is* that?

Old-school lapsed Catholic, he said,

- Oh, Jesus, Janet. I don't remember. I think it's ten Ah Fathis an' a Hail Mary.

Catholics keep track of things like that and earn brownie points and indulgences and grace. But I was asking about the real thing, and he didn't have an answer and I didn't have an answer either. And I don't. But I know it when I feel it.

Almost forty years ago, I came down with lupus. I'm still here. I write whenever I can. I garden for hours, even when I shouldn't. I guerilla garden six properties in the neighborhood, even though I really shouldn't. Even though they're grown up, I am still a very active auntie to the children, but now instead of babysitting and sleepovers, we meet for brunch or I go to the restaurant where they work or I go to their shows or their weddings. I work with my beloved Berklee students whenever I'm not in the hospital half the semester.

Grace is 12. She's got a cyst on her eyelid and a couple of warts on her back and a sensitive hip. She's fabulous. Her groomer, my friend Andrea, brings her home from the shop so I don't have to go get her. Andrea comes to Rehab often; one night she brought a film and we took over the "practice" apartment that people use to re-learn cooking and showering and we watched a movie and ate chocolate. They keep the apartment locked now, and we think it's our fault.

I'm not completely helpless. Though the day to day does indeed wear me down, all these years of crisis have left me easy in a crisis, which any fool can handle. Last year, I came across a Heimlich rescue in front of the Chipotle. I'm not strong enough to do the technique on someone, but I got the guy who was strong enough to do it right. I quickly became the co-pilot and, holding the girl's hand firmly, helped talk her through it and was chief vomit and snot wiper-upper. Every month, I watch the rescue videos on the internet because I want to be ready. When my downstairs neighbor's little French bulldog needs an allergy injection, she brings her upstairs and I inject her so fast she thinks I'm just playing with her. Professors at Berklee come to me when they have a headache --

- Heat or pain or both?

- Heat, then pain.

- Two Tylenol for now, and here are two Advil in case of pain later.

I recently ran into a very elderly couple at the CVS who were looking for a hand brace because the man's hand was broken and the cast wasn't covering the actual break. We couldn't track down any kind of doctor and they didn't have what they needed at this CVS, but I checked the internet, chose an appropriate brace (they approved) and sent them to the correct pharmacy near their house where a man named Randy would be waiting for them. I had to gently handle his broken hand to get a look at the cast and the brace. I said,

- Let me know if I hurt you.

- You don't hurt me.

It’s been a while since I attended the Paulist Masses. In 1997 and 1998, I was still attending but was beginning to lose interest. The Mass was enough for me; it was nicely done, simple, intimate. But then someone got the idea that we had to be entertained during Mass, so they brought in “ecclesiastical dancing.” I mean to say, they brought in one girl to step and twirl and pirouette around all over the chapel. This girl came down the aisle in a simple blue robe tied with a rope at the waist and bare feet which, I couldn’t help noticing, got dirty and dirtier while she danced. There was little or no music to accompany her, so every time she raised up on her toes, her ankles cracked, and I had to hold my breath and lock my lips to keep from laughing. When she came back more than once, I came to call her “the barefoot dancing Jesus girl.” This is not a particularly Christian thought, I know, but I couldn’t help it. The barefoot dancing Jesus girl started showing up more, and I started up showing up less. And, then, the Maundy Thursday Mass - the Mass that celebrates the Last Supper - did it. They brought up a bunch of disabled people - they all had wheelchairs and canes and walkers - and put them around a table and the barefoot dancing Jesus girl fed them stuff. It wasn’t the end of my searching and learning. It was just the last time, so far, I felt comfortable in an organized setting. I’ve tried Catholic Masses and Episcopal services and been to a few Jewish services and nothing has seemed to suit me just right. I get most of my spiritual clarity in nature, loving Grace, writing well enough to be channeling, laughing till I rock. Sometimes, if I’m quiet in garden, I can feel the earth’s energy flow up from all the way down at its core; it flows down from me, as well. It’s a slow vibration, quiet and dark. The ocean has a different vibe; just as live, but more evanescent, more rapid.

Over the last several years, based on many sources, I’ve formed an image of the Universe as being made of swiftly vibrating energy. It’s love and life and stillness and grace.

We slow down when we're born and speed up when we die and, in these lifetimes, of which I think we have many, we become matter. In my sense of the Universe, matter is the slowest form of energy, and I include humans and monkeys and deck chairs in there. We're slow, but not still. We're either contributing to the purposeful, powerful flow of that Universe and trying to determine the will of God, or we're pushing against it. And lupus and terrorism and politics and family squabbles are all distractions. And they matter because we're dealing with them now, in this body, in this lifetime, but they don't last. And when I'm still here in this body on this marvelous, difficult earth, I'll be in pain, because that's just the truth of it. I'll slip and slide more than waltz or walk, and I'll never get it right, but what else is there to even shoot for, but a bit of grace?

And I know this: that right shoulder has to go...